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## DNA Patents and the Invisible Citizen: The Role of the General Public in Life Science Governance

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### Abstract

*In 1998, the EU passed a Directive establishing the legality of DNA patents in European law. DNA patenting constitutes a commercial incentive for life science research and forms part of a wider commercial restructuring of life science research infrastructure. The patent field has been characterised by a relative institutional homogeneity promoting commercial incentives as vehicles for scientific innovation. Public consultation has been used extensively to democratise the governance of life science but not in relation to DNA patenting. Based on data from the first set of interviews with the general public in Europe on DNA patenting, we argue that public consultation in this area could benefit policy making by introducing greater awareness of the plurality of views on commercial incentives for research prevalent in the general public. Some people express concerns about commercial incentives for research, especially in health and medicine. We demonstrate that some of the concerns seem justified when viewed in the context of current developments; therefore, we argue that public consultation could inspire a more socially robust research infrastructure which is more conducive to maintaining public trust. However, there is a tendency to limit the use of public consultation to issues relating to specific technologies (rather than the infrastructures bringing them about), possibly because here the active participation of the general public is needed in the roles of consumers or donors – rather than as citizens providing a counterweight to techno-bureaucracies.*

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## 1. Introduction

Over the past few decades, Western governments have increasingly sought political legitimacy for decisions concerning the life sciences by way of public consultation. Science and technology studies (STS) have been part of actively questioning the types of expertise engaged in life sciences governance and propagating a more democratic approach with which the legitimacy of policy initiatives have been tested in the general public.<sup>1</sup> However, not all aspects of the life sciences have generated the same call for public consultation. DNA patenting, for example, has evaded consultations with the general public despite being the object of intense political contention.

Patenting of human DNA has developed gradually since the 1970s. In 1998, its legality in Europe was established with the passing of the EU Biotech Directive<sup>2</sup> harmonising the practice in the EU and the countries abiding to the European Patent Convention. The Directive was subject to a decade of intense debate in policy circles, and, in the course of this process, several advocacy groups managed to influence what has otherwise been described as a technocratic and secluded environment dominated by legal and economic experts.<sup>3</sup> However, the process generated neither a policy interest in nor academic studies of the views of the general public.

There is something curious about this absence of interest, considering how life science governance in general has undergone public consultation during the same time period. We have come to reflect on this because one author of this article has conducted the first public consultation in Europe specifically addressing DNA patenting<sup>4</sup> while the other author has contributed to some of the numerous public consultations in the field of biobanking.<sup>5</sup> Not least because potential biobank donors express specific concerns about DNA patenting,<sup>6</sup> the differences between the two fields – dearth versus abundance of public consultations – have spurred our curiosity about why some topics are selected for public consultation and others are not and about what is to be gained from such exercises. Drawing on a focus group study of views of DNA patenting among members of the general public in Denmark, we demonstrate a divergence between a plurality of views and concerns expressed by members of the general public about the role of commercial incentives in stimulating

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<sup>1</sup> A Irwin, “The Politics of Talk” (2006) 36 *Social Studies of Science*, 299-320; A Irwin, “Constructing the Scientific Citizen: Science and Democracy in the Biosciences” (2001) 10 *Public Understanding of Science* 1-18.

<sup>2</sup> 98/44 EC of the European Parliament and of the Council of 6 July 1998 on the legal protection of biotechnological inventions.

<sup>3</sup> S Borrás, “The Governance of the European Patent System: Effective and Legitimate?” (2006) 35 *Economy and Society* 594-610.

<sup>4</sup> M Andreasen, “Two Stories about Biotech Patenting from the ‘Silent Majority’ in Europe” (2008) Forthcoming, *Public Understanding of Science*.

<sup>5</sup> See overview in K Hoeyer, “The Ethics of Research Biobanking: A Critical Review of the Literature” (2008) 25 *Biotechnology and Genetic Engineering Reviews* 429-452.

<sup>6</sup> K Hoeyer, “Conflicting Notions of Personhood in Genetic Research” (2002) 18 *Anthropology Today* 9-13; K Hoeyer, “The Role of Ethics in Commercial Genetic Research: Notes on the Notion of Commodification” (2005) 24 *Medical Anthropology* 45-70.

innovation and the relatively homogenous views amongst institutions that sustain the life science research infrastructure. We suggest that awareness of the plurality of views among members of the general public could be a relevant resource in contemporary life science governance for purposes of increasing the robustness and legitimacy of policy making. Furthermore, we suggest that one of the reasons that no previous public consultations have been conducted might be a tendency to focus public consultations on technologies – rather than the politico-economic infrastructures bringing them about – and that the general public is consulted primarily when their active participation is needed, for instance, as consumers or donors. In other words, legitimacy is primarily sought when the general public possesses direct bargaining power, and, in such cases, they are asked to contemplate specific technologies rather than the politico-economic decisions that generate technological innovation. We do not wish to insinuate a conspiracy; our aim is to explore possible legitimacy issues concealed in the blind angle of this particular logic and what type of resource the general public potentially constitutes for life science governance if it is more broadly construed as also including infrastructural issues.

In the following, we first discuss the literature on the involvement of the general public in life science governance. Issues of public legitimacy characterise this literature, and, as we turn to findings from the focus group study of public views of DNA patenting in Denmark, we demonstrate mismatches between the current patent practice and the views, impressions and expectations that some people have. We explore concerns about using commercial incentives in life science (and especially medical) research and demonstrate the diversity of views among focus group participants of DNA patents as a means for stimulating innovation. We then outline the political choices that remain hidden in the blind angle of the current wave of public consultations by describing recent transformations in the politico-economic research infrastructure of life science in Denmark. Drawing on studies of the potential implications of these transformations, we substantiate the concerns held by some focus group members and suggest that public consultation informed by multiple types of expertise could create an impetus to increase the social robustness of current research policy through consultations.

## **2. Reflections on the literature on public consultation**

Developments within the life sciences and, in particular, molecular biology have given rise to prolonged public discussion and activism.<sup>7</sup> In relation to topics such as plant biotechnology, cloning, biobanks, pesticides, genetic testing, brain science, and, beyond the life sciences, nanoscience and information technology (IT), the opinions of the general public have not only been surveyed but even consulted through

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<sup>7</sup> MW Bauer and G Gaskell, “The Biotechnology Movement” in MW Bauer and G Gaskell (eds), *Biotechnology: The Making of a Global Controversy* (Cambridge: Cambridge University Press, 2002) 379-404; D Nelkin and MS Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (Ann Arbor: University of Michigan Press, 2004); J Turney, *Frankenstein's Footsteps: Science, Genetics and Popular Culture* (New Haven and London: Yale University Press, 1998); TH Nielsen, E Jelsøe and S Öhman, “Traditional Blue and Modern Green Resistance” in M Bauer and G Gaskell (eds), *Biotechnology: The Making of Global Controversy* (Cambridge: Cambridge University Press, 2002) 179-202.

comprehensive deliberative events, such as consensus conferences and citizen summits. None of these types of public engagement has been used in relation to DNA patents and the politico-economic research infrastructure of which they form a part. To contemplate this apparent inconsistency, it is instructive to consider how the contemporary popularity of consulting the public has been analysed; the phenomenon of public consultation has been the subject of a large body of academic literature. Two main strands in the literature on public consultation in life science governance comprise a primarily descriptive and policy-oriented discussion and a primarily normative political-philosophical discussion.

The *policy discussion* has revolved around how new and more active forms of public participation have been co-produced with new life science dilemmas.<sup>8</sup> Precisely defining the roles ascribed to the general public is not simple because different modes of consultation construct them differently. In some instances, the general public has been actively mobilised and in others it has mobilised itself.<sup>9</sup> In some modes of consultation, the public has been constructed as competent to deliver advice, and, in others, emphasis has been put on determining the competences it lacks and the knowledge it needs. These framings take different and often tacit forms. For instance, more arranged forms of consultancy, such as surveys, are at risk of framing issues for the public (e.g. through the questions asked, how the respondents are informed, what options for reply they have and how the data is interpreted), compared with more explorative approaches, such as qualitative enquiry or deliberative procedures, where participants have relatively more freedom to express or develop their own framings. However, concerns have also been raised about deliberative procedures, because certain (typically scientific) ideals of an “informed public” are maintained.<sup>10</sup>

In the *political-philosophical discussion*, public consultations are generally said to increase the political legitimacy of various technologies. In the literature, this role is typically expressed in the form of what we call, here, *discourses of citizenship*. Typically, the rationales for consultations as “extensions” of representative democracy have followed two lines of argument, one deontological and the other consequentialist.<sup>11</sup> From a deontological perspective, public consultation is a necessary part of protecting citizens’ democratic *rights*, thus challenging the discretionary powers otherwise tacitly ascribed to expert advisors. From a consequentialist perspective, public consultation is a way of maintaining public trust. Issues of mistrust are seen to emerge because technoscientific decisions are based on

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<sup>8</sup> N Marres, “Issues Spark a Public into Being” in B Latour and P Weibel (eds), *Making Things Public: Atmospheres of Democracy* (Cambridge, Mass.: ZKM/Center for Art and Media Karlsruhe and MIT Press, 2005) 208-217; H Gottweis et al, “Participation and the New Governance of Life” (2008) 3 *BioSocieties* 265-286; M Callon, “The Role of Lay People in the Production and Dissemination of Scientific Knowledge” (1999) 4 *Science Technology & Society* 81-94.

<sup>9</sup> J Hansen. “Framing the Public: Three Case Studies in Public Participation in the Governance of Agricultural Biotechnology” European University Institute, Department of Political and Social Sciences, Florence, 2005.

<sup>10</sup> See note 1 above and M Elam and M Bertilsson, “Consuming, Engaging and Confronting Science: The Emerging Dimensions of Scientific Citizenship” No. Discussion Paper One, STAGE, Gothenburg, 2003; S Rayner, “Democracy in the Age of Assessment: Reflections on the Roles of Expertise and Democracy in Public-sector Decision Making” (2003) 30 *Science and Public Policy* 163-170.

<sup>11</sup> See note 9 above.

expert advice rather than on the understandings of those affected.<sup>12</sup> Deontological and consequentialist perspectives are usually intertwined in an argument stating that a move towards good governance implies that technical decision making needs to be opened up and exposed to wider democratic debate to democratise expertise and thereby increase the public legitimacy of the decisions taken.<sup>13</sup> Accordingly, it is criticised when public consultation does not result in policy changes.<sup>14</sup>

The fact that the EU has not initiated a public consultation on DNA patenting is conspicuous given the intensity of policy controversy in the EU parliament, which is otherwise keen to position itself as democratic watchdog. This may, of course, be coincidental. However, it is curious that even within academic circles engaged with public consultation, little attention has been paid to DNA patenting.<sup>15</sup> This circumstance might reflect a tendency in academic and policy circles to view public consultation in relation to *technologies* but not in relation to the politico-economic choices regarding funding, property regimes and commercial competition that shape technology development more broadly.<sup>16</sup> It is worth considering whether this focus on technologies rather than infrastructures reflects an implicit assessment of the average citizen's potential status as an agent of change and resistance. It seems that consultation of the wider public is used primarily in cases where the support of the average citizen is needed or where individual citizens are in a position to provide actual resistance. For example, in the controversy about genetically modified (GM) crops, the average citizen needs to endorse the products as a consumer. Furthermore, the technology produces tangible crops and food products, which have been destroyed in acts of resistance by engaged segments of the population. Hence, control of public opinion was needed for the technology to develop.<sup>17</sup> A more recent case of extensive

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<sup>12</sup> U Beck, *Risk Society: Towards a New Modernity* (London: Sage, 1992); J Hansen, "Operationalising the Public in Participatory Technology Assessment: A Framework for Comparison Applied to Three Cases" (2006) 33 *Science and Public Policy* 571-584; S Jasanoff, "(No?) Accounting for Expertise" (2003) 30 *Science and Public Policy* 157-162; S Jasanoff, "Science and Citizenship: A New Synergy" (2004) 31 *Science and Public Policy* 90-94.

<sup>13</sup> See e.g. H Nowotny, "Democratizing Expertise and Socially Robust Knowledge" (2003) 30 *Science and Public Policy* 151-156; J Durant, "Participatory Technology Assessment and the Democratic Model of the Public Understanding of Science" (1999) 26 *Science and Public Policy* 313-319; A Liberatore and S Funtowicz, "'Democratising' Expertise, 'Expertising' Democracy: What Does this Mean, and Why Bother?" (2003) 30 *Science and Public Policy* 146-150; see also discussions in L Hennen, "Participatory Technology Assessment: A Response to Technical Modernity?" (1999) 26 *Science and Public Policy* 303-312; and see note 9 above.

<sup>14</sup> See note 1 above and A Bora and H Hausendorf, "Participatory Science Governance Revisited: Normative Expectations Versus Empirical Evidence" (2006) 33 *Science and Public Policy* 478-488; M de Jong and M Mentzel, "Policy and Science: Options for Democratisation in European Countries" (2001) 28 *Science and Public Policy* 403-412.

<sup>15</sup> See however E Einsiedel, "Publics and Gene Patents" in EF Einsiedel (ed.), *Emerging Technologies: Hindsight and Foresight* (Vancouver: The University of British Columbia Press, 2008).

<sup>16</sup> ER Gold and TA Caulfield, "The Moral Tollbooth: A Method that makes use of the Patent System to address Ethical Concerns in Biotechnology" (2002) 359 *Lancet* 2268-2270; M Levitt and S Weldon, "A Well Placed Trust? Public Perceptions of the Governance of DNA Databases" (2005) 15 *Critical Public Health* 311-321; H Gottweis et al, "Participation and the New Governance of Life" (2008) 3 *BioSocieties* 265-286.

<sup>17</sup> L Levidow, "Biotechnology Regulation as Symbolic Normalization" (1994) 6 *Technology Analysis & Strategic Management* 273-288.

public consultation is population-based genetic databases. Small collections of human biological material have been around for a century but they were not considered worthy of public consultation until the scale of the activities implied involvement of the general public as donors.<sup>18</sup> In these cases of widespread public consultation, public legitimacy is not just a democratic virtue; public acceptance is needed for research to develop and thrive.

In contrast, for average citizens, DNA patents are difficult to counter or resist in a meaningful way. There is no tangible object to destroy in the field – as with GM crops – and infringements of patent claims are not an option for the average citizen. Clinical geneticists are in a position to infringe patents<sup>19</sup> – and they were, in fact, consulted. The average citizen, however, is powerless to make his or her voice heard. Other types of intellectual property rights, such as those pertaining to movies, books, and music, can be easily challenged by the average citizen. In fact, many efforts are undertaken to persuade the public to respect copyright laws. DNA patents can only be infringed by genetic specialists; citizens wanting to oppose DNA patents are left with no option of resistance from below.<sup>20</sup>

Is there any reason to suppose that citizens see themselves as having anything at stake? Comprehensive Canadian studies have shown that members of the general public express considerable concern about DNA patenting.<sup>21</sup> Likewise, when a question about patenting was asked as part of a UK survey enquiring into issues related to human genetic information more broadly, the results indicated substantial concerns about private ownership.<sup>22</sup>

### **3. Method**

As a consequence of the absence of public consultancy in Europe, very little is known about the attitudes of the general public towards DNA patents and the ongoing restructuring of the politico-economic research infrastructure. We present some results from a consultation of the general public in Denmark. We draw on focus group material from a study conducted during the summer of 2006. Six focus groups on DNA patenting were convened twice with members of the general public from the

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<sup>18</sup> K Hoeyer, “The Ethics of Research Biobanking: A Critical Review of the Literature” (2008) 25 *Biotechnology and Genetic Engineering Reviews* 429-452.

<sup>19</sup> RS Eisenberg, “Why the Gene Patenting Controversy Persists” (2002) 77 *Academic Medicine* 1381-1387.

<sup>20</sup> We do not claim that there are no exceptions to this pattern and an interesting one is the case of animal testing: whereas this would seem to be very much like DNA patenting both in terms of being part of the research infrastructure and in terms of being at a distance from the citizen, it has nonetheless been the object of intense contestation from activists who have resorted to violence to reach their goals (e.g. JM Jasper and D Nelkin, *The Animal Rights Crusade: The Growth of a Moral Protest* (New York: Free Press, 1992)). As in the case of GMOs, however, there are real entities to attack which is in contrast to the immateriality of patents. In that sense, public consultancy still reflects the “bargaining power” of the average citizen rather than ideals of democratic legitimacy.

<sup>21</sup> EF Einsiedel, “Publics and gene patents” in EF Einsiedel (ed.), *Emerging Technologies: Hindsight and Foresight* (Vancouver: The University of British Columbia Press, 2008).

<sup>22</sup> MORI, “Public Attitudes to Human Genetic Information” Human Genetics Commission, 2001.

Copenhagen area (n=38). Potential participants who indicated strong opinions or specialised knowledge about the issue were excluded. The groups represented a broad composition in terms of age, sex, and education. The purpose of this was to produce a discussion which reflected a broad selection of world views. As is typical of qualitative research, the data produced establishes a typology of different positions, but reveal nothing about their distribution. Hence the results are not representative of the “general public” in a quantitative sense. Moreover, generalising the results to a European level or beyond clearly depends on presumed social and cultural similarities.

In the following sections, each respondent is referred to according to group (A-F) and number (1-10). The thrust of the results and details on methods are reported elsewhere;<sup>23</sup> here, the focus group material is used to demonstrate legitimacy issues resulting from 1) a mismatch between the property regime maintained by patent institutions and basic notions of ownership spontaneously expressed in the focus groups; 2) concerns expressed about decision making in a commercialised research infrastructure, and; 3) concerns about DNA patents as a means of achieving the public good in the health area.

#### **4. Clash of ideas about ownership**

It took ten years from the time a first draft of the EU Biotech Directive was presented to its passage in 1998. The directive was initially presented as a merely technical harmonisation exercise, thus signalling that it contained nothing politically new. However, many observers were less inclined to see it in such an innocent light, and various advocacy groups began lobbying to influence the Directive.<sup>24</sup> Eventually, these groups were consulted, thus making a break from tradition in an area where extra-parliamentary influence is normally confined to legal specialists and users. Patent institutions, such as the European Patent Office (EPO), have been described as unusually esoteric and embodying a rather narrow and homogenous perspective on both patenting and who constitutes a relevant stakeholder in patent matters.<sup>25</sup> These actors, dominated by a commercial agenda, have been portrayed as tremendously influential.<sup>26</sup>

During the focus group interviews, it quickly became obvious that conflict about DNA patent legitimacy was not confined to the policy level. Focus group members held strong views about DNA patenting and the type of incentives that they are seen

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<sup>23</sup> M Andreasen, “Two Stories about Biotech Patenting from the ‘Silent Majority’ in Europe” (2008) forthcoming, *Public Understanding of Science*; M Andreasen, “Who’s Credible? Expressions of Conflict and Consensus in Focus Groups about DNA Patenting” (2009) 4 *BioSocieties* 25-43.

<sup>24</sup> RE Gold and A Gallochat, “The European Biotech Directive - Past as Prologue” (2001) 7 *European Law Journal* 331-366.

<sup>25</sup> S Borrás, C Koutalakis and F Wendler, “European Agencies and Input Legitimacy: EFSA, EMeA and EPO in the Post-Delegation Phase” (2007) 29 *Journal of European Integration* 583-600.

<sup>26</sup> P Drahos and J Braithwaite, *Information Feudalism: Who Owns the Knowledge Economy?* (London: Earthscan Publications, 2002); O Williams, “Life Patents, TRIPs and the International Political Economy of Biotechnology” in A Russel and J Vogler (eds), *The International Politics of Biotechnology* (Manchester: Manchester University Press, 2000) 67-84.

to put in place. Some held very positive expectations, others were rather more sceptical. The first indication of this was the strong spontaneous reactions expressed when the interview participants were first introduced to the concept of DNA patenting. People were generally surprised that a gene could be patented, and some found the thought outright appalling:

*B5: It's totally unethical. Because it's a gift, it's a thing that exists in Nature. You can't patent other organisms; it's a level below what one can own. Spontaneously, that is. Not that I have thought it through carefully.*

*B2: If you find the gene that cures cancer. Then you patent it, and others will have to ask you for permission to cure others. That sounds insane, because we all have those genes that we do, and then somebody patents something I have inside me.*

The quote illustrates that the sanctioning of DNA patenting clashes with deep-rooted ideas held by some members of the public about ownership and that the concept of DNA patenting was spontaneously understood as a radically new form of ownership. While there was initially some confusion as to whether the patenting of genes represented an example of physical ownership, the interviews demonstrated that the surprise and reluctance which participants expressed about the ownership of DNA also revolved around sensitivities about commodifying the body – many questioned the legal distinction between isolated genes and their existence as natural part of a person – and in particular about patenting “products of nature”. Hence, many did not think of human DNA as suitable subject matter for ownership. Some maintained this scepticism throughout the interviews, whereas others adopted a positive view during the process, demonstrating how views of DNA patenting conform to what is usually described in terms of a traditional political left-right spectrum. But most respondents continued to talk about the patenting of DNA as an exotic and, to some, problematic form of ownership.<sup>27</sup> Hence, there was a mismatch between a perceived extension of the property regime as sanctioned by the Biotech Directive and basic notions of ownership expressed spontaneously by the respondents.

### **5. Concerns about the influence of commercial incentives on medical decision making**

Another focus of concern was decision making under conditions of commercial interest. The actors identified by focus group participants as decision makers in the DNA patent field comprise members of the formal political system, researchers, industry representatives, and other actors working with patenting. Some respondents expressed a general confidence in the ability of regulators to contain the possible negative side effects of patenting. Others, however, were suspicious of the effects on decisions when patents are involved:

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<sup>27</sup> M Andreasen, “Two Stories about Biotech Patenting from the ‘Silent Majority’ in Europe” (2008) Forthcoming, *Public Understanding of Science*.

*A5. I think that it is really hard to control. And I am anxious about it, because I don't think that they are able to control it. Because I think that it will be all about profits when there is a patent. And then it will be the profit they will be pursuing.*

In this example, an unspecified “they” cannot help pursuing profits. The fear that the introduction of patents as commercial incentives would lead to changes in behaviour was common. It was associated with the fear that private incentives would undermine the ability of actors to properly care for others; a fear directed not only at research institutions but also at doctors:

*A6. The question is also whether the pharmaceutical industry doesn't just have more money. They throw in a good bit of marketing and some vacations. “I have some happy pills. Does it work – no, but I have some vacations.” That's the problem when there's money in it.*

This example illustrates that expressions of distrust are based on the view that judgments become biased, perhaps unintentionally, when they become embroiled in a commercialised system of medicine production. DNA patents are thereby associated by some respondents with a wider set of commercial incentives that change decision-making processes in ways that are potentially detrimental for patients. More generally, concerns were expressed about the effect of commercial incentives on the quality of health care. In some cases, the respondents even described the medical products delivered by the pharmaceutical industry as potentially medicalising and sedating the public:

*A4. There is also another dilemma in relation to where the boundary is between the medicine I really need and all the holes in our lives, where pills are filled in instead of something else we must have. It might be some human contact that's missing, and then you are given happy pills.*

*A3. Yes, or for instance the overmedication many people are subjected to in order to be pacified. Then you get it because there isn't...*

*A8. Enough resources for care.*

Hence, the focus group participants express a concern about what happens to medical decision making when decision makers are motivated by commercial incentives. Some even contrast commercial incentives with the pursuit of proper treatments:

*C1. If it is something that might serve all of us, then no one should patent it.*

*C2. Industry gets too much power if they...get to patent a gene.*

*C4. Then it will more be to earn money than to get the right cure.*

The commercial incentive that DNA patents represent relates to the expectation that, in the pursuit of commercial gain, the well-being of others is ignored. This can clearly not be seen as an overall expression of resistance against DNA patenting, but it is nonetheless seems to represent a widespread concern.

### **6. Plurality of views of DNA patents as a beneficial research incentive**

The preceding sections demonstrate how DNA patenting was perceived in the focus groups as a new and, to some, problematic kind of ownership and how it provoked concerns about the decisions made in the public health area. Partially overlapping concerns also centred on the legitimacy of DNA patents as instruments in research governance. Among the most salient issues was the fear that patenting within the life science/technology area would promote a more unjust world, that it would promote immoral types of research, and, more generally, that it would fail in its goal to promote scientific and technological progress. Again, however, the views about DNA patents were not homogeneously negative; some interview participants hoped that commercial incentives would promote public health goals by accelerating research activities. Differences between positions reflect differences in world view between what we have elsewhere called a communitarian ideal and a libertarian ideal of society. Such polarisations emerged in relation to both issues of justice, morality and technoscientific progress<sup>28</sup> and of credibility ascribed to “experts”.<sup>29</sup> Despite such differences, the respondents seemed to agree that medical research should always aim for the common good – the purpose of promoting public health was clear, only the means was contested. In the following, we offer illustrations of these points.

First, the respondents talked about patenting as part of a wider infrastructure using financial incentives to promote research. Some doubted the efficacy of such incentives:

*B6. I can't really see why research shouldn't be there if there were no patents. With patents, on the contrary, research can also be stopped – for instance, someone might say that you are not allowed to do that, if you don't pay enough. In that way, you may contribute to the repression of a development, a common development project. There's something in that kind of thinking that offends me. Lots of development has happened without patents.*

Others, however, were confident that commercial incentives can productively promote research and public health. The preceding comment was countered by two respondents taking a more positive view of commercial incentives:

*B4. I think that one has to consider the fact that it takes many years to research and develop medicine. It is very expensive, and in*

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<sup>28</sup> *Ibid.*

<sup>29</sup> M Andreasen, “Who's Credible? Expressions of Conflict and Consensus in Focus Groups about DNA Patenting” (2009) 4 *BioSocieties* 25-43.

*consequence it would be a shame if one is just about to get a product at the market, and somebody snatches it.*

*B7. I agree that there is lots of research we wouldn't have had, if there wasn't the carrot that you can make a profit.*

The reference to “the carrot” clearly describes profit as a means rather than an end. The overall purpose of medical research is not to make money; but money can stimulate research and in this way be beneficial in the long term. Some feared that DNA patents – as an example of health-related patents more generally – would promote a health care system based on market size rather than medical need. This view implies seeing incentives as potentially changing the outcome of research, rather than just speeding it up or rewarding it. In such cases, the incentive is viewed as interfering with the overall purpose. This was expressed particularly clearly when people voiced concerns about those in greatest need in developing countries. Accordingly, some participants blamed global inequalities in access to health care on the use of the patent system as an incentive in health research:

*F1. Yes, it is an interesting aspect: what diseases it pays to treat versus diseases in which research has a more humane aspect. For instance, malaria that countless people die from compared with Western life style diseases.*

*F5. There's more money in developing a pill against obesity than a cure for AIDS.*

*F1. You know, the thing about AIDS is interesting, no doubt, but the thing is that it has not been developed for the Africans' sake... It may appear a bit paradoxical that quite a bit of AIDS research is actually carried out, but the big infected majority is not going to benefit from it. For whose sake is it done? Exclusively for economic reasons, apparently.*

Also, in interviews about DNA patenting carried out in Canada and USA, concerns about unfairness were central.<sup>30</sup> The Canadians, however, were worried primarily about their own access to health, whereas the Danish respondents seemed more concerned about global injustice.

The focus group results suggest a mismatch between the reportedly *narrow* perspective on patenting held by the patent institutions (that some of the respondents are likely to endorse) and the *multiple* perspectives present among members of the general public. The mismatch is apparent on three levels: 1) as a clash between basic ideas about ownership – some do not think of human DNA as a suitable subject matter for ownership; 2) as concerns about bias in medical decision making created by patents; and 3) as concerns about the role of DNA patents in the promotion of public health. Among these, the latter two involve suppositions about the actual

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<sup>30</sup> EF Einsiedel, “Publics and gene patents” in EF Einsiedel (ed.), *Emerging Technologies: Hindsight and Foresight* (Vancouver: The University of British Columbia Press, 2008).

effects of DNA patents – those concerned imagine that a commercial research infrastructure creates decision bias and detracts from the public good of the health care system.<sup>31</sup> To better understand the developments of which DNA patenting forms a part, we now turn to a description of recent trends within research governance in Denmark. This will allow us to consider what is happening with regard to the issues of concern to some of the interview respondents and thus to investigate to what extent these concerns are justified. The point is not to somehow demonstrate the moral superiority of those who were concerned – other kinds of knowledge might support the expectations of those more optimistic – but to investigate whether voices of concern that emerged with some force in the discussions – and presently lack representation in patent institutions – can be dismissed simply as ignorant.

### **7. A research infrastructure in transformation**

The plethora of policy changes instituted over the past few decades contribute to what can be termed a *commercialisation* of the research infrastructure. An emphasis on translational medicine attempts to speed up the route from what is typically called “bench to bedside”, i.e. from laboratory research to clinical application. The Danish version of this policy trend is called shortening the path “from thought to invoice”, which is a very straightforward way of highlighting the underlying commercial ambitions. The policy landscape in this way draws on implicit assumptions about unidirectional innovations (*from bench to bedside; from thought to invoice*) which can all be questioned. More importantly, the policy changes reflect assumptions about the effect of commercial incentives. Because the focus group participants were so engaged in debates about commercial incentives, we first briefly outline some of the key measures used to enhance translational research through commercialisation and, in the following section, assess to what extent the potential implications of this commercialisation supports the expectations of those who are concerned about public health. First, we specifically address three interrelated sets of changes in the research infrastructure—changes in property structures, research management and funding, and oversight procedures—before outlining the potential implications. The changes in Denmark are part of an international trend and therefore described accordingly.

DNA patenting is emblematic of changing *property structures* in the life science fields. Based on careful reading of the reasoning in the various US court cases that have extended patenting to DNA and living organisms, Gold argues that US courts have employed a market logic according to which courts leave it to commercial incentives to drive innovation.<sup>32</sup> It is an innovation-friendly logic based on trust in the benign power of consumer demand. Not only has the realm of private property been expanded; the designation of appropriate property holders has also undergone change. Beginning in 1980 in the US with the Bayh-Dole Act, property rights to the research

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<sup>31</sup> The expectations expressed by the respondents are here treated as an expression of the world views present in the groups. Designating the basis of the social negotiation of DNA patenting as world views highlights the inextricability of “views” and “knowledge claims” in controversies over technoscience (e.g. M Douglas, *Risk and Blame: Essays in Cultural Theory* (London: Routledge, 1992); S Jasanoff, “Science and Citizenship – A New Synergy” (2004) 31(2) *Science and Public Policy* 90-94.

<sup>32</sup> ER Gold, *Body Parts: Property Rights and the Ownership of Human Biological Materials* (Washington D.C.: Georgetown University Press, 1996).

conducted in universities and hospitals have been transferred from the funding agency to individual institutions.<sup>33</sup> The goal is to make public research agencies act more like private companies by filing more patents and shortening the path from “bench to bedside”. In Denmark, individual researchers previously possessed property rights to their own research, but, in 2000, these rights were transferred to the universities to provide an incentive for the individual organisation to support translation of research into intellectual property. In Denmark, it is now mandatory for public research institutions to pursue commercially interesting intellectual property rights.

The patent incentive for public research institutions has been strengthened in Denmark through changed *research management and funding*. For example, public institutions that take out patents or generate money on spin-off companies are rewarded with additional public funds. It is common in other national contexts, too. Universities are not rewarded financially, however, when researchers serve as advisers to government or in other ways try to enhance the direct societal utility of their research. In some funding programmes, collaboration with commercial partners is rewarded with an extra share of the public funds; in others, only agencies collaborating with private partners can apply. The new collaboration requirements provide commercial partners extra leverage in determining the terms of the collaboration – and thus the research agenda. Medical research in general and clinical trials in particular have undergone a privatisation during the past fifteen years, and, in the US, less than 35% of trials are now conducted in public institutions.<sup>34</sup> The field of genetics has a higher collaboration rate with the private sector than other life sciences.<sup>35</sup> A counter trend to commercialisation can be said to be under way in the form of demands for delivering open access to the datasets generated with public funds.<sup>36</sup> However, commercial stakes exempt researchers from open access demands, and, in a highly competitive research environment, open access to all non-commercial datasets might provide a push towards commercial partnerships.<sup>37</sup>

In terms of *oversight procedures*, life science research is in many respects more tightly regulated than ever before, but even the oversight institutions are gradually becoming commercialised to facilitate smoother technology transfer and to ease public budgets. The European Medicines Agency (EMA) was established to attract more clinical research to Europe through accelerated application processing. EMA operates on an 80-20 budget: applicants seeking approval of new drugs should supply 80% of the cost of the approval procedure themselves, a condition that positions them as clients more than as applicants.

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<sup>33</sup> M Fernandes and D Miska, “Beyond Bayh-Dole and the Lambert Review: An Initial Product Development and Transactional Model for the Interface between Universities and Business” (2004) 21 *Biotechnology and Genetic Engineering Reviews* 249-276.

<sup>34</sup> JA Fisher, “Coming Soon to a Physician Near You: Medical Neoliberalism and Pharmaceutical Clinical Trials” (2007) 8 *Harvard Health Policy Review* 61-70.

<sup>35</sup> D Blumenthal et al., “Data Withholding in Genetics and the Other Life Sciences: Prevalences and Predictors” (2006) 81 *Academic Medicine* 137-145.

<sup>36</sup> Organisation for Economic Co-Operation and Development (OECD), “OECD Principles and Guidelines for Access to Research Data from Public Funding.” OECD, 2007.

<sup>37</sup> K Hoeyer, MN Svendsen and L Koch, “OECD Guidelines on Open Access: Commercialization in Disguise?” (2008) 26 *Trends in Biotechnology* 479-482.

The range and interconnectedness of these changes makes the tendency of focus group respondents to discuss DNA patents in relation to commercialisation of the research infrastructure in general appear quite relevant. This could be seen as relevant not just to those who are concerned about the consequences of DNA patenting; rather, these changes may be seen even by those more optimistic as unintended adverse side-effects potentially undermining, ultimately, the beneficial effects of the system. DNA patents are part of a transformation of the research infrastructure in which increased reliance on commercial incentives is central. In the following section, we outline some of the potential implications of these transformations as a way of assessing the changes in light of the concerns expressed by the focus group respondents. This should be read as an assessment of trends in light of the concerns expressed by some respondents, rather than as an attempt of a comprehensive review.

### **8. Implications of commercialisation**

As described above, the respondents agreed that the purpose of medical research ought to be improved public health, but disagreed about the extent to which commercial incentives supported that objective. In this section, we first analyse the impact of commercialisation in light of some of the stated objectives of the establishing commercial incentives. We then outline what we believe might be some unintended effects. The first part will reveal the difficulty in attempting to settle the disagreement among the respondents, while the second part will take sides with the concerned respondents and argue that commercialisation might indeed deter the objective of improved public health.

A recent report from the European Commission on private sector involvement in medical research suggests that it primarily has a positive impact on available products.<sup>38</sup> The report analyses the results of the policies enacted to support commercialisation and notes an increased number of products. However, it involves the classical methodological “with/without” problem: we only know the effect of the current funding and property regime, not what we could have had. Other studies also indicate that industry sponsorship of research is associated with more available end products, although the most significant breakthroughs tend to use results from research that received a long preceding period of largely public funding.<sup>39</sup> Mostly, the translation rate is low, irrespective of the source of financing.<sup>40</sup> It is even more doubtful whether the changed property structures have succeeded in making universities and public hospitals generate profit. A handful of elite American universities earn significant income on their patent portfolios, but few universities around the world generate profit on patents. Even in the US, only one in twenty university patents is ever licensed, and only 5% of the licensed patents generate

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<sup>38</sup> E Zika et al, “Consequences, Opportunities and Challenges of Modern Biotechnology for Europe” European Commission, Institute of Prospective Technological Studies, Spain, 2007.

<sup>39</sup> RA Bouchard and T Lemmens, “Privatizing Biomedical Research - A ‘Third Way’” (2008) 26 *Nature Biotechnology* 31-36.

<sup>40</sup> D Contopoulos-Ioannidis, E Ntzani and J Ioannidis, “Translation of Highly Promising Basic Science Research into Clinical Applications” (2003) 114 *The American Journal of Medicine* 477-484.

appreciable royalties. European universities fare even worse.<sup>41</sup> When Denmark transferred intellectual property rights to public research institutions, the financial results were meagre; when first evaluated, the annual patent application cost was around thirty-two million DKK and the revenue was approximately sixteen million DKK.<sup>42</sup> Of course, if the overall purpose is to promote technology transfer, i.e. to generate products, it is not absolutely fair to judge policies on revenue. There can be reasons other than profit generation for filing patents.<sup>43</sup> The differing viewpoints among the focus group respondents about the impact of increased reliance on commercial incentive structures cannot be easily reconciled.

We suggest, however, that policies enacted to create commercial incentives influence not only speed and profit generation but operate at a more basic level as an influence on the direction of the research conducted, e.g. the types of conditions researched and knowledge produced. This corresponds to our analysis of the concerns expressed by some respondents about research addressing market size rather than medical need. Such changes are mostly unintended, and they are difficult to measure. Specifically, with respect to DNA patenting, it has been suggested that property structures interact with the topics deemed appropriate for research and the way the research is conducted and interpreted.<sup>44</sup> Commercial incentives also influence the research agenda quite directly. In one study, a group of researchers studied 3,862 research careers to assess the impact of patent activity on scientific merit.<sup>45</sup> It was shown that commercial collaboration was associated with high scientific merit, but also with a research agenda systematically related to areas of commercial interest. Obviously, commercial partners must investigate what seems likely to generate profit. Unfortunately, the people struck by the worst health hardships rarely compose attractive markets and, accordingly, the global inequality in health that most focus group respondents found worrisome keeps growing.<sup>46</sup>

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<sup>41</sup> A Webster and K Packer, "Intellectual Property and the Wider Innovation System" in A Webster and K Packer (eds), *Innovation and the Intellectual Property System* (London: Kluwer Law International, 1996) 1-19; A Webster and K Packer, "Patents and Technology Transfer in Public Sector Research: The Tension Between Policy and Practice" in J Kirkland (ed.), *Barriers to International Technology Transfer* (London: Kluwer Academic Publishers, 1996) 43-64.

<sup>42</sup> Forsknings- og Innovationsstyrelsen, "Kommercialisering af Forskningsresultater. Statistik 2005" Forsknings- og Innovationsstyrelsen, København, September 2006.

<sup>43</sup> MM Hopkins et al, "The Patenting of Human DNA: Global Trends in Public and Private Sector Activity (the PATGEN Project)" SPRU, University of Sussex, 2006.

<sup>44</sup> J Calvert, "The Commodification of Emergence: Systems Biology, Synthetic Biology and Intellectual Property" (2008) 3 *BioSocieties* 383-398; S Hilgartner, "Mapping Systems and Moral Order: Constituting Property in Genome laboratories" in S Jasanoff (ed.), *States of Knowledge: The Co-production of Science and Social Order* (London: Routledge, 2004) 131-141; D Kevles, "A History of Patenting Life with Comparative Attention to Europe and Canada -A Report to the European Group on Ethics in Science and New Technologies" European Commission, January 2002.

<sup>45</sup> P Azoulay, W Ding, and T Stuart, "The Impact of Academic Patenting on the Rate, Quality, and Direction of (Public) Research" National Bureau of Economic Research, Cambridge, Massachusetts, 2006.

<sup>46</sup> A Petryna and A Kleinman, "The Pharmaceutical Nexus" in A Petryna, A Lakoff and A Kleinman (eds), *Global Pharmaceuticals: Ethics, Markets, Practices* (Durham and London: Duke University Press, 2006) 1-32.

Changes in the research infrastructure might influence the data generated in a different way, too. Meta-analyses of the impact of industry funding have shown that industry sponsorship of clinical trials is correlated with pro-industry conclusions, such as recommendation of specific products and relatively more expensive treatments.<sup>47</sup> Industry sponsorship is also related to pro-industry conclusions in terms of the assessment of risk of exposure to passive smoking or other environmental factors.<sup>48</sup> In this way, commercial incentives seem to influence the kind of data used to write up clinical guidelines. Furthermore, 87% of the authors of clinical guidelines in the US have ties to industry (we found no comparable data from Denmark).<sup>49</sup>

The research agenda might be influenced even more fundamentally by commercialisation. It is largely taken for granted that if products can be sold, somebody must need them. Recent scholarship suggests, however, that the pharmaceutical industry not only solves problems already in existence; its research is increasingly aimed at *framing* disease categories in ways that are commercially attractive.<sup>50</sup> Consultants working in the pharmaceutical industry now describe the work of drug development as one of creating a “drug narrative” involving fabrication of particular notions of disease.<sup>51</sup> It is much more commercially interesting to develop products that can be administered for longer periods of time (by people who can afford the product), than to develop one time cures or low-tech interventions. New disease categories such as erectile dysfunction, baldness and social phobia thereby emerge out of a potent interplay between assessment of medical need, market size, and new sick roles for people not previously seen as ill. When medical knowledge reacts to commercial incentives, fabrication of illness becomes as vital as its alleviation.

All in all, the commercialised research infrastructure might not just amount to a different (quicker) way of reaching the same research results as that reached in response to other incentives. The type of knowledge produced might very well be different, and therefore we should analyse research results as co-produced with the structure of incentives (in the broadest sense of the word) that facilitate them.<sup>52</sup>

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<sup>47</sup> JE Bekelman, Y Li and GP Gross, “Scope and Impact of Financial Conflicts of Interest in Biomedical Research: A Systematic Review” (2003) 289 *JAMA* 454-465; H Melander et al, “Evidence B(i)ased Medicine - Selective Reporting from Studies Sponsored by Pharmaceutical Industry: Review of Studies in New Drug Applications” (2003) 326 *British Medical Journal* 1171-1173.

<sup>48</sup> DE Barnes and LA Bero, “Why Review Articles on the Health Effects of Passive Smoking Reach Different Conclusions” (1998) 279 *JAMA* 1566-1570; L Friedman and ED Richter, “Conflicts of Interest and Scientific Integrity” (2005) 11 *International Journal of Occupational and Environmental Health* 205-206.

<sup>49</sup> T Caulfield, “Profit and the Production of the Knowledge: The Impact of Industry on Representations of Research Results” (2007) 8 *Harvard Health Policy Review* 51-60.

<sup>50</sup> D Healy, “The New Medical Oikumene” in A Petryna, A Lakoff and A Kleinman (eds), *Global Pharmaceuticals: Ethics, Markets, Practices* (Durham and London: Duke University Press, 2006) 61-84.

<sup>51</sup> A Matheson, “Corporate Science and the Husbandry of Scientific and Medical Knowledge by the Pharmaceutical Industry” (2008) 3 *BioSocieties* 355-382.

<sup>52</sup> M Weber, “Science as a Vocation” in HH Gerth and CW Mills (eds), *From Max Weber: Essays in Sociology* (New York: Oxford University Press, 1947) 129-156.

Accordingly, the interest expressed by focus group members in a research agenda that would favour medical need over financial incentives – the goal shared despite disagreement about the role played by patents to this end – might deserve further attention.

## **9. Discussion – broadening the concept of expertise**

The paper started by comparing the present relationship between policy making and the general public in the area of DNA patenting with the policy and normative writings about “democratising” technoscience. Concluding that the absence of public consultation is somewhat anomalous, in the following sections, we demonstrated a mismatch between the narrow perspectives of present policy and patent institutions and the variety observed among a qualitatively broad selection of members of the general public. We show that this mismatch cannot be ascribed to an instance of ignorance – on the contrary, some of the concerns expressed about the ability of market-based public health to promote the common good seem quite justified.

Our study offers knowledge about how ordinary citizens feel affected by the use of DNA patenting. Concerns about the use of DNA patents centre on problems with bias and with the direction of research, particularly in health and medicine, concerns that we argue are well-founded when viewed in the light of current developments in and effects of the commercialisation of public health research. This knowledge could be used as the starting point of efforts to produce a more socially robust patent system in the life science area. Although our study illustrates a plurality of views, rather than universal reluctance, among members of the general public, the plurality nonetheless contrasts with the reportedly homogeneous institutional perspective on patents:<sup>53</sup> a profoundly commercial perspective that has been criticised as marginalising other views and strongly influencing policy as well as practice.<sup>54</sup>

As defined within the discourse of citizenship in science, technology and society studies (STS), this makes DNA patenting an obvious candidate for consultation with the general public as a way of increasing the public legitimacy of DNA patenting. We believe, however, that it can be perfectly justifiable for policy makers to balance the wish to embrace public concerns in a specific area (such as DNA patenting) against other priorities in the commitment to ensure the overall, long-term good of society. But we consider knowledge about the concerns of those affected to be an absolutely indispensable input to such an assessment. Hence, our criticism of the present state of affairs is primarily *procedural*: it is not about the actual decisions that have been made; rather, it is about how the system is fashioned to ensure its legitimacy through

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<sup>53</sup> S Borrás, C Koutalakis and F Wendler, “European Agencies and Input Legitimacy: EFSA, EMeA and EPO in the Post-Delegation Phase” (2007) 29 *Journal of European Integration* 583-600.

<sup>54</sup> P Drahos and J Braithwaite, *Information Feudalism: Who Owns the Knowledge Economy?* (London: Earthscan Publications, 2002); O Williams, “Life Patents, TRIPs and the International Political Economy of Biotechnology” in A Russel and J Vogler (eds), *The International Politics of Biotechnology* (Manchester: Manchester University Press, 2000) 67-84; ER Gold, *Body Parts: Property Rights and the Ownership of Human Biological Materials* (Washington D.C.: Georgetown University Press, 1996); S Harmon, “The Rules of Re-Engagement: The Use of Patent Proceedings To Influence the Regulation of Science ('What The Salmon Does When Comes Back Downstream')” (2006) *Intellectual Property Quarterly* 378-403.

involvement of and definition of its stakeholders. As is customary in relation to important policy changes, also the patent authorities have increasingly made an effort to consult the most important stakeholders. They should include the general public in that group. Moreover, the discrepancy between institutional logics and the broadness of understandings in this public – none of which can simply be rejected as “unfounded” – points to the public understanding of DNA patents as a resource, an opportunity, for socially more robust policy making.

Even though our interviews have shown that people see DNA patenting as a matter that affects society more broadly rather than themselves personally, this effect is not just something abstract: they find the organization of society in relation to public health to be consequential. They contribute to decision making with accounts of DNA patenting that are culturally embedded (i.e. underpinned by discernable world views) but also connected to citizen experience (e.g. about the effects of different kinds of actions and motivations on the provision of public health). The latter positions the average citizen as someone who is relevant in policy making for his or her view of and feeling of affectedness (perhaps a kind of “experiential expertise”).<sup>55</sup> We have suggested that there is a tendency to focus public consultation on specific technologies while remaining inattentive to political choices regarding the design of the research infrastructure. Furthermore, we have suggested that this prioritisation may relate to the fact that the average citizen holds no direct bargaining power to influence infrastructural issues. Our point is not to accuse anyone of obstructing public consultation on DNA patenting. No doubt there is an element of fortuitousness in the employment of public consultation, by virtue of which an endless number of life science topics have avoided it. However, by drawing on focus group material, we have shown that from the perspective of the discourse of citizenship, there is no relevant difference to justify the inconsistency in topics chosen for public consultancy that should render research infrastructure issues unexamined.

Our endorsement of the consultation of the general public reflects our subscription to a democratic model of the public understanding of science. We believe that the views of the general public should inform policy efforts to design the research infrastructure for life science and technology development, and we think that our results testify to their competence in deliberating on such matters. Conversely, our effort to compare the concerns expressed against documented facts can be seen as conflicting with a view of average citizens as competent. Whereas the respondents disagree about the use of private incentives as a means to promote public health, even those arguing in favour of such incentives find that the outcome should be evaluated according to the degree that it fulfils medical need. Given that the commercialisation of research potentially leads to pro-industry bias, to changed research agendas and to neglect of the world’s poorest inhabitants, those more supportive of DNA patenting are indirectly described as lacking knowledge about the effects of commercialising the research infrastructure. This can be seen as reintroducing a sort of *deficit*

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<sup>55</sup> See e.g. HM Collins and R Evans, “The Third Wave of Science Studies: Studies of Expertise and Experience” (2002) 32 *Social Studies of Science* 235-296; BM Myskja, “Lay Expertise: Why Involve the Public in Biobank Governance?” (2007) 3 *Genomics, Society and Policy* 1-16.

*representation* of the public understanding of DNA patenting;<sup>56</sup> we can be read as implicitly claiming that, if people knew more, they would be more sceptical. Usually, the deficit model has been the guiding (albeit tacit) motif among technocrats and others who explained popular scepticism about technoscience as expressing a lack of scientific knowledge. A standard reply has been that this conclusion presupposes a consensus about the positive meaning of technoscience.<sup>57</sup> One of the starkest blows to the deficit model has been the finding that more knowledge is only very weakly correlated with more positive attitudes.<sup>58</sup> This also presupposes consensus about how to interpret the “facts”.<sup>59</sup> Accordingly, we do not think that the portrait of current developments painted above would, in fact, change the opinions of all respondents. Whereas some people might become very concerned upon hearing our analysis of the implications of patenting on knowledge production, others might reject its relevance or emphasise expected benefits from patenting; they might even reject the negative depiction of commercialisation of research infrastructure as biased. If our expertise were to gain political influence in line with other types of expertise, it, too, could be presented with a demand of “democratising expertise”.<sup>60</sup> We believe, however, that it is important to avoid thinking of democratisation as a form of delegation which could solve the problem of expertise altogether. We do not subscribe to a model of unmediated public consultation; rather, we wish to emphasise the analytical responsibility that consultation entails. Any consultation involves a construction and interpretation of public interest. Rather than seeing consultation as an unmediated access to the public, to let them decide, we think consultations could be viewed as experiments concerning the credibility of *different* types of expertise. We share with the respondents themselves a belief in the importance of underpinning understandings with expert knowledge and the interest in drawing on several types of expertise. In several studies, members of the general public have been shown to position themselves within a deficit model of the public understanding of science and thus to canonise universal forms of knowing while downplaying their own competence and role in decision making.<sup>61</sup>

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<sup>56</sup> B Wynne, “The Public Understanding of Science” in S Jasanoff et al (eds), *Handbook of Science and Technology Studies* (London: Sage, 1995) 361-388; A Irwin and B Wynne, “Introduction” in A Irwin and B Wynne (eds), *Misunderstanding Science?* (Cambridge: Cambridge University Press, 1996) 1-17.

<sup>57</sup> P Sturgis and NC Allum, “Science in Society: Re-Evaluating the Deficit Model of Public Attitudes” (2004) 13 *Public Understanding of Science*, 55-74.

<sup>58</sup> NC Allum, D Boy and MW Bauer, “European Regions and the Knowledge Deficit Model” in MW Bauer and G Gaskell (eds), *Biotechnology: The Making of a Global Controversy* (Cambridge: Cambridge University Press, 2002) 224-244; H Peters, “From Information to Attitudes? Thoughts on the Relationship between Knowledge about Science and Technology and Attitudes towards Technologies” in M Dierkes and von Grote (eds), *Between Understanding and Trust - The Public, Science and Technology* (London: Routledge, 2000) 265-287.

<sup>59</sup> EF Einsiedel, “Understanding ‘Publics’ in the Public Understanding of Science” in M Dierkes and C von Grote (eds), *Between Understanding and Trust: The Public, Science and Technology* (London and New York: Routledge, 2000) 205-215.

<sup>60</sup> H Nowotny, “Democratizing Expertise and Socially Robust Knowledge” (2003) 30 *Science and Public Policy* 151-156.

<sup>61</sup> N Wright and B Nerlich, “Use of the Deficit Model in a Shared Culture of Argumentation: The Case of Foot and Mouth Science” (July 2006) 15 *Public Understanding of Science* 331-342; M Andreasen, “Who's Credible? Expressions of Conflict and Consensus in Focus Groups about DNA Patenting”

By reintroducing the call for multiple forms of expertise, consultation can provide a valuable input to the policy debate. Consulting the public can be valuable regardless of how members of the public rank themselves. This is because the choice of how to use patents in the research infrastructure is, in essence, a choice about the values and preferences that guide our research governance. This may seem like a trivial point, but the debate – and even the legal literature – is full of attempts to naturalise the recent expansions of intellectual property.<sup>62</sup> By reintroducing multiple values and world views, the general public stimulates the use of several types of expertise.

Bureaucratic patent institutions have come to embody and propagate the type of world view held by only some members of the general public. But the patent system influences everybody. The system is guarded from spontaneous protest because the average citizen holds no direct bargaining power. As a result the general public is dependent on the active arrangement of consultations to introduce a plurality of world views as a basis for the balancing of different measures used in research governance through the property regime. The general public has been excluded “from decision making on the ‘hard issues’ such as research funding, patenting or the regulation of the healthcare system”.<sup>63</sup> This can be interpreted as convenient manoeuvre facilitating neoliberal policies in research governance or simply as the effect of a habitual logic deeming some topics more relevant for public consultation than others. We believe, however, that when policy making is informed by a wider spectrum of world views, it stands a better chance of generating not only more legitimate but also more robust policies. Public consultation may produce input to policy making that brings nuances, legitimacy and robustness into the political process. It may be seen as *productively* halting the technocratic machinery. The concept of the general public can be and has been used for legitimising purposes,<sup>64</sup> but this does not subtract from its importance in policy making. In the end, good life science governance is about the integrity and happiness of *all* of those affected, not just those who are engaged or making noise, and for that purpose techniques for elucidating a plurality of views can prove most valuable.

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(2009) 4 *BioSocieties* 25-43. See also U Felt and M Fochler, “The Bottom-up Meanings of the Concept of Public Participation in Science and Technology” (2008) 35 *Science and Public Policy* 489-499; M Michael, “Ignoring Science: Discourses of Ignorance in the Public Understanding of Science” in A Irwin and B Wynne (eds), *Misunderstanding Science?* (Cambridge: Cambridge University Press, 1996) 107-125.

<sup>62</sup> DB Resnik, “Discoveries, Inventions, and Gene Patents” in D Magnus, A Caplan and G McGee (eds), *Who Owns Life?* (New York: Prometheus Books, 2002) 135-159; D Kevles, “A History of Patenting Life with Comparative Attention to Europe and Canada – A Report to the European Group on Ethics in Science and New Technologies.” European Commission, January 2002; RK Seide and CL Stephens, “Ethical Issues and Application of Patent Laws in Biotechnology” in D Magnus, A Caplan and G McGee (eds), *Who Owns Life?* (New York: Prometheus Books, 2002) 59-73.

<sup>63</sup> H Gottweis et al, “Participation and the New Governance of Life” (2008) 3 *BioSocieties* 265-286, at 277.

<sup>64</sup> *Ibid*; and J Hansen, “Operationalising the Public in Participatory Technology Assessment: A Framework for Comparison Applied to Three Cases” (2006) 33 *Science and Public Policy* 571-584.