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Despite recent evidence that suggests that knowledge production within the medical community is increasingly based on knowledge-making coalitions or what some have called the co-production of knowledge, there remains a strong expert led policy agenda in many countries in relation to human genome research. This article reports on the role of experts in defining the scope of discussion in relation to the biomedical use of human tissue sample collections or biobanks in Finland using the case of the Genome Information Center. It is argued that the rhetorical strategies should not be understood simply as subversive tactics, but rather as ways of engaging the public within particular contexts of creating commercial expectations and visions which are easier to negotiate from a policy perspective.

1. Introduction

Recently, Hess (2004: 706) has called for a more detailed study of emerging "knowledge-making coalitions" in biomedical research communities in an attempt to gain a more robust theoretical understanding of medical modernization (see also Brown and Zavestoski, 2004). The underpinnings of medical modernization are said to be rooted in the epistemic challenge that is being mounted by health social movements (HSM) and complementary and alternative medicine (CAM) professions against what Hess calls paternalistic progressivism. Research on medical modernization is also closely related to what Nowotny et al. (2001: 54) describe as the emergence of social conditions that allow, and necessitate, that "society is able to 'speak back' to science." The public shaping of science has indeed gained an important role in current social studies of the public's role in a number of research fields, including environmental movements and patient advocacy groups (Kerr et al., 1998; see also Fuller, 2000). Collins and Evans (2002) have argued that we are witnessing a "third wave" of science studies that they label as Studies of Expertise and Experience (SEE). Along these lines, Barry (2001: 2) has suggested that the technological society brings forth a "political preoccupation with the problems technology poses, with the potential benefits it promises, and with the models of social and political order it seems to make available."

This paper critically explores the emergence of medical modernization in relation to interpretations of the scope of informed consent in genome research in Finland. Despite an emerging trend in many countries in which either the authority of the medical community is being challenged or knowledge is increasingly co-produced (Nowotny et al., 2001), the authority of the medical research community in some countries is moving along very

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different paths of development in relation to the public and the development of more open forms of political action. This suggests that the strategic maneuvers by experts to strengthen the epistemic authority of modern scientific medicine and its "paternalistic" tendencies indicate very different trajectories of development (see Häyrinen-Alestalo and Kallerud, 2004; Häyrinen-Alestalo et al., 2004).

In this context, I am connecting the theoretical discussion surrounding medical modernization with what has been called an "economy of hope" in biomedicine as a powerful symbolic and rhetorical tool (see Franklin, 2003; Helén, 2004). Similar analysis of developments in biomedicine can also be found in the emerging field of sociology of expectations (Brown, 2003; Brown and Michael, 2003), where attention is directed towards the rhetorical strategies that scientists deploy. The notion of an "economy of hope" both moves the attention of analysis beyond epistemic questions relating to truth within the sociology of scientific knowledge, and extends the analytic framework of expertise and experience (SEE) to what I call Studies of Expectations and Visions (SEV). What differentiates SEV from SEE is the emergence of an amalgam of claims to truth/validity, and extension of expertise with the creation of visions of hope and a culture of expectations. As Helén (2004: 16) notes "the objects of profit seeking, are not primarily certain drugs or medical devices, but *prospects* of hope. The production, exchange and, to some extent, also consumption is entirely oriented toward the future. Therefore, this economy is virtual and, in fact imaginative, based essentially on expectations" (emphasis in original).

This hypothesis would suggest that policy models where the relationship between experts and the public is seen in terms of diffusion of expert knowledge to the public are not necessarily under threat in some contexts, but rather are being increasingly built upon a different framework. Such trajectories, however, require that expert–lay relationships be developed within particular frameworks which present themselves as natural and useful from the perspective of experts, as well as the general public. It is argued here that some scientists deploy arguments that the public has an easier chance of relating to, as opposed to scientific explanations alone. In relation to biomedicine, the economic aspirations of biomedical research have become a popular trajectory on to which expectations and national sentiment in relation to science can be based.

The strategies and tactics of experts are explored through an analysis of Finnish biomedical research and an emerging strategy to develop a national Genome Information Center in Finland, which would have access to a broad set of, already existing, tissue sample collections, patient health care information contained in the public health care system and other population registers—such as the cancer registry—and provide the basis for future collections as well. Although the case is quite similar to those in Iceland, the UK and Estonia, the Finnish case exhibits characteristics that seem to suggest that despite strong criticism in these countries, the authority of experts in Finland remains strong and plays an important role in activating public resources, by enlisting and developing a public sense of hope and opportunity. This suggests that the public is seen to have a dual role in decision making: on the one hand the public is expected to passively accept the visionary discourse of experts on development and research agendas, but at the same time they are also being recruited to be active supporters and encourage expert activities and agendas as a normative national project that needs to be carried out (cf. Snell, 2002). I argue that the construction of the passive/active citizen is considered by many as a necessary condition of, not only the medical modernization project in Finland, but also the development project of Finland as a leading knowledge economy (Häyrinen-Alestalo, 2001).

The material for this research has been collected from 36 interviews conducted between 2001 and 2005 with research scientists, medical doctors, government officials, as well as

other experts involved in various aspects of the use of human tissue sample collections and population registers in Finland. The interviews consisted of open ended questions related to the expectations that actors had in relation to biomedical research, its relationship to national science and technology policy and the most important issues that they thought needed to be addressed. The development of science and technology policy in Finland has been characterized as corporatist where a small group of major actors, such as representatives from the Ministry of Trade and Industry and Ministry of Education, help develop national policies through institutions such as the National Science and Technology Policy Council (see Pelkonen, 2004). Thus the number of key actors remains relatively small within the Finnish context.

Interview material has been supplemented with official government documents and policies—both national and international—legislation, various statistics and technical documents on tissue collections and their biomedical applications collected from 2000 to the present, as well as popular texts written by researchers who are working towards setting up the Genome Information Center itself. Both the written material and interviews were analyzed within the context of the sociology of expectations to highlight the strategies used to shape and order the information that is deemed important by experts, as well as enlist the support of readers of particular texts (see Myers, 1991; Douglas, 2005). The strategies of experts in biomedical research involving large human tissue sample collections are contextualized in light of increasing commercial expectations associated with such population information resources and their relation to the contexts in which new biomedical knowledge is being produced (Brown, 2003; Brown and Michael, 2003; Väliverronen, 2004).

2. Biobanks, publics and the expert agenda

Research on the biomedical collection and use of tissue sample collections, often referred to as biobanking, is producing an increasing body of literature on the ethical, legal and social implications of such activities (see for example Hansson and Levin, 2003; Knoppers, 2003; Waldby, 2002a), as well as discussions on the relationship between the source of samples (patients and donors) and the way the samples themselves are used. In particular, the increasing commercial expectations that are attached to biomedical research have increased the relevance of arguments that are deployed in the organization of public resources and scientific research. Although this body of research is often centered around particular countries as case studies, such as the Icelandic health sector database (Rose, 2001; Pálsson and Harðardóttir, 2002), UK Biobank (Kerr, 2004), or UmanGenomics (Hoeyer, 2004), there is clear evidence that a critical issue in these debates is the exploration of alternative views to medical expertise and agendas through the study of public opinion and action (Waldby et al., 2004). Such a trajectory would seem to indicate that the modernist medical project associated with the production of biomedical knowledge derived from tissue sample collections is being brought under question through sociological, philosophical and anthropological inquiry into the ways in which patients and donors relate to samples as extensions of their identities, and bodies, as well as the way in which such material is utilized in biomedical research and to what ends. The case of PXE International is a good example of the way in which the parents of two children who suffer from pseudoxanthoma elasticum (PXE) set up a non-profit organization to coordinate and collect resources (both financial, as well as tissue samples) to support the research of the rare disease (see Waldby and Mitchell, 2006). Since large pharmaceutical companies did not consider the study of a rare disease as

financially lucrative, parents began to organize and mobilize themselves in an effort to develop a cure.

Waldby (2002b: 240) has argued that despite technical attempts to detach bodily fragments from the donor by denying property rights (see also Beyleveld and Brownsword, 2000), there is a large body of evidence that illustrates how, in many cases, these fragments "retain values of personhood" for donors (Schepher-Hughes, 2001). Biomedical research that relies, to an increasing degree, on the availability of different types of fragments of the body—ranging from ova and sperm to epidemiological sample collections containing thousands of samples—would appear, according to many authors, to have to account for such a retention of values in some way in order to avoid conflict and encourage future access and availability of such resources. Corrigan and Tutton (2006) for example have pointed out how the term "research subject" has increasingly been replaced by the term "participant" in many medical guidelines and policies in an attempt to highlight the role of participation and public engagement in biomedical research, despite according to them, that in practice the change in terminology has meant very little in terms of the rights of the individual and could be considered inappropriate. The technical approach would therefore also have to position itself in such a way that would not undermine the epistemic authority of existing knowledge production regimes in biomedical research using collections of bodily fragments.

Nowotny et al. (2001: 23) argue that the development of science and technology has enlarged the "territory" of the political, especially in biomedicine, in a way that requires increased negotiation with the public sphere, which they refer to as the *agora*. They argue that "this is no longer the domain of a relatively closed bureaucratic-professional-legal world of regulation, but of broader cultural-political movements embodying antagonistic forms of interaction which have become part of the repertoire of how novel technologies are embedded and research products come to be accepted and used in wider social contexts." This would appear to be related to the epistemic challenge, which Hess (2004) discusses, to the new modes of knowledge production, such as the *agora*, by providing new contexts and actors who can participate and influence the knowledge production process itself, as well as challenge existing power structures.

Within the context of an increasing body of evidence that indicates a growing concern among actors between the body/patient and its fragments, as well as new knowledge production contexts, the case of biomedical research in Finland appears, however, as an anomaly that suggests the emergence and development of a system of human tissue use in research that does not correlate to the developments in many of the aforementioned countries, such as the UK. This development relies to a large extent on a very different type of relationship between experts and the public, where the trust of the public in expertise and experts has not been eroded and the territory of political interaction has remained relatively limited. Concomitantly, such a situation gives rise to new possibilities for experts and policy makers to influence the public in terms of the development and implementation of science and innovation policy in Finland.

The use of large epidemiological sample collections in genome research has raised numerous issues concerning the status of informed consent in re-using samples for purposes other than what they were originally intended for. Given that samples can be used decades after they have been collected the possibility of gaining re-consent is considered by many difficult or impossible because of the large number of samples and the fact that some patients might have died. Despite this challenge, a number of recent international declarations and conventions, such as the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being (ETS 164),[1] clearly emphasize the rights of the patient in decision making and that appropriate public discussions are organized when

necessary (Article 28). Finland, like most EU countries is a signatory to this convention and has changed its national legislation accordingly in 2001. Some have noted, however, that a major challenge with the declaration is that it does not specifically address the status of stored human tissue and as a result, there should be flexibility in the interpretation of both the informed consent clause for re-using samples already collected, as noted in a document prepared by members of the National Medical Research Ethics Council (Aromaa et al., 2002), as well as the way the public is consulted.

3. The public and trust in experts

Despite recent national and international concern for the public's distrust of institutions and politics, the Finnish public has consistently shown a high degree of trust in universities, science and the scientific community (Eurobarometer, 2002). Even more interesting is that in a representative questionnaire of 1054 Finns, the two most trusted institutions in Finland are the police and the military, followed by VTT (government research institution) and universities. In addition, the questionnaire indicated that 57 percent of Finns either agreed or agreed strongly that scientific research was significant in terms of social and economic development (Tieteen tiedotus ry., 2004: 37, 40). Such trust in government institutions is very different from the levels of trust that are shown for these same institutions in other countries, such as the UK.

Many researchers have noted that one reason for the public's distrust of medical expertise has in part developed in response to cases of medical impropriety. Trust in experts in the UK, for example, has suffered due to incidents, such as those at Alder Hey and Bristol Royal Infirmary, which raised a number of important questions concerning trust in the medical community. This has also been reflected in a heightened ethical and legal concern in the setting up of UK Biobank (see Tutton and Corrigan, 2004). This, however, does not explain the differences that exist between the UK and Finland in terms of trust towards the medical or research community more generally. In early 2005, the Finnish National Authority for Medicolegal Affairs (TEO) restricted the medical license of professor Urpo Rinne because he had neglected to provide appropriate care for his research subjects, all of whom suffered from Parkinson's disease. In a number of instances involving younger patients, Rinne had prescribed levodopa, despite the fact that it was known to produce uncontrollable movements and that there were alternative treatments that were considered more effective and safer. In other cases, he had delayed the commencement of treatment for up to one year. All in all, the misconduct and poor treatment had lasted for years and affected a large number of patients under his care (TEO, 2005). In another case, Finland's most cited medical researcher, Academy professor Jaakko Tuomilehto received an official reprimand from his employer, the National Public Health Institute, for violating good research practices by failing to gain the necessary permits through the required ethics review boards, as well as failing to acquire informed consent from patients in his research. The violations included 441 samples from 108 families that were sent to deCode Genetics without the acquisition of any type of permits or the existence of any contracts (National Public Health Institute, 2005).

Trust in experts, as well as the level of participation that the public is afforded regarding new genetics, is also uneven depending on what research areas are involved. Häyrinen-Alestalo and Snell (2004: 70) note that when the Law on Gene Technology (377/95) in Finland was revised in 2000, a passage concerning the hearing of the public was added to the text. In 2005, an Academy of Finland research program (ESGEMO) announced that it

would hold a public discussion concerning field trials for a genetically modified, non-flowering variety of birch tree. Earlier field trials resulted in activists destroying the field trial lot by cutting down the trees thus preventing the research from continuing. In biomedicine there have been a number of workshops and seminars concerning ethical and legal aspects of the use of human tissue sample collections, but for the most part these have been directed towards experts and not towards a discussion with the public.

Despite the fact that there have been a number of incidents where doctors have been found guilty of research improprieties and the level of public activism differs between different areas of biotechnology, Finland has not experienced a drop in trust in the authority of medical experts, as in other countries. As one molecular biologist noted concerning the willingness of people to participate in large population studies:

> The work of the National Public Health Institute is based to a large extent on large-scale longitudinal studies and they are possible as a result of the willingness of people to participate. That willingness disappears if we lose people's trust. This might sound flowery, but it's not. As a researcher in Finland one begins to appreciate more and more the high participation rates in relation to other countries. (Molecular biologist, 10 February 2005)

This anomaly in the level of trust in institutions and experts between Finland and many other European countries is an important contributing factor to strategies utilized and opinions expressed by Finnish experts relating to the proposition of the development of the Genome Information Center. In the following section I will outline the main developments of this recent trajectory in the relationship between the medical community's authority and the public, as it pertains to the proposed organization of the Finnish Genome Information Center.

4. Setting policy

In comparison to the broad range of discussions that have emerged out of the Icelandic government selling exclusive rights for the health sector database to deCode (Rose, 2001) and the discussions that have taken place in the UK concerning the setting up of UK Biobank, the discussions in Finland concerning the biomedical use of tissue sample collections have been related to the economic and commercial aspects of such ventures. The development of the Finnish Genome Information Center evolved from a commissioned study by the Finnish National Technology Agency (Technomedicum, 2003) on the possibility to utilize the extensive sample collections, as well as other population data available in a number of public databases, and has brought forth a discussion that has been led to a large extent by those who are involved in the development of the Finnish Genome Information Center, namely the researchers themselves and government officials.

This development was related to the initiative by the Academy of Finland (2003) to develop an affiliate molecular medicine research center that would serve as a satellite to the European Molecular Biology Laboratory (EMBL). In practical terms, the initiatives would require the more complete and efficient use of existing tissue sample collections, as well as other population information registers in order to support, not only science policy goals, but innovation policy goals as well. In the Academy initiative, it is noted:

> Compared to many other countries or regions, one of the Nordic countries' greatest strengths is its extremely wide-ranging and high-quality population-based registers, and patient and sample databases, whose compilation has been extremely well-received

> by decision-makers, researchers and the general population. (Academy of Finland, 2003: 16)

The policy discourse of the Academy itself reflects the way in which the public trust in the medical research community has been a major contributing factor to the collection of existing sample collections for various studies, but it also reflects the possibility that the positive view on research has for setting up a new Genome Information Center and the re-use of the existing collections in other research projects.

The Finnish National Technology Agency (Tekes) report on the utilization of large Finnish study cohorts in genome research focused on nine major studies that have been undertaken in Finland during the past ten years and represent a total of 190,000 existing samples with associated health care data. All of the epidemiological study cohorts have access to "relevant national registries, the most important being the Death Registry, the National Hospital Discharge Registry, the Cancer Registry, and the National Registry for Reimbursed Medicines" (Technomedicum, 2004: 6). In addition, the study focused on the applicability to use autopsy samples for research purposes. Because the autopsy rate in Finland has been quite high the number of available autopsy samples is over two million. The report suggests the setting up of a research system that would utilize a database federation infrastructure through which different projects could collaborate and combine different information resources. The center would therefore be a major boost to the internationalization of Finnish biomedical research, which has been emphasized in policy documents.

The set-up of the Genome Information Center involves two different, yet interrelated, forms of engagement with non-experts, both of which are a challenge to implement by experts. The first relates to whether or not researchers are required to re-gain informed consent for samples originally taken for another research project. The second engagement involves the policy aspects related to the organization and utilization of national resources.

For the first form of engagement, experts have tried to introduce a more liberal interpretation of informed consent where patients authorize research, but are not necessarily informed of the exact research that the samples will be used in (see Caulfield et al., 2003). This would clearly indicate that patients are seen as research subjects, as opposed to participants and that bodily fragments do not necessarily retain values of personhood, as suggested by Waldby. As a member of the National Advisory Board on Health Care Ethics commented in an interview on a document (see Aromaa et al., 2002) prepared on the epidemiological use of DNA samples:

> It was a brave and open-minded working group that wanted to provoke discussion about what was really worth protecting and tried to interpret as loosely as possible the existing laws on informed consent. . . . We wanted to challenge the existing notions by asking why one couldn't apply for a permit from the National Authority for Medicolegal Affairs for re-using samples originally taken for research, the same way one can do for samples originally taken for diagnostic or treatment purposes. The legislators and the Ministry for Social Affairs and Health have not yet reacted to this . . . in part due to the international legal obligations we have, which state that every time you develop a new purpose for the samples you should re-gain consent. (Member of National Advisory Board on Research Ethics, 19 October 2004)

The dilemma of how to interpret the scope of informed consent remains open, although Finland is preparing a new law specifically on biobanking, much like Sweden has done. Most researchers agree that to re-gain informed consent every time one develops a new

purpose for samples is not practical and hinders the progress of research, although a study has shown that gaining re-consent for large population research projects is quite feasible (Stegmayr and Asplund, 2002). At the same time, however, all agree that a regulatory framework through which permits would be gained is necessary to control and regulate research activities. It is important to note, however, that although the issue of informed consent is considered by many a cornerstone of patient–doctor trust and medical ethics, the loosening of the interpretations of informed consent has not involved the public in any way. In relation to medical modernization, the development of a policy that circumvents patients in terms of re-consent and introduces a medicolegal authority to act in the place of the patient could be said to represent the strengthening of medical paternalism, as opposed to the broadening of any possibilities to influence the decision-making process. In comparison to the Law on Gene Technology, there is also no formal requirement to have public hearings in order to find out what the public thinks of biomedical policy. Instead, what has emerged is an expert strategy that attempts to appeal to the public sense of urgency and hope.

In the following, I will examine the ways in which experts have framed the discussion surrounding the context of the general discussion relating to the policy aspects of genome research and the use of tissue sample collections.

5. Framing the context of discussion in Finland

The use of large collections of tissue samples that can be connected to numerous population information registers using social security numbers, as well as the ability to use autopsy samples for research purposes is a major undertaking that would necessitate some type of dialogue with the public as to the goals and ways in which these study and diagnosis samples could be used, such as in the UK. This is clearly stated in the international documents mentioned above and which Finland has signed and ratified.

Jallinoja and Aro (1999) have noted that Finns have a high level of trust in the health care system, as well as in genetic researchers. At the same time, however, they maintain fears concerning research on their own or their children's genes. This would appear to indicate that the trust relationship between researchers and their subjects is not straightforward (see also Eurobarometer, 2002; Kuusi, 2004: 104). The somewhat tenuous trust relationship between experts and the public does not mean that the question of whether or not to set up the Genome Information Center is self evident. Instead, recent writings by researchers reflect a strong imperative to frame the discussion in terms that are favorable to the research community while at the same time allowing the public to have an opinion, but only on certain issues. Given the fact that Finns are more hesitant about research on their own and their children's genes, while at the same time having a high level of trust for the researchers themselves, it is important to frame the discussion in terms that do not create suspicion and fear.

The views of Finnish biomedical researchers, however, in general indicate a strong feeling that the public trusts them and researchers can assume broader liberties in, for example, interpreting the scope of informed consent. As one molecular biologist noted:

> In short, I would like to see consent to be interpreted rather broadly, and that one would not be required to get re-consent. Getting re-consent for every new gene or new research is based on our very naïve assumption that we know what schizophrenia or hypertension is. . . . It's [public trust] definitely a competitive advantage! It indicates that past doctors have done something right because the average Finn, at a European level, regards medical research very positively. . . . This is a fantastic competitive

> advantage and maintaining this level of trust is a great challenge to gene researchers, as well as medical researchers. (Molecular biologist, 31 March 2003)

Relating the trust that the public has in researchers to the competitive aspects of international scientific research is an important framework into which discussions of science policy are increasingly framed. It also reflects a trajectory in the epidemiological research community that stresses the long-term nature of their research, where investments made today are part of a new infrastructure that will bear fruit in decades to come. In order to maintain the trust of the public, however, visions and expectations need to be deployed in order to create a sense of need and urgency. At the same time researchers emphasize that their actions and decisions are ethically sound since not following given policies would result in lost economic and financial opportunities. This forms a type of social reciprocity between researchers and the public, where researchers see that they must deliver particular types of results in order to maintain the trust of the public. National competitiveness, in both scientific and economic performance has become, in this sense, an important aspect of framing scientific justification, which has also been difficult for the public to oppose without being branded as unpatriotic or uncooperative. Expectations and visions, therefore, enter the lingua franca of scientists alongside truth claims and experience and expertise. Expectations and visions, however, are impossible to confirm in any way since they have not yet happened.

In addition to the policy and strategy documents I have discussed above, a number of important articles appeared in Finnish publications which reflected the aims of the researchers involved in the Genome Information Center project. From these articles and writings a number of themes arise concerning the arguments for the more efficient exploitation of existing collections in Finland, as well as the arguments for setting up the Genome Information Center. These arguments exemplify the narrative structure and content in which researchers want to frame the Genome Information Center and also reflect the ways in which researchers see their work to influence other areas of society. Two articles in particular reflect the framing that researchers would like to introduce to the discussion of the Genome Information Center; the first was published in a Finnish medical journal, *Duodecim* and the second was published in a more general discussion journal on science called *Tieteessä tapahtuu*.

In both articles, the Finnish case is discussed in comparative terms, where the position of Finland is seen from a competitive perspective. A major argument that is used for the further exploitation of existing collections is that it would give Finnish researchers a leg-up in relation to other countries that have only just begun to collect data, such as the UK (UK Biobank), Estonia (Estonian Genome Project) and Canada (CARTaGENE). This opportunity and advantage, however, has to be seized immediately, according to researchers. For example, in the leading article of the medical journal *Duodecim*, two of Finland's top genome researchers note that Finland has already done what many countries have only begun to do in the collection of samples and that this would provide an excellent opportunity to expand the existing collections. This would also, according to the authors, allow Finland to participate in future international comparative genome studies, since already it is not clear if national collections are large enough to provide useful epidemiological data on multifactorial causes of many common diseases, such as diabetes (Palotie and Peltonen-Palotie, 2004).

Besides the comparative aspect, justifications for the more efficient utilization of existing collections are always discussed in relation to the impact this will have on the development of the national economy. The relationship with genome research, which for a

long time was guided mainly by science policy in Finland, has become increasingly aligned in a much more concrete way with innovation policy, which emphasizes the commercialization of research results. The commercialization strategy would, according to the authors, prevent the benefits of Finnish national resources from slipping abroad.

> The information produced from the analysis of the material would most likely have a great impact on the national economy. The achieved results could create the opportunity to utilize funds invested into the Finnish healthcare system to commercializing the new knowledge and even offer the possibility to partially finance the healthcare system of tomorrow. (Palotie and Peltonen-Palotie, 2004: 1712)

Myers (1991: 64) has noted that in analyzing texts written by scientists it is apparent that "articles tell stories that try to enlist readers in a particular view of the present and future of the field." Currently, Finnish science and technology policy documents are strongly influenced by the need to encourage innovation and economic competitiveness, as is the case in many other European countries, which is also reflected in the way scientists develop their arguments. The framing of the Genome Information Center within this context, as opposed to ethical and legal questions or simply in medical terms, has the advantage of appealing to the public sense of urgency and notion of imperative for economic growth, despite the fact that there is a clear lack of evidence as to the economic impact of genome research on economic development or employment.

In another recent article (based on the Tekes report discussed earlier), on the utilization of existing epidemiological sample collections and other "national" resources, researchers frame the discussion even more in terms of commercially exploiting existing collections. In responding to criticisms that compare the use of these collections to opening Pandora's box, the researchers ask whether it is justified, from a taxpayers' perspective, not to exploit the huge commercial potential that these collections have developed for Finnish biomedical research?

> As a counter question one can ask whether it is justified from the perspective of Finnish taxpayers not to exploit the enormous commercial potential which Finnish biomedical research has produced during the past years? (Käpyaho et al., 2004: 10)

The article discusses the ethical and legal question in more detail than the other questions, but despite this discussion, it frames the question in economic terms. The question of whether to use or not to use tissue samples is not a matter that should account for variability in perspectives, but one of necessity and imperative. Indeed, economic incentives in scientific research become a moral imperative. To select "commercial potential" and use of taxpayer funds as the point on which to make a decision, the authors choose and order those arguments that they deem relevant to the discussion. By making it an imperative they also close the discussion before it can even begin. Despite emphasizing the role genome information has in developing national markets, the researchers note that invariably the use of these collections will entail a commercialization process that is international in nature and that the last link in this chain will most probably be global pharmaceutical and diagnostics companies. These strategies differ in form and scope from those that can be related to what Collins and Evans (2002) call Studies of Expertise and Experience (SEE) in that there is no experience and expertise that can be applied to the creation and development of expectations and visions. They maintain a different epistemological status all together. Experience and expertise certainly play an important role in the establishment of the credibility of the visions, and in this sense I argue that Studies of Expectations and Visions form an amalgam.

Hospital and research administrators are also one important source for the way discussions are framed within the biomedical research community as it relates to genome research. In relation to setting up closer ties between industry and biomedical researchers, one administrator noted the following:

> I think that there is a moral responsibility for the research community to understand that the exploitation of research must show somewhere. One must use all the available potential towards the exploitation of research results. Researchers tend to say that there is a social benefit from their research when new know-how and treatments are developed, but they completely neglect the fact that we could increase the potential ten-fold if we began to commercially exploit the results. (Research administrator, 7 October 2004)

The emphasis on a moral responsibility of researchers to contribute to commercialization underlines the strong normative context into which arguments for setting up the new Genome Information Center are framed. They also point to the way in which economic issues take precedence over social, ethical and legal issues in the way arguments are constructed.

The textual references of recent publications and interviews can be contrasted to those that appeared ten years earlier in a special issue of *Duodecim* that was devoted to genetic research in Finland. The imperative of commercialization and relevance of genetic research to economic development are not present in these articles, but rather authors note that research will have application to treating patients.

> No longer can we lull in the belief that genetics belongs to the theoretical and basic science researchers, because it is in exactly these areas of medicine that research is being applied surprisingly fast to patient treatment. (Kääriäinen, 1994)

An awareness of the willingness of patients and families to take part in research is already strongly present in the texts, but the change in the contextualization of the significance of the research, increasingly to commercial determinants and outcomes has increased significantly over the past decade in Finland.

The setting up of biobanks around the world has raised a number of critical issues concerning financing and the actual usefulness of the results that they produce. As one researcher in Finland wrote concerning the Genome Information Center initiative: “in principle the plan is worth supporting, but it is too grandiose and directed too much towards the production of economic profits” (Portin, 2005: 39). In the same article it is pointed out that one major challenge to the Genome Information Center is the development of a conflict of interest between the rights of individual patients and societal and scientific interests, which are also mentioned in UNESCO’s *International Declaration on Human Genetic Material*.

Despite criticism within the biomedical community, the project is strongly supported by policy makers and regulator alike and is seen as an important part of internationalizing and developing the Finnish biomedical research and development sector (see Academy of Finland, 2003).

6. Variation in medical modernization

Brown and Zavestoski (2004: 691) note that “health social movements challenge state, institutional and cultural authorities in order to enhance public participation in social policy

and regulation, and to democratize the production and dissemination of scientific knowledge in medical science and public health research." An important part of the medical modernization process, therefore, is the opening up of decision-making structures and issues so that they can be discussed. In this sense, HSM and CAM, as well as the *agora* (Nowotny et al., 2001) are only examples of the ways in which these structures have been challenged and opened up.

Although there is an increasing body of evidence that suggests that many countries and research areas in medicine have experienced such changes, such as PXE or breast cancer research, the case of genome research in Finland indicates a very different trend in terms of expert–lay relationships and the development of epistemic politics concerning genome research and biobanking initiatives. The creation of expectations and coupling of identical visions between science and technology policy and the rhetorical strategies utilized by scientists themselves, where the role of the public is seen to be as not only a passive receiver of policies through visions, but also an active supporter of such policies, extends the study of expertise and the public beyond the "third wave" in science studies.

The notion that bodily fragments retain values of personhood (Waldby, 2002a) is an important element in the discursive tactics employed by experts to mobilize tissue sample collections and interpret informed consent in broad terms. The moral imperative that is used to underline the relationship between the samples themselves and economic development is a strong argument used to contextualize the discussion. This suggests that values of personhood are framed more in terms of financial questions as opposed to other questions that the public might see as important, such as privacy. Väliverronen (2004: 373) has shown similar evidence in the ways in which the media in Finland have represented and popularized biotechnology and the ways in which there has emerged a national competition in which everybody is expected to contribute in one way or another. The commercial paradigm and its connection to biomedical research form a strong moral imperative to utilize samples that researchers are using in their arguments.

Historically, the high level of trust between experts and lay people is in part due to the strong traditions that the medical community has had in studying, characterizing and treating rare monogenic diseases that are over-represented in the Finnish population (see Norio, 2003). In addition, the successes of the welfare state in providing equal access to health care services and social benefit have resulted in less conflict and opposition to the state and its various institutions. In this sense, recent claims of the possibility of developing new markets and commercial opportunities from biomedical research merely bolster and reinforce what some have called an "official world view" of the way development can be accomplished on a national scale in Finland (Miettinen, 2002; Kettunen, 2001).

Häyrinen-Alestalo (2001), however, has questioned whether the strategy of a knowledge-based society, which has become a profuse science and technology policy strategy in Finland as part of developing a knowledge economy, is a good strategy for civil society. In relation to biomedical research and biobanks, it is clear that the high level of trust that the public has in the research community does not provide an impetus for the emergence of an active public sphere for political activity. At the same time, the emphasis that researchers are increasingly placing on the economic and commercial significance of their work tends to increasingly embed the discussion in economic and commercial terms that are almost impossible to predict and evaluate. Both written and interview material concerning biomedical researchers that utilize tissue sample collections indicates clearly a change in the rhetorical strategies and linkages used and applied to characterize the emerging field of genome research and its sub-disciplines. The move from purely "scientific" and expertise claims of the future of genome research to economic and commercial claims reflects to a

certain extent the role that science and research is seen to have in Finland today. The evocation of the economic imperative in texts and discussions highlights the increasingly closer link that is made between the textual content of researchers and that of science and technology policy makers. At the same time, this linkage in the epistemic grounding and goals of researchers and policy makers alike has a tendency to limit the possibility of public discussion, dissent and disagreement given the fact that the economic model is seen to be the only natural solution to current challenges.

It can be argued, therefore, that from an epistemic perspective, innovation and commercialization strategies at the national level play a much larger role in the formation and structural development of knowledge producing coalitions, as opposed to the role of the public in general, health social movements or CAM (see Kleinman, 2003). Instead, the creation of an economy of hope that is built on expectations and visions seems to play an increasingly prominent role, not just in policy discourse, but also in the way scientists reflect upon the significance of their work. Such concerns also have a strong influence on the funding decisions that small countries, like Finland, make concerning research and development. It is in this sense that the link between the expert and policy maker becomes even more prominent. The public is not seen in terms of the deficit model, where it needs to be educated, but rather as an active implementer of the visions and expectations. The economy of hope requires consumption and demand, not understanding. In this sense the public is both passive and active. Visions and expectations are accepted as natural in a passive manner, but the choices of individuals can be seen as active and operating within this economy of hope (see Helén, 2004).

7. Consequences and conclusions

The forms and models of social and political order in developing and governing technological societies have great variation across geographical, cultural, social and political boundaries. Recent explorations and theoretical developments that have highlighted the increased possibilities of the social shaping of science and technology, such as HSM, CAM and the *agora*, have emphasized the almost necessary role that the public should have in the setting of policies and therefore the emergence and development of different epistemic communities. In this article I have tried to identify an important link between the sociology of expectations and the study of medical modernization. The purpose of this connection has been to identify variation in the forms and strategies that have emerged in the way expectations and visions play an important role in the creation of an economy of hope. This economy of hope has an important bearing on the relationship between policy making, experts and the public. Features of this economy include a stronger relation between the strategies of researchers and policy makers and an increased emphasis on the role of the citizen as a passive/active participant (cf. Snell, 2002). The normative emphasis on dialogue that appears to underlie recent theories of expert–lay interaction tends to obscure some of the more important features of policy making, which in Finland continue to rely on a paternalistic role of the medical profession.

As Barry (2001: 48) notes "government is possible by making the individual members of the population interested, informed, and responsive. Liberal government relies on the existence of the informed citizen. . . . The citizen must be formed morally and technically." What the case of Finland highlights, however, is that experts can have varying degrees of influence in terms of the way the citizen should be informed and interested in technical and socially relevant matters. In addition, in the linking of particular science and technology

policies to broader political programs, such as the information society, experts are able to introduce technically difficult subjects within a more understandable framework. The notion of an economy of hope and its relation to the role of the public in decision making is key to understanding medical modernization.

This strategy should by no means be seen as a negative tactic by the medical community to subvert power from the public, but is merely seen to be an important condition for the efficient organization of research activities in relation to the way informed consent should be interpreted, as well as an important way for the medical community to justify their actions and find an ethical solution to their activities. Although this culture and organization of relations between actors has a tendency to create and reproduce a normative worldview of how development should progress, many have argued that it also provides considerable advantages in terms of the development and coordination of scarce resources in research and development. At the same time, however, there is an imminent concern relating to the rights of the individual in relation to informed consent.

In an attempt to avoid the emergence of a field of contestation between lay and expert knowledge claims over a particular scientific program to develop a major genome research center, scientists deploy an array of visions and expectations that are analogous to existing science and technology policies. Here I see that the Study of Expectations and Visions (SEV), both contributes to and goes beyond SEE. Scientists are appealing to the public's understanding of public funding, inefficiency and waste to recruit support and understanding for a major undertaking, but at the same time creating a powerful vision and imperative for action. In this sense, epistemic projects have a double effect: on the one hand they align major national resources according to the visions of scientists and enroll a multitude of organizations, researchers and institutions along with them. At the same time, however, they are very effective in setting the agenda as to what are the critical issues that should be focused on in this undertaking. The connection between epistemic authority and studies of expectations and visions (sociology of expectations) is an important contribution to the field of public understanding of science in that it extends current theories of expert–lay interaction beyond what Collins and Evans (2002) have termed the "third wave" of science studies.

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Note

1 Other important international documents include the *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (Council for International Organizations of Medical Science, CIOMS), *Universal Declaration on the Human Genome and Human Rights* (UNESCO) and the *Helsinki Declaration* (World Medical Association).

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