Viewpoint

# Who's autonomous now?

Kjetil Rommetveit[a]

a Centre for the Study of Sciences and the Humanities, University of Bergen, Norway

*«… society – as distinct from any plurality of individuals – is an abstract and, as such, is subject to our definition, while the individual is the primary concrete, prior to all definition, and his basic good is more or less known. Thus the unknown in our problem is the so-called common or public good and its potentially superior claims, to which the individual good must or might sometimes be sacrificed …»*
Hans Jonas 1969 [1]

*«Research that bears the prospect of advancing medicine and that can be carried out at no risk to individuals should be endorsed and facilitated. This calls for a shift of focus from autonomy and individual rights toward collective responsibility and solidarity.»*
Bioethicists Forsberg, Hansson, Eriksson 2009 [2]

Whereas most of bioethics' founding fathers (such as Hans Jonas) saw it as their main task to protect the individual patient, today mainstream bioethics seem to have made a 180 degree turn: the basic good to be protected is that of biomedical research, and so the individual (patient, citizen) should be willing to give up at least some of his autonomy and privacy. Clearly, many tendencies, policies and technologies have converged to produce this state of affairs. A main agent of transformation has been the concept of *genetic information*, and the roles such information may play in biomedicine and for dealing with societal challenges. However, bioethics itself also played an active role in promoting this unfortunate reversal of values. This text will cast a brief glance at what happened as the two emerging fields of bioethics and genetics met, as the language and practice of individual rights rose, and then tumbled.

It was the radically expanded research and biomedical complex following from WW II that brought ethics, law and patient's rights to bear on clinical and experimental biomedicine. In the 1960s a number of revelations of unethical experiments performed on unknowing human subjects shocked the western world and triggered responses from civil rights movements, politicians and lawyers alike. The field of genetic clinical research was still at an early stage, and not as such involved in these scandals. However, it was a major constituent of the techno-medical developments at the time and so found itself within the broader horizon of concerns. During the 1960s, clinical screening programs for certain genetic conditions were introduced (especially in newborn and prenatal care), and these gathered pace in the 1970s. Many of these programs targeted specific ethnic groups, and so the new practices raised the spectre of discrimination and exclusion of vulnerable groups and individuals. Already in 1975 a US report issued by the National Academy of Sciences recognised the need for improved regulations of practices it admitted had been introduced to the clinic «without prior testing and evaluation and not always for reasons of health alone» [3]. Thus, it would seem, genetic screening practices were ready for bioethical oversight. Informed consent became the main instrument for such oversight, i.e. the principle that the nature and risks of biomedical interventions (research and clinical) be made known to the patient beforehand, and that the subject gives his or her conscious consent for the intervention to go ahead. This principle entailed the reversal of long-standing relations of authority in biomedicine, according to which the researcher or medical doctor was to be the active, hence ‹autonomous›, party to decision making, and was part of a growing tendency throughout western societies in the 1960s and 70s.

The introduction of informed consent to genetics was further discussed in a 1983 US Report on the *Ethical, Social and Legal Implications of Genetic Screening, Counselling and Education Programs*. In that document, the principle of informed consent, which had already been accepted in a number of court cases, by the civil rights movement and in other parts of biomedical practice, was not being questioned. Rather, the decisive matter came to hinge on who was, in the end, granted the right to oversee practices of genetic screening. Thus, the document stated that:

*«Most of the mistakes, most of the ethical transgressions, most of the failures to observe people's rights, most of the breaches of confidentiality and informed consent and so on occurred early on when screening was being done by individual investigators or by interested lay groups, when it was being done in inappropriate places, and before the network of educators, counsellors, physicians, health officers, and the like were set up.»* [4]

Mistakes and ethical transgressions of screening programs were thus regarded as belonging to clinical genetics' pre-professional past and as something to be overcome by proper procedures. Breaches of informed consent were portrayed as failures to comply with professional standards, and not as problems of genetic clinical and research practices as such. One way of safeguarding the rights of individuals came through a

new profession devoted to the new clinical practices. This was *genetic counselling*, which made up another element within a solidifying and expanding genetic decision making complex. In the same document genetic counselling was framed as an extension of genetic screening, and both were seen to enhance conditions for decision making, hence also autonomy: «*Genetic screening and counselling have the same central purpose: to make people into informed decision makers about their genetic constitution, to the extent that it is relevant to their own well-being or that of their family.*» [5]

Thus, whereas the principle of informed consent had been formally accepted, the original view of bioethics, that the vulnerable patient had to be protected against the biomedical complex, was not taken on board. Rather, as can be seen from the previous quote, the view came to be that the emerging complex of genetic diagnosis and decision making fundamentally promoted the interests of the patient. When seen from the point of view of geneticists, this was hardly surprising: genetics early on came to be seen as the main force for modernizing medicine, for assuring the next step in the evolution of science-based healthcare across a number of areas. However, for bioethicists there were ample reasons for doubt: the specter of eugenics was never far off and kept on haunting both early-day screening practices and, later on, efforts to map the human genome. And even if the link between eugenics and genetics were regarded as weak, there was always the possibility of new forms of discrimination and exclusion, such as the creation of a new genetic underclass of people deemed too risk-exposed to be accepted into public health care and insurance schemes. Also, the information contents of DNA came with obvious threats to individual privacy, and these would only grow as the genome mapping project(s) got started, and as global research infrastructures were built for the exchange of patients' genetic (and phenotypic) information. Finally, such infrastructures generally came about as public-private partnerships with strong influxes of private and corporate capital. It would be naïve to think that most pharmaceutical companies or venture-driven start-up companies would be strongly concerned with the privacy or informed consent of individual patients. None of these doubts, however, had any lasting impact on the bioethical discourse that eventually merged with the new genetics. Here, I can only mention two reasons for how this came about:

First, at the very same time as bioethics merged with genetic screening, research and counseling, the principle and practice of informed consent was provided with a (quasi-) philosophical foundation through the concept of autonomy. Rather than seeing autonomy as a relational concept, as would follow from for instance Kantianism, phenomenology or communicative ethics, autonomy was framed through a psychological lense, i.e. as the capacity to choose. Main vehicles for this understanding were the 1979 *Belmont Report* [6] and, coming out of the same environment, Beauchamp and Childress' (1977) *Principles of Biomedical Ethics* [7]. Whereas there is little reason to doubt that these documents were committed to patients' rights, they framed them through a language that would eventually come to work against those very rights.

Second, the very character of the genetic object supported the positive valuation of the capacity to choose: no longer a physical intervention in the body, it mainly consisted in the provision of information about genetic risks. Thus, when understood as improved or enhanced capacity to choose, genetics could even be seen as contributing to the making of more informed decisions, hence even to improve the conditions for informed consent. Thus, rather than focusing on the powerful interests of pharmaceutical companies and the biomedical research complex and their obvious threats towards both autonomy and privacy, freedom of choice for individuals was placed center-stage. As stated by the 1983 report: «*Genetic screening and counseling are medical procedures that may be chosen by an individual who desires information as an aid in making personal medical and reproductive choices.*» [8]

This indicates how the 180 degree turn of mainstream bioethics eventually came about: instead of seeing the patient as intrinsically vulnerable and worthy of protection, it became possible to see him or her as enhanced and empowered by genetic information. Bioethics did not by itself create this situation, but it definitely contributed to it and legitimated it. In the 1980s mainstream bioethics (working mainly through ethics committees) emerged as the authorized caretakers of individual autonomy. Focusing firmly on the capacity to choose mainstream bioethics did not possess the conceptual or institutional tools to oppose developments but (mostly) went along with them instead. As genetics evolved into genomics and post-genomics, now targeting most of the common disorders in addition to the genetic ones, the imagination of the genetically enhanced decision maker was further promoted and universalized. In this sense, as problems with growing amounts of data collection, storage and usage started to emerge in biobank research, it also became possible for bioethicists to argue that informed consent was no longer protecting patient autonomy but was actually *working against* it by imposing obstacles and oversight from the outside.

What started out as bioethics' firm commitment to the rights of patients has been thrown off track. Inside bioethics this was made possible first by the close association of the principle of informed consent with a certain conception of autonomy: the capacity to choose. Later on, the same conception enabled the effective de-coupling of the two: informed consent may actually be seen as a threat to autonomy because it slows down biomedical progress. Whereas far from the sole responsible agent in this story, bioethics definitely has con-

tributed to the re-framing of individual rights in terms of collective interests which have by now become pervasive throughout the western world. This undoubtedly has made the career of many an ambitious bioethicist. But make no mistake: where Hans Jonas to see how far bioethics has drifted from its origins he would have turned in his grave.

**Correspondence**
Dr. Kjetil Rommetveit
Centre for the Study of the Sciences and the Humanities
University of Bergen
Postboks 7800
NO-5020 BERGEN

E-Mail: kjetil.rommetveit[at]svt.uib.no

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8. see 4.