

# Patient rights, risk, and responsibilities in the genetic era – a right to know, a right not to know, or a duty to know?

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## Abstract

**Introduction and objective.** As genetics tests ordered by physicians have implications not only for patients but also their relatives, they create a bioethical dilemma for both clinicians and patients. Especially when a patient is reluctant to undergo the test, know the genetic risk, and share such information with others. While international biomedical law recognises the right not to know one's genetic status, it has been criticised for many reasons. This paper outlines the arguments for and against the right not to know about genetic risk.

**Abbreviated description of the state of knowledge.** Both medicine and bioethics acknowledge that information about genetic risk affects not only the individual but also other family members. Consequently, many argue that such information is not a private matter and should be regarded not as a right but as an obligation, or even a duty. Thus, it is emphasized that one's right not to know is strictly related to the duty to inform others about any genetic risk. Yet others believe that constant proliferation of genetic testing and moralization of health issues poses a serious threat to patient rights and creates new opportunities for social surveillance and control. In both cases there can be observed an increasing 'bioethicization' of genetic discourse.

**Summary.** The paper suggests that the developments in genetics result in the emergence of new molecular ethics which stress that individuals have a moral and political duty to undergo the test, know the risk, and disclose that information to others. Consequently, it may transform the right to know into a duty and poses the question whether in the genetic context individuals should have the right to remain ignorant. Finally, the paper argues that genetic literacy becomes a source of biological citizenship.

## Key words

duty to know, biological citizenship, ethos of duty, genetic risk, genetic testing, right not to know

## INTRODUCTION

**Social implications of the new genetics.** Ever since sociology emerged as a scientific discipline, many prominent sociologists have stressed the importance of biology for both human behaviour and the organization of society. From Spencer's and Durkheim's metaphor of society-as-organism and the theories of Galton, Pearson, Lombroso, Woltmann, Rosenberg and Chamberlain to modern sociobiology, all these theorists argued that biological explanation can be meaningful in a sociological context [1]. It is significant because, as Włodzimierz Piątkowski and Michał Skrzypek observe, it inspired the transfer from the point of reference from 'biology' to 'medicine' [2]. Thus, the nature vs. nurture debate is important also in modern sociological discourse when there is an ongoing discussion on the origins of many diseases (obesity, heart disease or mental disorders), but also different patterns of human behaviours, such as intelligence, aggression, alcohol abuse, homosexuality and differences between males and females. While some deny any biological explanation of human behaviour it was Allan Mazur who pointed out that reference to biology can be meaningful in a sociological context [3].

This is important, because the 20<sup>th</sup> century witnessed the emergence of a new paradigm: genetic determinism [4] which permeates biology, medicine, society, politics and Western culture. The constant proliferation of genetic knowledge and developments of new genetic technologies, influence social relations and family ties. Genetics also play an important role in modern medicine and bioethics, because a large number of human diseases and syndromes, personality traits and behaviours are said to be linked to genetic factors. Consequently discoveries and the application of genetics transcend their original formulations. While they enable detection of new diseases, description and better prevention of those already known, there is also a high level of concern over their social implications [5, 6, 7, 8]. As genetic knowledge transforms our understanding of health, illness and disability [9, 10], it also influences social relations and family ties [11, 12, 13, 14] and social institutions, including medicine, law and insurance policies [4]. The new genetics changes the way individuals experience pregnancy [15, 16], frame their self [17, 18] and define social identity [19, 20, 21]. It also constructs new types of risk which becomes highly individualised [17, 22, 23, 24, 25, 26]. Moreover, as genes are shared with others, genetics transforms medical ethics and patient rights [27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37].

Genetic explanations shift our perception of family ties and entails medicalisation of family and kinship [11–14], and although family continues to be framed as a social rather than a biological entity, i.e. as a function of personal choices rather

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than 'natural' relatedness, it is increasingly perceived as determined by genetic inheritance and 'blood'. Consequently, as genetics constructs family relations as 'risky' [11], it also promotes the idea that disease is a property of the whole family [14, 31]. As a result, the nuclear model of family which dominates in the West extends to include a wider network of relatives, and as individuals gain knowledge about 'this thing that runs in our family' [26], people who earlier did not feel attached to their kin, reframe their concept of family ties. Thus, again, nature trumps nurture. It is significant that, as in the late modernity, family ties based on blood became increasingly weak, genetic concepts of hereditary diseases give a new meaning to family ties and kinship categories; it strengthens conventional ideas of reproduction and biological relatedness. On the other hand, genetics make the Western concepts of family, kinship and pedigree much more complex as the boundary between the biological and the social becomes blurred and problematic [11, 13]. This calls into question our taken for granted definitions of who is recognized as a 'family member'.

All in all, the constant proliferation of genetic knowledge and the application of genetic technologies provoke claims of a geneticization of society [6, 8], defined by Abby Lippman [15, 8] as a 'process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviours and psychological variations defined, at least in part, as genetic in origin' and as a 'process by which interventions employing genetic technologies are adopted to manage problems of health'. Others argue that 'genetic essentialism' reduces individual selves to molecular entities and equates human beings with their genes, and that a new wave of genetic determinism and fatalism emerges [4]. Although some argue that such claims are simplistic and unjustified, it was James D. Watson who said: 'We used to think our fate was in our stars. Now we know, in large measure, our fate is in our genes' [4].

Irrespective of such a debate, there can be observed an increasing geneticization of diagnostics [10] which provides new knowledge on a genetic basis of many diseases, personality traits and human behaviours. Although for ages people have defined themselves in biological terms, i.e. that of their blood, hormones, kinship and race, it seems that the decoding of the human genome has provoked a qualitative breakthrough. For that reason, Nikolas Rose argues that modern genetics promotes a 'new molecular ontology of life' [20, 38] which stresses the molecular basis of human existence and relies on a neo-ontological concept of disease in a context of genetic reductionism [10].

According to some sociologists, one of the most important consequences of such a 'molecularization of life' is that geneticization provokes a shift in the social perception of the risk: its main locus is no longer placed within external dangers generated by the State, government, industry or science, but becomes highly individualized and is located on the genetic level [23, 38]. Furthermore, as it is widely assumed both by the media [39] and the public [25, 40] that persons' defective alleles may be present in related individuals – the genetic risk is viewed as a collective entity. Modern 'risk-medicine' [41] claims that due to genetic testing the risk can be anticipated and prevented, there can be observed a growing concern over 'biosecurity'. Consequently, genetic risk becomes a public concern. Moreover, by stressing the hereditary character of many diseases and the availability of genetic technologies, testing itself is framed as a moral

practice, i.e. an act of purification, prudence, rationality, altruism and solidarity with others [14, 15, 16, 22, 23, 24, 25, 26, 31, 40, 41, 42, 43].

This is important, because while medicine no longer aims at 'enhancing' the human race, but is more focused on the prevention of diseases, it still enables new forms of surveillance and social control [7, 8]. Nevertheless, modern biopower is very subtle and difficult to spot. As it operates with a pseudo-neutral 'scientific' language which is not related by the public to power and control, it seems to be objective and politically neutral. It manages to mask its moral and political dimension under such clichés as the 'right to health', 'autonomy', 'choice' and 'responsibility'. Furthermore, as it presents itself as acting for people's good, it has managed to succeed: many people do not see the coercive and hazardous dimension of genetic testing [15, 41]. On the contrary, as it is carried out in the name of health, it is seen as something natural and much sought after [7, 15, 16, 43]. Thus, medical control is achieved through normalization, i.e. the construction of idealized norms of conduct, such as genetic testing. By this means, it enforces a moral dimension of health and imposes on individuals the imperative of (self)control and the (self)management of genetic risk. Consequently, the former political pressure to act responsibly is being replaced by an informal, cultural pressure which instils in society a new ethos of duty [16, 18, 22, 31, 43]. This, in turn, may transform Western ideas on autonomy, responsibility and blame [24].

The reason for this is that as most genetic tests ordered by physicians to their patients have implications not only for individuals but also their families, they create a bioethical dilemma for both clinicians and patients. Consequently, ethics becomes a concern not only of geneticists, bioethicists and other health professionals [44], but also of laypersons, including the families of affected individuals [11, 12, 13, 14, 15, 16, 22, 24, 25, 26, 40, 43]. As DNA is shared with others who may be vitally interested in information about genetic risk, many argue that such information is not a solely private matter, and should be regarded as a public issue [28, 31–32]. Nevertheless, the problem is that in many parts of the world, including Poland, the legal status of genetic disclosure is still unclear. As a result, it is individuals who become the gatekeepers of genetic information and control its dissemination. This is especially problematic when a patient is not willing to undergo the test, to know the risk and/or disclose such information to others. Such 'problematic patients' create tension between the professional duty to respect the patient's autonomy and privacy, and the physician's duty to prevent potential harm to at-risk relatives [34]. It also makes problematic the ethical principles of autonomy, beneficence, non-maleficence, truthfulness, confidentiality and non-directiveness, especially because there were cases when physicians have been sued for withholding information to those at-risk.

At the same time, while modern genetics promotes information about genetic risk, it also offers a new means of knowing and managing the genetic risk, as such medical procedures as: preimplantation genetic diagnosis, nuchal translucency, amniocentesis, chorionic villus sampling and restriction fragments length polymorphism allow parents to make some choice, for example by resigning from reproduction, not implementing a 'dirty' embryo into a mother's womb or aborting pregnancy that is 'at-risk' [15, 16,



22]. Consequently, passing 'faulty' genes to future generations is framed as being selfish, immoral and/or irrational [31, 45]. As genetic technologies are widely available, health seems to depend on one's will, self-control and self-discipline, and not 'God' or 'fate' [23]. Thus, disease itself becomes the result of personal negligence and lack of responsibility. Hence, by stressing that genetic risk is shared with others, medicine imposes on individuals moral duties toward others. Moreover, as DNA reveals the secrets of (family) life, genetic testing gains moral status [14, 30, 31, 42, 43] which seems to transform one's right to information into obligation, which may in turn leave little or no place for 'the right to not to know'.

**Impact of genetic testing on medical ethics and patient rights.** One of the fundamental principles of modern medicine is constituted by the ethical and legal doctrine of a patient's autonomy and the right to self-determination. This is founded on the premise about the empowering character of medical information which, it is assumed, enables conscious decisions and choices free of external pressure [19, 29]. Such a right imposes on health professionals a duty to inform patients about one's health status [34], and withholding information from a patient is seen as a form of the old paternalistic practice that destroys the relationship between both parties and may, additionally, become a source of allegation of negligence and malpractice. Claims about patient right to information are now grounded on the World Medical Association's (WMA) *Declaration on the Rights of the Patient* published in Lisbon in 1981 (art. 7a) [27]. In Polish law, the two main documents stressing patient right to know are: the *Patient Rights and Patient's Rights Ombudsman Act* promulgated in 2008, and the *Physician and Dentist Professional Act* from 1996 [46]. The most important implication of this right is that it promotes the informative model, which perceives the patient as a 'consumer' who is in the best position to make his/her own decisions and choices. For that reason, it is generally assumed that genetic knowledge is also a source of empowerment and benefits the patient by altering one's autonomy. This is presented as desirable as it may stimulate preventive actions and allows conscious and responsible life choices regarding education, career, reproduction and marriage [19, 25, 26, 29, 30, 33, 43].

The emergence of the informative model provoked the shift from the principle of beneficence to the principle of personal autonomy, which promotes a complementary although opposite right – 'the right not to know' or simply to 'ignorance' [27, 37, 43, 46, 48]. One of the first documents which recognized this right was the WMA Declaration (art. 7d) [27]. Nowadays, it is grounded in the *European Convention on Human Rights and Biomedicine* (art. 10 and *Explanatory Report*), and is also mentioned in UNESCO's *Universal Declaration on the Human Genome and Human Rights* (art. 5c) and the World Health Organization's *Review of Ethical Issues in Medical Genetics* from 2003 (art. 10.2) [27]. In Poland, the same right is guaranteed by the *Charter of Patient Rights*, adopted in 2008 (art 9.4.) and the *Physician and Dentist Professional Act* (art 31.3) [46]. Similar legislation can be found in most European countries.

At the same time, as it is widely acknowledged that the results of genetic testing have implications not only for the individual but also for their relatives, including children, it is emphasized that one's right not to know is strictly related to the duty to inform others about any genetic risk [34].

Moreover, some bioethicists have initiated a debate about whether bringing someone into existence can be harmful to him or her [45]. Though geneticists are guided by the principle of non-directive counselling, many professionals and laypersons believe that because of the inherited character of many conditions, information about the genetic risk is somehow different from other medical information. Consequently, they argue that one's right not to know the risk is in sharp conflict with a relative's right to know. For this reason, also in Poland, there can be observed an increasing 'bioethicization' of moral discourse and the moralization of health issues [43]. At the same time, one can notice a growing acceptance of different types of prenatal testing, including preimplantation genetic diagnosis (PGD).

Thus, this paper aims to outline the arguments for and against the right not to know about genetic risk. Its main objectives are:

- 1) to present the impact the new genetics have on patient right not to know about genetic risk;
- 2) to give critical analysis of the discourse of the new genetics.

I suggest that developments in new genetics result in the emergence of new molecular ethics which stresses that individuals have a moral and political duty to undergo the test, know the risk, and disclose that information to others. I also argue that genetic literacy becomes a source of biological citizenship.

## METHODOLOGY

Electronic databases and key articles were searched for papers on sociology of genetic testing and patient right not to know published in English from 2000 – 2010, inclusive. Key words (duty to know, genetic risk, genetic testing, risk management, responsibility, right not to know) were used to search published literature in English. The abstracts and papers that were judged relevant were scrutinised. Also investigated were references of obtained articles which helped in locating additional papers. In sum, twenty papers were included in the presented analysis. The source of empirical data presented here is qualitative. After all articles were collected, a thematic analysis was carried out, aimed at identifying the main arguments for and against the right not to know. A critical discourse analysis (CDA) was the basis for the analysis [47].

## RESULTS

**Arguments supporting the right not to know.** For many authors, the right not to know is the most evident in the context of genetic knowledge where, in most cases, information about diagnosis is not followed by effective therapy. For that reason it is emphasized that in such cases genetic information forces individuals to think about the things they did not want to think about [16, 30, 40, 41, 43], and thus creates a state of permanent anxiety and uncertainty and poses a threat to one's right to an open future. It is argued that people at risk may be waiting for the development of a disease and premature death, and thus may feel trapped by genetic knowledge about their future and become prisoners of their genes [22, 30, 41]. Moreover, being the most personal and private information, the knowledge about genetic make-



up can be also crucial to one's sense of identity, integrity and self-worth. It can therefore change one's perception of self and become a source of 'spoiled identity' [12, 26]. While still in good health, individuals informed about their future risk may become over-concerned with their health and turn into 'worried-well' and 'perpetual patients' [13, 40]. They may anticipate future disease and death, behave accordingly and reframe their social roles, expectations, attitudes and social relations [34, 35]. They can lose self-esteem and hope which may lead to psychological distress and suicidal thoughts. Thus, it is argued, not knowing may enhance personal autonomy [30, 36].

Genetic knowledge can also disturb social relations because it affects the whole family, life becomes full of secrets and family relations become 'risky' [11, 26, 31]. Thus, some stress that the right to ignorance protects the privacy of the entire family. This is especially so, because as Monica Konrad [13, 30] observes, those who find out that they will not develop disease themselves but, as carriers, will or already have passed bad genes to their children or that other family members will develop the disease, may experience a 'survivor guilt'. For that reason, such knowledge may have devastating consequences for family life and social relations and may be too terrible to share [12, 40]. Hence, as human genealogies become 'tentative' [11, 16], not knowing is sometimes bliss as it creates conditions for normal life, untroubled by the risk, and thus protects family members, especially children, from potential worry [48].

Additionally, genetic information brings a spectre of social stigma as people may be labelled by others as 'pre-symptomatic' patients [13, 41, 48]. And as individuals do not control what and when will be disclosed to whom by who, genetic information may become a source of power and surveillance in the hands of families, spouses, insurance companies, adoptive agencies, military services, employers and the State, and can lead to genetic discrimination [5, 7, 8].

Another problem is that the prognostic capability and accuracy of genetic tests is sometimes overestimated. On the one hand, the diagnostic process is prone to external influences which can affect (both positively and negatively) the result of the test. But even if the result is accurate, in the case of some conditions it is difficult to give a clear-cut diagnosis whether one will develop a disease, which can further increase anxiety and fear. Moreover, the range of the condition, for example, of Down syndrome, may oscillate from a very mild form, when the child shows only some visible signs but develops almost similarly to a healthy one, to severe, when a child is seriously handicapped. Still, professionals are inclined to talk about the condition as if it was a homogenous phenomenon, and parents themselves tend to imagine the 'worst scenario' [15, 16, 24, 25, 26, 40, 41]. Meanwhile, in many instances, the test results cannot be expressed simply as 'yes' or 'no'. Thus, as Susan Kelly [48] suggests, the rationale for choosing ignorance is the dilemma raised by the uncertainty of genetic tests, because they often cannot provide a '100 per cent guarantee' [35, 37].

Additionally, although many professionals argue that it is better to know, Tuija Takala [35] suggests that such a belief reflects the old paternalistic practice where it is the professionals who define what 'reasonable', 'benefit' and 'harm' mean, but, she argues, calling anxiety and the fear of potential social stigma, broken family relations and discrimination as 'irrational emotions', as Rosamond Rhodes

[31] does, also seems irrational, especially, when a person cannot benefit from such information. Jane Wilson [37] calls it a 'new paternalism'. Thus, some argue that questions regarding psychological effects (whether positive or negative) medical information can have on the patient is a non-medical judgement and should be reserved for the patient alone. Therefore, the mere fact that someone thinks it is better to know does not necessarily mean that genetic information is good for everybody [7, 15, 16, 41, 48]. Consequently, Takala [34, 36] argues that in a free society people should be allowed 'to be foolish'. And as many are concerned that people may meet external pressure to make 'the right choice' [15, 16, 22, 30, 43] they argue that knowledge cannot be forced upon people [35, 36, 49], and that people should be encouraged and not coerced.

Finally, those who support the right to ignorance claim that disabled people should be respected as they also deserve to live [49]. It is argued that not bringing a child into existence cannot be treated as avoiding harm, and that life with disability is better than no life at all [30, 34], especially that the disease may not manifest itself for many years. For that reason, it is knowledge not ignorance that can lead to harm because genetic tests do not prevent harm to children, but they prevent children from being born [37]. Thus, some observe that the disabled become 'the target group for a *search and destroy* mission'. Consequently, Takala [34] asks: 'How much suffering is too much to suffer?'. Especially in that as disability rights activists argue, much of their suffering is caused by social factors, including oppressive culture and discriminatory social policy, and not disability itself [6, 7, 8, 8, 14]. Thus, some stress that parents should have the right to decide about their future children's features.

All in all, it is emphasized that as genetic information may result in increased anxiety and psychic distress, disturbed social relations may be a source of social stigma, marginalization and discrimination, and that its psychosocial implications may be as troublesome as the biological condition and that disclosing genetic information may be in sharp contrast with the medical principle of *Primum non nocere*.

**Arguments opposing the right not to know.** At the same time, claims about the right not to know meet hard opposition as many argue that such a right, especially when it refers to genetic information, is in contrast to one's duties toward others. It is emphasized that as individuals share their genes with others, people should act accordingly to the principles of genetic prudence, altruism and solidarity with those who may benefit from such information, and who may be harmed by one's ignorance [14, 28, 29, 31, 43, 44].

There is also another, more philosophical argument – that knowledge is good in itself and that the right to remain in ignorance is a contradiction in terms, because in order to follow one's desires and preferences the patient needs to know [28, 29, 31]. Opponents stress that true self-determination requires information and that the right to ignorance deprives the patient of the real choice, and opposes one's right to autonomy, as the latter requires knowledge which is *sine qua non* of decision making. For that reason, it is argued that negative emotions, nervousness or other 'irrational' reasons, do not justify one's wish to remain in ignorance, and that the only question remaining is not whether to disclose, but how to do it.



Some also suggest that while a positive result may increase anxiety, depression or sadness, it may also positively influence family communication, trust and bonds between relatives, and it is ignorance that erodes trust [25, 40].

Finally, it is said that this right contradicts the modern model of doctor-patient relationship which overcame paternalism [44]. Because physicians now have a duty to inform patients, the 'right not to know' opposes the current trend, which makes both parties equal. Thus, claiming such a right would promote the return of the old paternalistic practice where the physician could withhold the information from the patient [27]. Moreover, it also violates the medical duty to protect at-risk relatives and thus may become a source of law suits for negligence and malpractice [29, 35].

**Duty to know.** One of the distinctive features of genetic discourse is its rhetoric of 'risk' which provokes a shift from the question: 'If I get a disease' to 'When I get a disease' [16, 23, 41]. At the same time, the risk is said to be shared with others and thus becomes a family matter [11, 22, 26, 43]. For that reason, while many emphasize that the right not to know may protect individuals from psychological and social consequences and may enhance one's autonomy, it should not be absolute, and should be denied when a third party is involved. For example, Rhodes [31] argues that when there is a risk of serious harm to those to whom a person is genetically related, one has no right to remain ignorant, but instead has a duty to know one's genetic make-up [14, 27, 28, 29, 32, 33], undergo the test and disclose such information to others. Moreover, she argues that such an obligation does not interfere with one's right to privacy as individuals do not have to know the results of their tests.

Many authors maintain that a rational and responsible person is the one who seeks genetic information and knows how to use it. Such a belief imposes on individuals the duty to know the risk and make 'appropriate' decisions and choices [18, 19, 22, 45]. As ignorance may cause harm, pain and suffering, or even an agonizing death to others, it is assumed to be morally wrong and cannot justify one's lack of responsibility. Thus, 'genetic literacy' [19] is presented as a condition *sine qua non* for personal autonomy [29], 'genetic maturity' and 'genetic Enlightenment' [23]. Furthermore, as the notion of duty becomes pivotal for both genetics and ethics, Ann Sommerville and Veronica English [33, 31] go a step further and argue that genetic privacy is an oxymoron. They argue, that because of shared DNA interests of an individual cannot be separated from those of other family members, which makes the concept of 'genetic privacy' a contradiction in terms as the information about a possible risk is relevant to the entire family.

Another rationale supporting the duty to know is that it helps avoiding disability and thus assures the well-being of a child [16, 22]. Many argue that bringing up a child who will suffer from a genetic defect is morally wrong and that such suffering should be avoided. For example, Julian Savulescu and Guy Kahane [45, 22] argue that parents have 'the moral obligation to create children with the best chance of the best life'. They stress the parental duty to assure the well-being of future offspring and to avoid disability. Thus, it is reasoned that no life is better than life full of suffering and pain.

Furthermore, some stress that having a disabled child has a negative impact on one's commitment towards other family members, and that the need to take care of the diseased

person may result in a loss of time and attention for the spouse, existing children and relatives. This argument is often linked to the financial costs disability has for the family, society and the State [43].

Some also claim that people should be motivated by the 'political economy of hope' [17, 21], i.e. they should undergo the test, because in the (near) future medical advances may offer some way of altering or even curing the condition.

Thus, as the notion of duty becomes central for both genetics and ethics, many authors argue against the right not to know and stress that the public dimension of genetic information imposes on individuals new types of duties. As people are said to be genetically different in less than 1 per cent, genetic risk is shared with others (children, the kin, relatives and other members of society), and consequently, such information cannot be a mere private issue. Instead, some argue, individuals have a moral and legal duty to pursue genetic knowledge about the risk and to disclose such information to others.

## DISCUSSION

**Homo geneticus as zoon genetikon.** There is strong evidence that the geneticization of medical discourse has a profound impact on individuals and society at large [5, 6, 8]. It is also widely recognized that the new genetics, including reproductive technologies and tests, exist in a broader socio-cultural context of personal responsibility for risk control [15, 16, 22, 24, 26, 40, 43]. Consequently, some emphasize that individual and collective identities become increasingly expressed in biological language [17, 20] and the biological dimension of human existence acquires political meaning as 'biologisation' leads to formulation of many political ideas in terms of blood, race, stock, kin and genetic pool. And although such a phenomenon is not completely new, as it was present in the past as well as in non-western cultures [1, 12], it seems that genetic discourse blurs the boundaries between the private and public dimension of citizenship. As many diseases are genetically transmitted, health and illness are no longer perceived merely as a private matter. On the contrary, many argue that the inherited character of many diseases obliges individuals to include the public dimension of genetic information [16, 28, 31]. Consequently, they stress not only the social, economic and political dimensions of genetic testing, but also the collective dimension of biology. As a result, each individual is pictured as a mirror of a larger group and the traditional idea of citizenship is being reinforced by its biological (genetic) dimension. On the other hand, human biology itself gains a political dimension [20, 21, 43]. Thus, *homo geneticus* becomes *zoon genetikon*: while people define themselves in terms of modern biology, at the same time the concept of 'biological citizenship' emerges [19, 20, 21]. And while people still define themselves in terms of gender, social class, religion or ethnicity, biological and genetic categories become increasingly popular frames for individual and social identities [18, 20]. Consequently, individuals define themselves in terms of decreased activity of neurotransmitters (serotonin – depression, noradrenaline and dopamine – ADHD), carriers of 'faulty' genes (BRC1 and BRC2 for breast and ovarian cancer or HTT for Huntington disease), or genetic predispositions to alcoholism, obesity, dementia or schizophrenia [20]. What is more, genetics affects

entire social groups, which can be observed by the search for genetic predispositions in certain ethnic groups<sup>1</sup>. As a result, as genetics promotes the idea of DNA Tribes, it reintroduce the category of race and leads to its medicalisation.

Furthermore, as many biotechnological corporations, including deCODEme, 23andMe, Navigenics, Knome or Illumina offer a way to decode one's genome, genetic knowledge becomes a kind of privilege, if not an obligation. This is so, because individuals are now urged to take control over their fate and may feel obliged to undergo the test, know the risk, and share that information with others. By emphasizing the inherited character of disease, genetics reframes traditional ethics and patient rights. It imposes on those 'at-risk' an imperative of rearranging their lives, seeking optimal means of knowing, managing the risk, maximizing the chances of survival, and acting accordingly to the principles of genetic prudence, responsibility, solidarity and altruism [19, 22, 31, 43]. As a result, genetic technologies are framed as unique technologies of the self [50] that enable effective (self)observation, (self)visualization, (self)management and (self)control. Genetic testing itself is framed as a moral practice and becomes an important component of the ideology of healthism. Thus, genetics sets up new rights and obligations: while people have a right to use genetic technologies, at the same time they are obliged to constant self-monitoring, self-surveillance and anticipation of the risk [22, 23]. They are expected to acquire information about the risk, disclose it to others and make 'responsible' life choices. As a result, concern for health becomes a moral imperative and political commitment. And although health becomes highly individualised, concern for health extends to include solicitude for others, including: future generations, family and relatives, the State and other members of society [16, 22, 31, 43]. It also strengthens the belief that knowledge about the risk is not only a kind of privilege but also an imperative, especially that in a genetic context personal decisions may affect others who can be harmed by one's own ignorance.

Thus, biological citizens are expected to participate in scientific researches that may lead to development of new therapies. They engage in education and collection of funds for those researches. Such actions result in the proliferation of many associations, support and advocacy groups organised around various diseases which become a core for collective identities. The genes themselves become a type of (bio) capital [20] which serves to integrate, organise and socialise individuals who create such translocal biomedical networks of genetic patients-citizens as: Alliance of Genetic Support Groups, Genetic Interest Group or Genetic Alliance. Some of them focus on a particular condition: Huntington's Disease Advocacy Center, PXE International, Children and Adults with Attention-Deficit/Hyperactivity Disorder or Tay-Sachs Disease Support Group. They all become active participants in a social, economic and political arena where they promote knowledge, educate, collect funds, mobilise individuals to

participate in researches, and lobby for positive legislation [17, 20, 21].

As modern societies are increasingly preoccupied with various types of risk, a feeling of (genetic) security becomes a commodity which results in a growing trust towards technological systems [15]. Moreover, the authority of medical experts extends from its technological and scientific dimension to include ethics. As a result, genetic professionals combine the roles of bioethicists, legislators and moral entrepreneurs. At the same time, the risk itself becomes both a medical and moral danger. On the other hand, as genetic technologies allow individuals to predict and manage the risk, they become an effective tool for those who devote their energy, time and money to secure themselves and their families [50]. Consequently, while health is often portrayed as a basic human right, it is increasingly (re)framed as a moral and political obligation. It is a gift and a task. Indolence or ignorance are perceived as irrational, irresponsible and a sin [31]. Health becomes a test of one's moral status, and genetic testing becomes a new type patriotism [20, 21, 43].

Thus, it seems that the constant proliferation of genetic knowledge and progress in diagnostic testing not only influences the way we think about the self, our bodies and social relations, but it also provoke a shift in emphasis from patient rights to one's obligations towards others. As an unintended consequence of the 'right to know', a new molecular ethics of duty emerges which frames biological citizens as responsible individuals who participate in testing and dissemination of genetic knowledge. It also imposes on individuals obligations towards: future generations, family members, distant others, the State and oneself [14, 16, 22, 26, 31, 43]. As a result, the distinction between the private and public dimensions of citizenship becomes more complex and blurred. For example, the desire to have children or becoming a spouse is no longer a mere personal issue. As third parties are involved, people are obliged to include the social, economic and political dimension of their choices. Consequently, genetic positivism constructs a new category of 'problematic' patients: those who do not want to undergo the test, know their risk, and disclose such information to others. Nevertheless, some sociologists ask whether, if we assume that people have a duty to do know their genetic risk and share that information, the only questions remaining are: 'Should it remain a moral obligation or become a legal duty?' 'Should it be enforced somehow?' and 'Should individuals who do not submit to such duties be punished by law?' Thus, it seems that genetic discourse aims not to support the free choice of the individual, but to promote the 'right' decision-making, and that individuals become political projects. Consequently, it enables new forms of surveillance and social control [7].

## CONCLUSIONS

Summing up, it seems important to note that while genetic discourse is often presented as objective and politically neutral, there is evidence that, in fact, perceptions of genetic risk are value-laden [15, 24] and that those values influence both professionals [25, 44] and lay persons alike [13, 16, 22, 43]. While the decision about genetic testing seems to be personal, voluntary and free of external pressure, there is evidence that the public dimension of genetic risk may

1. Sickle cell anaemia is the most common among Africans, Afro-Americans and people with Mediterranean heritage. Tay-Sachs disease occurs more often among Ashkenazi Jews and thalassemia affects mostly people with a Mediterranean background and those from the Middle East. Huntington's Disease is the most frequent among those with European ancestry (especially from Scotland, Wales and Sweden, but also in regions near Lake Maracaibo in Venezuela), and cystic fibrosis is more likely to occur among Europeans and Americans.



influence the individual's decisions whether to undergo the test, know the ensuing risk, and share that information with others. Such decisions may be influenced both by family members and relatives, the media and professionals, who may have a role in shaping these decisions and may, in turn, also influence the testing process. Moreover, the omnipresence of such pressure makes it difficult to resist [40, 41]. It seems that especially in group-oriented cultures, such as the Polish one, which are not so strongly attached to the individual's independence, families may be involved in this process. Consequently, individuals may well experience social pressure to make the right choices and be expected to place other's right to know above one's own right not to know.

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