24. nóvember 2009

Heilbrigðisnefnd Alþingis
b.t. Þuríðar Backman formanns

Efni: Tillaga að breytingu á frumvarpi til laga um heilbrigðisstarfsmenn, þingskjal 129, 116. mál.

Við undirrituð biðjum um eftirfarandi breytingu á frumvarpi til laga um heilbrigðisstarfsmenn:

Við II. kafla, **Löggiltar heilbrigðisstéttir**, 3. gr., *Tilgreining löggiltra heilbrigðisstétta* bætist einn liður svohljóðandi:

2. Erfðaráðgjafar

Númer annarra liða á eftir breytist samsvarandi.

Rökstuðningur:
Þýðing erfðafræði fyrir heilbrigðisþjónustu fer sívaxandi. Á Íslandi hefur undanfarin ár verið unnið markvisst að því að landsmönnum standi öflug erfðaheilbrigðisþjónusta til boða skv. viðurkenndum alþjóðlegum stöðlum. Slík þjónusta er veitt af heilbrigðisstarfsmönnum með mismunandi bakgrunn sem vinna saman sem heilstætt teymi. Ein lykilstarfsstétt í teyminu er erfðaráðgjafar (genetic counsellors). Erfðaráðgjafar eru jafnan einstaklingar sem lokið hafa viðurkenndu meistaranámi í þeirri grein. Námið er bæði fræðilegt og verklegt. Nám í þessari grein er viðurkennt í flestum löndum í kring um okkur. Nú þegar starfar einn erfðaráðgjafi á Landspítalanum.

Erfðaráðgjöf er ferli til að aðstoða einstaklinga við að skilja og aðlagast læknisfræðilegri, sálfræðilegri og fjölskyldutengdri þýðingu erfða á sjúkdómum. Ferlið samanstendur af því að túlka fjölskyldu- og sjúkrasögu til að meta líkur á því að erfðasjúkdómur komi fram. Einnig eru veittar upplýsingar varðandi erfðir, erfðarannsóknir, eftirlit, fyrirbyggingu og bjargráð. Síðast en ekki síst er veitt ráðgjöf sem undirbyggir og styður sjálfræði, upplýst val og aðlögun að viðkomandi áhættu eða sjúkdómi.

Ágæt yfirlit þar sem lýst er mikilvægi erfðaráðgjafar eru að finna í tveimur meðfylgjandi skjölum frá Eurogentest Network of Excellence sem miðar að samhæfingu og eflingu erfðaþjónustu í Evrópu (www.eurogentest.org):

"Recommendation for genetic counselling related to genetic testing" og
"Summary of the guidelines for genetic counselling".

Við á erfða- og sameindalæknisfræðideild Landspítala vinnum með Eurogentest og teljum stefnumörkun þess henta okkar þjóðfélagi.

Erfðaráðgjafar vinna flókið og vandasamt starf við margvíslega heilbrigðisþjónustu. Mikilvægt er að löggilda það starfsheiti þannig að eingöngu einstaklingar með viðeigandi

færni megi nota það. Almenn ákvæði laga um heilbrigðisstarfsmenn eiga einnig mjög vel við um erfðaráðgjafa bæði hvað varðar réttindi og skyldur.

Við erum tilbúin að veita frekar upplýsingar eða koma fyrir nefndina sé þess óskað.

Virðingarfyllst,

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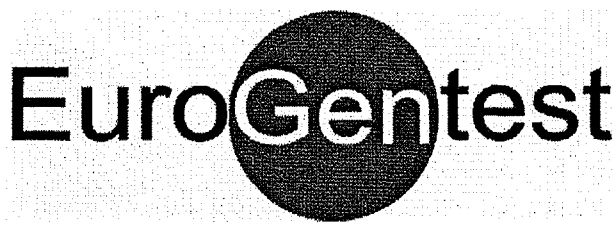

Recommendations for genetic counselling related to genetic testing

1. Introduction:

The main goal of the EuroGentest Network of Excellence (www.eurogentest.org) is to improve the quality of genetic testing. As patients' understanding of the results and consequences of the test is an integral part of genetic testing, EuroGentest also aims at improving the quality of genetic counselling services associated with genetic testing, across Europe. One of the goals is to establish recommendations for genetic counselling in connection with different testing situations.

2. Method:

To achieve this, the group assigned by EuroGentest for this task has collected and analysed international and European non-national guidelines and policies related to genetic counselling, as well as some relevant national recommendations and other documents. In addition, legislation related to genetic counselling in EU countries has been collected. Three workshops attended by experts on genetic counselling have been organized (May 2005, September 2006, December 2007). In addition, data has been collected with the help of surveys. The draft of the recommendations was distributed to European clinical geneticists and genetic counsellors and European National Human Genetic Societies for comments. The final version was written taking these comments into consideration.

3. Background:

3.1. Analysis of European legislation related to genetic counselling

Article 12 of the European Convention on Human Rights and Biomedicine (Council of Europe, 1997) requires appropriate genetic counselling prior to predictive or carrier testing (including tests to detect a genetic predisposition or susceptibility), but it has not yet been ratified by all Member States (http://conventions.coe.int/Treaty/Commun/ListeTraites.asp?MA=9&CM=7&CL=ENG). According to our study, most Member States as well as other European countries do not have specific legal provisions on genetic counselling; exceptions include Austria, France, Germany, Norway, Portugal and Switzerland.
(http://www.eurogentest.org/web/info/public/unit3/regulations.xhtml)

3.2. Analysis of international recommendations

Analysis of the international guidelines and policies related to genetic counselling identified several issues that were consistently cited as important. The most commonly mentioned were (1) appropriate training for the counsellors, (2) content of the information, (3) counsellees understanding of the information, (4) psychological support, (5) problems related to disclosure to the relatives, (6) need for consent, (7) autonomy, (8) confidentiality, and (9) fear of discrimination. (http://en.eurogentest.org/files/public/unit3/summaryofguidelinesMay06.pdf)

3.3. Analysis of data collected from European Human Genetic Societies

A survey on legislation, guidelines and generally applied practices in genetic counselling performed among the human genetic societies or contact persons in 38 European countries, in 2005-2006, found that there is no legislation directly related to genetic counselling in the great majority of these countries. There are, however, some professional guidelines related to counselling in some of the countries that do not have that legislation. According to the respondent, 13 countries have neither legislation nor guidelines. About half of the respondents considered that more regulation would be needed, but 10 respondents considered the existing national or international guidelines to be sufficient. (http://en.eurogentest.org/files/public/unit3/Results_of_survey_1_WP_3-1_Dec06.pdf)

4. Definitions:

This paper defines genetic counselling as follows:

Genetic counselling is a communication process that deals with the occurrence, or risk of occurrence, of a (possibly) genetic disorder in the family. The process involves an attempt by appropriately trained person(s) to help the individual or the family to (1) understand the medical facts of the disorder; (2) appreciate how heredity contributes to the disorder and the risk of recurrence in specified relatives; (3) understand the options for dealing with the risk of recurrence; (4) use this genetic information in a personally meaningful way that promotes health, minimizes psychological distress and increases personal control; (5) choose the course of action which seems appropriate to them in the view of their risk and their family goals, and act in accordance with that decision; and (6) make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder (modified from Frazer FC: Genetic counselling. Am J Hum Genet 1974:26:636-661, Biesecker and Peters: Process Studies in Genetic counseling: peering into the black box. Am J Med Genetics 2001:106:191-198).

The "appropriately trained person" that gives the genetic counselling is usually a genetic health care professional (clinical/medical geneticist, genetic counsellor or genetic nurse). In some situations, he or she can be another professional trained for a specific counselling task, such as an obstetrician in the case of pre-test counselling for risk of aneuploidy due to increased maternal age.

The recommendations apply to genetic counselling related to genetic testing, whereby the term genetic test is used mainly for tests performed in genetic testing laboratories (cytogenetics, molecular genetics and biochemical genetics) as part of genetic services. It is acknowledged that the same need for genetic counselling may exist when analysing other elements that may disclose equivalent genetic information (histological, imaging, family history, etc).

5. Different types of genetic testing situations and need for genetic counselling

The following chapters (5.1.-5.8.) briefly present the need for pre- and post-test genetic counselling in different testing situations. Depending on the context, the disease being tested and the implications for the individual and his or her relatives, there may be different needs. It is assumed that clinical utility of the tests concerned is adequate. This paper focuses on the average situations, but the authors realise that there may be exceptions in each category.

5.1. Diagnostic testing means a genetic test performed in a symptomatic individual to confirm or exclude a genetic condition. This is usually not very different from other medical tests performed in order to achieve a diagnosis, except for the possible involvement of relatives or implications concerning them. Pre-test genetic counselling may not always be necessary. As in case of any medical test, there should be free and informed consent which includes pre-test information, minimally what the test is for and what its implications are for the tested and for the family. If the test result is positive, the patient and the relatives should be offered genetic counselling. Even when the test result is negative, genetic counselling may be indicated.

5.2. Predictive testing refers to genetic testing in a healthy high-risk relative for a specific later-onset monogenic disorder. The mutation in the family leads to the disease or a considerably high risk for the disease (like in high risk familial cancers). There is not a complete consensus on the terminology: Some use "presymptomatic testing" as a synonym for "predictive testing" - and even prefer this term - while others restrict the terminology "presymptomatic testing" to mutations with full penetrance. Those in favour of "predictive testing" use the term in the context of mutations with incomplete as well as complete penetrance. Even if the family has previously been counselled, further pre- and post-test genetic counselling has to be offered, often accompanied by psychosocial evaluation and support.

5.3. Susceptibility testing (sometimes referred to as risk profiling) means a genetic test of a marker or simultaneous testing of several genetic markers with the aim to detect an increased or decreased risk for a multifactorial condition in a healthy individual. The clinical validity and utility of risk profiling for diseases of complex aetiology needs to be proven before clinical use. If the test is or is claimed to be capable of detecting high relative risk for a serious condition and thus has significant implications for risk assessment, treatment or prevention in a person or his/her near relatives, then pre- and post-test genetic counselling is needed. At present, this is rarely the case in multifactorial diseases when testing healthy individuals with non-specific family history.

5.4. Pharmacogenetic testing means testing for a genetic susceptibility for adverse drug reactions or for the efficacy of a drug treatment in an individual with a given genotype. They are ordered mainly by specialists other than clinical geneticists; and the need for proper genetic counselling by a genetic specialist will depend on whether the results have other implications than the decisions about the drug treatment for the person tested and his/her near relatives.

5.5. Carrier testing means a genetic test that detects a gene mutation that will generally have limited or no consequence to the health of that individual. However, it may confer a high risk of disease in the offspring, if inherited, from one parent (in case of X-linked inheritance, autosomal dominant premutation or chromosomal translocation) or in combination with the same or another mutation in the same gene from the other parent (in case of autosomal recessive inheritance). Pre- and post-test genetic counselling needs to be offered.

5.6. Prenatal testing refers to a genetic test (either to detect a mutation, linked haplotype or chromosomal change) performed during a pregnancy, where there is increased risk for a certain

condition in the foetus. Pre- and post-test genetic counselling for the prospective parents needs to be offered.

5.7. Preimplantation genetic diagnosis (PGD) means testing the presence of a mutation, linked haplotype or chromosomal change in one or two cells of an embryo in a family with a previously known risk for a Mendelian or chromosomal disorder, in order to select the unaffected embryos to be implanted. Pre- and post-test genetic counselling for the prospective parents has to be offered. This should be differentiated from preimplantation genetic screening (PGS), which aims at improved results of infertility treatment in families with no known genetic risks. In case of PGS, reproductive counselling by assisted reproduction professionals is usually appropriate.

5.8. Genetic screening means testing where the target is not high risk individuals or families, but where the test is systematically offered to the general population or a part of it (e.g. newborns, young adults, an ethnic group, etc.). All of the previously mentioned testing types can, in principle, be performed either in families at risk or as screening programs in different parts of the population. In screening programmes, pre-test information and post-test information has to be an integral part of the program, though the extent and content of information in these lower risk situations, and the professionals involved, may vary. In addition to this information, those who are found to be in a high-risk group, as a result of screening, should be offered genetic counselling.

6. General recommendations for genetic counselling

- Genetic counselling should be regarded as an integral part of the genetic testing process. Genetic counselling cannot be compulsory; medical acts are very exceptionally compulsory. It should, however, be offered and strongly recommended in most testing situations as explained above. If an individual insists on having a test without genetic counselling, the medical facts and possible consequences should be discussed by the clinician ordering the test. In these situations, non-genetics health care professionals have a responsibility to recognize their abilities and limitations with regard to provision of genetic services. Furthermore, both genetics and non-genetics health care professionals should not agree to testing without pre-test counselling in circumstances where doing so would go against their professional judgement. According to good clinical practice, predictive tests for future severe illnesses with no options for treatment or prevention should not be performed without pre- and post-test genetic counselling, psychosocial evaluation and follow-up.

- Genetic counselling has to be provided or supervised by a health-care professional appropriately trained for genetic counselling.

- Genetic counselling should be given in a language well understood by the individual. When this is not possible, options such as using an interpreter should be offered.

- Before actual testing takes place, there should be free and informed consent. In situations where testing children or other persons who are not able to give informed consent is considered, those individuals should be involved in genetic counselling and in the decision-making process, according to their capacities. Adequate authorisation for genetic testing of children or persons who are not able to give informed consent is required from their parents or legal representatives. Testing for adult onset conditions in children should only be considered when treatment or surveillance would begin in childhood.

-If the counsellee decides to proceed for the test, a description of the circumstances associated with the test should be sent, together with the sample, to the testing laboratory as the interpretation of the results depends on the context.

- The resources needed to perform genetic tests and to provide the appropriate pre- and post-test counselling should be developed and put in place simultaneously.

6.1. Pre-test genetic counselling

a) In pre-test genetic counselling individuals are informed about the purpose of the test, including up-to-date, reliable description about symptoms and natural history of the disease, prospects of prevention or early diagnosis and treatment, inheritance pattern, the risk of disease in the counsellee's situation, available reproductive choices, reliability and limitations of the test concerned, and possible psychological impact and other consequences of the test result to the counsellee and his/her family/relatives. Privacy and confidentiality of the results, as well as possible consequences related to its disclosure to third parties, such as insurance companies and employers, are discussed, when appropriate. The counsellor is not coercive in any way; this principle is also explained to the counsellee.

b) Pre-test counselling includes discussion about the rights to know and to decide including the right not-to-know.

c) Possible uncertainties due to present lack of knowledge are declared

d) The discussion about the need to inform relatives about the test result, as well as the best ways to do this, are initiated, especially in conditions where early diagnosis may improve the prognosis.

e) Depending on the resources available, as well as the context and the disease being tested, further genetic counselling sessions or consultation with a psychologist should be offered. The possibility of contact with a social worker and/or patient /lay support organisations should also be offered, where applicable.

f) Written materials and/or reliable Internet addresses related to the subject should be offered when available.

g) The counsellor should offer assistance in decision making, and encourage the counsellee to take ample time for it, whenever possible.

h) A written summary of the discussion should be prepared, if the counsellee so wishes.

6.2. Post-test genetic counselling

a) After disclosure of test results, the first focus is on the emotional impact on counsellee and others involved. Depending on the resources available, as well as the context and the disease being tested, follow-up contacts with the genetic counselling unit should be offered, and/or a consultation with a psychologist. The possibility to contact a social worker and patient/lay support organisations should also be offered. A written summary of the test result and issues discussed during the counselling should be, as a rule, given to the counsellee.

b) Points a) and b) from pre-test genetic counselling may have to be repeated.

c) Implications to the individual (including a follow-up plan, when relevant) and his/her near relatives should be discussed

d) A strategy to inform relatives has to be discussed with the counsellee (or, if necessary, a decision to discuss this further, after time for reflection).

e) Written material to help the counsellee to spread the information in the family may also be offered.

Depending on the emotional impact of the test result, it may be appropriate to discuss these issues in the disclosure session or in one or more follow-up sessions.

6.3. Information/counselling in screening programs

When a genetic test is offered within a genetic screening program to the general population, the situation is very different from that of genetic testing in at-risk families. Most importantly, the individuals in a screening program have not personally requested the test, and they may not know anything about the condition being tested.

For these reasons, it is extremely important to inform the public properly about the condition to be screened for, and the issues related to the screening program, including testing methods and their reliability, the implications of both "positive" and "negative" test results to the individual and his/her near relatives, the need for a confirmatory test, as well as the freedom to choose to participate. This may be achieved using different methods, including media, leaflets and programs in schools. Individual pre-test genetic counselling is, as a rule, not possible to organize, but should be made available for those who request it.

Communication with the population or population groups and individuals to whom screening is offered may be performed by health care professionals other than clinical geneticists/genetic counsellors/genetic nurses, provided that the professionals involved are appropriately trained and educated for the screening programme. Genetics specialists should be consulted when educational programs are planned,

If the resources do not allow for such comprehensive and well planned pre-screening information, the screening programme should not be implemented at all (with rare exceptions confining unquestioned health benefits to the individuals being screened, e.g. newborn screening for PKU).

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Summary of the guidelines for genetic counselling

Within the WP 3.1, a list of international and European non-national guidelines and policies related to genetic counselling has been collected. In addition, some relevant national documents as well as documents from other continents have been taken into account. We welcome further information on guidelines that deal with genetic counselling.

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Background
Progress in life sciences has raised concerns about the social, cultural, legal and ethical implications of the on-going development. Since the 1970s, the field of bioethics has grown considerably. The necessity of setting universal ethical guidelines for genetic services has been expressed in the past few years by scientists and practitioners themselves and by lawmakers and citizens. In addition, health professionals in the field find many practical situations so complicated that they have recognised the need for professional best-practice guidelines. Genetic counselling is the main topic of only a few policy papers, but it is included in the various recommendations concerning genetic services. Even if counselling is not mentioned explicitly, it is pointed out when talking e.g. about information, decision-making and patient's rights.

Policy papers
Bodies that have produced policies on genetic services can be divided into four categories: political institutions, professional organisations, ethical boards and patient associations. The policy documents can be broadly divided into two groups: there are official ratified policy papers and reports that serve as background material. There are altogether 56 documents listed on this website that deal with genetic counselling. The documents are produced by these bodies:

- International institutions (UNESCO, WHO, OECD)
- European institutions (Council of Europe, European Commission, European Parliament)
- International professional organisations (WMA, HUGO, FIGO, ISONG)
- European professional organisations (ESHG, ESHRE, EuropaBio)
- Professional organisations from other continents (ASHG, NSGC, AGS, SSO, ASCO, AAP, HGSA)
- Ethical Boards (Nuffield, Conference of European Churches, President's Commission)
- Patient associations (EURORDIS, GIG, IHA, DPI)

* Abbreviations

The list of the documents is at the end of the website.

Summary of the guidelines for genetic counselling

Even though the documents differ from each other, there are certain issues that are mentioned in most of them. These formulate the mainstream discourse of the counselling guidelines. In the guidelines genetic counselling is seen as a unique process of providing very special information. The conception of the speciality of genetic information defines the practices of ideal counselling: it is expected to give people the best possible capabilities to live with and act upon their genetic information. The key concepts play particularly important role in the documents that deal explicitly with the counselling. There are also papers where these issues are not covered, as they concentrate more on the particular issues of counselling. The topics and their content are summarized in the table below.

Subject	Summary of content
PERSONS INVOLVED IN COUNSELLING	
Counsellor	
Profession	Person who gives genetic counselling should be a professional specialist, as he needs to convey complex information. In common problems there is a growing need for non-physician healthcare providers and non-genetic specialist MD's to give genetic counselling. More education in genetics is needed.
Training	Genetic counsellors should receive appropriate and on-going training in genetic conditions, risk assessment, psychosocial issues, bioethics, service system, communication and patient perspective.
Co-operation within healthcare system	Genetic counselling team consists of a team of professionals.
Duties	Genetic counsellor has certain duties that include e.g. preparing for consultation, promoting public education, assisting in decision-making and being aware of the professional ethics.
Family	
Common information	Genetic information is common to the whole family, which can cause conflicts. Counselling should be available to at-risk relatives. It should be considered before the test how they are contacted. Patients have a duty to contact their at-risk relatives, but this should not be a condition for test, as sometimes they have good reasons not to. Disclosure should be agreed between the patient and the physician.
Cultural issues	When providing information, family's cultural and ethnic background should be taken into account.
Vulnerable patients	
Not able to consent	Tests should be done in the best interest of the patients that cannot give informed consent, or sometimes in the health interest of their family. Authorisation of the representative is required, but the persons need to participate according to their capacity.
Children	Tests should be done in the best interest of the child, or sometimes in the health interest of their family. Authorisation of parents is required, but the child needs to participate according to his capacity. The age at which the child is able to decide on testing should be flexible, and the older the child is, the more significance should be put on his assent. Information should be appropriate to child's capacity and needs, and the child should be involved in counselling as much as possible.
Public	Public should be educated about the availability of tests and about the impacts of genetic information. Public should also be involved in the dialogue on bioethics in general.
PRACTICES OF COUNSELLING	

Setting	Genetic counselling should be given in a private and comfortable place.
When to counsel	
Pre-test	Pre-test counselling should be available.
Post-test	Post-test counselling should be available.
Discussion before counselling	It is recommended to discuss with patients before counselling to identify their needs, to increase their understanding of counselling and to gather background information.
Periods	There should be enough of time between counselling and decision-making. The waiting time should however not be too long, at least the test results should be disclosed as soon as possible. Patient should be informed about the time between the appointments.
Consent	Informed consent should be asked always. According to the situation, it should be either in written or verbal form, written form is often advisable. There should be a free withdrawal from the consent. Consent needs to be asked also to inform the relatives.
Psychological support	Psychological support should be given to patients when necessary to adjust them to the situation, to help them to cope with stress and to assure their individual decision-making. Patient's psychological, emotional and social responses need to be taken into account. Sometimes it can be recommended to take a support person to the appointment.
Referrals	Referrals can be made to other professionals when necessary. Reason for a referral can be e.g. support, treatment or ethical reasons.
Follow-up	Effective systems for follow-up are needed.
Counselling integral part of testing	Counselling is integral part of genetic testing and more links between laboratories and clinical services are needed.
INFORMATION-GIVING	
Content of information	Information should consist of medical facts of the disorder, risk figures, benefits and harms of testing, limitations of the test, rellability of the test, implications of testing, familial implications, probabilities of inheritance, prevention and treatment, information on available support and alternative choices.
What kind of information	Information should be appropriate, balanced, honest, objective, full, sufficient, accurate, age-appropriate and based on up-to-date knowledge.
Understanding	Patient's understandlng needs to be assured. Clear language should be used and interpreters invited when needed. Written summary of information is advisable.
Ways to give information	It is sometimes useful to use alternative ways to distribute information, such as leaflets, videos and visual presentation.
Test type –based information-giving	
Predictive test	Appropriate counseiling should be given. It should include advantages and disadvantages of knowing the result, psychological and social issues, complex appearance of the disease and difficulties to quantify probabilities, possibilities to treatment and planning of life.
Prenatal test	Appropriate counselling should be given. Options, limitations and risks of test should be discussed. Psychological aspects need to be taken into account. Medical facts and child's future should be discussed.
Preimplantation test	Appropriate counselling should be given.
Carrier test	Appropriate counselling should be given and reproductive options discussed.

VALUES	
Non-directiveness	Non-directiveness needs to be ascertained to the patient. It does not mean abandoning patient, but personal conviction of the counsellor should not be involved. Non-directiveness is however difficult in practice and it needs to be considered case-specifically.
Autonomy	Gene test should always be voluntary, only in rare cases can compulsory testing be accepted. Counselling needs to respect individual's values and culture. No pressure should be put on the counsellee and every decision should be equally accepted. Independent decision-making should be encouraged, but counsellor can assist the patient.
Confidentiality	Confidentiality needs to be ascertained to the patient. Patient's private information needs to be protected from third parties. In the situations that non-disclosure would cause severe harm, confidentiality can be breached.
Right to know and to not know	Right to know and to not know genetic information are both important, but sometimes, if it is in the patient's interest, the right to know overweighs the right not to know.
Well-being	In counselling patient needs to be taken care of. Good should always overweigh harm.
Equal access	Everyone should have equal access to genetic testing and counselling.
Individual's interests	Interests of individual should prevail the interests of the society.
PROBLEMS	
Practical problems	Varying practices related to genetic testing and counselling is a problem, as the services should be equal for everyone. Lack of trained professionals, inaccuracy of test results, risks involved in testing and costs of counselling are also problems to be solved.
Ethical problems	
Discrimination	There is a chance that there will be discrimination on basis of genes in the society. Testing can also stigmatize on basis of one's ethnic origins. Testing for sex-selection should not be allowed in order to avoid discrimination on basis of sex. Testing creates attitudes towards disabled people, and in counselling the quality of disabled people's lives is often defined without their contribution. Eugenics needs to be seen as a threat; a rich society includes all kinds of people.
Conflict between values	There is often conflict between confidentiality and duty to warn and provide care and between the right to know and the right to not know. These need to be handled sensitively.
Disclosure	It is sometimes difficult to decide what information to disclose, e.g. unexpected findings and information not related to disease.
Society	In genetic testing the beneficence of both the individual and the society needs to be thought. Increasing range of options that gene tests bring changes society. One of these options is commercial genetic testing in connection which proper counselling should be guaranteed.
Determinism	The use of genetic information may lead to deterministic thinking, and science may be considered as godhead.
Cultural norms	There are different cultural norms on health. Therefore dialogue is needed especially because of the cross-border patients.
RELATION TO OTHER HEALTHCARE	
Genetic testing is different	Genetic information differs from other health information because it has familial and generational implications, it is predictive and the emphasis is not on treatment, it is severe, private and complex and deals with special ethical dilemmas.
Exceptionalism is not good	It is not good to think that genetic testing is too exceptional. This leads to deterministic thinking. Genetics should rather be integrated into mainstream healthcare.
FUTURE DEVELOPMENTS	
Techniques increase	Genetic testing techniques will increase and more guidelines will be needed.
Focus on risk	Focus of testing will be more and more on risks of illnesses and the class of healthy ill will grow. This brings more choices and freedom but ethical dilemmas also need to be thought more carefully.

Professional practices	Patient and physician's roles are changing and more interchange of information is needed. The role of counselling is increasing. Counselling needs to be evaluated and researched.
Healthcare and society	Genetics will be integrated more into everyday healthcare and healthcare costs need to be reviewed. Differences between countries continue to exist, as value basis is always different in different cultures.

* Abbreviations:
UNESCO: United Nations Educational, Scientific and Cultural Organization
WHO: World Health Organization
OECD: Organisation for Economic Co-operation and Development
WMA: World Medical Association
HUGO: Human Genome Organisation
FIGO: International Federation of Gynecology and Obstetrics
ISONG: international Society of Nurses in Genetics
ESHG: European Society of Human Genetics
ESHRE: European Society of Human Reproduction and Embryology
EuropaBio: The European Association for Bioindustries
ASHG: American Society of Human Genetics
NSGC: National Society of Genetic Counselors
AGS: American Geriatrics Society
SSO: Society of Surgical Oncology
ASCO: American Society of Clinical Oncology
AAP: American Academy of Pediatrics
HGSA: Human Genetics Society of Austraiasia
Nuffield: Nuffield Council on Bioethics
EURORDIS: European Organisation for Rare Diseases
GIG: Genetic Interest Group
IHA: International Huntington Association
DPI: Disabled People's International

List of policies and guidelines related to genetic counselling

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