Nutrition and genetics is a fast growing field that is challenging dietitians' competency in both basic knowledge and professional practice. To increase dietitians' awareness of the ethical questions arising in this new field, the European Federation of Associations of Dietitians' (EFAD) Professional Practice Committee (PPC) has collaborated with experts to develop the following background document about ethics of nutrigenomics. This paper, authored by Professor Berge Solberg, is to be read as an extension of the Ethics and Good Practice and the Supplements to the Code of Ethics

Ethics and Good Practice
http://www.efad.org/en-us/professional-practice/ethics-and-good-practice/

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The ethics of Nutrigenomics

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What is ethics?

Before entering the terrain of the ethics of nutrigenomics, we must be sure that we have a common understanding of ethics. Ethics talk is very often needed when a certain question might have many answers. Then we are into the field of reflection, reasoning and justification. In general people do not have to reflect upon whether it is right or wrong to lie to a good friend. We know it is wrong. Our morals tell us that. But our morals do not tell us whether is right or wrong, good or bad to do predictive genetic testing of a child. Then we are into ethics. Here we must investigate what is at stake, along with motives, concerns, consequences and justifications. After carefully having explored this, we might want to make a policy, a law or formulate a code of conduct. Ethics talk starts when morals don't give us an answer – an answer to questions where *we* – very often a community - feel that something is at stake.

How to identify what is at stake in nutrigenomics?

Having a common understanding of ethics, the next step would be to identify the ethical issues attached to nutrigenomics. What is really at stake in this field? There is of course a subjective side of this question – different people would identify different ethical issues. On the other hand, some ethical issues have been discussed for decades within science as well as in society in general. It is possible to identify them without too much of a subjective bias. In this presentation, we will lean heavily on the established ethical discourse within genomics and personalized medicine, because it is reasonable to believe that nutrigenomics raises many of the same questions (Hurliman et al 2017). However, it is important to note that such a presentation is just a draft. New ethical issues may suddenly arise with changes in technology or cultural values and there will never be a final list of ethical questions.

Prevention and the risk of informational harm

One of the preconditions for prevention through nutrigenomics is genetic testing. Predictive genetic testing has been debated for several decades. It is the only part of medicine where a right *not to know* is highly respected (Chadwick et al 2014). One of the reasons for this is a mutual understanding that some types of predictive genetic information can harm people – what has been called "informational harm". It is the fear that healthy people are turned into anxious at-risk persons or patients without a very good reason. Or that people loses their sense of an *open future*. Extra safeguards are often put in place regarding predictive genetic testing of children, since children cannot consent and their whole future is at stake.

Dietitians need to be aware of the risk of informational harm if predictive genetic disease information is disclosed as a consequence of nutrigenomic testing. Steps should be taken to avoid such disclosure.

The risk of integrity- and privacy breaches

Genetic information is considered to be extremely sensitive information. Classical topics in the ethics of genetics are the risk of misuse of genetic information by insurance companies, employers, police, etc. Genetic information is about families and relatives, but genetic information can also reveal that someone is not part of the biological family. This means that there might be information and secrets hidden in genetic data that could pose serious threats to people's integrity and privacy, if they end up in the wrong hands.

It is of vital importance that clients within the field of nutrigenomics, have consented to genetic testing. Clients should be in control of their genetic data, by being informed about, and having consented to, potential secondary use and sharing of their data (i.e. research / commercial use). Clients should be able to trust the security, confidentiality and integrity of laboratories, storage facilities and health personnel dealing with their genetic data.

Personalized approaches and the risk of "me-medicine"

Personal medicine is a buzzword in medicine today (Abettan 2016). Tailored approaches in treatment, drug development as well as in dietetics seem to be a promising way to go. Differences in our genomes should lead to differences in the way we approach patients/clients, and genomics based advices could have a huge motivational force. But there might be a catch. Personal medicine and nutrigenomics seems to emphasize that we are all different, and embezzle the fact that we have so much in common. Population based and standardized strategies for improving health and diets, may suffer when the idea of tailormade advices based on genomics get popular. The philosopher Donna Dickenson has called broad strategies "we-medicine" (Dickenson 2013). As a contrast, she calls tailormade approaches "me-medicine". The potential harm is if "we-approaches" loses terrain to "me-approaches" on the basis of ideology rather than scientific considerations of effect. There is a strong, western cultural trend towards "individualization" were tailormade health advices ideologically fits in.

Nutrigenomics must find the balance. Genomics based tailor made advices should not be pushed to a degree that they undermine public belief in effective broad population based strategies and advices.

The risk of an "unhealthy" relation to the social activity of eating

Health is characterized partly by a certain peace of mind. We often say that an aspect of being healthy is to forget about health. When one gets sick, one "remembers" the body. The philosopher Hans Georg Gadamer pinpointed this "concealed" nature of health in this famous quote:

"Without doubt it is part of our nature as living beings that the conscious awareness of health conceals itself. Despite its hidden character, health nonetheless manifests itself in a kind of feeling of wellbeing. It shows itself above all where such a feeling of well-being means that we are open to new things, ready to embark on new enterprises and, forgetful of ourselves, scarcely notice the demands and strains which are put upon us. This is what health is." (Gadamer 2015, p 143-144)

This quote should not be interpreted as an argument against prevention and scientific dietetic advices, but only a warning that tailormade prevention might occupy your thoughts more than broad and often simple strategies. Nutrigenomics has a potential for motivating individual lifestyle changes and thereby creating health. On the other hand, if nutrigenomics brings the genes onto the table, so to speak, the rich social practice of eating may become affected. Eating and drinking is more than nutrition, it has a social and cultural dimension that makes it a central part of a good life.

Dieticians should keep in mind that "health" is a thick concept where optimal, personalized nutrition represent one dimension of the concept, while the feeling of wellbeing and "forgetfulness of ourselves", represents another dimension. Both dimensions need to be considered.

Direct-to-consumer-testing and the risk of hyping genetics

Many commercial companies offer dietetic advices based on personal genetic testing today. As Ahlgren et al. (2013) have pinpointed, *consumer protection is crucial* on this arena. All of the concerns above are particularly relevant concerns with regard to the DTC-industry and consumer protection. But in addition to the concerns mentioned, it is important to note that the DTC-companies are the leading agents marketing the idea that healthy nutrition needs to be based on genetic information. The main risk here is that the companies oversell this idea, far beyond the science underlying this field.

The immediate risk of hyping and overselling is that consumers waste their money on dietetic advices without effect. A more profound risk is that these companies manage to influence popular culture in the sense that people in general tend to believe that malnutrition primarily has a genetic explanation. We know for sure that the most important determinants for what people anywhere on earth eat and drink, are what country they live in and what socio-economic class they belong to. That means that on a general level, political explanations are far more important than genetic explanations.

Dieticians should be updated on the scientific foundation for advices given by the DTC-companies and be able to call attention to hype and overselling of genetics in this field.

References:

Abettan, C. 2016. Between hype and hope: What is really at stake with personalized medicine? Med Health Care and Philos (2016) 19: 423. doi:10.1007/s11019-016-9697-2

Ahlgren J, Nordgren A, Perrudin M, Ronteltap A, Savigny J, Trijp H, Nordström K & Görman U (2013). Consumers on the Internet: ethical and legal aspects of commercialization of personalized nutrition. *Genes & Nutrition*, Volume 8, Issue 4, pp 349–355.

Chadwick R, Levitt M, Shickle D. (2014, ed.). The Right to Know and the Right Not to Know. Genetic Privacy and Responsibility. 2nd Edition. Cambridge: Cambridge University Press.

Dickenson, D. (2013). Me medicine vs. we medicine: Reclaiming biotechnology for the common good. Columbia University Press.

Gadamer H.G. (2015) The Enigma of Health: The Art of Healing in a Scientific Age. John Wiley & Sons.

Hurlimann T., Robitaille J. Vohl M.C., Godard B (2017). Ethical considerations in the implementation of nutrigenetics/nutrigenomics. Personalized Medicine, Vol. 14, No. 1 , Pages 75-83.

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