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PERSONAL GENOMIC PASSPORT: HEALTH BENEFITS AND ETHICAL RISKS

У статті висвітлені досягнення сучасної молекулярної біології, що лежать в основі концепції геномної паспортизації. Обговорені напрями використання цього інструменту в здоров'язбереженні, медицині та освіті. Розглянуті переваги цього інструментарію у групах дітей та підлітків. Проведено обговорення та оцінку ризиків від впровадження геномних паспортів.

Ключові слова: *особистий геномний паспорт, секвенування нового покоління, етичні ризики*

The article highlights the achievements of modern molecular biology, which are the basis of the concept of genomic passporting. Areas of use of this tool in health care, medicine and education are discussed. It was considered advantages of this toolkit in groups of children and adolescents. A discussion and risk assessment of the implementation of genomic passports was conducted.

Key words: *personal genomic passport, next-generation sequencing, ethical risks.*

The accumulation of data on the genetic causes of diseases raises the question of the possibility of characterizing an individual as a set of predispositions and issuing personal genomic passports. Such a system would reduce the risks of developing diseases or promptly apply gene therapy to eliminate them in different age groups from newborns to the elderly. The genomic passport system can be especially useful for children and adolescents, since during this period cognitive and physiological functions are formed. At the same time, genomic certification carries risks that are primarily ethical in nature. At a discussion at the Belgian Public Health Research Institute Sciensano, two main problems were postulated in the issue under consideration: *ontological vulnerability* (information about predisposition to diseases reminds people of constant risk) and *situational vulnerability* (for example, discrimination causing psychological and economic harm) [1].

Genomic passportization aims to develop personalized medicine. Personalized medicine uses the concepts of the genetic and environmental basis of disease to individualize prevention, diagnosis, and treatment. It should be noted that decoding a personalized genome using next-generation sequencing (NGS) technologies often relies on traditional genetic approaches. Genomic studies have made it possible to establish the causes of monogenic diseases such as hemophilia, cystic fibrosis, and breast cancer. These diseases are still included in the prenatal skinning program, so their inclusion in the genomic passport is less controversial today. Today it is

becoming obvious that non-synonymous mutations not only in exonic regions, but even in introns can lead to diseases due to disturbances in the regulation of gene activity. This is relevant for diseases such as prothrombin disorders, schizophrenia or colon cancer. The importance of a personal genetic passport also lies in the fact that the cause of a disease can often be imprinting, de novo germline mutations and epigenetic mechanisms of inheritance, which are not easy to identify using classical genetic methods and require the use of other omics in addition to genomics [2].

Precision medicine for monogenic, oligogenic, multifactorial and infectious diseases is based on the effective application of NGS technologies in combination with modern analysis algorithms and genetic user concepts of expression and penetrance. Much of this approach relies on whole exome sequencing (WES), which is used to conduct mass screening of structural and regulatory genes to determine the allele frequencies of disease-associated polymorphisms in different populations and thus detect pathogenic genetic changes (mutations or polymorphisms) that contribute to the emergence of faulty protein sequences [3].

A public health research biobank Michigan's BioTrust for Health together with Private Access™ pilot tested a dynamic simulation of informed consent for the use of residual dried bloodspot (DBS) cards from newborn screening. Over 50% of the 187 pilot testers indicated their willingness to create an account if the simulation were to go live and recommend it to others [4]. This circumstance allows us to count on the approval of society for genomic passportization, which can be implemented on a voluntary basis.

It should be noted separately that a genomic passport can reveal a person's abilities, since behavioral science has already made progress in establishing the genetic cause of intellectual, psychological, and behavioral characteristics. This brings new opportunities and new risks. It is very important to determine the vectors of personality development when the person himself finds it difficult to determine them, but everything should be done to avoid predictivity in this matter [2].

Increased interest in genomic passporting caused by COVID-19 pandemic. There is a group of people who are genetically resistant to the virus. They do not get sick in moderate or severe form, but can be latent carriers of the disease. Others, on the contrary, are highly susceptible to this disease. This circumstance should be taken into account when planning anti-epidemic measures. Therefore, mass genomic passportization can help reduce mortality from epidemics and pandemics [5].

Thus, genomic passporting based on the mass application of next-generation sequencing technologies can provide convenient and useful tools for the public health system. This approach can be used in career guidance and when choosing a profession. These tools can be especially important when working with children and adolescents, both from a medical perspective and in the educational process. This approach allows you to maintain health, which is the basis of its benefits. At the same time, it also carries risks. Thus, a person, knowing about the possibility of getting a fatal and incurable disease, can increase the likelihood of its development through psychosomatic mechanisms. When using genomic passporting to determine abilities, there is a risk of excessive predetermination of a person's fate. Another tangible risk

is the danger of leakage of information about a person and their stigmatization. Therefore, genomic passporting is an important element of public health and education, but its successful implementation requires assessment and minimization of risks.

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ДО ПИТАННННЯ НАДАННЯ ПСИХОЛОГІЧНОЇ ДОПОМОГИ В ОКРЕМИХ ЕКСТРЕМАЛЬНИХ СИТУАЦІЯХ

У статті відображено фактори, які впливають на стан людини, що опинилася у складній екстремальній ситуації. Розглянуто окремі питання надання психологічної допомоги. Розкрито підхід до організації й змісту надання першої психологічної допомоги.

Ключові слова: *людина, екстремальна ситуація, перша психологічна допомога, стрес, заходи першої психологічної допомоги.*

The article reflects the factors that affect the condition of a person who finds himself in a difficult extreme situation. Separate issues of providing psychological assistance are considered. The approach to the organization and content of psychological first aid is revealed.

Key words: *person, extreme situation, psychological first aid, stress, psychological first aid measures.*