

Chapter 1 : Genetics and Ethics | Bioethics Research Library

Overview. Ethical issues surrounding genetics continue to be a focus of the Bioethics Research Library. The Library is grateful for support of the National Human Genome Research Institute (NIH) and its predecessor from to

Received Jan 28; Accepted May From Darwin through the Asilomar Conference and the Universal Declaration on the Human Genome and Human Rights, much has been achieved, but much still remains to be done. The use of biological materials that are already being stored and the adequacy of new technologies, such as clustered regularly interspaced short palindromic repeats CRISPR , are some of the current challenges of this possible and necessary interaction. This paper will discuss some ethical aspects involved in current genetics. This change in understanding from obscure and dogmatic ideas intensified the debate between new knowledge and ancient traditions Lucas Scholars reflected on how to overcome this, as for example, Thomas Huxley with his conference on science, religion, and education Huxley Huxley made a comprehensive approach to these three aspects, without prejudices. Applying the biological knowledge generated by Darwin to explain social aspects, as in the case of Eugenia Galton , only increased the need for this reflection. During the same period, Gregor Mendel proposed his work Mendel , which made no further contributions to the discussion, perhaps because his focus was on plants. In the 20th century, some social applications of the theory of evolution were negative Stoddard , whereas others were positive Moreno The first one used genetics arguments to justify racism Stoddard , while the second integrated genetics with social perspectives Moreno In the late s, however, the possibility of changing this structure with the emergence of what was then called genetic engineering generated new questions. When this DNA alteration was possible, researchers were surprised by the mechanism they now had at their disposal and the risks associated with this manipulation. Led mainly by Paul Berg and David Baltimore, a group of scientists from a committee of the US National Academy of Sciences proposed a voluntary moratorium on research in this new area Berg et al. The Asilomar conference was attended by scientists mostly biologists, as well as medical doctors, and lawyers and 16 journalists. This conference was a milestone in the history of science, because scientists self-reflected on their own practices. The Asilomar document is a precursor of the precautionary principle, which originated in the thoughts of Albert Schweitzer Schweitzer , and was first used in the s Raffensperger and Tickner The precautionary principle states that any risk of serious or irreversible damage requires taking measures to prevent its occurrence. The challenges of research on human subjects had been discussed in light of the abuses committed during World War II, especially with the development of the Nuremberg Code in Trials of war criminal before the Nuremberg Military Tribunals This document contains a requirement that all participants authorize, through informed consent, their inclusion in research projects. In order to transform words into action, WMA proposed a second version of the Declaration of Helsinki, in , which proposed, among other things, creating research ethics committees that would review all research projects involving human subjects WMA The core of this proposal is not new; Thomas Percival, in , had already proposed that all new innovative applications in health first be discussed with other, more experienced, professionals Percival In , the National Institutes of Health created, with the same purpose, the first committee on recombinant DNA, based on proposals made at the Asilomar conference Hutt Regulatory aspects This reflection on the appropriateness of genetics research, by both scientists and society as a whole, generated the need for rules to guide scientific activity. Many other countries all around the world made efforts in the same direction. In Brazil, the first standards for health research were established in Brasil It is important to note that neither of these documents, the Belmont Report, Brazilian regulatory statement, or Oviedo Convention, mentioned genetics research. This regulatory document established eight special research areas that required local and national approval for their execution. Research in human genetics was the first special thematic area included in the document. Another special area in genetics was, specifically, cooperative research between researchers from Brazil and indigenous populations Brasil Later, more detailed and specific rules for these three special areas were also published Brasil ; ; Other documents also had repercussions for research in human genetics, such as those relating to storage of biological material Brasil The combination of review directives, regulatory

aspects, and ethical reflections on medical genetics research had different effects. Some committees had more familiarity with these topics because, in some cases, there was already an institutional culture of the ethical appropriateness of research, and the researchers were recognized as qualified in their respective areas of scientific expertise. In these institutions, genetic research projects submitted for evaluation by the research ethics committee had procedures similar to any other projects. However, if an institution was not familiar with a research area, or if the ethics committee did not include researchers in the field of genetics, the review process was slow and often conducted without a proper understanding of the purpose and suitability of the research. This example from Brazil can also be applied to other Latin American countries Lemke et al. Two important issues were also evaluated, as subsets, in the same papers: In PubMed, 5. The two papers in SciELO were very specific—one commented on forensic aspects and the other on prenatal genetic screening. These data reveal that more scientific information about these topics is necessary, in order to provide a useful background for reflection on important ethical issues. It is, in fact, rather difficult to believe that there were so few publications on these relevant topics in the SciELO database. These findings, especially in SciELO, could be explained by the selection of keywords by the authors. Ethical reflections and research in genetics The concept of dangerous knowledge, proposed by Van Renselaer Potter, refers to knowledge that accumulates more rapidly than the wisdom required to use it Potter Recognizing research in genetics as a source of dangerous knowledge does not entail avoiding or proscribing it. On the contrary, recognizing the potential for dangerous knowledge entails the need for extended discussion on the various aspects of research, including ethical, legal, and social issues ELSI. As a result, a document was published containing proposed guidelines for research on the human genome Human Genome Organization, HUGO Despite all of these advances, many ethical, legal, and social issues still deserve to be reflected on in genetic research, such as the use and storage of biological material and precaution in the use of new technologies. Currently, there are adequate standards for storage of biological material Dietrickx and Borry ; however, many researchers have large biological collections in different countries associated with old research projects, which were planned and conducted before the current regulatory system was proposed. Stored biological materials have an inestimable scientific value because they are evidence of conditions that often no longer exist, but when they come from traditional populations, such as indigenous groups, other social and historical issues must be factored in to the discussion. The most important is to identify solutions that align the different perspectives in order to preserve both biological and social memory. Novel ethical solutions should be used rather than simply applying currently prevailing guidelines to situations of the past. Joint and unprejudiced decisions that include all parties are essential for identifying suitable solutions. Reflections are important in this techno-science era, especially when a new technology is introduced and applied to genetic research without major studies about ethical and social issues. One of the key issues is the irreversibility of the actions involved and the introduction of new features into the gene pool. One of these new techniques is CRISPR clustered regularly interspaced short palindromic repeats , which is used to edit portions of the genome. From its introduction in Jansen et al. CRISPR is a good example of the concepts of dangerous knowledge, precautionary principle, and techno-science. Many other aspects involving individuals, society, and nature could be involved, such as human dignity, justice, respect of persons, and retrospective and prospective responsibility. The rapid development of scientific knowledge and immediate implementation of new technologies made it difficult to identify what is technology and what is science. This idea had already been proposed in the s, under the name of techno-science Hottois ; Latour , when scientific knowledge was generated and applied too quickly; it is worth noting that more than articles were published on CRISPR, from to The lack of reflection associated with the use of this technique is evidenced by the lack of publications that address it. Finally, the precautionary principle is an important approach to this issue, because CRISPR meets the criteria for potentially serious and unpredictable risks, if measures are not implemented to prevent those risks before there is real damage. Genetics deals with all of those aspects. Much more than fearing genetic advances, or questioning the need for ethical reflection on research to implement these advances in society, it is essential to rescue and update ethical zeitgeist of the s. The complex interaction between genetics and ethics demonstrates the need for an interdisciplinary approach to assess the adequacy of genetic practices and the ethical

reflections about them. Compliance with ethical standards The author declares that he has no conflicts of interest. Ethical approval This article does not contain any studies with human participants or animals performed by the author. Potential biohazards of recombinant DNA molecules. Summary statement of the Asilomar conference on recombinant DNA molecules. Diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. On the origin of species by means of natural selection, or the preservation of favoured races in the struggle for life. Dietrickx K, Borry P. New challenges for biobanks: Le signe et la technique. Research on recombinant DNA molecules: South Calif Law Rev. Identification of genes that are associated with DNA repeats in prokaryotes. Ethical issues in international collaborative research on the human genome: Attitudes toward genetic research review: Kennedy Inst Ethics J. The ethics of modernity: Rowman and Littlefield; Rev Med Suisse Raffensperger C, Tickner JA. Protecting public health and the environment: Schweitzer A The words of A. The rising tide of colour against white world-supremacy.

Chapter 2 : Genethics Health Research Info

Overview of policy and ethics resources available through the National Human Genome Research Institute.

But many medical tests that start out as optional become less and less optional as time goes by. Who should decide when genetic tests are done? Should insurance companies or employers have access to the results? If prenatal genetic tests become more common, will people with certain genetic traits, diseases, or even predispositions suffer increased discrimination? Will "designer babies" become the norm? For some, the opportunities presented by genetic testing and therapies smack of eugenics, the use of selective breeding to create "superior" people. More broadly, who "owns" the genetic information-or the life forms-that come from research? These questions arise with increasing frequency in industry, where patents are granted for genetically engineered plants and animals, and for genetic sequences. Companies argue that without patents, they are left with no guarantee that they can recoup their investment when they discover key genes. But do patents stifle progress and the free exchange of ideas, so important in science? Others worry that reckless experimenting will have unforeseen, potentially catastrophic consequences. For example, the prospect of transplanting animal organs into people xenotransplantation raises concern that new diseases could jump from animals to humans, as SARS and "mad cow" disease have. Currently, treatments are focused on somatic cells, that is, cells in the body. Any alterations are not passed on to later generations, because DNA in the germ cells-eggs and sperm-is unaffected. But so-called germ line gene therapy is certainly possible. It could cure diseases before they happened, but might cause other unexpected problems that would persist in later generations. Food for Thought The genetic modification of plants for food is a hot-button issue around the world. Genes transplanted to corn, potato, soybean and other food strains can confer desired traits, such as resistance to pests, which lessens the need for toxic pesticides. Though genetically modified foods are thought to be safe to eat, their impact on the environment may not be fully known. A strain of mice used for cancer research, called Oncomouse, was the first mammal to be patented! This cloned sheep, Dolly, foretells the prospect of human cloning, one of many reproductive possibilities under debate.

Genetics, research, and ethics as keywords. In order to find similarities and differences between genetics research and ethics between international and Latin American scientific literature, a search was conducted using PubMed (US National Library of Medicine) and SciELO (SciELO-Scientific Electronic Library Online) databases, through January

Committee on Ethics Committee on Genetics This document reflects emerging clinical and scientific advances as of the date issued and is subject to change. The information should not be construed as dictating an exclusive course of treatment or procedure to be followed. Genetic testing is poised to play an increasing role in the practice of obstetrics and gynecology. Clinicians should be able to identify patients within their practices who are candidates for genetic testing. Candidates will include patients who are pregnant or considering pregnancy and are at risk for giving birth to affected children as well as gynecology patients who, for example, may have or be predisposed to certain types of cancer. The purpose of this Committee Opinion is to review some of the ethical issues related to genetic testing and provide guidelines for the appropriate use of genetic tests by obstetrician-gynecologists. Expert consultation and referral are likely to be needed when obstetrician-gynecologists are confronted with these issues. Although ethical questions related to genetic testing have been recognized for some time, they have gained a greater urgency because of the rapid advances in the field as a result of the success of the Human Genome Project. That project—a year multibillion-dollar program—was initiated in 1990 to identify all the estimated 20,000 genes and to make them accessible for further study. The Department of Energy and the National Institutes of Health earmarked portions of their budgets to examine the ethical, legal, and social issues surrounding the availability of genetic information. It is important to note at the outset, given the increasing complexity of this field and the quickness with which it advances, that expert consultation and referral are likely to be needed when obstetrician-gynecologists are confronted with many of the issues detailed in this Committee Opinion. The pace at which new information about genetic diseases is being developed and disseminated is astounding. Thus, the ethical obligations of clinicians start with the need to maintain competence in the face of this evolving science. If a patient is being evaluated because of a diagnosis of cancer in a biologic relative and is found to have genetic susceptibility to cancer, she should be offered counseling and follow-up, with referral as appropriate, to ensure delivery of care consistent with current standards. In fact, genetic screening for any clinical purpose should be tied to the availability of intervention, including prenatal diagnosis, counseling, reproductive decision making, lifestyle changes, and enhanced phenotype screening. One of the pillars of professionalism is social justice, which would oblige physicians to "promote justice in the health care system, including the fair distribution of health care resources" 1. Obstetrician-gynecologists also are ideally positioned to educate women. When they, or experts in genetics to whom they refer, counsel on genetics, they should provide accurate information and, if needed, emotional support for patients burdened by the results or consequences of genetic diagnoses, be they related to preconception or prenatal care, cancer risks, or other implications for health. Finally, clinicians should familiarize their patients with steps that can be taken to mitigate health risks associated with their genetic circumstance eg, having a colonoscopy if there is a predisposition to colon cancer 2. Although that might seem like a medical panacea, the potential risks associated with wide-scale genetic testing are substantial. Many incidental findings will come to light, and yet, although those tested may be tempted to believe otherwise, genetic findings do not equate directly with either disease or health: Informed Consent Genetic Exceptionalism Before the appropriate process for obtaining consent for genetic tests is considered, it is necessary to confront the broader question of whether the consequences of the results of those tests are substantively different from the consequences of other "medical" tests, for which specific consent is not always obtained. Some ethicists argue against what has been called the "exceptionalism" of genetic tests 5. They maintain that many medical tests have consequences for patients that are similar to those of genetic tests. For example, there can be discrimination by insurance companies against individuals either with a genetic disease or with a disease that is not linked to any particular gene. Results of nongenetic tests, as well as genetic tests, can divulge information about family members eg, tests for sexually transmitted diseases. As

such, some authors have concluded that many genetic test results "may cause stigmatization, family discord and psychological distress. Regardless of whether a test is genetic, when this combination of characteristics is present testing should be performed with particular caution and the highest standards of informed consent and privacy protection should be applied" 6. However, others argue that genetics should be treated as a unique class and be subject to a more rigorous process for consent. They base their belief on several factors. Genes, they argue, do not merely inform patients and their health care providers about the diagnosis of an extant illness. They also foretell the possibility or in some cases the certainty of a future disease, thus allowing "perfectly healthy" individuals to be subject to discrimination based on a predisposing gene. The DNA sample which can be viewed as "a coded probabilistic medical record" makes genetic privacy unique and differentiates it from the privacy of medical records" 7. Some believe that this information is even more sensitive given the uncertainties attached to genetic results ie, the reliability of tests, the penetrance of genes, and the unavailability of efficacious interventions to reduce the consequences of genetic diseases. Additionally, the consequence of being found to carry a particular gene has resonance not only for the individual who is tested but also for family members. Patients should be informed that genetic testing could reveal that they have, are at risk for, or are a carrier of a specific disease. The results of testing might have important consequences or require difficult choices regarding their current or future health, insurance coverage, career, marriage, or reproductive options. The health care provider ordering tests has a responsibility to use and interpret those tests correctly or to refer to someone with relevant expertise. Because completing all these tasks is particularly difficult when direct-to-consumer marketing of genetic tests is used, that marketing approach has significant limitations 9. These enterprises receive compensation only if an individual, after counseling, chooses to undergo a test, bringing the standard of neutral counseling into question and further rendering the use of a market-driven approach to testing ethically problematic. In the end, the physician plays an important role in providing adequate, neutral counseling; ensuring informed consent; and providing follow-up for genetic tests. Particular caution should be exercised when obtaining consent for collecting genetic material that may be stored and, therefore, can have future clinical or research applications. The American College of Medical Genetics ACMG recommends that when samples are obtained for clinical tests, counseling should address the anticipated use of samples, including whether their use will be restricted for the purpose for which they were collected and if and when they will be destroyed. When samples will be used for research or the development of diagnostic tests, the ACMG recommends that consent should include a description of the work eg, its purposes, limitations, possible outcomes, and methods for communicating and maintaining confidentiality of results. Current and future use of samples for research should follow state and federal regulations governing protection of human participants in research. Two authors recently suggested that the "best consumer advice, given current law, is that one should not send a DNA sample to anyone who does not guarantee to destroy it on completion of the specified test" 7. Others argue for the creation of a repository of samples donated by genetic altruists to be used for many different types of research 4.

Genetic Testing in Children and Adolescents Testing of children presents unique issues in counseling and consent. Although it is most commonly pediatricians or geneticists who are called on to test children for genetic diseases, obstetricians may be asked to test already born children of parents who, through the process of prenatal testing, have been found to be carriers of genetic diseases. In such cases, the physician should balance the rights of the parents to have information that can optimize the ongoing health care of their children against the rights of the children to have their best interests protected. There will be circumstances in which it can be determined that a child is at risk for an untoward clinical event in the future, but there may be no information about interventions that have the potential to reduce the likelihood of that event or the magnitude of its effect. In that circumstance, the benefits of testing a child are not always clear eg, BRCA testing in a young child. These societies highlighted additional points about benefits and burdens that should be included in counseling, some of which follow: Timely medical benefit to the child should be the primary justification for genetic testing in children and adolescents. If the medical benefits are uncertain or will be deferred to a later time, this justification for testing is less compelling. If the medical or psychosocial benefits of a genetic test will not accrue until adulthood, as in the case of carrier status or adult-onset diseases, genetic testing generally should

be deferred. Further consultation with other genetic services providers, pediatricians, psychologists, and ethics committees may be appropriate to evaluate these conditions. Testing should be discouraged when the health care provider determines that potential harms of genetic testing in children and adolescents outweigh the potential benefits. A health care provider has no obligation to provide a medical service for a child or adolescent that is not in the best interest of the child or adolescent. The ASHG and ACMG concluded, "Providers who receive requests for genetic testing in children must weigh the interests of children and those of their parents and families. The provider and the family both should consider the medical, psychosocial, and reproductive issues that bear on providing the best care for children" 8. Physicians obstetricians and pediatricians also have a responsibility to provide information to patients regarding newborn screening. More detail about this issue can be found elsewhere Prenatal Genetic Testing Genetic testing of the fetus offers both opportunities and ethical challenges. Preconception and prenatal genetic screening and testing are recommended for a limited number of severe child-onset diseases because such screening and testing provides individuals with the chance to pursue assisted reproductive technology in order to avoid conception of an affected child, to consider termination of a pregnancy, or to prepare for the birth of a chronically ill child. With advancing genetic technology, however, physicians may increasingly face requests for testing of fetuses for less severe child-onset conditions, adult-onset conditions, or genetically linked traits. Principles regarding testing of children provide some guidance for when prenatal testing might be appropriate but this decision is significantly complicated by the various purposes that prenatal testing can have: Therefore, testing the fetus for adult-onset disorders with no known therapeutic or preventive treatment save prevention by pregnancy termination should raise caution in a way similar to the manner in which testing of children can. In pregnancies likely to be carried to term, consideration should be given to whether, as in the case of testing children, the decision to test should be reserved for the child to make upon reaching adulthood. However, consideration also should be given to personal preference, that is, the interests individuals may have in terminating a pregnancy that may result in a life such as life that will be affected by Huntington chorea that they feel morally obliged or prefer not to bring into the world. Because these often are wrenching decisions for parents, referral to parent support networks eg, National Down Syndrome Society, if that is the diagnosis of concern , counselors, social workers, or clergy may provide additional information and support Genetic Data and the Family In a large number of instances, when patients receive the results of genetic tests, they are party to information that directly concerns their biologic relatives as well. This familial quality of genetic information raises ethical quandaries for physicians, particularly related to their duty of confidentiality. For example, a woman who discovers that she is a carrier of an X-linked recessive disease during the workup of an affected son might choose not to tell her pregnant sister about her carrier status because she does not believe in abortion and fears that her sister might consider an abortion In another example, a woman identified as a carrier of a gene predisposing individuals to cancer might not wish to share the information with relatives, some of whom might even be patients of the same physician who tested her, because such sharing would disclose her own status as a carrier. In both the previously cited cases, information obtained with the consent of one individual could assist in the management of another. How assiduously that confidentiality needs to be guarded is the subject of some debate. Some have argued that genetic information should be subject to stringent safeguards because, even though there may be uncertainty about the ultimate biologic consequence of a given gene, the social consequences discrimination and stigmatization can be substantial Conversely, there are those who argue against the withholding of important information from potentially affected family members Those who subscribe to this belief feel that when information applies to family as much as to the proband, an obligation arises that extends from the physician to those potentially affected family members but no further. Two of these rulings addressed the question of how physicians must fulfill this duty and reached different conclusions. In another case, the court did not decide how the physician could satisfy the duty to warn, other than requiring that "reasonable steps be taken to assure that the information reaches those likely to be affected or is made available for their benefit" As these alternate decisions illustrate, the legal limits of privacy are evolving, emphasizing the need for patient communication and case-by-case evaluation. Recommendations of Other Organizations Organizations that promulgate guidelines for genetic care and

counseling also have proposed different approaches to the disclosure of genetic information. According to the ASHG, disclosure is acceptable if "the harm is likely to occur, and is serious, immediate and foreseeable. In summary, "the harm from failing to disclose should outweigh the risk from disclosure. The commission indicated that disclosure is required when four conditions are present: Role of the Obstetricianâ€™Gynecologist The best way for the obstetricianâ€™gynecologist to avoid the challenging choice between involuntary disclosure and being passive in the face of risks to kindred is to anticipate the issue and raise it at the first genetic counseling session. At that session, the patient needs to be educated about the implications of findings for relatives and why voluntary disclosure would in many circumstances be encouraged as well as the possibility that relatives might prefer not to know the results. Some bioethicists have even suggested that these sessions should be used as an opportunity for clinicians to articulate the circumstances under which they would consider disclosure obligatory, thus allowing patients to seek care elsewhere if they found the conditions for testing unacceptable Macklin has referred to this as the "genetic Miranda warning" Similarly, even if the health care provider would not disclose without consent under any circumstance, the initial counseling session could allow the health care provider to refer the patient elsewhere if they find they have an irreconcilable difference or have an objection of conscience in expectations about disclosure. A particularly thorny issue related to the ownership of genetic information might be results that bear on paternity. It is possible that prenatal assessments and family testing might reveal that the husband, partner, or other putative father is not the biologic father. In , the Committee on Assessing Genetic Risks of the Institute of Medicine recommended that in such situations the health care provider should inform a woman but should not disclose this information to her partner In some cases, it is not merely a matter of acting to protect families. For example, suppose a child is born with a disease that is caused by an autosomal recessive gene, and the husband does not carry the deleterious gene because he is not actually the father. If the physician were to maintain the charade of paternity, then the counseling given to both parents ie, there is one chance in four that each subsequent child will have the same disease would be false and might lead the husband to argue against more children or for unnecessary amniocenteses in all future pregnancies, or inappropriately lead to concern for others in his family. Other circumstances exist in which the interests of a pregnant woman and family members might diverge. If the father did not want to know his own status, a conflict would arise, pitting her right to know about her fetus against his right not to know about himself.

Chapter 4 : Ethical issues in predictive genetic testing: a public health perspective

Fact Sheet 19 | ETHICAL ISSUES IN HUMAN GENETICS AND GENOMICS 1 1 Page 1 of 3 calendrierdelascience.com Updated 15 August This fact sheet describes some of the ethical issues that can arise because of the use of genetic testing.

Genetic research is now leading to a better understanding of the genetic components of common diseases, such as cancer, diabetes, and stroke, and creating new, gene-based technologies for screening, prevention, diagnosis, and treatment of both rare and common diseases. Nurses are on the forefront of care, and therefore will participate fully in genetic-based and genomic-based practice activities such as collecting family history, obtaining informed consent for genetic testing, and administering gene-based therapies. This new direction in healthcare calls for all nurses to be able to effectively translate genetic and genomic information to patients with an understanding of associated ethical issues. This article will present six genetic and genomic healthcare activities involving ethical issues of importance to nurses. Approaches nurses can use to integrate comprehensive and current knowledge in genetics and genomics into their practice to most fully meet the needs of their patients, families, and society will also be described. The Online Journal of Issues in Nursing. By identifying the genetic factors associated with disease, it is possible to design more effective drugs; to prescribe the best treatment for each patient; to identify and monitor individuals at high risk from disease; and to avoid adverse drug reactions National Human Genome Research Institute, New genomic discoveries and their applications bring great hope for a more personalized approach to treat disease. The field of genetics, until recently, has focused on rare, single-gene diseases, such as muscular dystrophy. This evolution is creating new, gene-based technologies for the screening, prevention, diagnosis, and treatment of both rare and common diseases, such as cancer, diabetes, heart disease, and stroke. Although these new directions raise hopes for disease prevention and treatment, they also bring challenging ethical issues to patients and healthcare providers alike See Table 1. The United States U. Department of Energy DOE recognized the potential for ethical challenges in genetic and genomic research early on. Ethical Challenges for Nurses: Seeds for Thought Privacy and Confidentiality Who should have access to genetic information? Who owns and controls it? How can families resolve conflicts when some members want to be tested for a genetic disorder and others do not? Discrimination Should employers be able to require job applicants to take genetic tests as a condition of employment? How does genetic and genomic information affect members of minority communities? Nurses are at the forefront of patient care, and will participate fully in genetic-based and genomic-based practice activities, such as collecting family history, obtaining informed consent for genetic testing, and administering gene-based therapies. Nurses will need to be able to effectively translate genetic and genomic information to their patients with an understanding of associated ethical issues. This new direction in healthcare calls for nurses to integrate into their scope of practice the emerging field of genetics and genomics. The increased availability of personal genetic information also challenges nurses to understand the ethical issues associated with activities such as informed decision making, informed consent and genetic testing, genetic and genomic research testing protection, maintaining privacy and confidentiality of genetic information, preventing genetic discrimination, and strengthening genetic and genomic care around the world. This article will provide an overview of the above six activities associated with genetic and genomic healthcare in which nurses are involved and a discussion of the ethical issues inherent in each of these activities. Approaches nurses can use to integrate comprehensive and current knowledge regarding genetics and genomics into their practice to most fully meet the needs of their patients, families, and society will also be described. Genetic and genomic research is creating new areas for nursing involvement in the informed, decision-making process. As Skirton et al. The implication for nurses is that they will increasingly be involved in discussing these issues with patients in all areas of healthcare during the process of obtaining consent. Areas of informed decision making and consent in which nurses will be most involved include gathering family history and requesting medical information. Each will be discussed in turn. Gathering Family History Nurses practicing in primary healthcare settings and specialty care, such as oncology, will continue to be involved in

obtaining and reviewing patient family histories. When family history is needed for other family members, the nurse promotes confidentiality by gathering family history again from additional family members. Requesting Medical Information Nurses in all practice settings may be involved in requesting medical information from patients and their relatives. In these cases the nurse can explain this need and the process to the family members and facilitate their written consent for the release of their medical information.

Informed Consent and Genetic Testing The use of genetic testing from pre-conception through adulthood is expanding rapidly. Genetic testing is increasingly used across the life continuum for screening, diagnosis, and determining the best treatment of diseases. Obstetric and pediatric nurses have traditionally been involved in the genetic testing process with prenatal screening for genetic conditions such as spina bifida and Down syndrome, and newborn screening for genetic conditions such as phenylketonuria PKU. Nursing involvement in genetic testing has expanded to specialties such as oncology, with genetic testing now available for hereditary breast, ovarian, and other cancers. Nurses in all practice areas will be increasingly involved in the genetic testing process, helping the patient understand the purpose and also the risks and benefits of the genetic test, as part of the informed, decision-making and consent process. The use of genetic testing from pre-conception through adulthood is expanding rapidly. As a result of this expansion, new ethical issues are emerging related to genetic testing and informed consent. These new issues create ethical challenges for nurses and all healthcare providers. Currently expanding areas include newborn screening and genetic testing of children. These new ethical challenges will be described below.

Newborn Screening Genetic Testing Newborn screening is an expanding use of genetic testing. A technology called Tandem Mass Spectrometry is now being used by many state newborn screening programs, allowing screening for more than 24 different genetic disorders using one simple test American Academy of Pediatrics, This expanded newborn screening raises new issues around informed decision making. As noted by the American Academy of Pediatrics, genetic testing differs from other types of medical testing in that it provides information about the family. Thus the screening results may have associated psychological, social, and financial risks. Psychological risks for parents who are carriers may include parental guilt. A child diagnosed with a genetic condition may face lowered self-esteem and risk insurance and employment discrimination. Newborn screening may identify infants who are carriers for a particular condition, such as sickle cell anemia. On the other hand, identifying infants as carriers may lead to misunderstanding and misinterpretation by the parents and others that could interfere with the parent-child relationship and result in potential social discrimination. As recommended by the Institute of Medicine and the American Academy of Pediatrics, newborns should not be screened specifically to identify their carrier status. Carrier status findings that are obtained incidentally through the newborn screening process should be given only to parents who have had previous counseling and who have given their consent American Academy of Pediatrics, ; Institute of Medicine, Furthermore, many genetic conditions are still difficult to treat or prevent, which means that the information gained from newborn screening may be of limited value in terms of treatment. At present, most states have mandatory newborn screening programs that require all infants to be screened unless the parents refuse. This is called informed dissent, with minimal information provided to parents. An informed consent process, on the other hand, would involve discussion with the parents about the risks, benefits, and limitations of newborn screening before agreeing to the testing. Having an informed consent process for newborn screening has the potential for more prompt and efficient responses to positive results. The American Academy of Pediatrics has recommended that pediatric providers give parents the necessary information and counseling about the risks, benefits, and limitations of newborn screening, and that they collaborate with genetics professionals and prenatal care providers in providing this complex information to the parents. There are currently two states that require informed consent for newborn screening, Wyoming and Maryland. Thirteen other states require that parents be informed about the newborn screening before the testing is done on their infant. All but one state, South Dakota, allow parental refusal of newborn screening for personal or religious reasons American Academy of Pediatrics, Genetic Testing of Children

Another emerging ethical issue with regard to informed consent is the possibility of testing children using predictive, genetic screening for adult-onset diseases such as cancer, diabetes, heart disease, and stroke. Studies have shown that many adults choose not to have genetic testing for adult-onset disorders. At present, genetic testing

of children and adolescents to predict adult-onset disorders is deemed inappropriate when the genetic information has not been shown to reduce morbidity and mortality if interventions are begun in childhood. The goal of GWAS is to identify common genetic factors that have an impact on health and disease. A genome-wide association study is defined as any study of human genetic variation that involves the entire human genome to identify genes associated with common traits, such as high blood pressure or diabetes, or to determine if a person has or does not have a specific disease or condition U. Department of Health and Human Services [U. This research has the potential for a better understanding of genetic factors that affect human health, and for improving disease screening, diagnosis, prevention, and treatment. To move forward with this new research, the U. The nature of the genetic and other information gained through GWAS underscores the importance of the informed consent process that accompanies this research. Traditional consent involves individuals agreeing both to participate in the research and to the public release of their genetic data. However, some participants may only want to participate and not to agree to share their data. The traditional approach has the potential of limiting the number of individuals willing to participate in the research. A binary-consent process involves research participants agreeing to participate in the primary research project, but choosing not to share their genetic data. The tiered approach is the most ethically sound approach for patients in that it offers them several opportunities to become informed about the research directions and to consider how they wish their genetic information to be shared. Nurses practicing in research settings should be aware of these potential changes in the genetic-informed and genomic-informed consent process so that they can properly educate individuals and families who are considering participating in GWAS and other genomic research.

Maintaining Privacy and Confidentiality of Genetic Information

Genetic technologies are creating new sources of medical information for individuals, families, and communities that raise important ethical, legal, and social issues. Nurses need to be familiar with the nature and sources of genetic information so that they can assure privacy and confidentiality for their patients. Genetic information is defined as heritable, biological information National Human Genome Research Institute, Privacy, as defined by the ANA Code of Ethics involves the right of the individual to control their own body, actions, and personal information. Genetic information obtained from family history and genetic testing, however, may reveal information not only about the health risks of the individual patient being seen, but also of other family members who may not be aware of the health concern. An ethical dilemma arises for nurses and other healthcare providers when a patient does not choose to share genetic information with other family members when it may be important to their health. The nurse can be guided by the ANA Code of Ethics for Nurses to seek help and counsel from experienced individuals of the Ethics Board within their institution. Nurses should also be aware of broader societal privacy concerns. Genetic testing on DNA can be done on stored blood or tissue samples that have been collected for other purposes, for example, newborn screening samples. Data banks of DNA are being established, and genetic disease registries also exist. Preventing Genetic Discrimination Genetic discrimination was identified early on in the Human Genome Project by the Ethical, Legal, and Social Implications program at the National Human Genome Research Institute as an ethical issue that needed to be addressed before the benefits of the Human Genome Project could be fully implemented. Although many are hopeful about the use of genetic information to improve health and combat disease, many are concerned about the potential for misuse, involving, for example, insurance and employment discrimination. Individual concerns include worries that genetic information may be used to deny or limit insurance coverage or to determine who is hired or fired. There is concern voiced that some insurers may choose not to insure people who are healthy but genetically pre-disposed to future disease onset National Human Genome Research Institute, Nurses in all practice settings will be involved in the ethical management of genetic information. Nurses share the responsibility with other healthcare providers to protect clients and their families against the misuse of their genetic information. Nurses must work with healthcare teams and institutions to create practice environments in which their clients can be assured that their genetic information is shared in a professional manner Consensus Panel, Many lawmakers, scientists, and health advocacy groups believe that there is a need for Federal Legislation to prevent genetic discrimination. GINA is designed to prohibit improper use of genetic information in insurance and employment decisions. When these protections are enacted, Americans

will be free to use genetic and genomic information in medical care without the fear of misuse.

Chapter 5 : Ethics | Understanding Genetics

A Shortage of Genetic Counselors Exists For a person undergoing genetic testing to respond intelligently and maturely to test results, he or she will need counseling from a professional equipped to consider the ethical implications. Unfortunately, few such professionals are available.

Autonomy Ethical Analysis Autonomy can be defined as self-determination, self-rule, or self-governance. Autonomous agents or actions presuppose some capacity of reasoning, deciding, and willing. Moral, social, and legal norms establish obligations to respect autonomous agents and their choices. Respect for personal autonomy implies that agents have the right or power to be self-governing and self-directing, without outside control. In the context of genetic testing and screening, respect for autonomy refers to the right of persons to make an informed, independent judgment about whether they wish to be tested and then whether they wish to know the details of the outcome of the testing. Autonomy is also the right of the individual to control his or her destiny, with or without reliance on genetic information, and to avoid interference by others with important life decisions, whether these are based on genetic information or other factors. Respect for autonomy also implies the right of persons to control the future use of genetic material submitted for analysis for a specific purpose including when the genetic material itself and the information derived from that material may be stored for future analysis, such as in a DNA bank or registry file. Even though respect for autonomy is centrally important in our society, it is not absolute. It can be overridden in some circumstances, for example, to prevent serious harm to others, as is the case in mandatory newborn screening for phenylketonuria PKU and hypothyroidism. In particular, cases have held that competent adults have the right to choose whether or not to undergo medical interventions. **Implications for Health and Social Policy.** The National Academies Press. A report from the Office of Technology Assessment similarly stressed the importance of knowledge and consent: The consent of the patient is required to remove blood or tissue from his or her body, and also to perform tests, but it is important that the patient be informed of all the tests which are done and that a concern for the privacy of the patient extends to the control of tissues removed from his or her body. They have privacy if they are left alone and do not suffer unauthorized intrusion by others. Once persons undergo genetic tests, privacy includes the right to make an informed, independent decision about whether—and which—others may know details of their genome e. Various justifications have been offered for rules of privacy. First, some philosophers argue that privacy rights are merely shorthand expressions for a cluster of personal and property rights, each of which can be explicated without any reference to the concept of privacy. In making this argument, Judith Jarvis Thomson holds that privacy rights simply reflect personal and property rights, such as the rights not to be looked at, not to be overheard, and not to be caused distress. Being able to control access to themselves enables people to have various kinds of relationships with different people, rather than being equally accessible to all others. A third approach finds the basis for rights to privacy in respect for personal autonomy. Decisional privacy is often very close to personal autonomy. The language of personal autonomy reflects the idea of a domain or territory of self-rule, and thus overlaps with zones of decisional privacy. **Page Share Cite Suggested Citation:** However, their scope is not unlimited, and they do not always override all other competing interests, such as the interests of others. **Legal Issues** In the legal sphere, the principle of privacy is an umbrella concept encompassing issues of both autonomy and confidentiality. Constitution, as well as state constitutions. This includes a right to make certain reproductive choices, 13 such as whether to use genetic testing. An entirely different standard of privacy protects personal information. A few court decisions find protection for such information under the constitutional doctrine of privacy, 15 but more commonly, privacy protection against disclosure of personal information is found under common law tort principles. **Confidentiality Ethical Analysis** Confidentiality as a principle implies that some body of information is sensitive, and hence, access to it must be controlled and limited to parties authorized to have such access. The information provided within the relationship is given in confidence, with the expectation that it will not be disclosed to others or will be disclosed to others only within limits. The state or condition of nondisclosure or limited disclosure may be protected by moral, social, or legal principles and rules, which can be expressed in

terms of rights or obligations. In health care and various other relationships, we grant others access to our bodies. They may touch, observe, listen, palpate, and even physically invade. They may examine our bodies as a whole or in parts; and parts, such as tissue, may be removed for further study, as in some forms of testing. Privacy is necessarily diminished when others have such access to us; rules of confidentiality authorize us to control and thus to limit further access to the information generated in that relationship. Rules of confidentiality appear in virtually every code or set of regulations for health care relationships. Their presence is not surprising, because such rules are often justified on the basis of their instrumental value: Hence, rules of confidentiality are indispensable for patient and social welfare; without those rules, people who need medical, psychiatric, or other treatment will refrain from seeking or fully participating in it. Another justification for rules of confidentiality is based on the principles of respect for autonomy and privacy, above. Respecting persons involves respecting their zone of privacy and accepting their decisions to control access to information about them. When people grant health care professionals access to them, they should retain the right to determine who else has access to the information generated in that relationship. Hence, the arguments for respect for autonomy and privacy support rules of confidentiality. Finally, duties of confidentiality often derive from explicit or implicit promises in the relationship. On the one hand, rules of confidentiality are sometimes infringed through deliberate breaches. On the other hand, rules of confidentiality are often infringed through carelessness, for example, when health care professionals do not take adequate precautions to protect the confidential information. Some commentators argue that both carelessness and modern practices of health care have rendered medical confidentiality a "decrepit concept," since it is compromised routinely in the provision of health care. First, not all information is deemed confidential, and patients do not have a right to expect that such information will be protected from disclosure to others. For example, laws frequently require that health care professionals report gunshot wounds, venereal diseases, and other communicable diseases such as tuberculosis. Second, health care professionals may also have a moral or legal right and sometimes even an obligation to infringe rules of confidentiality, for example, to prevent a serious harm from occurring. In such cases, rules of confidentiality protect the information, but they can be overridden in order to protect some other value. Judgments about such cases depend on the probability of serious harm occurring unless confidentiality is breached. Any justified infringements of rules of confidentiality should satisfy the conditions identified earlier in the discussion of justified infringements of the principle of respect for autonomy. The protection of confidentiality is thought to serve an important public health goal in encouraging people to seek access to health care. In fact, the first doctor-patient confidentiality statute was passed in New York during the smallpox epidemic to encourage people to seek health care. Various legal decisions have protected confidentiality of health care information, 21 as have certain state and federal statutes. An alternative set of legal principles—those penalizing discrimination see below—protects people against unfair uses of certain information. Equity Ethical Analysis Issues of justice, fairness, and equity crop up in several actions, practices, and policies relating to genetic testing. It is now commonplace to distinguish formal justice from substantive justice. Formal justice requires treating similar cases in a similar way. Standards of substantive or material justice establish the identity of the relevant similarities and differences and the appropriate responses to those similarities and differences. One crucial question is whether genetic disorders or predispositions provide a basis for blocking access to certain social goods, such as employment or health insurance. Most conceptions of justice dictate that employment be based on the ability to perform particular tasks effectively and safely. For these conceptions, it is unjust to deny employment to someone who meets the relevant qualifications but also has a genetic disease. Frequently these questions of employment overlap with questions of health insurance. Practices of medical underwriting in health insurance reflect what is often called "actuarial fairness"—that is, grouping those with similar risks together so insurers can accurately predict costs, and set fair and sufficient premium rates. Although actuarial fairness may be intuitively appealing, critics argue that it does not express moral or social fairness. According to Norman Daniels, there is "a clear mismatch between standard underwriting practices and the social function of health insurance" in providing individuals with resources for access to health care 22 see Chapter 7. The fundamental argument for excluding genetic discrimination in health insurance amounts to an argument for establishing a right to health care. Tristram

Engelhardt notes, depending on whether it views those needs as unfair or as unfortunate. Other individuals, voluntary associations, and even society may be motivated by compassion to try to meet those needs. If, however, the needs are viewed as unfair as well as unfortunate, society may have a duty of justice to try to meet those needs. One prominent argument for the societal provision of a decent minimum of health care is that, generally, health needs are randomly distributed and unpredictable, as well as overwhelming when health crises occur. Another version of the argument from fairness holds that health needs represent departures from normal species functioning and deprive people of fair equality of opportunity. Thus, fairness requires the provision of health care to "maintain, restore, or compensate for the loss of normal functioning" in order to ensure fair equality of opportunity. While our and other societies attempt to discourage such habits by education and taxation, there is general agreement that access to full health care must be ensured once illness develops. If a tendency to abuse alcohol, for example, were to have a genetic predisposition, an additional argument could be made for providing the same level of health care to everyone since a person does not choose his or her genetic propensities. The argument that society should guarantee or provide a decent minimum of health care for all citizens and residents points toward a direction for health policy, but it does not determine exactly how much health care the society should provide relative to other goods it also seeks. And, within the health care budget, there will be difficult allocation questions, including how much should be used for particular illnesses and for particular treatments for those illnesses. Questions of allocation cannot be resolved in the abstract. Certain needy people are provided health care, including some genetics services, under government programs such as Medicaid see Chapter 7. In addition, some legislative efforts have been made to prohibit discrimination based on genotype. To date, most genetic testing has been done in the reproductive context or with newborns, to identify serious disorders that currently or soon will affect the fetus or infant. However, the types of genetic conditions or predispositions that can potentially be tested for are much broader than those signaling serious, imminent diseases. These include characteristics such as sex or height that are not diseases, potential susceptibility to diseases if the person comes into contact with particular environmental stimuli, and indications that a currently asymptomatic person will suffer later in life from a debilitating disease such as Huntington disease. The genetic anomalies that can be tested for range widely in their manifestations, their severity, their treatability, and their social significance. Most medical testing is done within a physician-patient relationship. With genetic testing, however, the potential range of contexts in which it can be undertaken is large. Already, in the public health context, more than 4 million newborns are tested annually for metabolic disorders so that effective treatment can be started in a few hundred. Researchers are inviting people to participate in family studies and undergo genetic testing, including collection of DNA samples for present or future analyses. There are a growing number of nonmedical applications of genetic testing as well. In the law enforcement context, DNA testing is undertaken to attempt to identify criminal offenders. At least 17 states have DNA fingerprint programs for felons. Employers and insurers may require people to undergo testing for genetic disorders for exclusionary purposes. One challenge for policy posed by this wide array of testing settings is that many of the existing legal Page Share Cite Suggested Citation: For example, some state statutes governing confidentiality deal only with information provided to physicians and might not cover information provided to Ph. There seems to be great variation among institutions and among providers in the amount of attention paid to autonomy, confidentiality, and privacy. Other obstetricians run the test on blood gathered from the woman for other purposes, so the woman does not even know she has been the subject of the test unless the obstetrician delivers the bad news that she has had an abnormal result.

Our Issues. Whenever we hear about the latest developments in gene editing there is broad agreement among scientists, members of industry, and ethicists that we should not proceed with such technologies without broad public approval.

Breast milk is very important for the good health and growth of every child. It has all the nutrients that babies need. There are however other women who might not be able to produce enough milk to help nurture their kids. This might be because of stress or other health related problems. There is a solution however for women going through this. You can now make goat milk formula at home. It has almost all the same nutrients as breast milk. You can make homemade goat milk formula using these 4 recipes: Like most of the season always gets you down more than it should. Well, this is what psychotherapist call seasonal depression. The primary aim of this procedure is to provide a structure where the dental implants can be placed in the alveolar bone structure. The bone graft does the procedure, and this is putting bone graft material to the bone in the jaw which will then adhere to it and form a new bone. Five Clear Indicators You Should Look in Medical Malpractice July 23, In situations where a medical malpractice has occurred, it is usually not that difficult to realize, especially if you are the victim of the malpractice. A recent report from the CNN group suggested that anyone who has suffered and maybe still suffering from serious medical illnesses look for any warning signs that may indicate that they were victims of a medical malpractice. This was the greatest amount of all of the 34 countries that the study surveyed. But you still find that with this hefty price tag, many Americans are still struggling with above-average obesity and infant mortality issues which are still on the rise. In fact, goat milk in of itself is excellent for not only newborns and babies but also for adults. They can cause great harm to you if you do not get checked out by a qualified dentist and get treatment early enough. Periodontal diseases have some really bad effects on your mouth and your body as well. There are several misconceptions about periodontal diseases and the effects that they have. Dental implants Toronto are some of the main solutions to the condition in case of extreme cases that seem irreversible. We have decided to let you know about theses misconceptions and to tell you what is true and what is not. Here are some top misconceptions about periodontal diseases.

Chapter 7 : Current|Update|Genomics|CDC

November 1, With Machine Learning, Researchers Get New Clues in the Hunt for the Source of Mysterious Virus (STAT News) - Thousands of viruses are out there in the wild, circulating in animal hosts and only gaining attention when they infect people.

This article has been cited by other articles in PMC. Abstract As a result of the increase in genetic testing and the fear of discrimination by insurance companies, employers, and society as a result of genetic testing, the disciplines of ethics, public health, and genetics have converged. Whether relatives of someone with a positive predictive genetic test should be notified of the results and risks is a matter urgently in need of debate. Such a debate must encompass the moral and ethical obligations of the diagnosing physician and the patient. The decision to inform or not will vary depending on what moral theory is used. Utilising the utilitarian and libertarian theories produces different outcomes. A number of cases from the literature are reviewed, as well as the moral theories that have dominated public health and medical practice in the United States. Suggestions are made regarding ethics education for public health and medical practitioners, which specifically relate to the emerging ethical dilemmas posed by the growing availability of predictive genetic tests. There are three forms of genetic testing: Diagnostic testing involves identifying current disease states. This includes prenatal and newborn screening—the most common forms of genetic testing. Carrier testing determines whether an individual carries a certain genetic trait. If a genetic disorder is dominant, the disease characteristics will be expressed when a person has one abnormal chromosome. If a genetic disorder is recessive, the disease characteristics are present when the individual has two abnormal chromosomes. The third type of genetic testing, predictive testing, is used to determine whether a person has a genetic mutation that will lead to a late onset disorder. This type of testing is usually conducted in otherwise healthy individuals with a positive family history and no symptoms of disease. The debate over these issues has historical roots. In this article we examine the moral and ethical implications of genetic testing and potential discrimination from perspectives that are dominant in the US healthcare system. In the early to mid s individuals in the US who were continually ill or mentally retarded were involuntarily sterilised. One example of mandatory sterilisation in the US occurred in when Justice Oliver Wendell Holmes Jr, a well known judge, ruled in the Buck v Bell case in favour of mandatory sterilisation of Carrie Buck. Carrie Buck, her mother, and her seven month old daughter were labelled by the court as feebleminded. Approximately 60 more sterilisation procedures followed throughout the US. African American children were required to undergo mandatory testing before entering school. Having sickle cell anaemia or being a carrier did not prevent a child from entering school. Refusal to participate in genetic testing did. The African American community, bioethicists, lawyers, and the medical profession viewed this as discrimination because other populations were not targeted for other possibly debilitating diseases. Legislation was passed granting money to fund sickle cell programmes in states with voluntary testing. This, in effect, overturned mandatory testing requirements. Americans feared that the development of genetic tests and the enactment of mandatory testing would decrease individual rights to privacy and lead to discrimination. It was realised that insurance companies could require testing and either refuse healthcare coverage, decrease benefits, or increase premiums. In , the Equal Employment Opportunity Commission issued guidelines stating that individuals who thought they had been discriminated against by an employer because of predictive genetic testing had the right to sue that employer. Additionally, the Health Insurance Portability and Accountability Act HIPAA , enacted in , prevented insurance companies from denying health care based on predictive testing for individuals transferring from one plan to another. Reasons for not billing their insurance company included fear of genetic discrimination; fear that future insurability might be jeopardised; fear of discrimination against their children, and fear that existing laws were not adequate to protect them against discrimination. Employees who filed claims and sought medical attention for carpal tunnel syndrome were required to submit blood samples. The samples were subjected to genetic testing to identify a genetic defect that predisposes an individual to nerve injury and forms of carpal tunnel syndrome. Public health practitioners are tasked with identifying possible exposures and recommending testing for

communicable diseases that are reportable conditions. If genetic disorders become reportable conditions due to the expansion of mandatory screening, public health practitioners could be faced with issues of disclosure. Lachman¹⁶ for example, has described a scenario in which widespread immunologic genotyping would be required to reduce the transmission of global, drug resistant infections. Not only is confidentiality an issue for health care, insurance coverage, and employment, but information from a genetic test can affect an entire family. Furthermore, a person may make life altering decisions based on the results of a genetic test. More and more often primary care physicians are serving as counsellors as the prevalence of genetic testing increases. It is not necessarily the case that the majority of primary care physicians are trained in medical genetics, diagnostic testing, and genetic counselling. However, respondents reported their knowledge of genetics and genetic testing as either fair or poor. One question of particular interest for this essay is whether or not family members should be informed of the test results. What are the moral obligations of the patient and the physician? Should the physician who has diagnosed the patient inform the family of the disorder and recommend testing? The answers to these questions are not easy and will vary depending on who is asked and what moral theory is used. The answers may also depend on other factors, such as the severity of the disorder.

Utilitarian perspective Two moral theories to consider when answering the above questions are utilitarianism and libertarianism. This perspective promotes the good of society over that of the individual. Factors taken into consideration when calculating total happiness include intensity, duration, certainty, propinquity, fecundity, purity, and extent. Informing at risk family members may decrease the intensity of pain for them through medical intervention; decrease the duration of symptoms through medical intervention; decrease the probability pain will occur certainty ; delay the onset of the symptoms propinquity ; increase the quality of life purity through adequate planning and lifestyle changes, and prevent the passing on of the disorder extent. This allows other members of society to be screened and make decisions that affect their families. The information could dissuade individuals from having children and passing on the genetic defect. Knowing of a disorder or preventing the passing of a genetic disorder by a couple deciding not to have children could save large amounts of money for treatments often paid for by society. The orientation of public health professionals toward population health has led to the application of the utilitarian perspective in the case of cystic fibrosis screening in the United States and thalassaemia screening in other countries, 21 but as the NTD example illustrates, such screening can also involve decisions about resource sharing. A communitarian perspective would place emphasis on the moral values of a defined community. As public health undertakes screening for more ubiquitous, less penetrant conditions, including chronic disease, decisions regarding programme implementation and disclosure policy can be expected to move in this ethical direction.

Libertarian perspective Libertarians believe personal autonomy has the highest moral value. Individuals have the right to privacy, freedom of speech, and freedom from harassment. Physicians are traditionally expected to uphold patient privacy rights except in cases of mandatory reporting. In matters of public health, liberty rights are often in conflict with the utilitarian perspective. The expectation exists that individuals will consent to testing not just for their own good but for the sake of their family and society as well. Also social stigmatism is attached to genetic disorders. Individuals diagnosed with a genetic disorder are often discriminated against and harassed by other members of society or even family and friends. Libertarians believe people have the right to live without such fear, discrimination, and social stigmatism. For family members, there is also a right to not know. Family members may not want to know about their risk for a genetic disorder. A libertarian would conclude that each person has a right to be happy and make choices without being influenced by physicians, counsellors, and other members of society. Risk communication in the medical and public health contexts can be viewed as acceptable, but the ultimate decision is up to the patient. On the other hand, family members may view their rights differently. They may feel they have the right to know about their risk in order to be able to make fully informed decisions. Several theories of justice support the position that each person has the right to receive basic social goods such as medical treatment. The physician is always at the centre of the debate as to whether to inform family members of their risk. The physician is not only dedicated to protecting the confidentiality of patients, but also to the concept of doing no harm. She had four sons who underwent screening and were identified as carriers. One of her sons was 32 years old and the father of a six year old

when he first developed symptoms of ADPKD. Another son, who was 30 years old, divorced his wife and sold their home to keep from burdening her or planning a family. He did not have problems until he was He later died from another cause without having ever developed symptoms. He quit school and took a good paying job to live life to the fullest. He also never married. This example illustrates elements of both utilitarianism and libertarianism. There are several critical points in the case described above that pose challenges both for families and the larger society, and which warrant ethical consideration. The second son, had he not divorced, would have exposed his family to the various costs resulting from kidney failure beyond age 54, and the eventual need for dialysis or transplant. This could have significantly burdened his wife, and clearly played into the calculus of his decision to leave. The regrettable suicide of the first son, in a raw utilitarian sense, removed the cost of a single dialysis or transplant from society. There are countervailing utilitarian considerations, such as years of gainful employment lost and the effect on their wives. A physician or a genetic counsellor might offer a clear explanation of the decisions, but nonetheless both would eventually reveal a type of utilitarian reasoning operating in the final decisions being made. The rarer, recessive form of polycystic kidney disease appears in the neonatal period, and, for those who survive, can result in insidious renal failure during childhood. Utilitarian considerations have also formed the basis of prenatal screening protocols for conditions that are likely to result in early childhood fatality or which result in severe or disabling childhood illness. In the making of these decisions, however, they demonstrated the use of the libertarian point of view, which states that each person has the right to make an informed decision. Each family member was allowed the opportunity to make the decision he felt was best. Though ethical decision making need not always translate into legal action, physician failure to warn of the possibility of the transmission of an adult onset, genetically associated condition, such as familial cancer, has resulted in lawsuits. On the other hand, each family member had the right not to know. If they had not known about the disorder, they might have lived much happier lives. This is certainly so for the son who committed suicide. Also, the sons who left family members and the one who committed suicide took away the personal liberties of their families to decide what was best. Finally, it should not be forgotten that the decision to make dialysis machines available—for example, in the case of the 55 year old mother—is a societal one, as is the system developed to allocate transplant organs such as kidneys.

Chapter 8 : Genetic and Genomic Healthcare: Ethical Issues of Importance to Nurses

*To help nurses provide competent care in the genomic era, the American Nurses Association and the International Society of Nurses in Genetics, Inc., have co-published *Genetics and Ethics in Health Care: New Questions in the Age of Genomic Health*, a new resource for students, nurses, educators, researchers, and others in academia, government, and industry.*

Ethical Issues in Genetics. A majority are unaware of the progress made in routine and exotic genetics, and most are caught off guard by each new technology. The first time most families in the West learn about the practical issues in genetic testing is when a friend or relative needs a test urgently during pregnancy. To make matters worse, apart from bioethics conferences there is still virtually no common public or scientific international conversation about gene therapy, reproductive rights, or genetic patenting. You might think it is a bad time to look ahead to the next century. After all, there is more than enough work to do now: Genetics education must be required for every physician, ethics training for every young scientist, and reproductive issues training should be given to every minister and politician. These are issues for today. With our attention focused on the technology of the month in these included cloned sheep and monkeys, babies from frozen eggs, headless frog embryos, a 63 year-old mother, sperm from dead men, and septuplets we seldom take the time to accomplish even these contemporary objectives. Bioethics is growing quickly but it is unlikely to catch up with science. In such a world it is difficult to spend time forecasting or critiquing future utopias. However, if the problems of today and the need to remember historical atrocities in genetics are important, it is just as critical to plan ahead. The next years will see changes more dramatic than the 20th century, which saw the creation of molecular genetics, the rise and fall of eugenics, and the creation of a U. It is time, I believe, to use some imagination to think about what might come to be in the world of genetics in the next years. Only by looking at the long-term outcomes of our current genetic research will we see the compelling need to confront the most basic questions posed by genetic medicine. And, in any event, it has not escaped the attention of this author that it is no more dangerous to exercise a little imagination about our future than it is dangerous to fail to be prescient about possible surprises, such as human cloning. One shape in the crystal ball is not difficult to discern. Some areas of genetic medicine, such as the effort to identify simple genetic etiology for complex diseases and traits, will plainly begin to fall away during the next few years. Genetic diagnosis and gene therapy will become more and more effective as partners to environmentally- and nutritionally-based medicine and pharmacology. Costs of genetic services will fall precipitously just as evidence accumulates about the costs associated with having particular genes. Virtually every culture will have to cope with an unparalleled pressure to conserve social resources by applying pressure to individuals in an attempt to modify their reproductive behavior and other life choices. One very important role of bioethics is to think about how allocation of resources, crafting of laws, and education of children and professionals should be used to prepare for such a future. However, history is a very poor guide in this regard. Bioethics knows how to react to Dolly the cloned sheep. It is not so great at predicting or laying the ground for new science or paradigm shifts in medicine. It is clear from the public reactions to Dolly, and other recent scientific claims in the areas of developmental and molecular genetics, that bioethics has not done much to improve the potential for sustained conversation about genetics. Without reconstruction of the institutions of society to meet new challenges, there is little chance we will be prepared for the innovations that are coming. In this essay I describe three kinds of change that seem to be approaching in the next years. For each of the three waves of coming change in genetics, I have thus concentrated on the kind of institutional weakness—and thus the kind of opportunity for reform—that is present. A Vision of Making Babies First, I think it is easy to imagine a world years from now in which parents have much more control over the inheritance of children. Gene therapy and pre-implantation diagnosis for cell embryos will be thoroughly assimilated into obstetrics technologies. Indeed all that remains for such technologies to be assimilated are a few technological advances. First scientists must improve the ability, and reduce the cost, of successful in vitro fertilization. Second, in vitro fertilization IVF must be made more intimate, more thoroughly integrated with sexual reproduction. Couples who are not

infertile will be reluctant to use pre-implantation diagnosis until it is integrated, or at least not so dissonant, with sexually-initiated and consummated reproduction. Infertility treatments today are in the dark ages in this regard. IVF is difficult, painful, risky, expensive, and culturally stigmatized. But advances are likely. Think of this century. The birth control pill revolutionized sex by making it possible to have sexual relations without having children. The pill thus increased the control couples and individuals have over the meaning of their pregnancies. In the next 50 years pre-implantation diagnosis and infertility treatment will advance from a clinical and impersonal process to something more realistically sexual in nature. Whether it is a pill, a method for extracting the products of sexual relations, or a non-invasive mode of in vivo gene therapy, there will be a way to integrate genetic diagnosis with other more ordinary reproductive activities. But these fears can be allayed. At that point there will be widespread calls for the use of early embryo diagnosis. Couples who are not infertile will begin using diagnostic processes to sort embryos for desired characteristics. How much should parents be able to use such technologies to design their offspring? What are the moral objections to design of offspring that are most useful in initiating public conversation? In my research group, we closely watch debates about uses of reproductive genetics. These matters are highly politicized. A large number of my colleagues around the United States hold that we need to deal with prenatal diagnosis in the way that we deal with all matters of pregnancy, that is, in terms of the need to preserve the rights of women to choose about their desired outcome. The present US and European policies allowing infertile and fertile couples to do as much as they like with genetic testing are rooted in reproductive rights. The countervailing trend in global law is toward thinking of pregnancy in terms of the health of the fetus. This century has seen increasing technological advances around pregnancy, prenatal care, and neonatal intensive care. The idea that parents have a responsibility to make sure that their fetus has the opportunity to flourish is an old one, but new technologies have made that responsibility more tangible. Today a pregnant woman who wants to give birth will be strongly encouraged to seek prenatal care and to eat a particular diet. The law in many nations makes parenthood revocable for cases of neglect or abuse. Tomorrow we will likely see outright pressure or even requirements that parents think of their offspring as having a right to flourish. I have argued in my recent work that research shows that children who are the product of high-technology pregnancies and neonatal care are more likely to think of their lives in different ways. How will it feel to be born as a child of this new era? I believe that there are opportunities to think about this future that steer a path between the simple rights of mothers on the one hand, and the mandates of prenatal care on the other. Debate about new reproductive technology so far has focused on laws that would ban particular technologies like cloning. It is time to draw on other social metaphors. The one area where there is widespread consensus about how unorthodox pregnancy should be handled is the area of adoption. Policymakers must seek consensus-oriented and procedural methods of forming policy, rather than chasing the hopeless grail reconciling a priori fetal rights with a priori maternal autonomy. New genetic manipulation can be an important tool for parenting, but its responsible implementation depends on assessing the motives of particular parents in the same way that we assess the motives of couples who would adopt. Not every 63 year-old will be a good mother. Most parents would have trouble raising a clone. A Vision of Lifeguards at the Gene Pool The second element of our genetic future is public health uses of genetic testing. The future is likely to involve some public pressures on adults and institutions to avoid passing on some alleles. The pressure in the next 20 years may come from insurers, but in the long term there will be comprehensive practice guidelines in medicine, embodied by various medical associations, insurers, global health organizations and governments, that could lead to national and regional policies. These policies will make it difficult to pass on genes that are associated with particularly bad outcomes. There are many fears about such a future. How are we to draw a line between responsible stewardship of the future on the one side, and dangerous abuses of the power of creation on the other? I want to comment on only one aspect of this issue, namely the relationship between public health genetics and eugenics. In Western political and philosophical history, from Plato to Aristotle to Hobbes, our deepest ideas about human nature have been rooted in crude, non-molecular accounts of human heredity, many of which have been used to explain or fortify education, health, and political practice. Most genetic professionals take the wise lesson that it is wrong to attempt to persuade families about genetic choices. It is a merit worthy ideal.

However, not only has the ideology of non-directive counseling been ineffective in preventing counselor or physician bias as study by Wertz and Fletcher suggests⁵, it has completely ignored the role of economics and social context in pressuring families. If the genetic counselor is available only for families who can pay for the testing, such counseling is by definition directive, namely directed at helping those who can pay. Likewise, how are genetic counselors to protect us from eugenics in a future where state-sponsored genetic screening seems unavoidable? A genetic counselor cannot be non-directive about a test if the test is mandated. The genetic counseling role is likely to expand in importance, whether genetic counselors are around or not. However, the chief sin to be avoided is not directiveness but rather inappropriate pressure. None believe that we will return to the sterilization practices of eugenics. But public sponsored genetic testing programs will make it likely that more parents will use genetic tests as a part of planning for birth. The public in many nations will begin to pressure families to avoid births where discrete genes can be identified as disease-related. How is the public to be defined for such a purpose? Who will choose which traits to include in screening efforts? Before we can answer such questions there must be a comprehensive global public health effort to regulate the spread of genetic testing, and in particular an effort to establish global cooperation in assessing the efficacy of genetic tests and the relationship between particular genes and environments. There must also be a new emphasis on retraining journalists, politicians, and ministers about genetics so that genetic testing will not always result in hysteria about eugenics. The debate about eugenics is not helpful in thinking about genetic testing, and in fact has resulted in the development of institutions that hardly protect us from anything, least of all eugenics. Careful, cautious progress into the future of genetic public health policy depends on the establishment of new institutions whose task is to link environmental, genetic, and policy information. Genetic counseling is great, but there are only 1, genetic counselors in the United States and a scant few elsewhere. It is thus more important that we ensure that the conceptual resources of genetic counseling are present in clinical services of all kinds. Families must be able to turn to someone, even if only a minister, to interpret and cope with the new issues. These professionals will be directive, reflecting the culture and meaning of their professions and societies. However they must bring concern for the family and individual liberty to the table as well. A Vision of Genetic Myopia The third issue for the future is perhaps the most difficult one.

Chapter 9 : Genetics and ethics: a possible and necessary dialogue

The genetic modification of plants for food is a hot-button issue around the world. Genes transplanted to corn, potato, soybean and other food strains can confer desired traits, such as resistance to pests, which lessens the need for toxic pesticides.