

Policy advice by Douglas Karo

Starting from the positions that the human genome belongs to everyone and to their descendants and that any person's specific genomic endowment is not the result of his or her choice, then I believe that fairness and equity require that the genome can only be used for the collective benefit of all living now and living in the future and that no one may be legally discriminated against or discriminated in favor of because of knowledge of his or her particular genome. This means that we have gone quite far down the wrong path and must make big changes quickly.

Thus, the challenges are to form a global regime where there is collective benefit to all from study and use of the human genome and to form a global regime where use of genetic information to discriminate among people is illegal and where such use is effectively prevented from occurring.

This approach deals with the concerns that an individual does not have the right to disclose individual genetic information because such information also is a disclosure of ancestors' and descendants' genetic information and with concerns that the technology and systems to keep genetic information secure and private are fallible and that the information will escape. But making discriminatory use of such information illegal and enforcing strong penalties for such illegal use, prevents much of the harm that could occur and this is the best that we can expect to do while also getting the benefits from the genome.

Even with non-discrimination laws, there is potential harm from disclosure of personal genetic information. Nevertheless, when an individual wishes to disclose personal genetic information, he or she must have the consent of living parents, siblings, and children of siblings. There also is a 'right to be forgotten' (analogous to the GDPR feature) where consent may be withdrawn and reasonably effective efforts must be made to remove identification of the genetic material in public records.

For genetic research and development and application, an international organization (probably associated with the U.N.) will hold all patents related to the human genome and will negotiate licenses and collect license fees and royalties to be used for the collective benefit of mankind (probably through U.N. programs). The fee and royalty schedule will be set to encourage advancement in human genomics without promoting additional increases in income and wealth inequality. In some cases, promoting no cost use of a patent may be the most effective action. The international organization also will be responsible for determining what, if any, modifications to the human genome will be allowed. In particular, modifications (additions, deletions, changes) to a human genome will be considered to remain a human genome and be subject to control by this international organization.