Health Council of the Netherlands

Non-anonymised contact after stem cell donation

Executive summary

Stem cells are special body cells with the ability to develop into different types of cells. Blood-forming stem cells are important for the formation of blood cells, including red blood cells, white blood cells and platelets. Transplantation of blood-forming stem cells (hereinafter: stem cell transplantation) is used, among other indications, in the treatment of various types of cancer, such as leukaemia, lymphoma and multiple myeloma, and in disorders of the immune system. For allogeneic stem cell transplantation, a patient receives healthy stem cells from a living donor. This can be a family member, but in most cases, the donor is unrelated and anonymous. Stem cell donors are generally young (under 35 years of age). Most Dutch recipients receive stem cells from a donor abroad.

Stem cell donor and recipient may wish to have contact

Under current legislation in the Netherlands, the identity of the stem cell donor may not be disclosed to the recipient, and vice versa. Stem cell donors and recipients are only allowed to communicate with each other through anonymised correspondence after the donation. However, recipients and donors of stem cells may wish to have non-anonymised contact with each other after transplantation. Matchis, the Dutch stem cell donor organisation, has informed the Ministry of Health, Welfare and Sport that it would like to offer stem cell donors and recipients the opportunity to exchange personal data after the donation, as it regularly receives such requests. On 7 August 2027, a new EU regulation on substances of human origin will come into force, which provides the Netherlands the opportunity to change its policy on non-anonymised contact. Non-anonymised contact after stem cell donation is permitted in countries relevant to Dutch practice, such as Germany and the United States. The Minister of Health, Welfare and Sport asked the Health Council to evaluate whether the ban on non-anonymised contact between donor and recipient should be lifted. The question only relates to contact after transplantation has taken place. The minister also asked what the advice would mean for non-anonymised contact after donation of other substances of human origin. The advice has been composed by the standing committee on Ethics and Law.

Ban serves to guarantee voluntariness and to protect donors and recipients

The current ban on non-anonymised contact after stem cell donation is based on various ethical and legal principles. Originally, the ban is intended to guarantee the voluntariness of the donor. Through personal contact with the recipient, the donor may feel pressured to donate again to the same

recipient if re-donation is medically necessary. The ban also serves to protect the recipient from pressure or undue influence by the donor. If personal data were to be exchanged, the donor could ask the recipient for compensation for the donation. In addition, the ban protects donors and recipients from possible negative emotions resulting from a personal meeting. The meeting itself could be overwhelming or disappointing, or lead to contact that causes grief, stress or regret. Finally, the ban may be intended to preserve the donor pool.

Dilemma: The duty to protect versus respect for personal freedom

Non-anonymised contact between donor and recipient can also have benefits. If the recipient can personally thank the donor for their gift, this can contribute to the recipient's well-being, and contact with the recipient can give the donor a greater sense of purpose. The ban on non-anonymised contact thus touches on the personal freedom of the donor and recipient to know each other's identity. The committee identifies the following ethical-legal dilemma: the government has a duty to protect donors and recipients from the risks of non-anonymised contact, but at the same time should respect their personal freedoms as much as possible.

Absolute ban is effective, but too extensive a measure

The committee evaluates, using an ethical-legal framework, the extent to which an absolute ban on non-anonymised contact after stem cell donation is still justified. In doing so, it examines the objectives, effectiveness, proportionality and subsidiarity of the ban, and the extent to which there are unintended negative consequences. The committee concludes that the ban is effective in guaranteeing the voluntariness of donors, and that it protects against virtually every other possible risk of non-anonymised contact. According to the committee, these are commendable objectives. However, an absolute ban is not the most proportionate measure to achieve them. A qualified ban can achieve the same result while preserving as much personal freedom as possible. Therefore, the committee states that it is desirable to allow non-anonymised contact after stem cell donation under certain conditions.



Advice: Conditionally allow non-anonymised contact after stem cell donation

The committee advises allowing non-anonymised contact after stem cell donation under certain conditions. This policy follows the 'no, unless' principle: there is a general ban on the exchange of personal data after stem cell donation, but in exceptional circumstances data exchange could be permitted. The exceptions relate to two conditions. The first condition is the introduction of a two-year waiting period before personal data may be exchanged. This is intended to guarantee the voluntariness of the donor in the event of re-donation. The likelihood of re-donation is highest in the first two years after donation. The waiting period also prevents the donor from only wanting to donate again if the recipient is willing to provide something in return. This reduces the risk of the donor

exerting pressure on the recipient for compensation. In addition, a waiting period allows the recipient to take time for physical and mental recovery. The second condition is informed consent from both parties for the exchange of their data. It is important that both the recipient and the donor are properly informed about the potential harms and benefits of non-anonymised contact. The consent must be obtained in writing and independently from each other. Recipients who are minors can give consent for the exchange of their personal data from the age of 16.

Implications of the advice for donation of other substances of human origin

The committee has examined the possible implications of its advice for legislation on non-anonymised contact after donation of other substances of human origin. At present, the committee sees no reason to reconsider existing legislation on contact after donation of gametes. The same applies to the donation of blood products, breast milk, urine and faeces. As the consideration for stem cell donation does not address the interests of deceased donors, their family members and recipients, the committee cannot anticipate what this advice might mean for contact after post-mortem (organ) donation. However, it does see leads for considering non-anonymised contact after donation of a kidney or liver tissue from a living donor.

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