



Biobank – between consent and justice

- Format** 2-hour workshop at CordSavings
- Location** BioArk, Monthey
- Output**
- Mapping of the various ethical challenges related to the safeguarding of umbilical cords
 - Analysis of CordSavings' offer from the perspective of the values of the startup
- Follow-up**
- Clarify the ethical foundations of the mixed model envisaged by CordSavings
 - Develop a manifesto with other players in the sector for Swiss biobanks and their commitment in terms of key values

“The workshop confirmed the sensitive ethical issues related to our activity, we had thought about it and made some provisions. Now we have the same clear view together on the points to pay attention to and the measures to follow”

Jeanne Nicolas, CordSavings Director.

CordSavings is a Swiss limited company offering pregnant women and all families expecting a child the opportunity to collect and store stem cells contained in umbilical cord tissue and blood. The company provides the sampling kit to be used directly during delivery. It then ensures that the cryopreservation procedure of the placental blood and the storage of this same blood in a biological bank is carried out. Placental blood can then be used for therapeutic purposes, for example for the use of stem cells. Legally, placental blood is the property of the child who is born. His parents are the managers. The conservation contract can be concluded for a few years (e.g. 5 years) or for a longer period (e.g. 50 years).

Broadly speaking, there are three uses of donation: autologous (for oneself), related allogeneic (for the family) or allogeneic (for others). The field of activity of placental blood conservation is marked by a distinction between conservation for others (allogeneic) and conservation for oneself (for the child or a relative). The Swiss Red Cross thus maintains a network of conservation for others, based on the principle of solidarity. Women may choose to donate the umbilical cord blood during childbirth.

For the time being, CordSavings offers a “private” offer, where families can choose to keep their biological materials for the child or a relative. In the long term, the company would like to offer an original mixed service. For every three private conservations, the company would organize one conservation for others. The objective is to create a virtuous circle where the private dimension maintains and improves the public offer made available to all.

Ethical risks

The ethical risks faced by CordSavings are of several kinds:

Consent

First, the biobank represented by CordSavings is faced with the question of the consent of the person whose biological material it holds. Since this is a voluntary initiative that the person (the mother) must initiate, the question of consent arises very differently than in the context of research biobanks (where a patient is offered to contribute to the research). In addition, the lengthy preparation procedure required for conservation promotes enlightened and informed consent. It is particularly important that the expectant mother be informed of the proven therapeutic options at the time of her choice.

The biobank must be in a position to make realistic promises based on the scientific literature of the moment, risking, if not already falling into, false advertising. Since the child is the owner of his biological material, the question of his own consent arises. However, this risk is a crosscutting risk in all situations where

parents decide on behalf of the child. A risk of instrumentalization arises if the biological material of the newly born child has been preserved for therapeutic purposes for other family members (e. g. family allogeneic, sibling).

Data management

Second, CordSavings must be transparent about the management of data related to stored biological materials. The conditions of collection, storage and use of the child's or mother/family's data must be an integral part of the contract and of explicit and informed consent. Interestingly, the question of "unclaimed pockets" arises in a similar way to the case of banks and their "unclaimed funds". How can we ensure that the company can track families and individuals in order to maintain a means of contact once the conservation contract has expired? Here again, the conditions for using these "unclaimed pockets" must be an integral part of the contract.

Social justice

Third, conservation for oneself raises questions of social justice. It works in a similar way to private insurance that only the best informed/ wealthiest people can take out . The "for oneself" model could thus be accused of maintaining, or even amplifying, social injustices by offering people with means insurance against a blow to their child. In France, the National Consultative Ethics Committee has taken a stand against private biobanks on the basis of an argument that the use of products derived from the human body should be from anonymous, free and non-directed donations. In addition, there may be a competitive relationship between private offers for oneself and public solidarity systems.

CordSavings' resources

In response to these ethical risks, the model chosen by CordSavings offers interesting resources. The procedure for storing biological materials seems to ensure the explicit and informed consent of the mother/family. Social justice issues are addressed in two ways. On the one hand, the price of the procedure is within a range that seems acceptable in view of the investments made by parents at the birth of a child (around CHF 2000.- for an initial conservation offer). On the other hand, the envisaged model combining donation for others and conservation for oneself would make the valuable biological material available to a larger number of people. This model, which combines insurance logic and solidarity logic, could be particularly interesting to counter the risk that private biobanks will increase in number, to the detriment of solidarity donations in public systems.

Values of a (bio)bank

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It is interesting to see how the debate on values around the CordSavings model as a biobank is similar to a debate on values about banks in general. In its communication, CordSavings also plays on the Swiss dimension of its work, linked to the values of honesty, solidity, transparency and rigor. All these are positive values associated with the (sometimes dreamt of) model of a Swiss bank. This discourse on the values related to the conservation exercise is coupled with a discourse on the values of insurance, another Swiss specialty. CordSavings is designed as a place where women and families can insure themselves against the bad luck of an illness. The question of social justice may also reappear on this dimension with the distinction between private and voluntary insurance and public and compulsory insurance.

Follow-up

- Clarify the ethical foundations of the mixed model envisaged by CordSavings
- Develop a manifesto with other industry players for Swiss biobanks and their commitment to key values

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