



Cystic Fibrosis Research News

Title:

Organoids for personalized treatment of Cystic Fibrosis: Professional perspectives on the ethics and governance of organoid biobanking

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What was your research question?

What do professionals in the field of CF or organoid technology consider the ethical aspects of storing and using organoids for personalized medicine research?

Why is this important?

Research on living cell lines and stem cells raises specific ethical questions and practical challenges. This is a new and rapidly developing field, and currently existing regulations and guidelines do not sufficiently address these challenges. Moreover, there are many different stakeholders involved, such as patients, researchers, and commercial parties, and they may have different competing interests. The perspectives of professional experts can offer valuable insights for solving this issue, because of their skills and experience. Mapping these perspectives helps ensure that the storage and use of organoids in research is done in an ethically responsible way.

What did you do?

We interviewed 21 professionals in the field of organoid technology, biobanking, or CF research and care. In these one-hour interviews, we asked them about their perspectives on certain complex ethical or practical topics, such as informed consent or sample ownership.

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What did you find?

We identified three key challenges, and some suggestions of professionals on how to address them: (1) The challenges associated with commercial involvement, trust, and ownership, (2) Navigating the blurring boundary between the domains of research and of clinical care, (3) Appropriate approaches to the informed consent procedure.

What does this mean and reasons for caution?

In order to ensure that organoid biobanking for precision medicine is done in an ethically responsible way, there should be mutual consideration for the interests of all involved parties. The most important goal is to find a balance while also ensuring a healthy research climate.

What's next?

Patients are one of the most important stakeholder groups, but they were not part in this study. It is crucial that they are given a voice, by studying and including their perspectives.

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