European Cystic Fibrosis Society

Journal of Cystic Fibrosis
The Official Journal of the European Cystic Fibrosis Society

Cystic Fibrosis Research News

Title:

MINI-GUTS IN A DISH: PERSPECTIVES OF ADULT CYSTIC FIBROSIS (CF) PATIENTS AND PARENTS OF YOUNG CF PATIENTS ON ORGANOID TECHNOLOGY

Authors:

Sarah N Boers[1], Karin M. de Winter- de Groot[2], Jacquelien Noordhoek[3], Vincent Gulmans[3], Cornelis K van der Ent[2], Johannes JM van Delden[1], and Annelien L Bredenoord[1]

Affiliations:

[1] Julius Center for Health Sciences and Primary Care, Department of Medical Humanities, University Medical Center Utrecht, Internal post Str. 6.131, P.O. Box 85500, 3508 GA, Utrecht, The Netherlands.

[2] Department of Pediatric Pulmonology, Wilhelmina Children's Hospital, University Medical Center Utrecht, Internal post KH.01.419.0, P.O. Box 85090, 3508 AB, Utrecht, The Netherlands.

[3] Dutch Cystic Fibrosis Foundation (NCFS), Dr. A. Schweitzerweg 3A, 3744 MG, Baarn, The Netherlands. J.Noordhoek@ncfs.nl, V.Gulmans@ncfs.nl

What was your research question?

We aimed to explore the patients' view on organoid technology. This novel stem cell technology makes it possible to grow mini-organs in a dish out of human tissues. Our specific question was: What are the experiences, opinions, and attitudes of adult patients with CF and parents of young patients with CF regarding organoid technology?

Why is this important?

Patient-specific mini-guts, grown out of rectal biopsy materials (taken from the end of a patient's large intestine), are increasingly used as a CF disease model and as a personalized drug testing tool. Although organoid technology has great promise for CF research and care, it raises ethical questions. The mini-guts can be stored in so-called Living Biobanks that provide access to academic and for-profit parties. What type of patient consent is desirable, who 'owns' organoids, to what extent is commercialization desirable, and how do patients view the relationship to the mini-guts grown out of their rectal-biopsy material? To responsibly develop organoid technology, it is vital to explore and include patients' views.

European Cystic Fibrosis Society

Journal of Cystic Fibrosis
The Official Journal of the European Cystic Fibrosis Society

Cystic Fibrosis Research News

What did you do?

We have conducted 23 in-depth interviews with 26 respondents: 14 adults with CF and 12 parents of young people with CF in the Netherlands. The interviewer discussed several topics with the respondents, such as their views on their relationship to mini-guts grown out of their rectal-biopsy material, the ownership of organoids, and the biobank storage of organoids. We have analysed the interviews and identified four themes that resonated among all our respondents.

What did you find?

Despite general enthusiasm, respondents also have an ambivalent attitude. (1) They regard the mini-guts to some extent as a sensitive use of their tissue. They are genetically identical 3D immortalized chunks of cells that can be used as a personalized drug testing tool. (2) The open-endedness caused by long-term biobank storage sparks hopes for future drug discovery and concerns on whether the mini-guts will be used in their best interests and according to their value. (3) Commercialization is approached with cautiousness. (4) Respondents mention the importance of sound patient consent, patient engagement, responsible stewardship, and conditions for commercial use.

What does this mean and reasons for caution?

These themes give a first impression of the views of people with CF and parents of young people with CF on organoid technology. Their views should be integrated into the design of policies surrounding organoid technology. We argue for the development of sound initial consent procedures that should be coupled with long-term engagement of participants (e.g. return of clinically useful results) and responsible stewardship (e.g. ethical handling of mini-guts and personal information). Public-private partnerships should be established responsibly. Further research is needed to analyse differences in sub-groups of patients with CF and among different countries and health care systems.

What's next?

We will further examine the patient perspective and develop ethical guidance for the design of a European CF Organoid Biobank in the project HIT CF. This project aims to develop 'personalized treatments' for people with CF with uncommon genetic profiles throughout Europe and is funded by the EU under the Horizon 2020 framework.

Cystic Fibrosis Research News

Original manuscript citation in PubMed

https://www.ncbi.nlm.nih.gov/pubmed/?term=MINI-GUTS+IN+A+DISH%3A+PERSPECTIVES+OF+ADULT+CYSTIC+FIBROSIS+(CF)+PATIENTS+AND+PARENTS+OF+YOUNG+CF+PATIENTS+ON+ORGANOID+TECHNOLOGY

cfresearchnews@gmail.com