



# FAIR Data in citizen science

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# TOPFIT Citizenlab

- Large consortium:
  - Knowledge institutions
  - Healthcare organizations
  - Companies
  - Citizens / patients
- Focused on improving health & wellbeing
- Emphasis on inclusion of citizens in research, through citizen science



# Citizen science

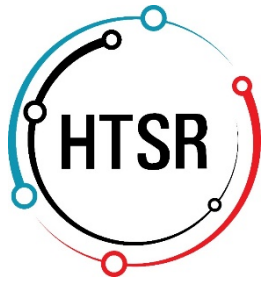
- Citizens / patients work together with scientists
- Citizens / patients have a role larger than being a subject  
they are involved in for instance conception of the idea, choosing methodology, setting up the experiments, collecting data, analyzing data, interpreting data, writing down results, and/or disseminating results
- Democratization of science → science is opened to people who normally do not have access to science



# Citizen science

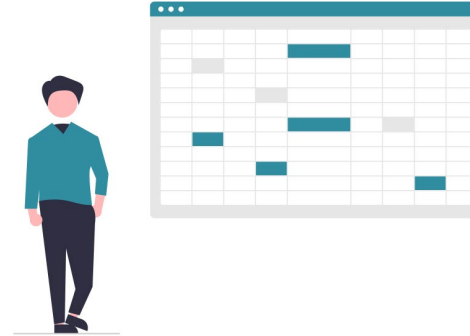
- Openness and transparency are cornerstones
- Principle 7 of the ECSA Citizen Science Principles:  
*“Citizen science project data and meta-data are made publicly available and where possible, results are published in an open access format. Data sharing may occur during or after the project, unless there are security or privacy concerns that prevent this.”*





# Data within TOPFIT Citizenlab

- Quantitative data
  - Surveys (closed questions)
  - Activity trackers (future plans)
  - Data diaries
- Qualitative data
  - Interviews
  - Focus group discussions
  - Cocreation sessions
  - Surveys (open-ended questions)





# Survey data

- Survey on
  - patient preferences for a website where citizens and scientists can collaborate on science projects
  - Survey on the different roles/tasks that patients want to have in science projects
  - Survey on topics of interest for a citizen science project
- Mix of closed and open-ended questions



# 4TU FAIR Data Fund - what is it?

## ○ What is it?

- A data fund by 4TU.ResearchData, offering researchers a budget (up to €3,500) to cover the costs of making their data FAIR.
- For researchers and projects from TU Delft, TU/Eindhoven and **University of Twente**.
- For situations where there are **no other resources available** to make data FAIR.
- Not intended to replace data management costs.

## ○ Goal:

- Increase the **quality** and **value** of the data.
- Make them **reusable** over an extended period of time.
- Increase the **visibility** and the **impact** of the research.





# FAIR Data Fund - why apply?

## Why did we apply?

1. Importance of FAIRifying data in citizen science
2. Difficulties with personal/health outcome data
  - Balance anonymization and openness
  - Incorporate from start!
3. Short time investment

## But also:

1. Acquiring own research funding
2. FAIR is receiving increasing attention
  - For example in grant proposals, or when submitting papers to scientific journals





# FAIR Data Fund - how to apply?

- Call was shared through the **Open Science Community Twente** and the news feed on the **University of Twente Employee Portal**
- **Time schedule:**
  - Call for applications opened on **Monday 1<sup>st</sup> March 2021**
  - Call for applications closed on **Wednesday 31<sup>st</sup> March 2021**
  - Notification of outcomes on **Friday 30<sup>th</sup> April**
  - **New round in autumn!** ([FAIRdatafund@4tu.nl](mailto:FAIRdatafund@4tu.nl))





# FAIR Data Fund - how to apply?

- **What to fill in:**

- Brief description of dataset, data collection, file formats and volume (GB) of total dataset
- FAIR data refinement needed (e.g. metadata, anonymization, translation, integration)
- Who will conduct the data refinement and how long will this take? (e.g. student assistant for approximately 120 hours)
- Aim with refined and published dataset
- How will you make the dataset: Findable, Accessible, Interoperable, Reusable (100 words each)
- Budget template (hiring personnel: tasks + time, software, equipment, promotional)
- Summary (max. 50 words)

- **Ask help or feedback from data stewards!**



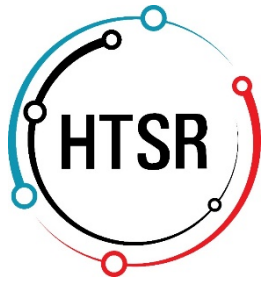
# FAIR Data Fund - received





# Key points for our Citizen Science data

- **FAIR data refinement:**
  - Most importantly: creating metadata, anonymization, translation
  - Uploading and storing data in repository
  - To be conducted by a student assistant
- **Main goal:**
  - Not only making 'our' data FAIR, but create a 'protocol' to be used within the TOPFIT Citizenlab.
- **Budget:**
  - Student assistant
  - Promotion (outreach to citizens)



# Work in progress!

- Recruiting student
- Drafting 'data dictionary':
  - E.g. replace 'MST' by 'hospital X', and 'Mrs. Jansen' by 'patient X'
  - Currently manually, but hopefully automatically in future projects
- Planning: finalize 'FAIRification' in November 2021
- Write 'protocol' for FAIRification of Citizen Science data
- 4TU.ResearchData Community for assistance





# Questions?

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