Please answer our survey and express your opinion about data sharing for health research. We want to hear from you to understand your boundaries and preferences.

Questions should take 10 minutes only. We hope you can help!

Section A: Informed Consent

We are a group of researchers from the Copenhagen Center for Health Technology (CACHET). Before we start collecting data, we need to be sure you read, understand and agree with the following:

What is the purpose of this survey? To understand people's opinions about health research for a university/academic project.

Which data will be collected? Voluntary demographics (e.g., age, gender), opinions about research and preferences about data sharing.

Will this data be linked to me personally? No, this survey is anonymous: no personally identifiable data is collected (e.g., name, e-mail, IP address, geo-location).

How will data be processed? Statistical analysis will be conducted by the principal researcher for scientific reports, which will only contain aggregate results.

How will data be stored? The anonymous answers will be stored at a secured repository hosted at the university until the end of the project (October 2021).

How can I delete my data? You can click on Exit and clear survey on the top right of the page or contact us with a unique ID code which you will create.

How to contact us? - Responsible researcher: PhD candidate, Giovanna Vilaza: gnvi@dtu.dk - Director of the CACHET Research Centre: Prof Dr Jakob Bardram: jakba@dtu.dk - Data protection officer at DTU, Ane Sandager: anesa@dtu.dk

A1.   Do you confirm that:
  - you are more than 18 years old;
  - you have read and understood the information above; - and you
voluntarily agree to participate in this survey?

Yes ☐

No ☐

Section B: Demographics

B1. **What is your age group?**

18-27 ☐

28-37 ☐

38-47 ☐

48-57 ☐

Above 57 ☐

Prefer not to say ☐

B2. **What is your gender?**

Female ☐

Male ☐

Non-binary ☐

Prefer not to say ☐

Prefer to self-describe ▼

Prefer to self-describe

☐

B3. **What is your education level?**

Less than High School/Secondary School ☐

Completed High School/Secondary School ☐

Completed a Bachelor's degree/Undergraduate ☐

Completed a Master's degree/Graduate ☐

Completed a PhD degree or above ☐

Prefer not to say ☐

Other ▼

Other

☐

B4. **Which of these digital devices do you have and use?**

Computer (desktop, laptop) ☐

Tablet (iPad) ☐

Smartphone (Samsung, iPhone) ☐

Wrist wearables (Apple Watch, Garmin, Fitbit, Polar) ☐

Smart home devices (Alexa, Google Home, Hive, Philips Hue) ☐

Other ▼

Other

[   ]

B5. **In which country do you currently live?**

Afghanistan ☐

Albania ☐

Algeria ☐

Andorra ☐

Angola ☐

Antigua and Barbuda ☐

Argentina ☐

Armenia ☐

Australia ☐

Austria ☐

Azerbaijan ☐

Bahamas ☐

Bahrain ☐

Bangladesh ☐

Barbados ☐

Belarus ☐

Belgium ☐

Belize ☐

▼

Benin ☐

Bhutan ☐

Bolivia (Plurinational State of) ☐

Bosnia and Herzegovina ☐

Botswana ☐

Brazil ☐

Brunei Darussalam ☐

Bulgaria ☐

Burkina Faso ☐

Burundi ☐

Cabo Verde ☐

Cambodia ☐

Cameroon ☐

Canada ☐

Central African Republic ☐

Chad ☐

Chile ☐

China ☐

Colombia ☐

Comoros ☐

Congo ☐

Cook Islands ☐

Costa Rica ☐

Côte d'Ivoire ☐

Croatia ☐

Cuba ☐

Cyprus ☐

Czech Republic ☐

Democratic People's Republic of Korea ☐

▼

Congo ☐

Denmark ☐

Djibouti ☐

Dominica ☐

Dominican Republic ☐

Ecuador ☐

Egypt ☐

El Salvador ☐

Equatorial Guinea ☐

Eritrea ☐

Estonia ☐

Ethiopia ☐

Fiji ☐

Finland ☐

France ☐

Gabon ☐

Gambia ☐

Georgia ☐

Germany ☐

Ghana ☐

Greece ☐

Grenada ☐

Guatemala ☐

Guinea ☐

Guinea-Bissau ☐

Guyana ☐

Haiti ☐

Honduras ☐

Hungary ☐

▼

Iceland ☐

India ☐

Indonesia ☐

Iran (Islamic Republic of) ☐

Iraq ☐

Ireland ☐

Israel ☐

Italy ☐

Jamaica ☐

Japan ☐

Jordan ☐

Kazakhstan ☐

Kenya ☐

Kiribati ☐

Kuwait ☐

Kyrgyzstan ☐

Lao People's Democratic Republic ☐

Latvia ☐

Lebanon ☐

Lesotho ☐

Liberia ☐

Libya ☐

Lithuania ☐

Luxembourg ☐

Madagascar ☐

Malawi ☐

Malaysia ☐

Maldives ☐

Mali ☐

▼

Malta ☐

Marshall Islands ☐

Mauritania ☐

Mauritius ☐

Mexico ☐

Micronesia (Federated States of) ☐

Monaco ☐

Mongolia ☐

Montenegro ☐

Morocco ☐

Mozambique ☐

Myanmar ☐

Namibia ☐

Nauru ☐

Nepal ☐

Netherlands ☐

New Zealand ☐

Nicaragua ☐

Niger ☐

Nigeria ☐

Niue ☐

Norway ☐

Oman ☐

Pakistan ☐

Palau ☐

Panama ☐

Papua New Guinea ☐

Paraguay ☐

Peru ☐

▼

Philippines ☐

Poland ☐

Portugal ☐

Puerto Rico ☐

Qatar ☐

Republic of Korea ☐

Republic of Moldova ☐

Romania ☐

Russian Federation ☐

Rwanda ☐

Saint Kitts and Nevis ☐

Saint Lucia ☐

Saint Vincent and the Grenadines ☐

Samoa ☐

San Marino ☐

Sao Tome and Principe ☐

Saudi Arabia ☐

Senegal ☐

Serbia ☐

Seychelles ☐

Sierra Leone ☐

Singapore ☐

Slovakia ☐

Slovenia ☐

Solomon Islands ☐

Somalia ☐

South Africa ☐

South Sudan ☐

Spain ☐

▼

Sri Lanka ☐

Sudan ☐

Suriname ☐

Swaziland ☐

Sweden ☐

Switzerland ☐

Syrian Arab Republic ☐

Tajikistan ☐

Thailand ☐

The former Yugoslav Republic of Macedonia ☐

Timor-Leste ☐

Togo ☐

Tokelau ☐

Tonga ☐

Trinidad and Tobago ☐

Tunisia ☐

Turkey ☐

Turkmenistan ☐

Tuvalu ☐

Uganda ☐

Ukraine ☐

United Arab Emirates ☐

the United Kingdom of Great Britain and Northern Ireland ☐

United Republic of Tanzania ☐

United States of America ☐

Uruguay ☐

Uzbekistan ☐

Vanuatu ☐

Venezuela (Bolivarian Republic of) ☐

▼

Viet Nam	☐
Yemen	☐
Zambia	☐
Zimbabwe	☐
Other	▼

Other

Section C: Health

C1. **In general, would you say your health is:**

Excellent	☐
Very good	☐
Good	☐
Fair	☐
Poor	☐
Prefer not to say	☐

C2. **How interested are you in health-related topics?**

Extremely interested	☐
Very interested	☐
Moderately interested	☐
Slightly interested	☐
Not interested	☐
Prefer not to say	☐

C3. **Have you ever participated in a research study about health?**

Yes	☐
No	☐
Prefer not to say	☐

Section D: Research data repository

The following definition is very important for the next questions. Please read it carefully:

A research data repository is an online database containing data collected in previous studies. De-identified or anonymous data is stored to be re-used in the future by multiple researchers.

D1. **Do you know any example of a research data repository?**

Yes ☐

No ☐

Not sure ☐

Prefer not to say ☐

D2. **Your current opinion about this idea of data repositories for health research is:**

Positive ☐

Negative ☐

Indifferent ☐

Prefer not to say ☐

Section E: Sharing your data with a repository (I)

How comfortable do you feel about having the following data stored in a research repository?

Please consider that any information shared is <u>de-identified or anonymised</u> before being analysed by researchers.

E1. **Health questionnaires (online or in-person):**

	Very uncomfortable	Uncomfortable	Neither	Comfortable	Very comfortable
Clinical diagnosis (physical)	☐	☐	☐	☐	☐
Clinical diagnosis (mental)	☐	☐	☐	☐	☐
Family health status	☐	☐	☐	☐	☐
DNA samples	☐	☐	☐	☐	☐
Food consumption	☐	☐	☐	☐	☐
Alcohol consumption	☐	☐	☐	☐	☐

	Very uncomfortable	Uncomfortable	Neither	Comfortable	Very comfortable
Sleep	☐	☐	☐	☐	☐
Blood samples	☐	☐	☐	☐	☐

Section F: Sharing your data with a repository (II)

How comfortable do you feel about having the following data stored in a research repository?

Please consider that any information shared is <u>de-identified or anonymised</u> before being analysed by researchers.

F1. Passive monitoring through a phone or wearable device:

	Very uncomfortable	Uncomfortable	Neither	Comfortable	Very comfortable
Screen time	☐	☐	☐	☐	☐
Apps used	☐	☐	☐	☐	☐
Frequency of social communication (calls/text)	☐	☐	☐	☐	☐
Content of social communication (calls/text)	☐	☐	☐	☐	☐
Distances travelled per day	☐	☐	☐	☐	☐
Places visited every day	☐	☐	☐	☐	☐
Physical activity levels (heart rate)	☐	☐	☐	☐	☐
Stress/emotional levels (heart rate)	☐	☐	☐	☐	☐

Section G: Motivations

G1. Still in the context of research data repositories, how motivated do you feel by the following reasons to contribute to one of them?

	Not motivated	Slightly motivated	Moderately motivated	Very motivated	Extremely motivated
Helping future patients	☐	☐	☐	☐	☐
Helping the researchers	☐	☐	☐	☐	☐
Receiving results about myself	☐	☐	☐	☐	☐
Getting financial compensation	☐	☐	☐	☐	☐

	Not motivated	Slightly motivated	Moderately motivated	Very motivated	Extremely motivated
Proposing questions to be investigated	☐	☐	☐	☐	☐
Receiving the results of the research	☐	☐	☐	☐	☐

Section H: Access options

H1.   How desirable/undesirable do you think the following access options for a health research data repository are?

	Very undesirable	Undesirable	Neither	Desirable	Very desirable
To receive information about the projects using my data	☐	☐	☐	☐	☐
To not be contacted after I share my data	☐	☐	☐	☐	☐
To decide who can have access to which parts my data	☐	☐	☐	☐	☐
To have the repository managers deciding who can get access	☐	☐	☐	☐	☐
That public or academic institutions are eligible for access	☐	☐	☐	☐	☐
That private labs and companies are eligible for access	☐	☐	☐	☐	☐

Section I: Concerns

I1.   How concerned do you feel about the following risks of having your health data stored in a research repository?

	Not concerned	Slightly concerned	Moderately concerned	Very concerned	Extremely concerned
Being vulnerable to cyber-attacks and blackmailing	☐	☐	☐	☐	☐
Having my data used for projects that I think are unethical	☐	☐	☐	☐	☐
Having my data used for profit without me knowing about it	☐	☐	☐	☐	☐
Being socially discriminated because of certain information I shared	☐	☐	☐	☐	☐
Agreeing with terms and conditions that I do not fully understand	☐	☐	☐	☐	☐
Being asked to provide more data in the future	☐	☐	☐	☐	☐

Section J: Feedback

J1.   **Do you allow your anonymous answers for this survey to be stored in an open repository and be accessed by other researchers?**

Yes ☐

No ☐

J2.   **This survey is anonymous, which makes it impossible for us to know which answer is yours. If later on you want to access your answers or have them deleted, please create an ID code for you now (e.g., hello123), and send it to us by e-mail:**

Contact: gnvi@dtu.dk or jakba@dtu.dk

J3.   **Please, let us know if you have any comment or feedback about this survey:**

Thank you so much for your time and answer! We really appreciate that.

Do you want to receive the final survey results? Please contact: Giovanna Vilaza, PhD candidate, at gnvi@dtu.dk or Prof. Jakob Bardram, at jakba@dtu.dk