

Authors: Adamu Adamu Habu (main researcher), Tristan Henderson (1st supervisor), and Loraine Clarke (2nd supervisor)

Introduction: Many countries exemplify the European Union General Data Protection Regulation (GDPR) and legislated data protection and privacy laws. Some of these laws created rights for individuals (data subjects). Researchers use these rights as a methodology for data collection in research. We are using two research scenarios to investigate how researchers can use data subject rights as a methodology for data collection in a citizen science context. The first scenario involves a medical audit (pages 5 to 20), while the second one investigates price discrimination (21 to 37). We have conducted a thematic analysis of stakeholder interviews to improve the design. Our work is currently being prepared for publication, so I can only share some of the prototypes at this time.

Design approach: User centered

Users/stakeholders: Four groups of stakeholders are involved. The first group consists of data subjects, who are members of the public. They exercise or delegate the exercising of their data subject rights, analyse their data, report the results, and can choose to donate their data. In some citizen science projects, they are also involved in formulating research question(s) and study design. The second group is that of the researchers. This group is responsible for formulating research question(s), designing the study, providing training materials, conducting data protection impact assessment, handling delegation, and aggregating & disseminating the results. The third group encompasses data protection officers who work for the data controllers. They handle the processing of data subject requests and decide whether to provide data to the citizen scientist or not. The fourth and final group consists of the Data Protection Authority, which becomes involved in the event of a dispute. For example, if there is a disagreement over access rights, a mediation complaint may be filed before the Privacy Commission.

Challenges: We mainly focus on data protection. Our users shaped our direction to consider usability.

Lesson learnt: Always involve end users on your design

Note: This work is currently written up for publication as such not all details can be disclosed. Our initial prototype (see below) was amended following feedback from stakeholders.

Contents:

- Persona – page 2
- Workflow diagram – page 3 & 4
- Medical audit prototypes – pages 5 to 20
- Price discrimination – pages 21 to 37

Example user persona

Name: Sarah Johnson

Summary quote: "To invite citizen scientists (nonexperts members of the public) to help uncover hidden knowledge using data subject rights."

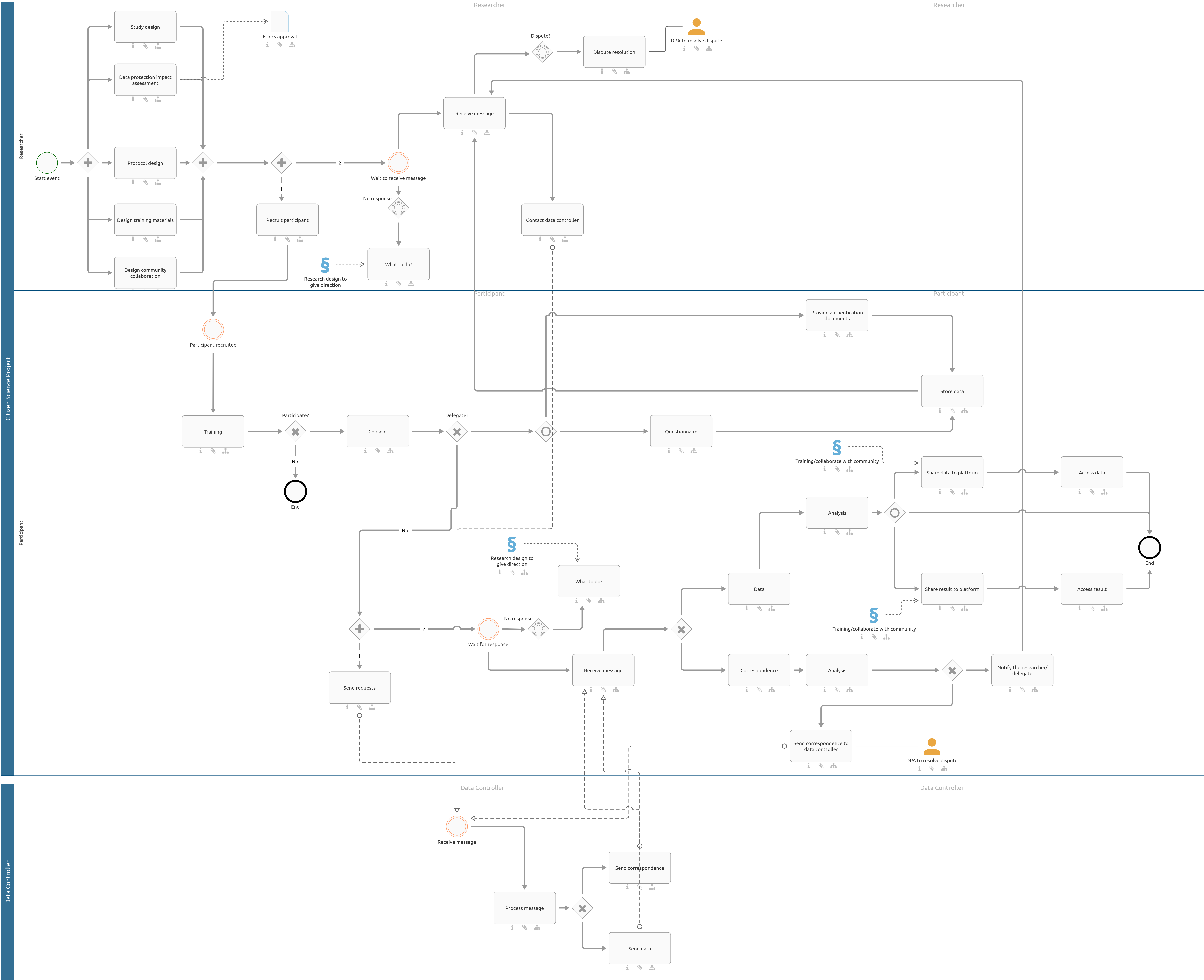
Demographic profile: Sarah is a researcher at the university who is passionate about using data subject rights as a methodology to collect data.

End goals: Sarah seeks to engage volunteers in citizen science project to externally audit medical data held by General Practice.

Scenario: Sarah's motivation for the study is that her findings could impact the way insurance companies compute claims. To achieve this, she is inviting volunteers to exercise their right-to-data portability, as enshrined in some data protection regulations, to obtain a copy of their machine-readable data for external audit. Sarah and her team will take the lead in the process of exercising the rights. Once the volunteers have analysed their data locally, they can share the results of the analysis with Sarah. Additionally, any volunteers who are willing to donate their relevant data for research may do so.

Challenges:

- However, not all companies may provide data download tools.
- Some volunteers may also find it difficult to exercise their rights and obtain the data. Therefore, Sarah is taking the lead by asking volunteers to delegate the exercise of their rights to her. She will lead the process and negotiate with the companies for the data.
- Volunteers would need to provide identity documents, consent letters, and some information about themselves for Sarah to take the lead in the delegation process.
- Data controllers would provide the data directly to the volunteers. For privacy reasons and ease of research workload, the participants should analyse their data locally and share the result of the analysis with Sarah.
- Volunteers who are willing to donate their relevant data for research may do so. However, it is important to preserve the privacy of those volunteers. This data may also be used by other researchers.



Medical data citizen science project

Home

Medical data

More to explore

Join or Sign in

Medical data of data subjects are held by many data controllers, for example, hospitals and General Practitioners (GP). This data is essential in improving healthcare services, simplifying insurance claims, and statistical and planning purposes. External investigations of medical data of data subjects held by data controllers can help determine the accuracy of these data for accountability. The study aims to understand whether users can verify the accuracy of their Medical data held by their GPs (or hospitals).

To achieve this medical data verification, a data portability will be used to request data subjects' medical data held by their GPs (or hospitals).

Open account



Your email address

[Forgot password?](#)

Password

Login

Don't have account? Sign up Here!

Sign up



Sign up



Your first name

Your last name

Your email address

Password

Use at least 8 characters and contain numbers

Confirm password

Sign up



Please check your email

We've sent a code to [hello@email](#).

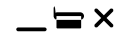
Verify





Medical data

Support



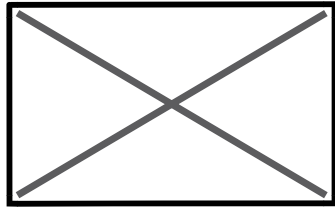
Action ...

- Support [+]
- Consent [-]
- Delegation
- Document upload
- Questionnaire
- Request template
- Mail box
- Results
- Data donation
- Profile

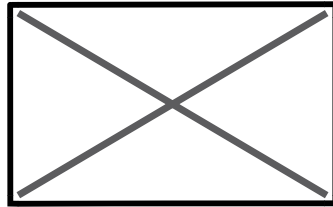
Progress



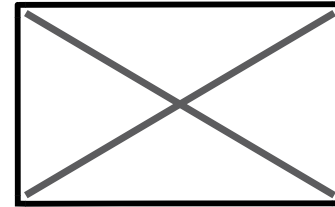
Support documents



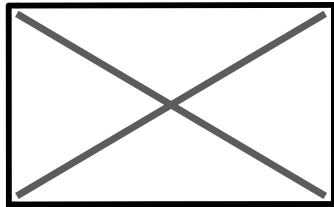
▶ Study



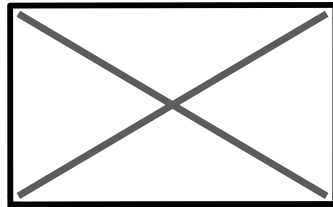
▶ Delegation



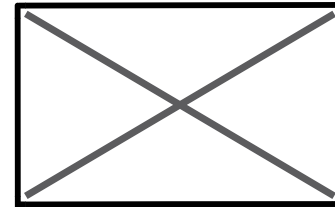
▶ Data subject req.



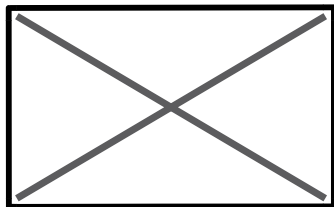
▶ Identity doc



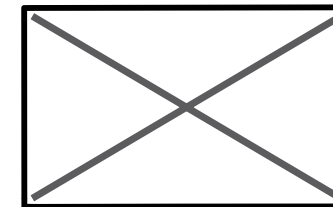
▶ Correspondence



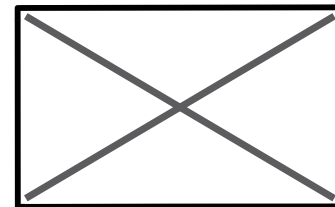
▶ Results



▶ Data donation



▶ Community



▶ Your profile





Action ...

● Support [+]

● Consent [+]

● Delegation

● Document upload

● Questionnaire

● Request template

● Mail box

● Results

● Data donation

● Profile

Consent to participate

Progress



☐ *[Illegible text]*

☐ *[Illegible text]*

☐ *[Illegible text]*

I agree to participate

I decline participation





Decline_message



Action ...

Progress



- Support [-]
- Consent [-]
- Delegation
- Document upload
- Questionnaire
- Request template
- Mail box
- Results
- Data donation
- Profile

Thank you for your time!!!

If you change your mind, we are more than
happy to have you....

Change your mind?

I agree to participate





Medical data

Delegation

Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Document upload
- Questionnaire
- Request template
- Mail box
- Results
- Data donation
- Profile

Delegation options

Progress

Delegate?

Yes

No

Support

Delegation

Community



Medical data

Participant
may decide to
send
documents to
researcher

Document upload

Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Document upload [-]
- Questionnaire [-]
- Request template
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile

Document upload

Progress



International passport 02 May 2024

View

Delete

Consent letter 02 May 2024

View

Delete

Letter from GP 02 June 2024

View

Delete

New upload

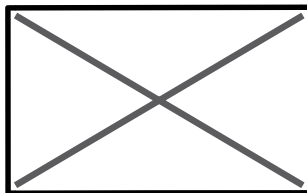
Type the description



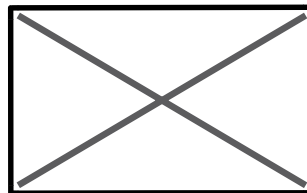
upload

Files to be
uploaded
from the
participant's
local machine

Support



Documents



Community





Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Document upload [-]
- Questionnaire [-]
- Request template
- Mail box
- Results
- Data donation
- Profile

Progress



Pre request questionnaire

What is the name of the GP you want us to send the request to?

Within a period of one year, how many times have you ever exercised any of your data subject rights to your GP?

☐ zero ☐ 1 - 3 ☐ 4 - 5 ☐ more than 5

Which of these did you exercised?

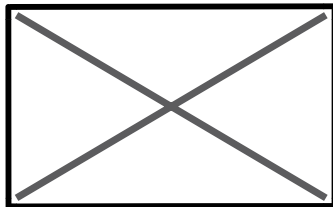
☐ Right of access ☐ Right to data portability ☐ Right to object

Would you be able to provide us with information that will assist the GP in identifying you, for example your Community Health Index (CHI) number.

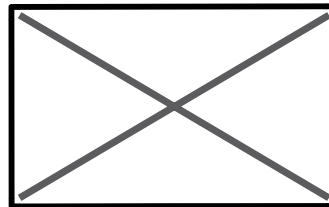
Save

Edit

Support



Questionnaire





Community





 Medical data

Requests

—  

Action ...

Progress



Sending data portability request to GP

447204 447205 447206 707 447207 004472087000707 004472097000707 447208 707 00 00472140 70047212
 0040404040407 00 70047212 00 70047212 447209 00472140 00 004072 00 447209 00472140 004072 00472140
 000070007000004 00472140 00472140 004072 00 00472140 00 00 00472140 0040404040407 004072 004072 447209
 447206 00 70077000404040700 00 0044720700072 447209 004072 70047212 70047212 00 70047212 447206
 0044720700072 0044720700072 004072 7240404072 0044720700072 7007 0044720700072 004072 00 447209 707



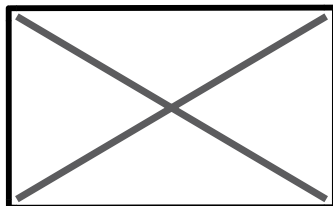
[Download template](#)



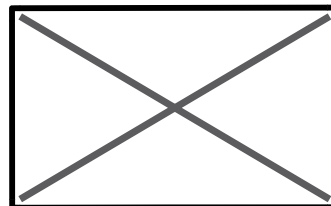
View

Request sent?

Support



Data subject req.



Community





Medical data

Questionnaire

Action ...

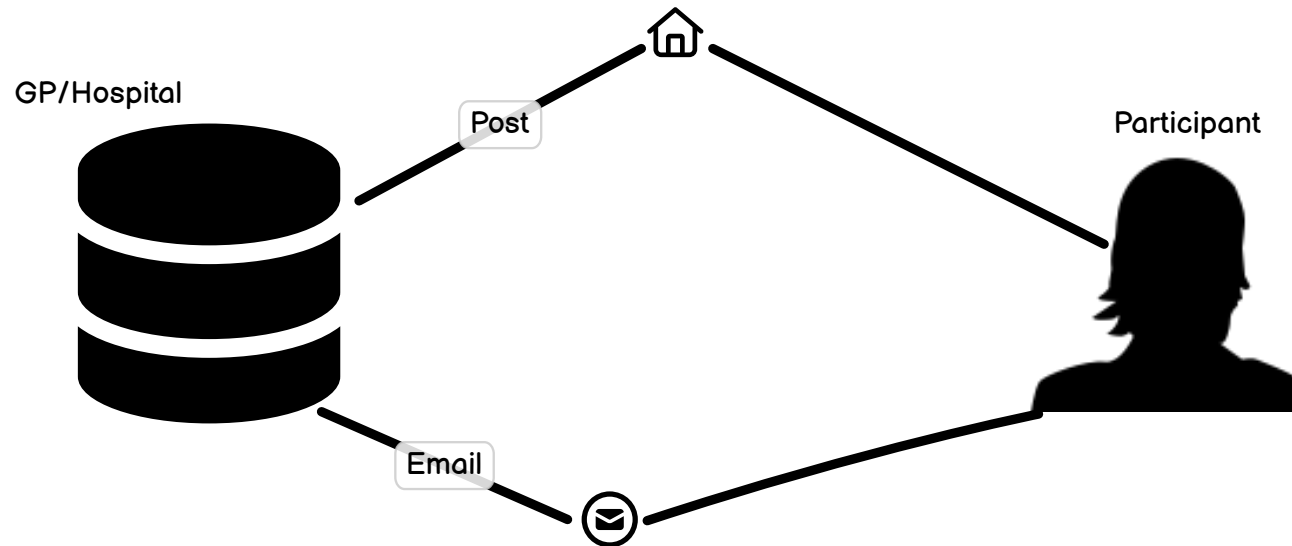
- Support [-]
- Consent [-]
- Delegation [-]
- Document upload [-]
- Questionnaire [-]
- Request template
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile

Progress



Thank you so much !!!

You now wait until you receive correspondence
from your GP or Hospital





Medical data

Mail box



Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Document upload [-]
- Questionnaire [-]
- Request template
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile [-]

Progress



Mail box with research team

GP declined requests

4 May 2024



View



Delete

Researcher's reply



5 May 2024



View



Delete

Participant may receive messages from the researcher

New message: Text input



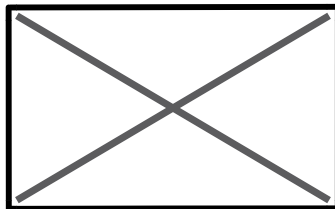
Attach



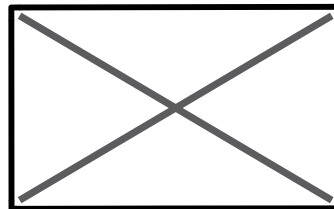
Send

New message

Support



Correspondence



Community





Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Document upload [-]
- Questionnaire [-]
- Request template
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile [-]

Progress



Reporting result analysis

GP provided the data?

☐ Yes ☐ No

Medical history disclosed?

☐ Yes ☐ No

TB record correct?

☐ Yes ☐ No

Malaria treatment with the GP correctly reported?

☐ Yes ☐ No

Would you be able to comment if third-party sharing was reported?

Please type your response

Rate data controller

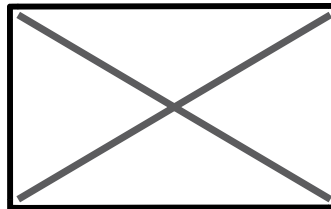
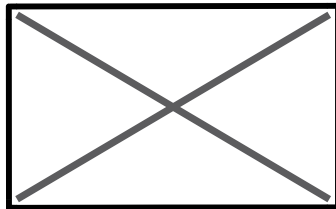


Tap the star to change rating

Save

Edit

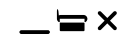
Support





Medical data

Data donation



Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Document upload [-]
- Questionnaire [-]
- Request template
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile [-]

Progress



Data donation

Caution notice!

You are about to upload a data that sensitive and personal. Try to sanitize the data you want to donate. Guidance can be found in resources below or seek help from the community platform!

File:

Select



Choose file

Rate data controller



Tap the star to change rating

Your data

Delete



GP data

4 May 2024

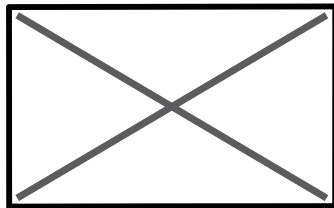


View

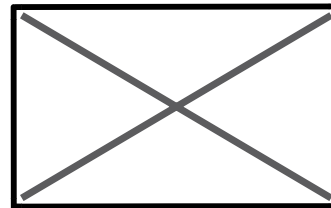


Download

Support



Data donation



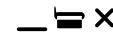
Community





Medical data

Data donation



Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Document upload [-]
- Questionnaire [-]
- Request template
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile

Progress



Caution reminder



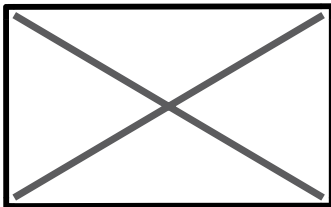
Browse and choose files from local machine



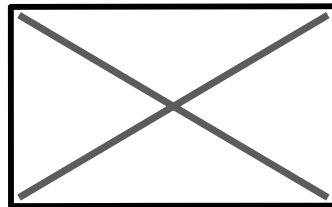
Upload



Support



Data donation



Community



User's activities citizen science project

Home

Tracking user's activities on websites

More to explore

Join or Sign in

Some businesses rely, directly or indirectly, on personal data collected from data subjects. As part of their advertising campaigns, these businesses track the visitors to their websites and collect sensitive data. Security, privacy, and ethical issues may arise due to this tracking. The study aims to use data rights (in particular, the right of access) and learn more about the data they collect. A second aim is to understand whether these data controllers disclose the necessary information as a legal obligation to data subjects.

For this scenario, the study will select some companies that track data subjects' data on their websites. Then the right of access will be used to request data subjects' website activity information held by the data controllers and information about data retention and third-party sharing.

Open account

X

Your email address

Forgot password?

Password

Login

Don't have account? Sign up Here!

Sign up

Sign up



Your first name

Your last name

Your email address

Password

Use at least 8 characters and contain numbers

Confirm password

Sign up



Please check your email

We've sent a code to [hello@email](#).

Verify





Tracking user's activities on websites

Support

Action ...

● Support [+]

● Consent [-]

● Delegation

● Questionnaire

● Request template


● Document upload

● Mail box

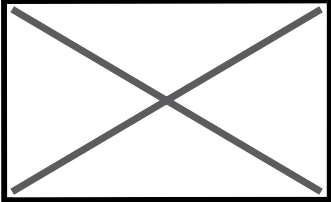
● Results


● Data donation

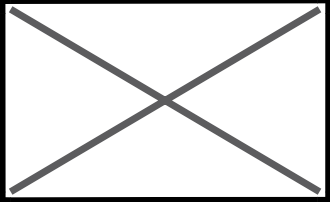
● Profile


Progress 

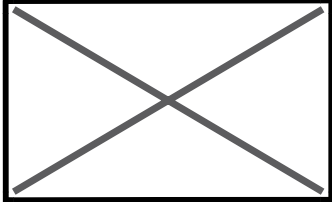
Support documents




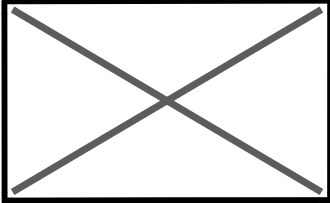
 Study




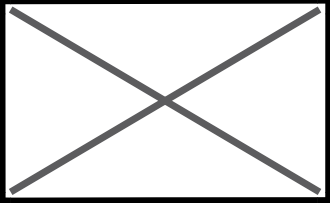
 Delegation




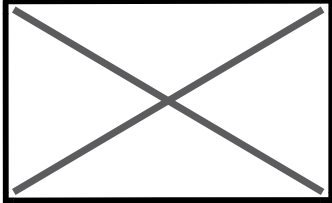
 Data subject req.




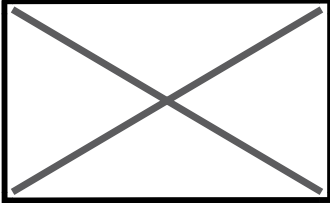
 Identity doc




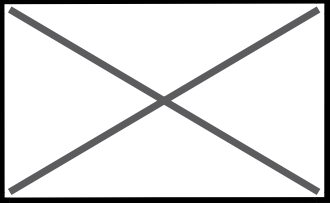
 Correspondence




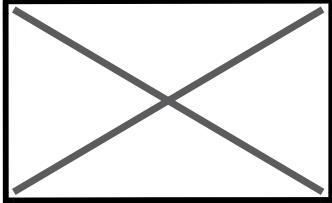
 Results





 Data donation



 Community



 Your profile





Tracking user's activities on websites

Consent

Action ...

● Support [+]

● Consent [+]

● Delegation

● Questionnaire

● Request template

● Document upload

● Mail box

● Results

● Data donation

● Profile

Consent to participate

Progress

☐

Give your consent for the collection and processing of your personal data for the purpose of participating in the research project. You understand that your participation is voluntary and that you can withdraw your consent at any time. You agree that your data will be used for research purposes only and will be kept confidential.

☐

☐

I agree to participate

I decline participation



Tracking user's activities on websites

Decline_message

Action ...

● Support [-]

● Consent [-]

● Delegation

● Questionnaire

● Request template

● Document upload

● Mail box

● Results

● Data donation

● Profile

Progress

Thank you for your time!!!

If you change your mind, we are more than
happy to have you....

Change your mind?

I agree to participate



Tracking user's activities on websites

Delegation

Action ...

● Support [-]

● Consent [-]

● Delegation [-]

● Questionnaire

● Request template

● Document upload

● Mail box

● Results

● Data donation

● Profile

Delegation options

Progress

●

◐

○

○

Delegate?

Yes

No

Support

▶ Delegation

▶ Community



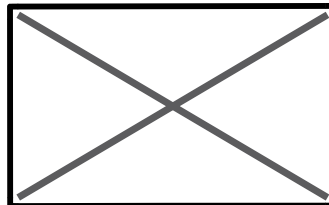
| Action | ... |
|--------------------------|-----|
| ● Support [-] | |
| ● Consent [-] | |
| ● Delegation [-] | |
| ● Questionnaire | |
| ● Request template [-] | |
| ● Document upload [-] | |
| ● Mail box [-] | |
| ● Results [-] | |
| ● Data donation [-] | |
| ● Profile | |

This page detailed how a data subject can make a request to a data controller.

[Download template](#)



I have sent the request





Tracking user's activities on websites

Questionnaire

Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Questionnaire [-]
- Request template
- Document upload []-
- Mail box
- Results
- Data donation
- Profile

Progress

Pre request questionnaire

Which of these data controllers did you want us to send the request to?

☐ Tesco☐ Aldi☐ All

Within a period of one year, how many times have you ever exercised any of your data subject rights to TESCO?

☐ zero☐ 1 - 3☐ 4 - 5☐ more than 5

Within a period of one year, how many times have you ever exercised any of your data subject rights to ALDI?

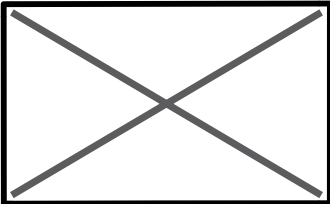
☐ zero☐ 1 - 3☐ 4 - 5☐ more than 5


Would you be able to provide us with information that will assist the data controllers in identifying you, for example your user name.

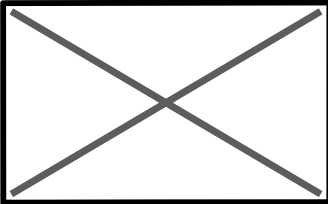
Save


Edit

Support



 Questionnaire



 Community



Tracking user's activities on websites

Questionnaire

Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Questionnaire [-]
- Request template
- Document upload [-]
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile

Progress

Thank you so much !!!

Please wait until you receive a response from TESCO/ALDI

TESCO/ALDI

Post

Email

Participant





Tracking user's activities on websites

Some participants may not require documents upload

Document upload

Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Questionnaire [-]
- Request template
- Document upload [-]
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile

Document upload

Progress



Letter from tesco

02 May 2024

View

Delete

Letter from DPA

02 June 2024

View

Delete

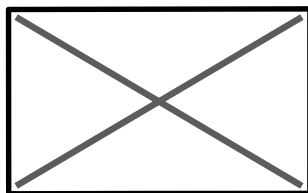
New upload

Type the description

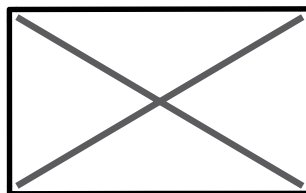
upload

Files to be uploaded from the participant's local machine

Support



Documents



Community





Tracking user's activities on websites

Mail box

Action ...

• Support [-]

• Consent [-]

• Delegation [-]

• Questionnaire

• Request template [-]

• Document upload [-]

• Mail box [-]

• Results [-]

• Data donation [-]

• Profile [-]

Progress

●

◐

○

○

Mail box with research team

Need your help with TESCO4 May 2024

View

Delete

Researcher's reply

5 May 2024

View

Delete

New message: Text input

Attach

Send

New message

Support

Correspondence

Community



Tracking user's activities on websites

Results

Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Questionnaire
- Request template [-]
- Document upload [-]
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile [-]

Progress

Reporting result analysis

Has the data controllers provided the data?

☐ Yes ☐ No

Was the data provided within 30 days?

☐ Yes ☐ No

Did the data controller disclose whether they are sharing data with third party?

☐ Yes ☐ No

Did the data controller disclose why they are collecting the data?

☐ Yes ☐ No

Would you be able to comment if third-party sharing influences your shopping habits?

Please type your response

Rate data controller

Tap the star to change rating

Save

Edit

Support

Results

Community



Tracking user's activities on websites

Data donation

Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Questionnaire [-]
- Request template
- Document upload [-]
- Mail box [-]
- Results [-]
- Data donation [-]**
- Profile [-]

Progress

Data donation

Caution notice!
You are about to upload a data that sensitive and personal. Try to sanitize the data you want to donate. Guidance can be found in resources below or seek help from the community platform!

File:

Select

Choose file

Rate data controller

Tap the star to change rating

Your data

Delete

Tesco data

4 May 2024

View

Download

Support

Data donation

Community



Tracking user's activities on websites

Data donation

Action ...

- Support [-]
- Consent [-]
- Delegation [-]
- Questionnaire [-]
- Request template
- Document upload [-]
- Mail box [-]
- Results [-]
- Data donation [-]
- Profile

Progress

Caution reminder

Upload

Browse and choose files from local machine

Support

Data donation

Community

