Maastricht University

Introduction

Introduction

This questionnaire aims to assess the acceptance of Blockchain Technology for health data sharing. It is is part of a research study at Maastricht University. The questionnaire is most conveniently completed using your PC and should take about **ten minutes**. Please read the provided descriptions and thoroughly answer the questions.

An Electronic Health Record (EHR) is an electronic collection of a patient's medical history over time. The use of EHRs improves patient care, decreases healthcare errors, and pushes forward new health developments.It is widely recognized, that sharing of these records has a positive effect on health outcomes and innovation.

GDPR Regulation

The questionnaire will be treated anonymously, and your responses will be kept confidential. If you have any questions about this research, contact Lilly Baltruschat at l.baltruschat@student.maastrichtuniversity.nl or supervisor Visara Urovi at v.urovi@maastrichtuniversity.nl. By clicking the button below, you acknowledge the following: Your participation in the study is voluntary. You are above 18 years of age. You are aware that you may choose to terminate your participation at any time for any reason.

○ I consent, begin the study
○ I do not consent, I do not wish to participate

Technological background and attitude towards data sharing

When I think of Blockchain, I think of one or more of the following

☐ Investing
☐ Security
☐ Digital Currency (Ethereum/Bitcoin)
☐ Decentralization
☐ Data sharing

☐ Payment method

☐ Trust

☐ [_____] Other

The first section is about your technological background.

Please indicate your agreement with the following statements.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Usually, I am the first to try out new technologies.	○	○	○	○	○
In general, I am up to date with new technologies.	○	○	○	○	○
I am familiar with data sharing platforms (e.g. Dropbox, Facebook, Google Drive).	○	○	○	○	○
I am familiar with Electronic Health Records (EHR).	○	○	○	○	○
I am familiar with Blockchain Technology.	○	○	○	○	○
Usually, I am the last to try out new technologies.	○	○	○	○	○

This section is about your attitude towards data sharing.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Sharing health data is important.	○	○	○	○	○
I am willing to share my health data with anyone.	○	○	○	○	○
I am willing to try out new technologies to share health data.	○	○	○	○	○

I would be more willing to share my health data, ...

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
... if I could decide how my health data is used.	○	○	○	○	○
... if I could decide who has access to my health data.	○	○	○	○	○

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
… if I would get paid for it.	○	○	○	○	○
… if I would get more information about the state of my health or my risk factors.	○	○	○	○	○

Imagine you decided to share your health data.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I want to be notified when my data is accessed/used.	○	○	○	○	○
I want to know why my health data is being used.	○	○	○	○	○
I want to know where my health data is located.	○	○	○	○	○
I want to know who uses my health data.	○	○	○	○	○
I want to have a say every time my data is being used.	○	○	○	○	○

LUCE

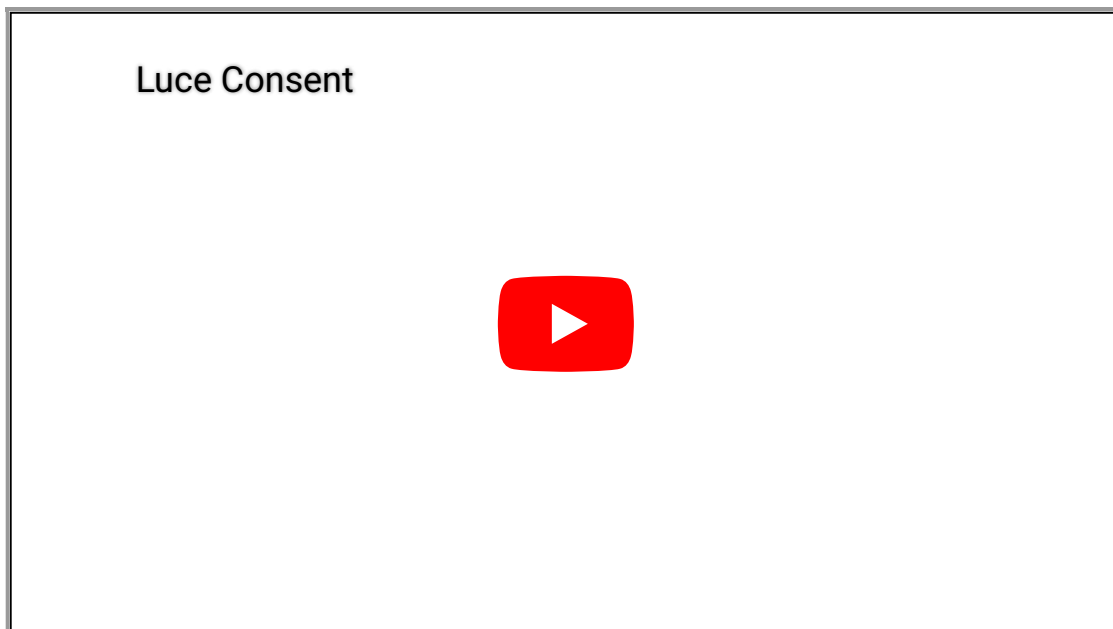**Health Data Sharing and Blockchain**

The potential of health data sharing is hindered by data fragmentation as well as privacy and security concerns. Blockchain technology can tackle these issues. While the prominent Blockchain example in your mind might be Bitcoin, Blockchain technology can support health data sharing in a transparent and decentralised manner.

Blockchains create a shared record of all transactions made in a network of distributed computers. The transactions can hold information about who accesses which personal health records and for which purpose. Once a transaction is approved, it cannot be altered or modified. Transactions are approved collectively in the network through a shared consensus mechanism between all members of the network. This model has no central authority that dictates who can access which data.

Using a blockchain-based solution you can decide if and how to share your health data. As your data is shared, the blockchain network creates immutable records of all health data record accesses. LUCE is an example of a prototype platform that utilizes Blockchain to facilitate health data sharing for research purposes. LUCE offers you (the

health data provider) the option to decide under which conditions a data requester can access your data. Further, you can change your consent as well as remove the data at your convenience. This model enforces the General Data Protection Regulation (GDPR) of the European Union.

Please watch the video below to better understand how to use LUCE.

Luce Consent

After reading the description of Blockchain based solutions like LUCE, and after watching the video, you should better understand blockchain based solutions' features and how it is functioning. Please indicate your agreement with the following statements.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
A Blockchain based solution offers sufficient options to control who has access to my data and what it will be used for.	○	○	○	○	○
A Blockchain based solution allows me to revoke my consent at any time.	○	○	○	○	○
Being able to personalize the use conditions of my health data is important to me.	○	○	○	○	○
A Blockchain based solution makes it easier to control who uses my health data.	○	○	○	○	○
A Blockchain based solution would make it easier to control what my health data is being used for.	○	○	○	○	○

The following questions relate to the security of data.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I believe Blockchain technology is secure.	O	O	O	O	O
I would feel secure using a Blockchain based solution to share EHR.	O	O	O	O	O
Being able to choose who and how my data is used makes me feel that my data is secure.	O	O	O	O	O
Using a Blockchain based solution increases security when sharing my health data.	O	O	O	O	O

These statements are about your trust in a Blockchain based solution such as LUCE.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I believe a Blockchain based solution will do everything it can to secure my data.	O	O	O	O	O
I believe that a Blockchain based solution is trustworthy.	O	O	O	O	O
I believe that a Blockchain based solution is reliable.	O	O	O	O	O

When thinking of blockchain based solutions for health data sharing, to what extend do you agree to the following statements?

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
A financial compensation for sharing my data would decrease my trust in a Blockchain solution.	O	O	O	O	O
A financial compensation for sharing my data would increase my trust in a Blockchain solution.	O	O	O	O	O

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
My trust in a Blockchain solution for sharing my data is independent from any financial compensations.	O	O	O	O	O
I might overlook trust because of my desire to be financially compensated for sharing my data	O	O	O	O	O

The following statements relate to how you believe using a Blockchain based solution benefits you.

A Blockchain based solution would make it easier for me...

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
... to share my health data.	O	O	O	O	O
... to access my health data.	O	O	O	O	O
... to control who has access to my health data.	O	O	O	O	O
... to keep track of my health data.	O	O	O	O	O
In general, I think blockchain based solutions are useful to facilitate data sharing.	O	O	O	O	O

This section captures your attitude towards using a blockchain based data-sharing solution such as LUCE.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Learning how to share data with a Blockchain based solution would be easy for me.	O	O	O	O	O
Sharing data on a Blockchain based solution is clear and understandable.	O	O	O	O	O
Overall, a Blockchain based solution is easy to use.	O	O	O	O	O

These questions relate to your believes that social factors will influence the use of a Blockchain based solution.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
My family and friends will think that I should share health data using a Blockchain based solution.	O	O	O	O	O
People in the healthcare sector (doctors, nurses, etc.) will ask me to share my data using a Blockchain based solution.	O	O	O	O	O
I have the necessary knowledge to use a Blockchain based solution.	O	O	O	O	O
I have the necessary resources to use a Blockchain based solution.	O	O	O	O	O
I think healthcare stakeholders (hospitals, doctors, insurances, etc.) are technologically able to use a Blockchain based solution.	O	O	O	O	O

These statements capture your likelihood of using a Blockchain based solution. Please indicate whether you agree or disagree with the following statements.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I would use a Blockchain based solution to share my health data.	O	O	O	O	O
I plan on using a Blockchain based solution when I want to share my health data in the future.	O	O	O	O	O
I prefer a Blockchain based solution over traditional data sharing solutions.	O	O	O	O	O

In summary, what do you think about using Blockchain based solutions for health data sharing?

_____

Demographics

What is your age?

O 18-29

O 30-39

O 40-49

- ○ 50-59
- ○ 60-69
- ○ 70-79
- ○ above 80

What is your gender?

- ○ Male
- ○ Female
- ○ Non-binary / third gender
- ○ Prefer not to say
- ○ Other

What is your highest educational level?

- ○ Middle School
- ○ High school
- ○ Bachelor
- ○ Master
- ○ PhD
- ○ [   ] Other

What is your nationality?

- ☐ American
- ☐ Belgian
- ☐ British
- ☐ Dutch
- ☐ French
- ☐ German
- ☐ Italian
- ☐ Spanish
- ☐ [   ] Other

What is your occupation?

- ○ Unemployed

- ○ Employed
- ○ Self-employed
- ○ Student
- ○ Retired
- ○ [   ] Other

What is your annual average income?

- ○ Less than 10.000€
- ○ Between 10.000€ and 30.000€
- ○ Between 30.000 and 60.000€
- ○ Higher than 60.000€
- ○ Prefer not to say

End of Survey

Congratulations, you have reached the end.

If you wish to receive an email with the outcome of this study, feel free to provide your email address below.

[   ]

Powered by Qualtrics