



Timely Workshop

Today's aims

- 1 Get to know each other
- 2 What is the problem we are trying to solve and how data can help with this?

(Break)

- 3 Understand your views on the Timely project

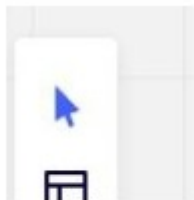
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2. **You can share your opinions however you want:** out loud, in the chat to the group or using post it notes on this board
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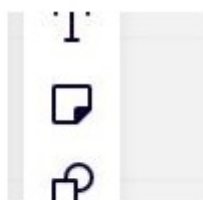
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Mouse
Top of the tool
bar



Post-it
4th down on the
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Zoom
Bottom right of the board



Ice Breaker

You have **1 minute** each to tell the group:

1. Your name
2. Your pronouns
3. The town or city you live in
4. Something interesting that happened to you recently



Who are we?



UNIVERSITY OF
CAMBRIDGE
Department of Psychiatry



Anna Freud
National Centre for
Children and Families



UNIVERSITY OF
BIRMINGHAM



University
of Essex

NHS

Cambridgeshire
Community Services
NHS Trust

NHS

Cambridge
University Hospitals
NHS Foundation Trust

NHS

Cambridgeshire and
Peterborough
NHS Foundation Trust



Cambridgeshire
County Council

PETERBOROUGH
CITY COUNCIL

Who are we?



Emily



Rachel



Anna



Alisa



Tia

What is the problem we are trying to solve?



Studies show that 1 in 6 young people aged 5-16 years had a probable mental health problem in 2021. That's 5 young people in every classroom of 30.

When a young person is struggling with their mental health it can be hard for the adults around them to realise that they need help.

Their doctor or teacher might notice that something is off, but not have the "full picture" of what is happening in their life.

If can we link data together in a database, we might be able to find ways to get young people **the right kind of help** and **at the right time**.



How could
using data
help?

In the UK we have many services that help the public.

Places like...



Schools



Your GP
(doctor)



Accident & Emergency



Hospitals



Social Services



Mental Health
Services

When you go to see someone at one of these services, they keep information about you. For example...



Schools might know if students have been absent a lot

GPs might know if their patients have been having headaches



A&E might know how many young people in the area have broken bones

Social Services might know about families who have been having problems at home



Mental health services in the community might know if more young people in the area have been struggling with depression



Patient data saves lives: Asthma

for a preventative appointment.

YouTube

BUT WHEN RESEARCHERS GET ACCESS TO THIS TYPE OF DATA THEY DO NOT SEE ANY IDENTIFIABLE INFORMATION



Miss Max Jones

Miss o2mKr8a 9Wbas6B

Researchers can't see this

Nonsense numbers & letters

Max Jones	→	73e2c83 2bd927v
NHS# 1234567	→	NHS# 923ensdv28p
CB2 1TN	→	msa72e0zg173

Miss Max Jones, NHS# 1234567, living at CB2 1TN attended A&E with a sprained ankle on the 6th of May, 2017

Miss 73e2c83 2bd927v, NHS# 923ensdv28p, living at msa72e0zg173 attended A&E with a sprained ankle on the 6th of May, 2022

No way for researchers to decode this

That means things like:

- Names
- Addresses
- Phone numbers
- NHS numbers
- Names or addresses of family members

Zoom poll!



Do you have any questions or
comments?

Does anything worry you?

DISCUSS!



Take a break



So...

What is the Timely
project trying to do?



Let's look at
some examples
of what using
linked data
could look like in
the real world...



MAX'S JOURNEY



Max does okay in school, even though they get in trouble sometimes. Their favourite subject is Maths. They like playing football.



One day Max sprains their ankle at a football game. Their grandad takes them to A&F.



A social worker has come to speak to Max about possibly needing a SEND (special education needs & disabilities) plan, but it was decided Max didn't need one.



Max misses a few days of school because their parents take them on a camping trip.



Max's grades in Science start to slip. Their parents get them a tutor and their grades improve.



Max's mum takes them to the GP because they have been complaining about a stomach ache. They are given a prescription.

KEY



What the school know



What the NHS know



What social services know



WHAT THE "FULL PICTURE" LOOKS LIKE WITH ALL THE INFORMATION PUT TOGETHER





ALEX'S JOURNEY



Alex is smart, but they gets into fights a lot with other children at school.



Alex's dad has taken them to A&E 5 times in the last year complaining of headaches. Doctors aren't sure what's wrong.



Alex misses school often because they say they can't be bothered and would rather stay home and play video games.



Alex's mum is worried about them. She takes them to a GP appointment. The GP puts in a referral to CAMHS. The next available appointment is in 8 months.



Alex's grades have been slipping for the past year. They don't do much homework and don't do well on tests.



A social worker has been to the family home because the school is concerned. Alex seems quiet and sad, but their parents insist they're just being moody.

KEY



What the school knows



What the NHS knows



What social services know



WHAT THE "FULL PICTURE" LOOKS LIKE WITH ALL THE INFORMATION PUT TOGETHER

Alex gets into fights at school.

Alex has missed a lot of school days this year.

Social worker has been to the house...

Alex is on a CAMHS waiting list, but won't get help for some time.

Alex's grades have slipped...

5 A&E visits but no diagnosis.

...but isn't too concerned.

...but teachers say they're smart

Looks like Alex is struggling... someone needs to check in on them.

Computer program looking at all the information together



SO CAN WE DO THIS?

...not yet!



First we would need to look at lots and lots of data to see if we can **learn to tell apart** “these young people are probably doing okay” and “looks like these young people are struggling.”

The first thing we would need to do is **link** all the different types of data together in a single digital database.

Some of the information we need to include could be quite **sensitive** in nature.

Let's look at some examples...

- 1 **GP:** the young person has a substance misuse problem



- 2 **Mental health:** a child has disclosed abuse; a child is a young carer



- School:** whether a child receives free school meals, or if there are welfare concerns about a child

- 4 **Community services:** vaccination records, dental records, 2 year old health visitor checks.



- 5 **Social care:** if a child is a 'looked after child', if there are safeguarding concerns, if they are involved in county lines

Zoom poll!

What do you think about
the Timely project so far?

DISCUSS!

Today we...

- 1 Got to know each other
- 2 Understood your views on how data can be used
- 3 Understood your views on the Timely project

How are you feeling after today's session?

Vote!

1



Relaxed

2



Nervous

3



Excited

4



Confused



Next
Steps

In the next couple of months we will:

Workshop 2 (31st May)

Work together to make a plan for how we will share information and keep it safe on the Timely project.

Workshop 3 (21st June)

Exploring ways in which we can explain this to other people clearly

In **July** we'll get a new group of people who know nothing about the project and show them what we've been working on. We'll do a survey to see what they think and we'll analyse the results.

We hope to continue working on this project with you beyond July, although we don't know exactly what that will look like yet!



Timely Workshop 2

Today's aims

- 1 Recap - what is the timely project about?
- 2 Understand your views on keeping data safe
- 3 Understand your views on what kind of people, organisations and projects should be able to use the data.
- 4 Understand your views on who should make decisions about the Timely project data.

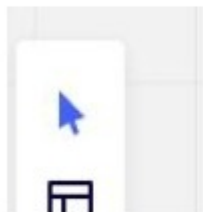
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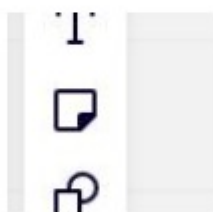
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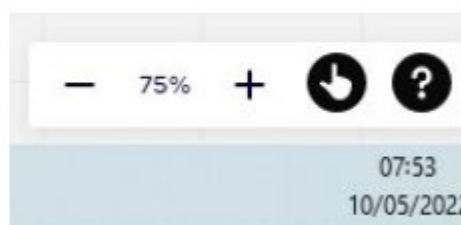
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Bottom right of the board

You have **1 minute** each to tell us :

Your name and pronouns

The town or city you live in

If you were marooned on an island, what 3 things would you bring with you?



Ice Breaker



Recap

What is the problem we are trying to solve?

Studies show that 1 in 6 young people aged 5-16 years likely had a mental health problem in 2021.

That's 5 young people in every classroom of 30.

When a young person is struggling with their mental health it can be hard for the adults around them to realise that they need help.

Services (like the NHS, schools, and social services) already collect data which could indicate that something is wrong, but this data is not stored in one place so it's hard to see "the full picture"



What is the Timely project trying to do?



This means that things like your name and date of birth have been removed

The Timely project would like to link **de-identified data** from different services in one database.

We would then like to use this de-identified data to train computer programs ("algorithms") to learn the difference between "this young person is probably doing okay" and "it looks like this young person is struggling".

Right now we are just in the **research** phase of trying to understand **if** we can do this - this is why there is no identifying information in the database



Any questions
so far?



Today's
workshop

It's also important for researchers to see data from different **areas** of the UK



...but, individual data stays **local** & researchers can only get **summaries** from each database



How many girls aged 12-17y have been diagnosed with anxiety in these 3 locations?



This is important because:

1. We can understand when patterns might be different in different areas of the UK
2. Some symptoms or diagnoses are **rare** so we need to "find" more people to be able to train the algorithms to help them

What do you think about researchers being able to see data from all 3 locations?

DISCUSS!





What do you
think we should
be doing to keep
data safe?

DISCUSS!



There is **no identifying information** (for example, name and date of birth) in the data. Researchers only being able to access **relevant information**.

For example:

For a project about young people aged 13 - 15 with anxiety, researchers wouldn't be able to see the data of 17 year olds with bipolar disorder.



Researchers have to **explain their project** and how the data will help their project.

For example:

Only allowing researchers working on projects which will actually help young people in some way.

We'll come back to this one and give you some more examples!



Researchers have to **get permission** to use the data.

For example:

- Going on a training course on how to use the database
- Asking researchers to sign a document, which tells them how they are and are not allowed to use the data



The data is physically and electronically **locked away**.

For example:

- Researchers have to be given unique login information so that what they do in the database can be tracked
- The computers that the data is stored on are locked away in a secure building.



Researchers can only download **permitted information**.

For example:

The researcher puts the information they want to download in a file. The data protection expert reviews what the project needs and what is in the file, to make sure it is OK.



Do you have any questions or
comments?

Does anything worry you?

DISCUSS!



Take a break

Zoom poll!



Deciding which
projects are
'safe projects'



We talked about using the database to help young people with mental health problems...

...but linking data from the NHS (GPs, hospitals, A&E etc.) could be useful for projects looking to improve **physical health** as well.

If you were a physical health researcher what might you want to find out?



People from the NHS?

For example, a your local NHS Trust wants to know how to make waiting times shorter.



People from local councils?

For example, a social worker wants to know what kind of issues young people in their area are having.



People from charities?

For example, the charity Cancer Research wants to understand how inequalities can affect access to cancer treatments.



People from universities?

For example, a researcher wants to know how we can better help parents going through divorce to support their children.



People from private care homes?

For example, a children's care home wants to know how to better support the mental health needs of young people in their care.



AN IMAGINARY START-UP

Technology start-ups?

For example, a start-up company wants to use the database to create a new mental health support app for young people.



Big medical companies?

For example, AstraZeneca want to use the data to develop and sell a better drug for depression.



Big technology companies?

For example, Google wants to create an "early detection" system to help young people with diabetes preserve their eyesight.

Should these projects have access to your de-identified data?

Definitely!

I'm not sure...

No way!



CANCER RESEARCH UK

AstraZeneca 



ParkviewCare
Changing lives. Shaping futures.

Google

NHS

Google



maybe not
as helpful
as the
others?



AN IMAGINARY START-UP



What are the **pros** and **cons** of for-profit corporations accessing the data?

Their project might benefit the public e.g. Google helping with diabetic eye disease

If for-profit organisation pay to access the data it can help us to pay for costs which keep data safe

They might not be bound by the same values as health care providers or charities

It will cost money to run the database. If for-profit corporations pay to access the data we can provide access to the NHS and charities for less.

If for-profit organisations pay to access the data it can help us to pay for groups like this

They might make money from accessing the data

There could be unintended negative outcomes

What can we do to make it **safer** for for-profit corporations to access the data?

Only allow for-profit organisations to use the data if they are using it for a project for social good

Ensure that only 'safe people' for not-for profit organisations can access the de-identified relevant information.

Ensure that for-profit organisations are only allowed to access de-identified information that is relevant to a specific project which has been approved by a committee

Only allow for-profit corporations to access the data if all payments are used to run the database and PPI

Who should decide which projects are safe?

The committee

Therapists/doctors

Mental health researchers

school leaders

data security experts (experts in data technology)

The founder (Anna)

Organisations who are providing the data e.g. mental health trust or local council

young people with lived-experience of mental health

CAMHS representation

Ethics experts

Parents with children with lived experience of mental health

Information governance experts (experts in data law)

Not on the committee:

- commercial organisations
- politicians
- journalists/news agencies

Any final thoughts?

About linking data together?

About the Timely project?

About keeping data safe?

Do you have any concerns?



Today we...

- 1 Recapped what the timely project is about
- 2 Understood your views on keeping data safe
- 3 Understood your views on what kind of people, organisations and projects should be able to use the data.
- 4 Understood your views on who should make decisions about the Timely project data.

How do you feel after today's workshop?

Vote!

1



2



3



4



5





Next
Steps

Workshop 3 (21st June)

Exploring ways in which we can clearly explain the project and our plan for keeping data safe to other people.

Focus group

In July we'll get a new group of people who know nothing about the project and show them what we've been working on. We'll do a survey to see what they think and we'll analyse the results.

Future work

We hope to continue working on this project with you beyond July, although we don't know exactly what that will look like yet!



Timely
Workshop 3

Today's aims

- 1 Recap - what is the timely project about? How are we keeping data safe?
- 2 Understand what information we need to tell the public about the database.
- 3 Hear your thoughts on how when and where we should share this information.

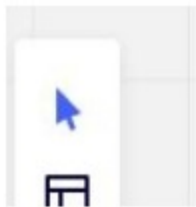
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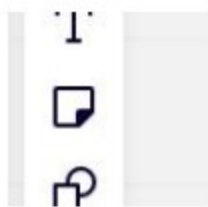
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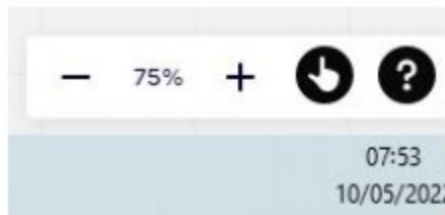
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Zoom
Bottom right of the board

Where do you stand?

Coffee

Tea

Morning person

Night owl

Cats

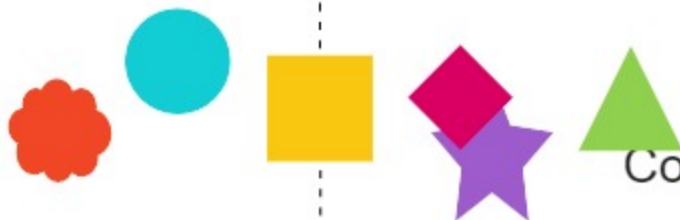
Dogs

Beach

Countryside

Scrunch

Fold





Recap

There are 2 parts to the project, but today we want to focus on just building the **database**

1

Building a linked database of de-identified data. This will enable researchers from lots of different projects to do research to help young people's physical and mental health

2

our project is just one example of how the database could benefit young people

Our project (Timely) will use the database to create computer algorithms to spot patterns in the data to tell apart young people who are likely to be struggling with their mental

What is the problem we are trying to solve?

There are many services in the UK which **routinely** collect data about young people. However this data is **stored separately**, making it very difficult for researchers to use this information in a helpful way.

For example, consider people with chronic health conditions. They might often see their GP, attend specialist services and will miss school due to their health.

It's difficult for researchers to **see the "full picture"** of what is going on with that person.



Your GP



A&E



Social Services



CAMHS



Hospitals



Schools

What can we do?

In order to help researchers understand the physical and mental health issues affecting young people (and find solutions!), we need to **link** all this data in one place.

By doing this in several **locations** we can also get results which are more helpful and diverse.



How will we keep data safe?

We will be sticking to the five safes

Safe data: There is no identifying information (for example, name and date of birth) in the data. Researchers can only access relevant information.

Safe projects: Researchers have to explain their project and how it will help the public.

Safe people: Researchers have to get permission from a committee to use the data.

Safe settings: The data is physically and electronically locked away and all activity in the database is recorded.

Safe outputs: Researchers can only download permitted information.





Any questions?

Communicating
with the public
about building a
database



Why? Transparency is an important part of ethical research

Lets people know what we'll be doing and why

Gives people the option to get more information

Gives people the opportunity to ask questions or voice concerns

Gives people the opportunity to opt out

What is it important to tell people about the **purpose** of the database?



What is it important to tell people about the **benefits** of the database?

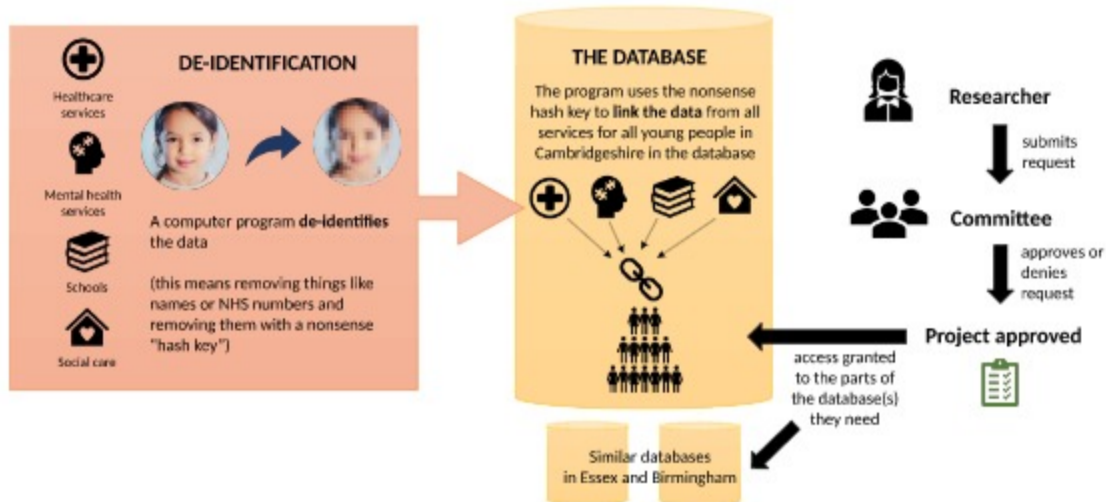


What might people **worry** about that we should clarify?



What **details** do we need to explain?

What happens inside the database?





Grab a post it! You have **5 mins** to write a Tweet about the database



Take a break

Who should we be telling
about the database?



How should we be telling them about the database?

Parents/ guardians

Young people

Professionals

Opting out

What do people need to know about opting out?

How can we let people opt out easily?

What is an **under-served group**?



The voices of some groups in society are less heard than others, particularly people from minority ethnic, religious or gender backgrounds. This is also true for research and can mean that findings are not relevant to all, or at worse are unhelpful or harmful.

It is essential that we are communicating about the project with people from under-served groups.

How do you think we should reach **under-served groups**?

Today we...

- 1 Recapped what the timely project is about.
- 2 Understood what information we need to tell the public about the database.
- 3 Heard your thoughts on how when and where we should share this information.

How are you feeling after today's session?

1



Relaxed

2



Nervous

3



Excited

4



Confused



Next
Steps

Focus group

In July we'll get a new group of people who know nothing about the project and show them what we've been working on. We'll do a survey to see what they think and we'll analyse the results.

Community of interest

We are working to keep this group active in the long term - to support the database, the Timely project, and other similar projects about young people's health and well-being. We will be in touch with more details as soon as we can!

Timely
Workshop 4



Today's aims

- 1 Introductions to the project and each other
- 2 Understanding how easy it is to find information in the communications tools.
- 3 Get your feedback on how we can improve the communications tools

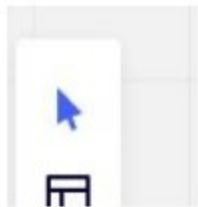
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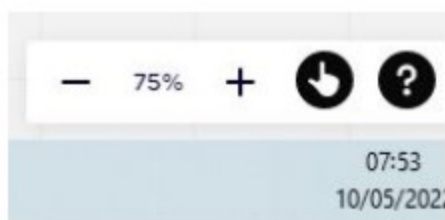
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Post-it
4th down on the
tool bar



Zoom
Bottom right of the board

Icebreaker

If you could only eat one type of food for the rest of your life, what would it be?



When I pick your post-it note, tell us:

1. Your name
2. Your pronouns
3. What town or city you live in
4. Why you picked that food

What is the Community of Interest?



Public and Patient Involvement means working in partnership with patients and the public to plan, manage, design and carry out research.
It's really important!

So we have created a network of parents and young people (including you!) who can have a voice on a range of different research projects aiming to support young people's physical and mental health.

What is the project we're talking about today?



CamCHILD database

Linking together **routinely** collected information in a **de-identified** database to support **research**

Young people aged 0 to 17y



Any Questions?

Try and find the following information in the leaflet



1. Why is the Cam-CHILD database being created?

2. How will a researcher get access to the database?

3. Will it be possible to identify the people whose data is in the database?

You have 5 minutes!





Discussion!

How easy/difficult was it to find the information?
What could we do to make things easier?



Try and find the following information in the booklet

1. How do we de-identify the information in the database?


2. What kind of data will be included in the database?

3. What is the Data Access Committee?




You have 5 minutes!



**Discussion!**

How easy/difficult was it to find the information?
What could we do to make things easier?



Discussion!

Is there anything in the information that worries you?





Take a break

Discussion!

Is there anything in the information that confuses you?



Discussion!

What could we do to make things clearer?

Why aren't we asking for consent?

Not required under law -

GDPR says that data can be used without consent if it is for the benefit of public health

Consent has to be informed - this would mean everyone reading lots of information about the project

Excludes hard-to-reach groups - which makes research less effective at helping these groups

People can opt out - we will be communicating about what we're doing to ensure that people are aware and can opt out

What do you think of the language?

Works well



**Needs
improvement**



What do you think of the images?

Works well



Needs improvement



What do you think of the layout?

Works well



**Needs
improvement**



Can you think of a time you've heard or seen information about health or research?



**What made you
notice it?**

**What made it
memorable?**

What images would make you think of a database for young people's mental and physical health?

You have **5 minutes!**

Activity!

1. Open **Google Images**
2. Right click on your chosen image and click **copy image**
3. Use **Ctrl V** to paste them below



Is there anything
we've missed?

Today we...

- 1 Introduced you to the project and each other
- 2 Understood how easy it is to find information in the communications tools.
- 3 Got your feedback on how we can improve the communications tools

How are you feeling after today's session?

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Relaxed

2



Nervous

3



Excited

4



Confused



Next
Steps

Community of interest

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