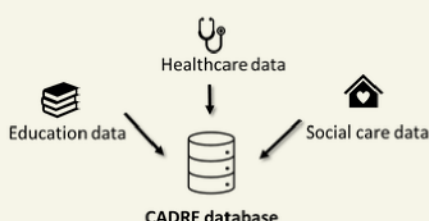# CADRe
CHILDREN AND ADOLESCENTS DATA RESOURCE

LESSONS FROM PATIENT AND PUBLIC INVOLVEMENT

WHAT IS IT?

The CADRE database will link together **routinely collected, de-identified** data from health, care, and education.

Healthcare data

Education data → CADRE database ← Social care data

HOW COULD IT HELP?

- Researchers could **better understand** the healthcare needs of young people
- Service providers could find ways in to **improve local services**
- Healthcare professionals could then implement these findings to ensure young people get the right kind of help, **earlier**

WHAT WE WANTED TO KNOW

▶ What does the public think about the development of a linked database of de-identified, **multi-agency data**?

▶ Should we be using routinely collected data to, for example, identify young people who need support for their **mental health**?

▶ What types of projects or organisations should have **access** to the database, and who will decide this?

▶ How should we **inform and communicate** with the public about our project?

We carried out a series of workshops with the public to answer these questions

THE WORKSHOPS MAY-JULY 2022

4x workshops and 1x questionnaire

Young people 11-15 yrs
Young people 16-24 yrs
Parents and carers

Recruited through organisations for minority groups to **maximise diversity!**

Participants from Cambridgeshire, Essex, Birmingham and other parts of the UK

FINDINGS

Young person (11-15yr group)

> I *really love the idea*. I think it's really clever. The idea of being able to find all that information all in one place. I just think the idea of having it all in one place to help identify, like, patterns and stuff is just a really, really good idea and I think it will be *massively beneficial* for so many young people.

PARTICIPANTS WERE ENTHUSIASTIC ABOUT THE PROJECT
The public thought...

- Services don't talk to each other enough - the database could help collate **multi-agency data** into one place. Our participants were surprised this wasn't already being done!
- Database **access** decisions should be made by relevant experts and community representatives
- Different audiences should be **communicated** with in different ways, and specific efforts should be made to reach under-represented groups
- Information about the project should be **clear, visual,** and **easy to understand**

SHOULD MULTI-AGENCY DATA BE LINKED IN A SINGLE DATABASE?

84% AGREE
Over 16's (including parents)

77% AGREE
Under 16's

HOW DO YOU FEEL ABOUT THE PROJECT OVERALL?

90% SAY MORE POSITIVE THAN NEGATIVE
Over 16's (including parents)

89% SAY MORE POSITIVE THAN NEGATIVE
Under 16's

DO THE BENEFITS OUTWEIGH THE RISKS?

86% AGREE
Over 16's (including parents)

77% AGREE
Under 16's

Results from questionnaire (N=51)

LINKING DATA TOGETHER HAS SIGNIFICANT POTENTIAL TO HELP YOUNG PEOPLE

- Get young people the right kind of help, **earlier**
- Stop young people from **"falling through the gaps"**
- Can especially benefit young people who hide their symptoms or don't have adults in their lives who can spot **mental health symptoms**

IF DONE CORRECTLY, MEANING...

- Data must be interpreted carefully by a **trained professional**
- There should be **appropriate measures** to ensure there is enough accurate data to give a "full picture", and it is stored safely
- Public should be **informed** about research outcomes and implications

Parent

> In terms of policy and legislation in this country, the voice of the child is only becoming more and more important. *All children*, whatever their age, whatever their capacity, *should have a say* in things that are affecting them

THE PROJECT MUST EARN THE PUBLIC'S TRUST

✓ Researchers should use the data with the right *motivations and intentions* (i.e. to help young people's well-being)

✓ Researchers should also be able to demonstrate a track record of *competence*

Communication materials with the public should build trust by:

1. Emphasizing the benefits of the research

2. Being transparent about how and why the data is being used

3. Demonstrating that feedback from patient and public involvement has been incorporated

IN SUMMARY, PUBLIC SUPPORT DEPENDS ON:

Building **trust** between the project team, researchers, practitioners, and the public through clear and open communication

TRUST **DIVERSITY** **TRANSPARENCY**
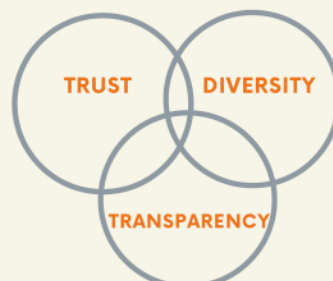
Involving of the public in the **co-creation** of the database, with **representation** from under-served groups

Acknowledging that the **risks** are not zero, but being clear how those risks are handled and what **benefits** justify them