Is open publishing really open to the public?
Co-designing public-facing materials to accompany published research

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Brighton, Southeast England

Thurso
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Ullapool
Inverness
Fraserburgh
Mallaig
Fort William
Aberdeen
Oban
Perth
Dundee
Scotland
Atlantic Ocean
Greenock
Glasgow
Edinburgh
Berwick-upon-Tweed
Galashiels
Campbeltown
Ayr
Dumfries
Alnwick
North Sea
Stranraer
Carlisle
Newcastle upon Tyne
Coleraine
Sunderland
Derry
Northern Ireland
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Belfast
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Hastings
Exeter
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Bournemouth
Portsmouth
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Newquay
English Channel
France
Plymouth
Penzance
Falmouth
Atlantic Ocean

Camberley
Woking
Dartford
Margate
Ramsgate
Guildford
SURREY
Maidstone
Farnham
Horley
Sevenoaks
KENT
Canterbury
Gatwick Airport
Tunbridge Wells
Dover
Ashford
WEST SUSSEX
EAST SUSSEX
Folkestone

Brighton

AKRIVIA HEALTH

Oxford, UK

https://akriviahealth.com/

"**5.1+** million de-identified patient records from some of the largest mental health providers in the UK".

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Who are Akrivia?

They are a company that works with NHS trusts specialising in **mental health and dementia care**.

Starting as a grant-funded organisation in 2009, Akrivia spun out from the University of Oxford in 2019 with support from the **National Institute for Health Research**.

Akrivia's mission is to improve patients' lives by **changing the trajectory of mental health and dementia research**, so we can better understand these conditions and provide better care.
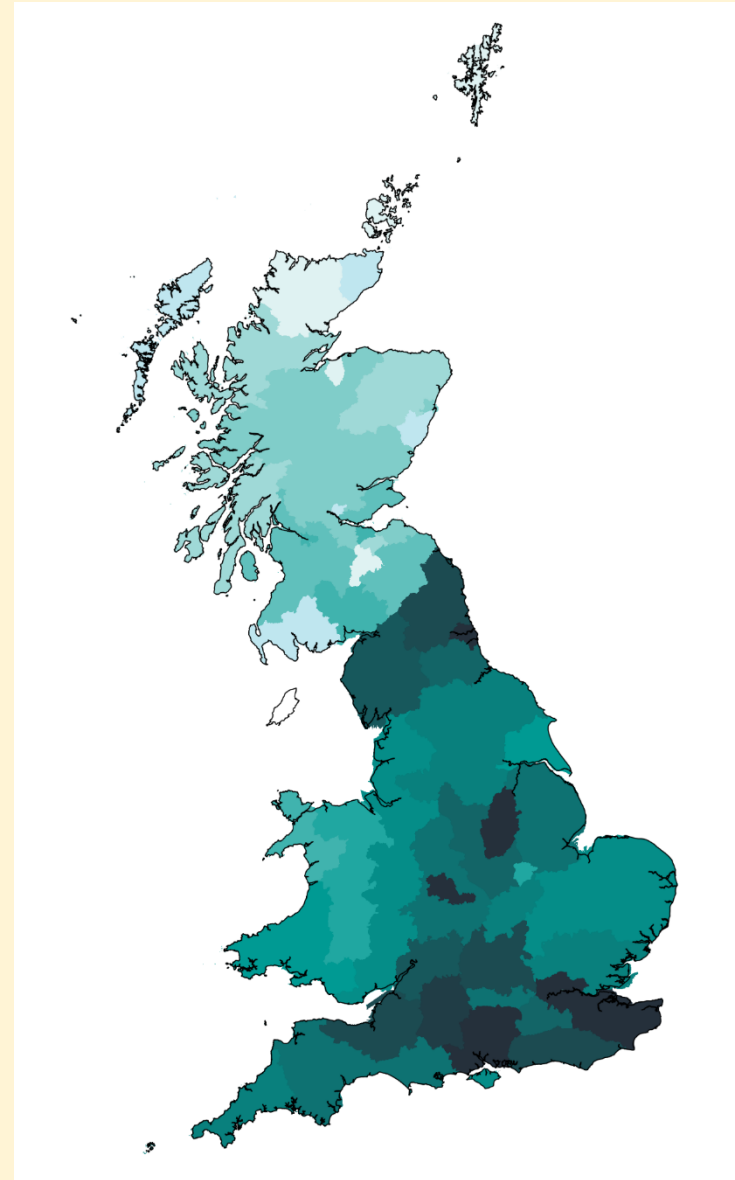
What do they do? Using Natural Language Processing to Structure Mental Health Clinic Data

| Select informative clinical notes | Annotate clinical notes | Train and fine tune AI model | Structured data | Analysis of data |

Patient, 78, male, retired constructions worker. Prior history of depression on his 50s with intrusive thoughts, which has been properly controlled with SSRI, citalopram 20 mgs daily. Complains now about memory deficits and confusion in the morning. MMSE today was 24 out of 30. Score was 27/30 on May 2015. Possible Alzheimer's.

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Concepts

drugs	symptom	score	diagnosis
citalopram	intrusive thoughts	24	depression
	memory deficits	27	Alzheimer*
	confusion		

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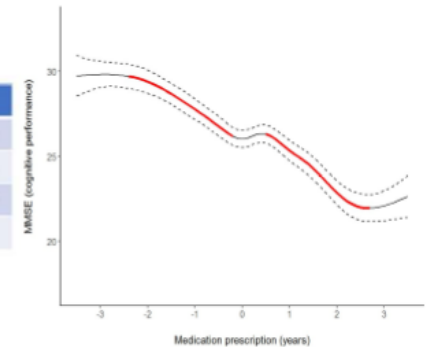
How Akrivia Supports Research with Sensitive Data

1

Project idea conceived

Researchers collaborate to discuss potential project

2

Project proposal created

Project scope, design and method defined

NO

3

Project proposal reviewed

Local oversight committee at NHS trust approve or reject the project proposal

YES

4

Project authorisa-tion entered

Access enabled to each approved

5

Search within de-identified data

Authorised project team can search approved NHS trust's de-identified data

6

Data Analysed

Analysis conducted on selected de-identified data which may lead to research publication

Akrivia database

Audit process

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How can we make Akrivia's research more OPEN?

Aims

- Consultation on content and layout of webpage
- Coproduction of an infographic
- Tailor information to patients, public and NHS staff

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Our Approach: Participatory Co-Design

Without making assumptions in advance:

- We invited 6 patient representatives from Southeast England to 2 sessions.

- Participants included people who were: deaf, dyslexic, autistic, had anxiety and chronic pain.

1. 2-hour Online Pre-Workshop Information-Giving Session

2. Face to Face day-long Workshop to design information materials

   - In London

   - Catering provided

   - Participants paid £25 per hour, travel expenses paid

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Workshop content

Pre-workshop session:

- Aims and ways of working together

- Who are Akrivia

- Understanding Akrivia's Data

- What is done with the data?

- What are the benefits of what Akrivia does?

- Reading through the current website content and discussing.

In-person workshop:

- Aims and ways of working together

- Recap

- Further discussion of website

- Design Infographic content and sharing:
  - What? Content
  - How? Format and visuals
  - Where? How to share it
- Infographic mock up and review

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Value for the NHS | These must be included in infographic

Akrivia offers services for the NHS, for free, in 4 domains:

Creation of structured data
from free text data enables easier and safer access to data for research

Point-and-click software in a secure data environment
where researchers and recruiting teams can ask questions and analyse data without needing technical skills in coding

Clinical trial recruitment
driving funding into NHS trusts in the Akrivia network and providing more opportunities for patients to get involved in clinical trials

Research support
provided to facilitate clinical audits and research programmes to effectively use the data
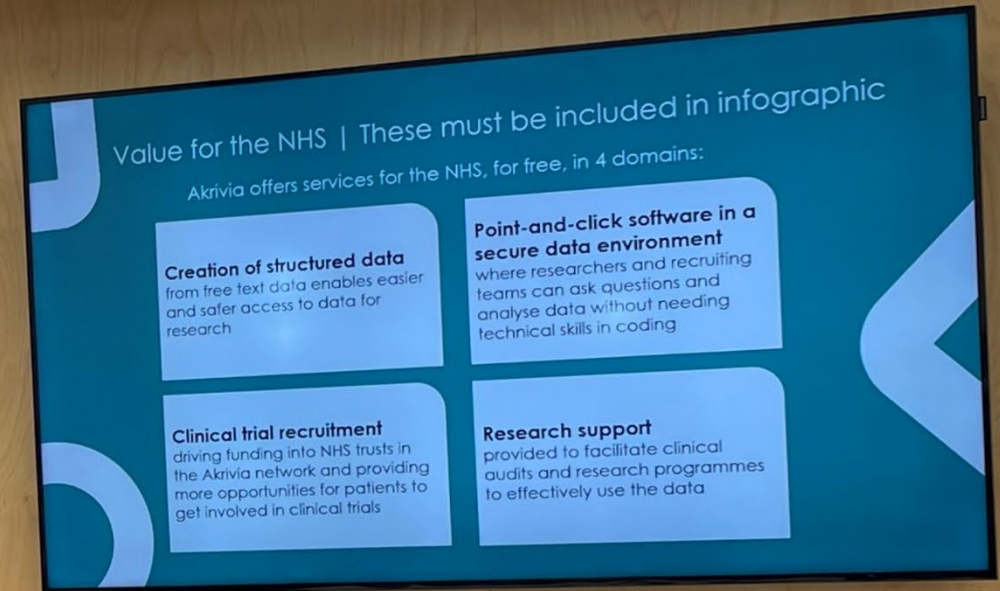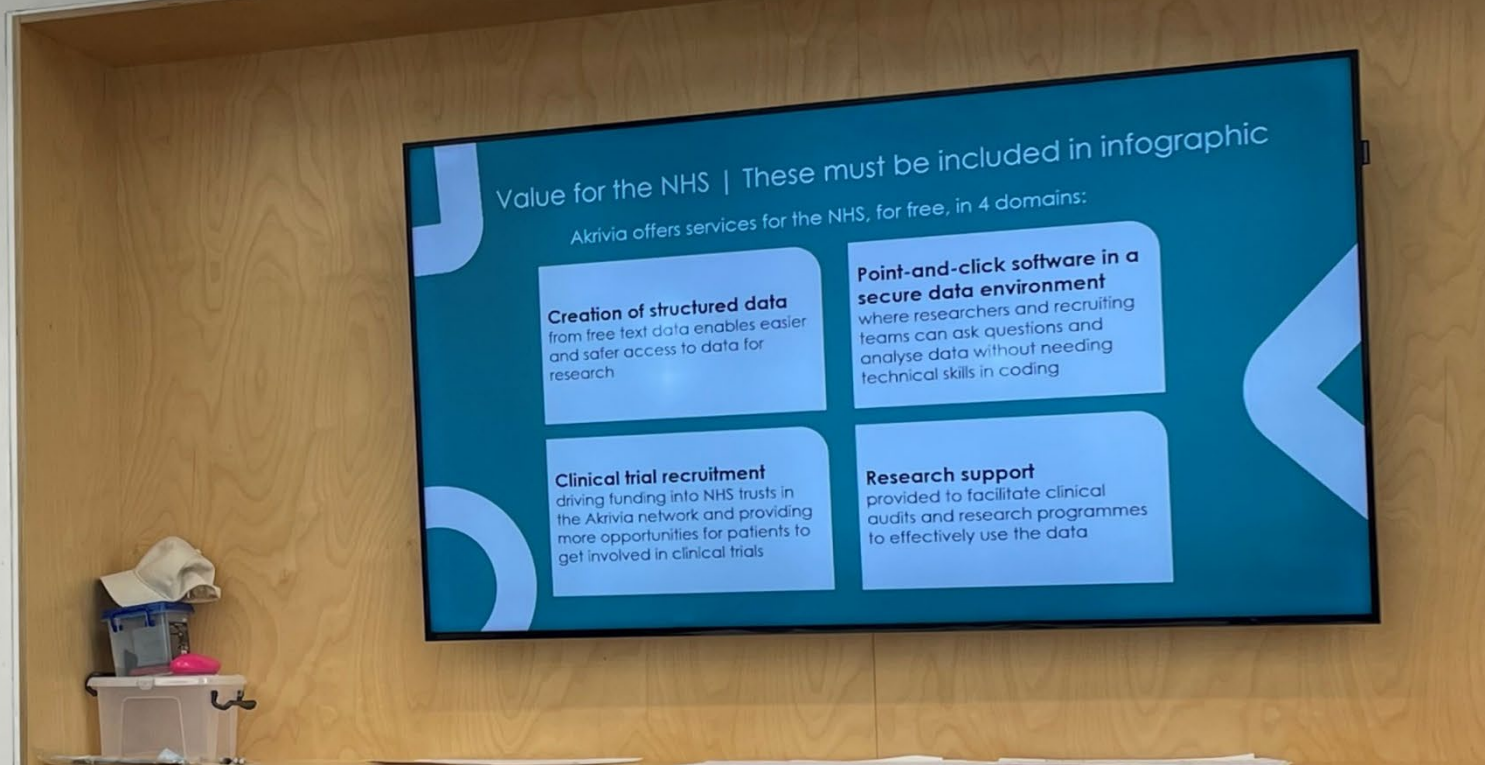
Task overview

For each task we will do the following four activities:

01
Generation
5 mins per task
After presenting each question, we will individually generate ideas on post-it notes.

02
Sharing
10 mins per task
The facilitators will then share the ideas with the group.

03
Discussion
15 mins per task
As a group we will then discuss and elaborate on the ideas, including grouping them together.

04
Prioritisation
5 mins per task
You will each get 5 points which you can award to ideas which you think are the most important. You can award multiple points to one idea.

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What participants said should be included in the infographic

NHS / Public Benefits

Why do it? What problem does it fix?

How does research improve patient care?

What types of health conditions are studied?

How will you address higher prevalence of problems for minorities?

Tell me about…

Privacy/ anonymity

Are you selling my data?

Security

How data is processed

Data Quality

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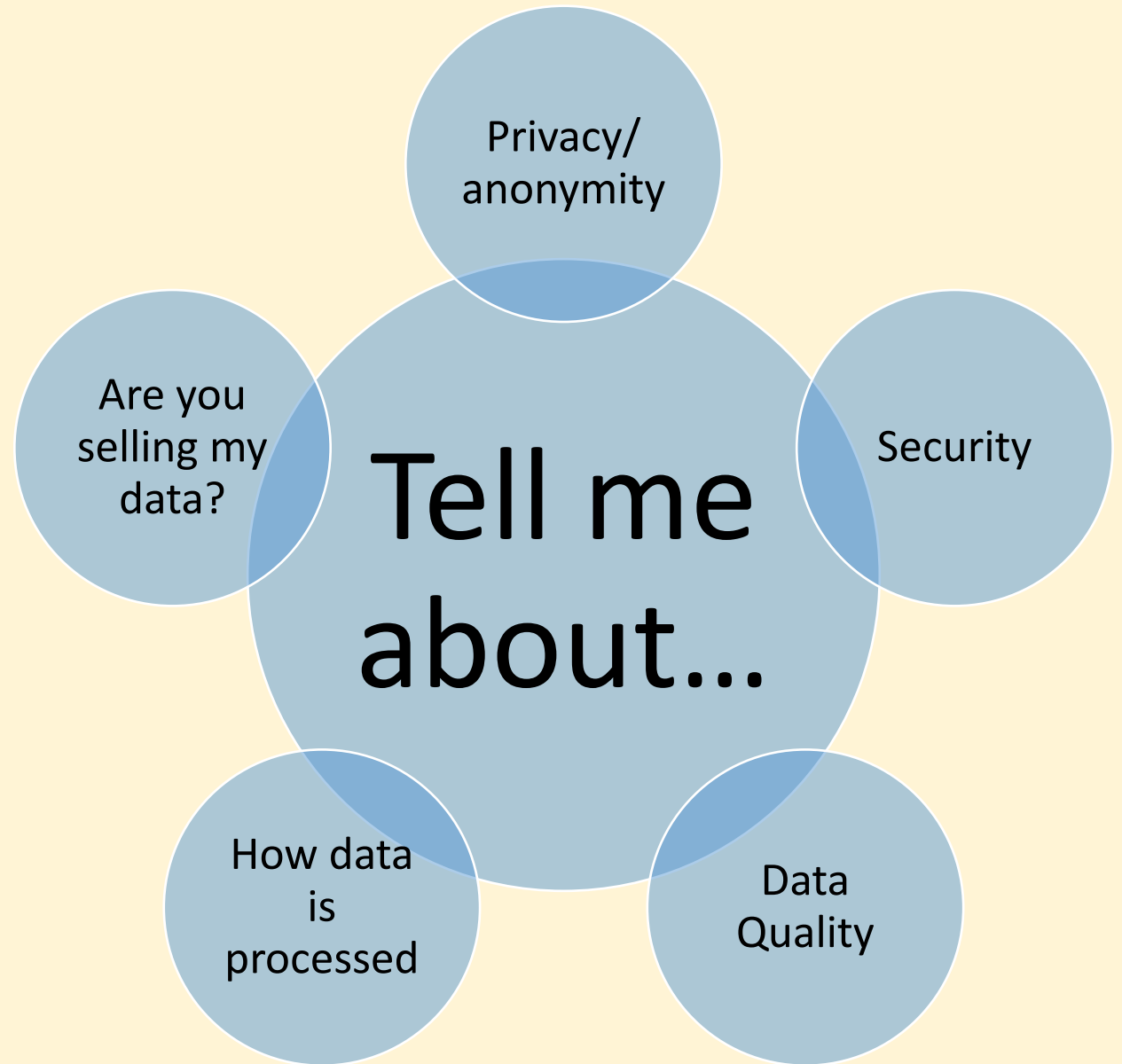
Show data streams & privacy levels in images

Use boxes and headlines to divide information up

Colours:
Bright but not too bold.
High, but not stark, contrast for accessibility.

AKRIVIA HEALTH

- Akrivia Health are a company who work with healthcare organisations to make structured data out of unstructured mental health and dementia data. This allows research to be done on real world data
- We understand that transparency is key for building public trust in the use of health data in research, therefore this infographic is to explain who we are and what we do
- Insert USP - how is Akrivia different to other people?
- We are able to offer their services free to the NHS by providing secure access to the anonymised data for private research companies to conduct research on

HOW DOES THE NHS BENEFIT?
We offer our services to the NHS free of charge. NHS data on mental health is often free text and difficult to analyse. We use Natural Language Processing to make structured data out of unstructured data such a doctors notes. We make this data available to the NHS in an easy to use format with intelligent filters. We also facilitate research projects into the data, and assist the NHS in setting up clinical trials.

have similar diagram to online workshop slides of the technical architecture - making it clearer, where Akrivia come in, where NHS/uni's come in etc. and to include info of how data is anonymised

HOW DO WE DO IT?
We are provided access to data by the NHS. We use articificial intelligence to restructure the data into tables. We also de-identify data to make it anonymous.

PRIVACY AND SECURITY
Any data held by Akrivia is stored in best-in-class cloud environment called Amazon Web Services. This means any data is safe, private and only accessible by approved individuals.

Like image of health improving - mental and physical - impacting whole person/communities

WHAT DO WE ACHIEVE?
1 in 8 people are living with a mental disorder, yet just 4.6% of health research focuses on mental health. Because mental health data is difficult to work with and is highly sensitive, we reorganise the data to make it easy to work with.
Add something about: Talk about holistic health data, research solutions created, opportunities for patients.

SCAN ME

What does my data look like?
Scan the QR code to have a look at some example data.

Diagrams and Images – attractive, clear, cheerful. Avoid meaningless ones

Include a link to simple website and data platform examples so people can find out more

First infographic mock-up made in workshop

AKRIVIA HEALTH

- Akrivia Health are a company who work with healthcare organisations (such as NHS trusts) to support mental health and dementia research being done on data collected as part of patient care.
- We are unique in our focus on mental health and dementia: according to the World Health Organisation, 1 in 8 people are living with a mental disorder, yet just 4.6% of health research focuses on mental health.
- We are able to offer our services for free to the NHS by providing secure access to an anonymised version of the healthcare data for private research companies to conduct research on. Data is not sold, only accessed.
- We understand that transparency is key for building public trust in the use of health data in research, so we have co-developed this infographic with a group of patients to explain who we are and what we do.

HOW DOES THE NHS BENEFIT?

We began in the NHS, so we provide our services to the NHS free of charge. Because mental health data is difficult to work with and is highly sensitive, we reorganise the data to make it easy to work with. We make this data available to the NHS in a secure research platform with intelligent filters. We also support good use of the data in research projects, and assist the NHS in using this data to identify patients suitable for clinical trials.
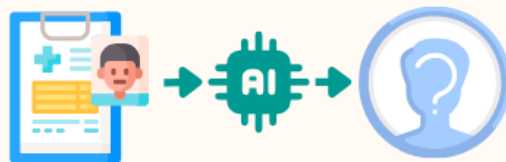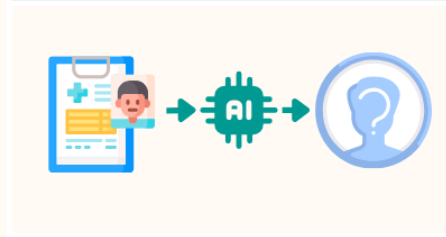
HOW DO WE DO IT?

The NHS grant us to securely copy healthcare data they choose. We de-identify the data, removing information like patient names. As a lot of mental health data is free text, such as doctors' notes which are hard to use in research, so we use artificial intelligence to structure free text data into tables. We then provide tools and support to use this data in research.

WHAT ABOUT PRIVACY AND SECURITY?

Any data held by Akrivia is stored in best-in-class cloud environment called Amazon Web Services. This means any data is safe and only accessible by approved individuals. By structuring free text data into tables, we are minimising the need for NHS researchers to read private patient information.

WHAT DO WE ACHIEVE?

Our approach to improving access to healthcare data supports a more holistic view of patient health, while improving patient privacy. The data is actively used by NHS teams to conduct research to improve the quality of their services, such as addressing inequalities in healthcare.

What does the data look like?

Scan the QR code to have a look at some example data.

SCAN ME

Second infographic mock-up made following feedback

AKRIVIA HEALTH

Who are "Akrivia Health" and why do we exist?

- According to the World Health Organisation, **over 12%** of the world's population is living with a mental health condition*, **yet less than 5% of health research focuses on mental health**. Akrivia Health exists to change this.

- With an exclusive focus on mental health and dementias, we work with healthcare organisations (such as the NHS) to support research being conducted on data collected as part of patient care – in order to improve treatments and patient lives.

- We understand that transparency is key for building public trust in the use of health data in research, so **we have co-developed this infographic with a group of patients to explain who we are and what we do.**

* World Health Organisation. (2022). World Mental Health Report.
https://www.who.int/publications/i/item/9789240049338.

**World Health Organisation. (2020). Mental Health Atlas 2020.
https://apps.who.int/iris/handle/10665/345946

How does the NHS benefit?

We provide our services to the NHS **free of charge.** Because mental health data is complex and highly sensitive, we remove personal information and reorganise the data to **make it easy to work with.** We then share the reorganised data with the NHS in a secure research platform with intelligent filters.

We also help NHS researchers to understand and use the data for research, and help the NHS to find patients who might be a **great fit** for different types of research.
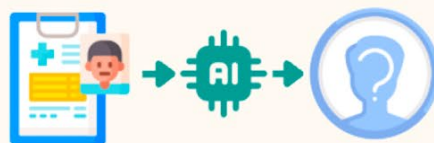
How exactly do we do this?

The NHS lets us securely copy healthcare data. We remove personal information like patient names and addresses. As a lot of mental health data is handwritten, such as doctor's notes, this can be hard to use in research.

We therefore use artificial intelligence within a secure environment to sort this information into tables, which makes it much easier for researchers to use **without them having access to private information.** We then teach NHS researchers how to use it.

What about privacy and security?

All data held by Akrivia is **safely stored in a secure cloud environment** hosted by Amazon Web Services (who have no visibility or ownership of this data, as it has been encrypted). This means that the data can only be accessed by approved individuals. Our Information Governance and IT Security teams also work hard to proactively ensure our system is secure at all times.

What do we achieve?

Through this work, we are able to provide a **fuller picture of patient health** while improving patient privacy. This enables NHS teams to conduct research to improve the quality of their services, such as **addressing inequalities in healthcare.**

What does the data look like?

Scan the QR code to have a look at some example data.

SCAN ME

Generalisable lessons for making open science infographics for the public

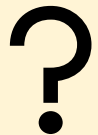- **Design:** Cut back the **text** to the bare minimum

- **Design:** Go for simplicity and visual clarity, not clutter/distraction.

- **Choice of content:** What is important to you (the scientist) may not be as important to the public

- **Clarity:** Words which have obvious meaning to you may be ambiguous to the public

- **Purpose:** Start with the WHY

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Participant feedback

- Having the online session was beneficial as it allowed the complex content to be delivered with time to process before the interactive co-design.

- Participants agreed that there is a need to communicate with the public about the work which is going on. It is important to communicate this in a way which is concise and digestible

- It was a strength to have the Akrivia team there. They are the people who own, write and run the website. Therefore, they could respond in real-time as to how to change it.

- Having a quick turnaround and something visual resulted in high engagement, as it appeared to make PPI members feel like their voices were actually influencing the output.

"it wasn't half as bad as I thought it was going to be"

- Feedback from one satisfied participant ☺

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Thank you for listening

Any Questions?

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