

Enhancing Transparency, Awareness, Accessibility of Healthcare Data Access for Research: the iCARE website redesign project

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BACKGROUND & AIM

The iCARE (Imperial Clinical Analytics, Research and Evaluation) Secure Data Environment (SDE) is committed to further enhancing its website to improve awareness of processes and procedures for appropriately accessing healthcare data for research. Our iCARE SDE is a cloud-based, big data analytics platform that offers clinicians, allied healthcare professionals, researchers, and data scientists access to large-scale, curated project-defined data for research via a HRA Research Ethics Committee compliant application and approval process, with lay partners embedded at each step to ensure patient and public benefit. By improving our website for researchers, patients, and the public, our ongoing work aims to further increase the awareness, accessibility, and transparency of the iCARE processes and use of healthcare data for research.

OBJECTIVES

- The primary objective was to review and enhance the content of the iCARE website, aligning with The Alliance Transparency Standards 2-6:
- Improve transparency of the application process and criteria, aligning with five safes framework (Standard 2)
 - Clearer and accessible website navigation (Standard 3)
 - Work with lay partners and researchers to ensure content is clear and transparent (Standard 4)
 - Comprehensive review of website content and FAQs, with ongoing review (Standard 5)
 - Transparency of data use and auditing, with accessible and user-friendly project lay summaries (Standard 6)

APPROACH



OUTPUTS

- The updated iCARE website enhances accessibility, clarity, and transparency through feedback from community partners and researchers. It now contains:
- **For researchers** - detailed steps streamlining the application process, reducing communication delays, and providing applicants with clearer expectations, and clarifies the analysis tools available in the iCARE SDE.
 - **For the patients and the public** – clear descriptions of the rigorous data access requirements and processes that researchers follow, and the measures taken to ensure the ethical and secure access and use of healthcare data for research in the iCARE SDE.
 - We also integrated an educational guide, **Navigating Digital Health**, on how data and artificial intelligence is used in healthcare and research, which was co-developed by lay partners for researchers and the public.

iCARE facility



Information for researchers



Information for patients and the public



iCARE high performance analysis environment

The iCARE Environment is a cloud-based, big data analytics platform. It allows clinicians, researchers and data scientists to access large-scale, highly curated databases for the purposes of research, clinical audit and service evaluation. The iCARE Environment has a number of data analysis tools available, such as Python, R and STATA.

The iCARE Environment sits entirely within the Imperial College Healthcare NHS Trust (ICHT) infrastructure. This, combined with the iCARE Team's robust method of data de-identification, make the Environment an incredibly secure platform. The fact that it can be accessed remotely using the Trust's Virtual Desktop Infrastructure means that researchers can perform their work remotely, and are therefore not constrained by location.

Linkage to whole systems integrated care (WSIC) data

As the iCARE Environment holds both ICHT data and Northwest London WSIC data, linkage can be performed between the two datasets all whilst keeping the data completely de-identified. This allows researchers to examine both primary and secondary care data for patients in the region, thus broadening the spectre of research questions that can be answered.

New database curation

The iCARE Environment allows for the curation of new, bespoke patient datasets. By expanding the datasets that are available to researchers on the Environment, the iCARE team can widen the scope of potential research.

Information for researchers



Explore and get access to data

Access for Imperial College Healthcare NHS staff

Staff accessing information within the Imperial College Healthcare NHS Trust and iCARE Environment can request access to the Metadata Catalogue. To request access please email us.

Publicly available datasets

Our curated datasets are available via:

- Details of the [iCARE Data Model \(VLS\)](#)
- Details of the [Whole System Integrated Care database](#)
- Details on our [NIHR Health Informatics Collaborative datasets](#)
- [NIHR Innovation Gateway](#)

Transparency

We are aiming to make information about the datasets (known as metadata) we hold for use in research available in the public domain as soon as possible. We are working through an automated process at the current time to ensure we can meet the Trust's rigorous security rules.

Patients and the public frequently asked questions



Patients and the public FAQs

[Expand all](#)

Are private companies going to profit from using my data?

Are you selling data?

As a patient or member of the public, what's in it for me?

Navigating digital health



Learning about data and AI has never been this easy. From apps monitoring our blood sugar to clinical researchers asking us about our personal information, the world of data in healthcare can be scary. We are here to help.

Why we have built the website

- **Education for everyone** – Our content was created in collaboration with members of the public with the support of experts. If this is your first time learning about data or artificial intelligence, you are in the right place.
- **Learn your way** – The guide has been written for you to use in any way that suits you. You can read it online or print it and read it like a booklet. We have podcasts, animated videos and illustrative examples throughout enhance your learning.
- **Take your time** - We know you are busy. Our content is designed to be absorbed in small chunks.

Types of data used in research

We will now learn about data in healthcare research. Data may be joined up, shared or created to help us with research in healthcare.

Is the data joined up or linked to other data?

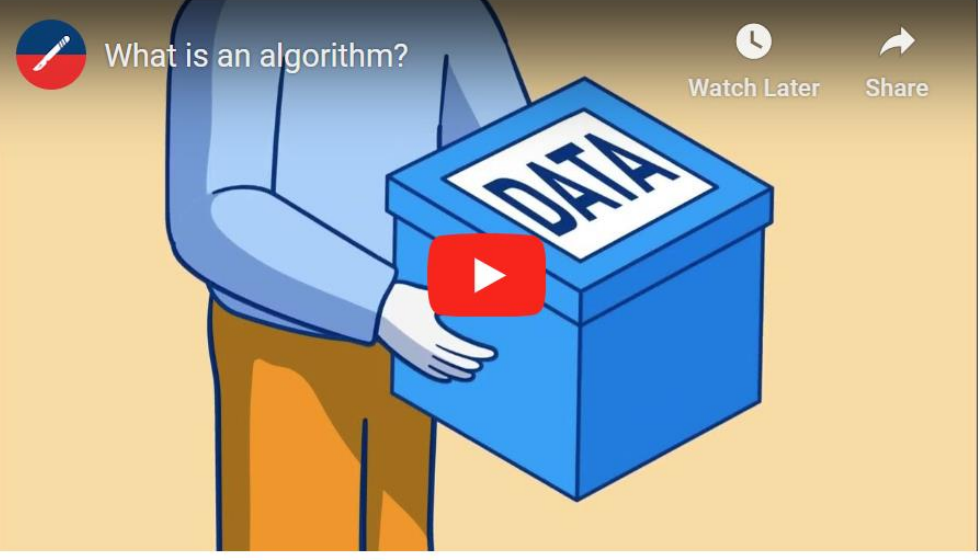
Linked data involves joining different pieces of data to each other. This is really important when we need to better understand patients, their health and their care needs. Linked data can help us to have a deeper understanding of people's health.

For example, we find all the medical records of people who have had lung cancer. We then join that to information about where they live. This could be helpful. It may allow us to investigate if where you live has an effect on your chance of getting lung cancer. It may also allow us to understand if the hospital nearby have enough lung cancer treatment services to look after the patients in that area. We may also want to link data from patient questionnaires to data about their illness or where they received care.



Video: What is an algorithm?

We now know that AI is built using algorithms, but what exactly are they? Watch this two-minute video to find out.



IMPACT

We anticipate that the redesigned iCARE website will improve awareness, clarity, and access to healthcare data for research by meeting The Alliance Transparency Standards and involving community partners and researchers in its redesign.