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Improving transparency of processes for accessing ICNARC data for research purposes

Caitlan Wolsey[1], Alexander Bondarciuc[1], Esther Ansah-Asamoah[1], James Doidge[1], and David Harrison[1]

[1]Intensive Care National Audit & Research Centre (ICNARC), London, UK

Background

The Intensive Care National Audit & Research Centre (ICNARC) is an independent, not-for-profit, scientific organisation. Our mission is to help improve the quality of critical care through audit, research and education conducted with and in the interests of patients and those who care for them.

ICNARC coordinates national clinical audits in adult critical care and in-hospital cardiac arrest and undertakes multicentre research studies through our Clinical Trials Unit.

ICNARC has recently invested in a full website redevelopment which provided a platform to make improvements against the following Pan-UK Data Governance Steering Group Data Access Transparency Standards [1]: Open application form and guidance (Standard 1); Transparent application process and criteria (Standard 2); Consider target audience (Standard 4); and Transparency of data use and auditing (Standard 6).

Introduction

Our primary objective was to improve our data application processes and our data use register.

The purpose of this was to ensure transparency for those applying to use ICNARC data, to ensure both the process and the public benefit of use of our data can be understood by patients and the public, and to ensure the public have a mechanism to provide feedback.

Methods

We developed new and improved data access forms, along with supporting documents, guidance and tools for the website, ensuring these were clear and transparent for those applying to use ICNARC data.

We consulted with patients and the public about the content they felt should be included, particularly within the updated data use register, and developed this with their input. The updated data use register supports regular updates and publishing of lay summaries, technical summaries, and public benefit statements.

To make the process clearer, we worked with patients and the public to design an infographic to detail how ICNARC data are used. We also incorporated case studies of public benefit and a feedback form for members of the public.

Results

We have used our website redevelopment as a platform to improve how we communicate our data services both to those applying to use ICNARC data, and to patients and the public.

The new data services area of our website (https://icnarc.org/data-services/) ensures that it meets the Transparency Standards and has allowed us to communicate how ICNARC data are used in a clearer and more effective way.

Conclusions

Our updated website has received positive feedback patients and the public. We anticipate the developments will continue to improve access to data and ensure transparency in the process and the use of ICNARC data.

References

1. Macaulay Y, UK Health Data Research Alliance, Pan-UK Dat Governance Steering Group, HDR UK Public Advisory Board, Five Safes Action Force. Pan-UK Data Governance Steering Group Data Access Transparency Standards. Zenodo 2023; https://doi.org/10.5281/zenodo.8262453

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