

The Royal Marsden BRIDgE TRE Transparency Project

Abstract

The BRIDgE platform is the Royal Marsden's Trusted Research environment, which aims to transform clinical practice and improve outcomes for patients by enabling data analytics and AI development using real-world cancer data within secure, collaborative, cloud-based workspaces. This project evaluated the BRIDgE website against the new UK Health Data Research UK Transparency Standards, leading to changes to implement the following: Open Access Application form and Guidance (Standard 1), Transparent Access Process and Criteria (Standard 2), Clear website navigation (Standard 3), Consider Target Audience (Standard 4), Regular Review of Website Content (Standard 5), and Transparency of Data Use and Auditing (Standard 6). Our primary aim was to improve the content and sign posting so that patients and researchers would be better informed, resulting in increased website traffic and requests via our Contact Us page.

Information about the transparency project and the updates to the website were presented to a patient panel for feedback and a leaflet was co-designed with patient representatives. Changes included a new BRIDgE home page, which was re-designed to make navigation simpler and clearer (see Figure 1), improved signposting, so both patients and researchers were aware of the sections meant for their consumption, such as the new Researchers' Frequently Asked Questions (FAQ) page, which contained detailed instructions on how to request data, the governance workflow and costing structure (see Figure 2). Finally, we expanded the Research Projects and Publications page (see Figure 3), and added a Case Study from one of the Researchers, detailing their personal experience on the platform.

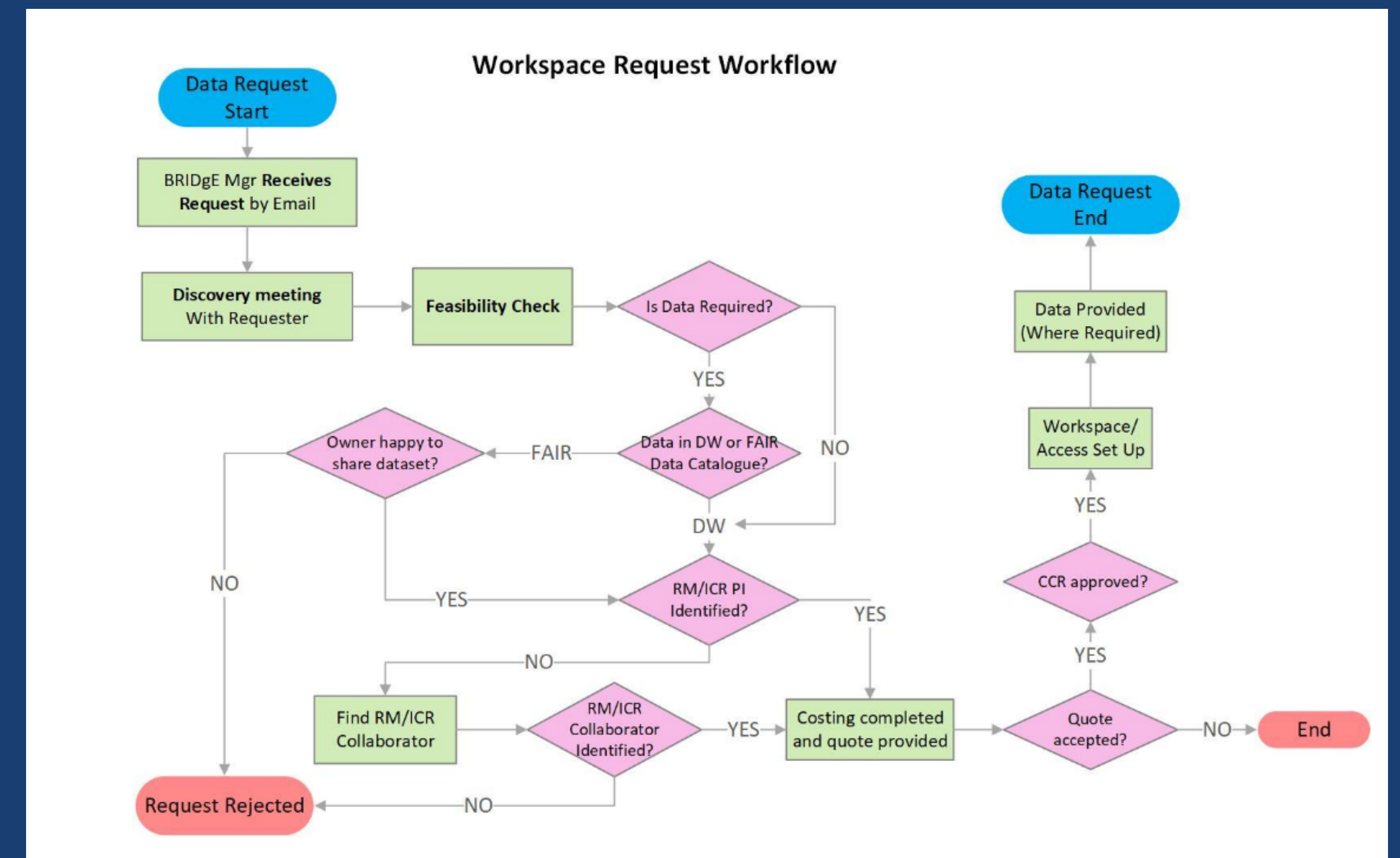


Figure 2: FAQ Page Data Access Workflow

Figure 3: Research Projects and Publications Page

Impact of this project

We anticipate that the impact of this project will be that patients will be more informed about Trusted Research Environments in general and what BRIDgE specifically enables in terms of innovative research and data security, leading to greater assurance for patients that their data is being used securely for their benefit. Researchers will get the benefit of the new FAQ page, which includes a great deal more information than was previously available about the platform, the data access methods, and the governance processes. We envisage that this will lead to more traffic on the site and a greater number of requests for information and workspaces via the Contact Us page. Finally, the patient leaflet will be the first time that patients in our waiting areas will be able to read about research informatics at the Royal Marsden and the work of our data scientists, in paper form.

The resources developed using the funding from the transparency project are the revamped BRIDgE website <https://www.cancerbrc.org/BRIDgE> and (soon to be published) patient leaflet.

Figure 1: Home page