

Improving Transparency of NHS Trust uses of data for Research Purposes

Claire MacDonald (Head of Clinical Data Science Unit, MFT Safe Haven), Dr Anthony Wilson (Group Research Informatics Officer, MFT Safe Haven), Adam Shepphard (Research Communications Manager, MFT)

AIMS

The Clinical Data Science Unit (CDSU) and Research Communications Department (RCD) of Manchester University NHS Foundation Trust (MFT) to collaborate and develop a public-facing website which meets the Data Transparency Standards published by the UK Health Data Research Alliance.

BACKGROUND AND INTRODUCTION

In 2022, the UK Health Data Research Alliance published a Data Transparency Standards white paper (UK Health Data Research Alliance, 2022). This guideline encourages organisations using health data for research to take an approach which creates increased transparency around how this data is utilised and what the proposed benefits of projects may be.

The guidelines are split into six themed standards encouraging organisations to; publish their application forms and application process, have a clearly marked website which considers their target audience and is regularly reviewed, and to publish a register of projects which have used their data.

MFT CDSU operates a Safe Haven for research using health and social care data which includes a public panel for reviewing project applications. As such, it was felt that adopting the Data Transparency Standards would be a crucial step in furthering our public involvement and transparency of operations within the service.

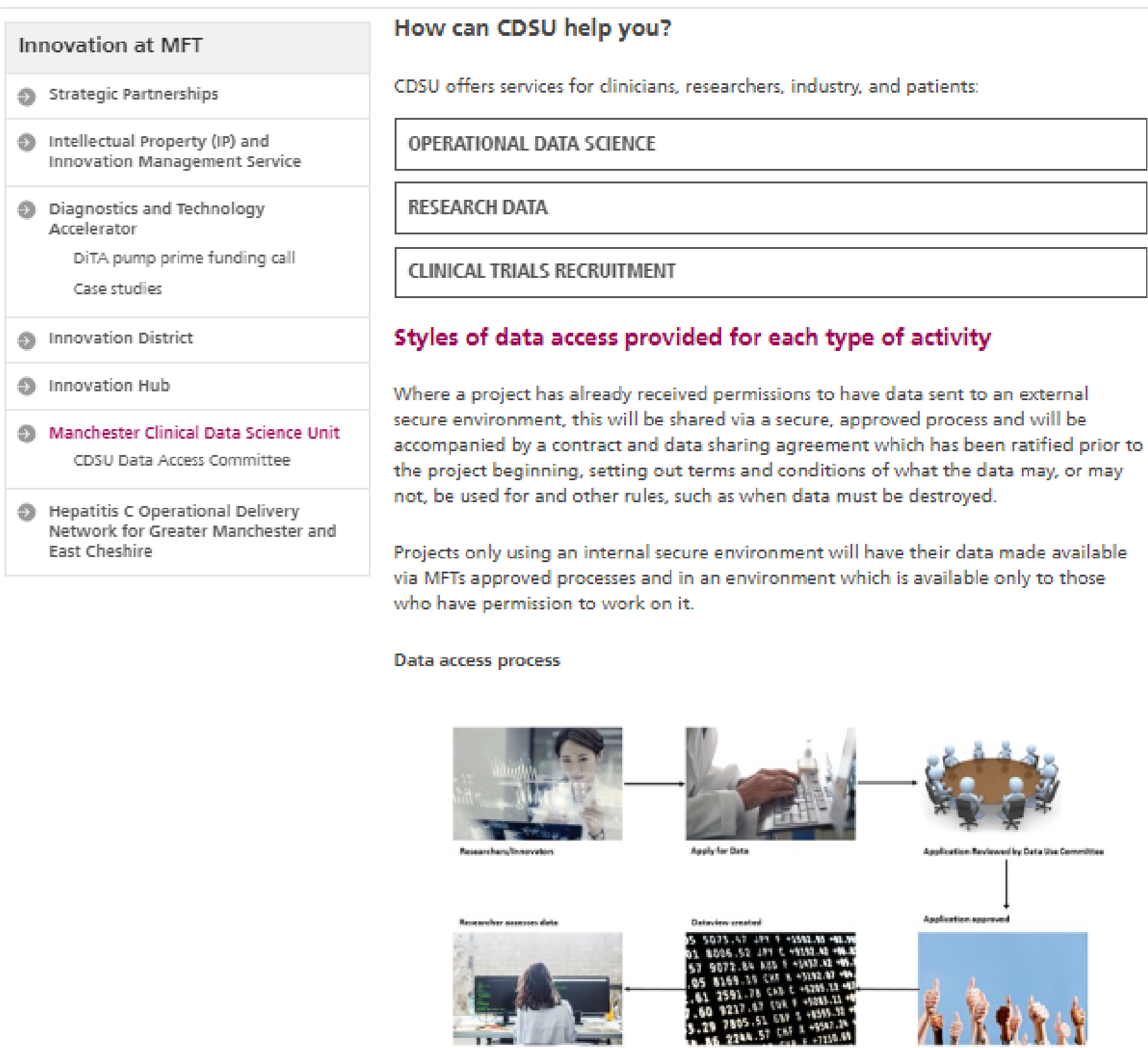


Figure 2: Main page sections

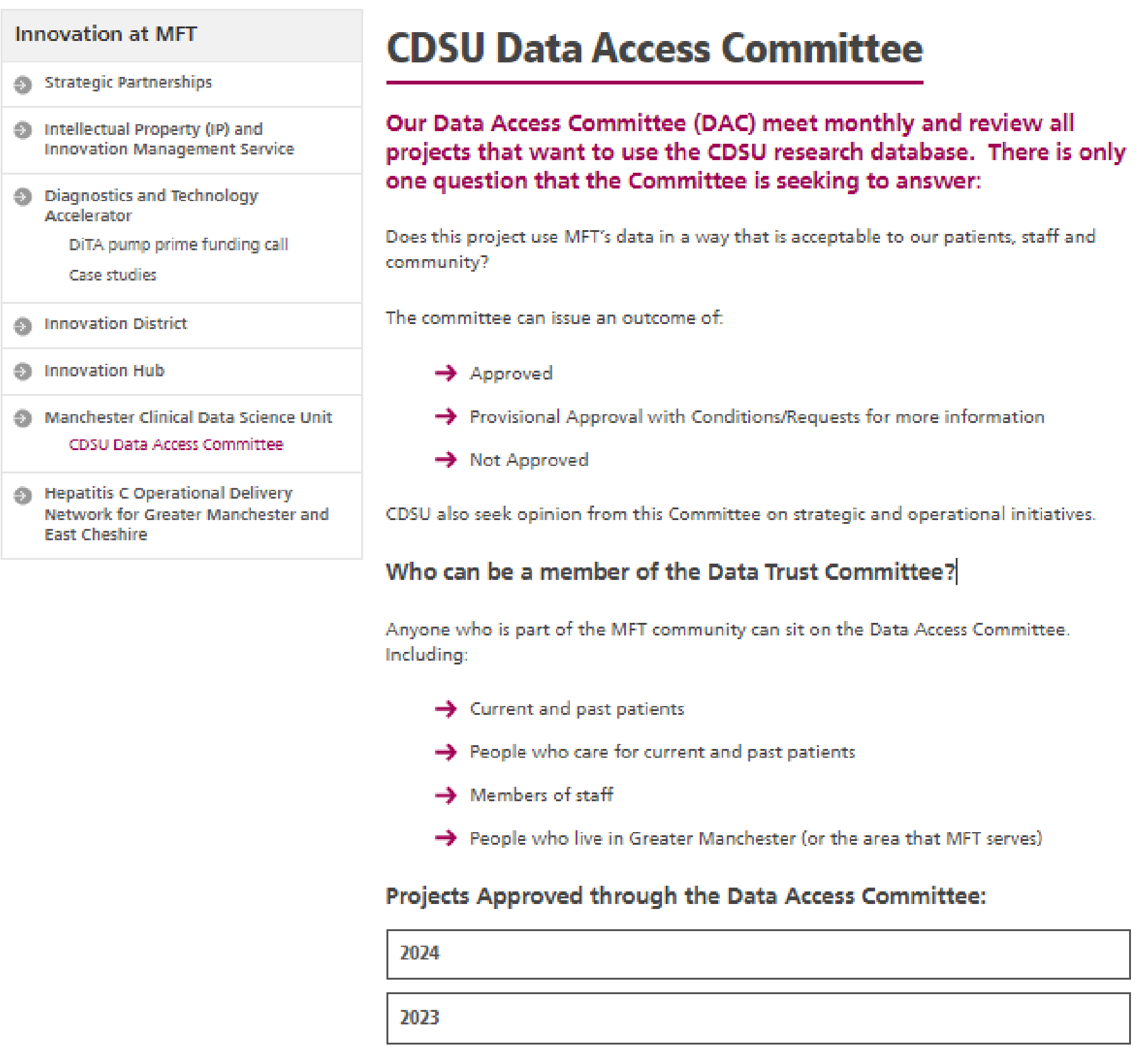


Figure 3: DAC page sections

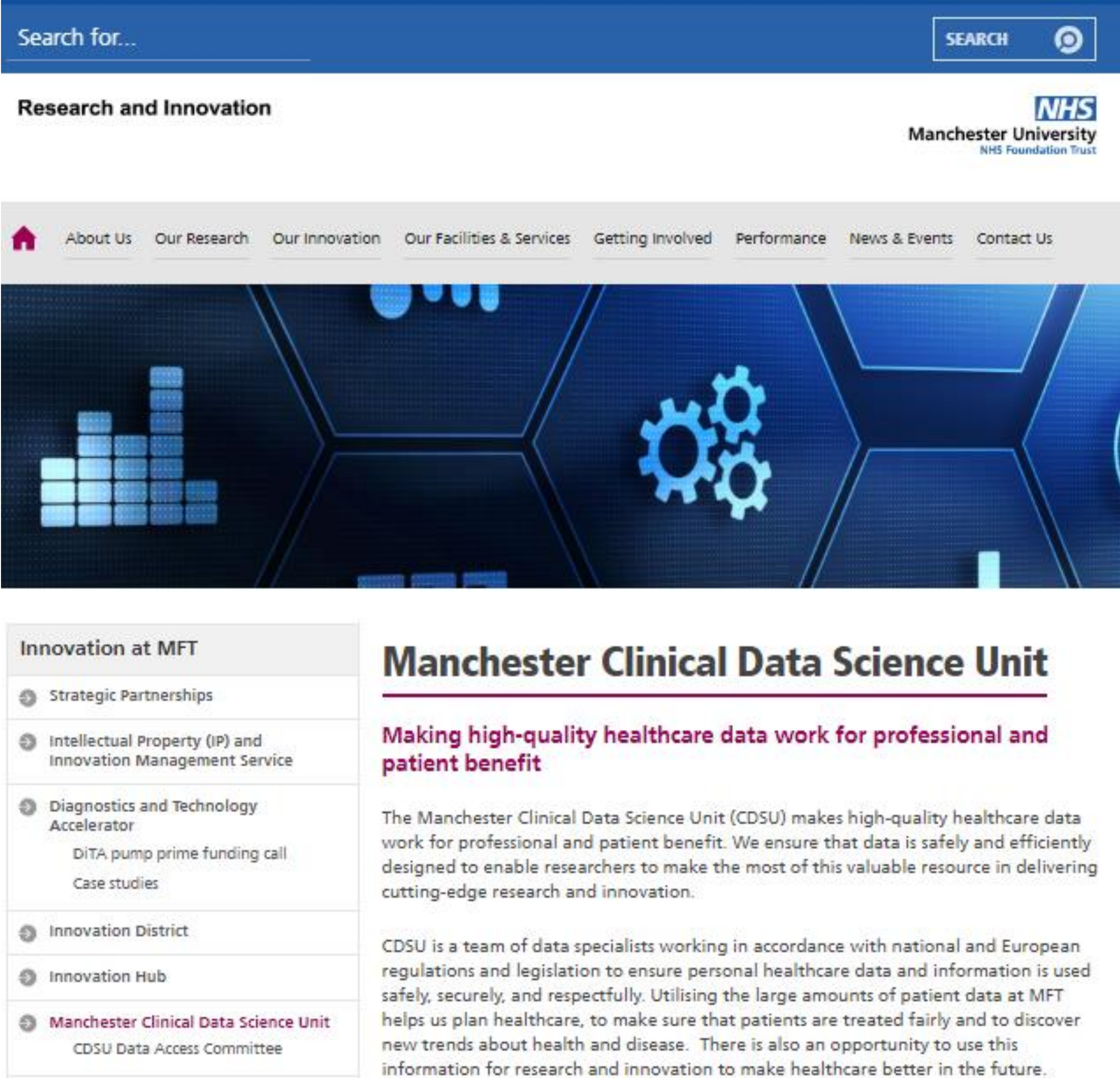


Figure 1: CDSU website main page

APPROACH

CDSU and RCD adapted the already existing MFT intranet site to be an outward-facing public website (Figure 1), hosted on the MFT Research and Innovation website and accessible for two main audiences; public citizens and researchers. Existing processes and descriptions were adapted to try and meet the Data Transparency Standards in the best-fit way, working within the constraints of existing Trust site infrastructure and publishing rules, and content was reviewed by the RCD. Agreed content and website structure was then sent to the CDSU Data Access Committee (DAC) for review and approval before publishing on the website.

OUTPUTS

A public-facing website was published near the end of March 2024 with dedicated sections for CDSU workstreams (Figure 2) of Operational Data Science, Research Data and Clinical Trials Recruitment and a direct means to contact CDSU. The DAC has its own dedicated tab (Figure 3) explaining their role in reviewing projects, listing all projects which have received approvals so far.

CONCLUSIONS and LESSONS LEARNED

The website is published (<https://research.cmft.nhs.uk/innovation-at-mft/manchester-clinical-data-science-unit>) but will still require some further edits to the content. There is also a planned change for the MFT content management site so there may be some temporary disruption while this move is enabled. There is an existing schedule in place to review the site content for relevance every 6 months.

There are constraints on content and structure due to the MFT comms rules on publications and the content management site MFT use. This meant that we are unable to easily meet certain criteria in the Data Transparency Standards, such as structuring the content in a particular way or providing a downloadable copy of files.

The CDSU website will be a useful engagement tool, encouraging more interest in the service and types of project undertaken and we are working to make more information available.



ACKNOWLEDGEMENTS

Clinical Data Science Unit Data Access Committee, Manchester University NHS Foundation Trust reviewed content and structure of the website. This work was supported by the Health Data Research Alliance and Health Data Research UK (insert award reference number), an initiative funded by UK Research and Innovation, Department of Health and Social Care (England) and the devolved administrations, and leading medical research charities.

REFERENCES

UK Health Data Research Alliance (2022), Improving transparency in the use of health data for research: Recommendations for a data use register standard, <https://zenodo.org/records/S902743#.ZDgTHcrMKUn>
MFT Clinical Data Science Unit (2024), <https://research.cmft.nhs.uk/innovation-at-mft/manchester-clinical-data-science-unit>