

Project Outcomes template

Name of project	<i>Fabry Disease Symptom Tracker App</i>
Project partners	<i>Amicus Therapeutics UK Operations and Salford Royal NHS Foundation Trust (Part of Northern Care Alliance).</i>
Duration	<i>This project was due to run for 15 months after the commencement date in December 2022, however due to severe delays the project completed in May 2025</i>
Project overview	<i>Project aims and objectives:</i> <i>The aim of the Project was to develop a digital service, through a third party, that tracks the symptoms of Fabry patients. Reported symptoms would feed into each individual patient's Electronic Patient Record and trigger an activity with the inherited metabolic disorders service (or associated clinical service) to improve patient reported outcomes via threshold monitoring and reporting.</i>
Project outcomes	<i>Unfortunately, due to multiple reasons the project was not able to achieve its planned outputs despite the best efforts of all of the project team involved at both Salford and Amicus.</i> <i>The app was developed and ready to launch, however, the work to get to this point took more time and effort than any of the team members could have anticipated. The app was then not able to launch as the company involved was liquidated.</i> <i>As a team we could not find a suitable alternative and took the decision to close the project</i>
Conclusions and learnings	<i>When using a third party to support with the development of technology it can be challenging, and the project team has less control over what can be achieved. The company within the collaboration was already partnered with The Northern Care Alliance however the project still faced challenges trying to implement the work. If we were to implement the project again, we would consider the possibility of developing the functionality of the NHS app and to have representation from any third party on the project steering group.</i> <i>We have learnt from other projects that some patients do find these apps useful, however not all patients are able to access them, unfortunately we have not been able to conclude either way from the current project.</i>
References	<i>Digital app for patient monitoring found helpful in small study</i> <i>Smartphone app for monitoring Fabry disease found to be helpful: Study</i>