

## EXECUTIVE SUMMARY

### A Collaborative Working Project between Bristol-Myers Squibb Pharmaceutical Limited ("*BMS*"), and Manchester University NHS Foundation Trust ("*Manchester University*")

Name of Project:	Title: A Prospective Hypertrophic Cardiomyopathy Registry for Northern England and Scotland
Project Overview:	This Project seeks to address the need for a standardized registry of hypertrophic cardiomyopathy (HCM) patients in the UK as a pilot across several sites in Northern England and Scotland. Registries are crucial for advancing our understanding of HCM and its treatment. They provide large-scale, real-world data that can inform clinical practice, guide treatment decisions, and shape future research. Existing registries, such as the Sarcomeric Human Cardiomyopathy Registry (SHaRe) have provided valuable insights into the natural history, genotype-phenotype correlations, and long-term outcomes of HCM. The registry's findings will not only benefit patients in the target region but also contribute to the global knowledge base on HCM management, potentially influencing future diagnosis/management guidelines and research directions.
Project Objectives:	<p>The principal objective of this Project is to optimise care for people with obstructive HCM (oHCM), an Inherited Cardiac Condition (ICC), by supporting the creation of a comprehensive registry of HCM patients in the north of England and Scotland. This collaborative working aims to assess the feasibility and to setup a new registry with the ultimate purpose of enabling Manchester University to collect and analyze real-world data to assess the long-term safety, efficacy, and outcomes, including treatments, thereby improving patient care and contributing valuable insights into HCM management.</p> <p>Objectives</p> <ol style="list-style-type: none"> <li>1. To assess the long-term outcomes/management of standard of care therapies for oHCM patients in real-world clinical practice in northern England and Scotland.</li> <li>2. To identify factors influencing treatment response and outcomes.</li> <li>3. To evaluate the impact of standard of care therapies for oHCM patients on quality of life, healthcare utilization, and economic burden.</li> <li>4. To compare outcomes of oHCM patients with historical controls from existing HCM registries.</li> </ol>
Patient/NHS/BMS benefits:	<p><b>For Manchester University:</b></p> <ul style="list-style-type: none"> <li>• The first registry setup in the UK of obstructive HCM patients.</li> <li>• Greater efficiencies in accessing obstructive HCM data for research purposes and a deeper understanding of their obstructive HCM patients.</li> <li>• Potential to improve healthcare outcomes for obstructive HCM patients they serve.</li> </ul> <p><b>For BMS:</b></p> <ul style="list-style-type: none"> <li>• BMS would gain from the reputational gains associated with working in collaboration a major ICC center.</li> <li>• BMS would gain the opportunity to support the first ever obstructive HCM registry in the UK. The project could be shared with other localities across the NHS and with the potential to extend to the south of England and Northern Ireland for a UK-wide database, or to include non-obstructive HCM patients.</li> <li>• Real world data/evidence collected for obstructive HCM patients in Northern England and Scotland to enhance research.</li> </ul> <p><b>For patients</b></p> <ul style="list-style-type: none"> <li>• Insights gained from the registry may lead to improved patient care, optimized treatment strategies, and enhanced quality of life for individuals with obstructive HCM</li> </ul>
Stakeholders:	Manchester University; BMS
Agreed arrangements	BMS will provide funding of £50,000 and a resource-based contribution of £15,539. This provides a £65,539 total investment towards the project. Manchester University will provide £57,652.41 as a resource-based contribution towards the project.
Timelines:	The project will commence from March 2025 and last for 15 months.