Evaluation of a new digitally enabled, clinical scientist-led clinic designed to optimize care for people with Hypertrophic Cardiomyopathy (HCM) and left ventricular outflow tract obstruction (LVOTO).

The clinic, developed by Guy's and St Thomas' NHS Foundation Trust (GSTT) in partnership with Bristol-Myers Squibb (BMS), incorporates digital technologies and novel treatment pathways. The evaluation was conducted by the Health Innovation Network South London (HIN) to assess staff and patient perspectives, clinic effectiveness, and digital platform integration over an 18-month period starting January 2024.

Background and Clinic Overview

Hypertrophic cardiomyopathy (HCM) is characterized by abnormal thickening of the heart muscle, with LVOTO affecting up to 70% of patients, leading to symptoms such as breathlessness and chest pain.

The clinic employs a clinical scientist-led model, where the clinical scientist performs diagnostic tests including echocardiograms and reviews patients with consultant oversight, streamlining the care process. Patients are monitored frequently with appointments including ECGs, echocardiography, clinical assessments, and medication reviews consolidated into single visits. A clinical nurse specialist (CNS) supports the clinic by conducting pre-assessments and preparing patients for treatment.

The digital platform Ortus-iHealth (Ortus) facilitates bidirectional communication, remote symptom monitoring, video consultations, and sharing of educational resources, commissioned as a pilot for digital cardiovascular care by NHS England.

Evaluation Approach

The evaluation used a mixed-methods design incorporating qualitative interviews with 9 staff members and 10 patients, alongside an anonymous patient survey completed by 15 patients. It focused on the effectiveness of the clinical scientist-led clinic, patient experience, digital platform use, and sustainability considerations. Some evaluation aims related to digital patient identification using Cogstack (an AI-powered information retrieval and extraction platform from unstructured health records), and development of best practice exemplars were out of scope due to implementation delays.

Effectiveness of the Clinical Scientist-Led Clinic

The clinic is described by staff and patients as well-organized, efficient, and providing continuity of care through a consistent point of contact. The clinical scientist's role, combining diagnostic testing and patient review, enables a "one-stop-shop" model that avoids delays and repetition. Patients expressed strong trust in the clinical scientist's expertise and appreciated clear, thorough communication, which made them feel well cared for.

The Clinical Nurse Specialist role further enhances the service by conducting pre-assessments and supporting patients through treatment stages.

While the clinic appointments are efficient, patients reported challenges with long waits for blood tests and prescription collection outside of clinic control. The clinic team has taken proactive steps to mitigate these issues, such as pre-booking blood tests online.

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Geographic barriers persist for patients living outside London due to travel time and costs, though flexible appointment scheduling helps mitigate this. The clinic serves patients across London and Southeast England, promoting equitable access within these regions.

Clinic capacity is limited primarily by the availability of time, staff, and dedicated space for echocardiograms, which are essential for monitoring.

Patient Understanding and Self-Management

Most patients reported improved understanding of their HCM LVOTO condition through the clinic's clear explanations and education, with 87% of survey respondents noting increased knowledge. Patients described the care as exceeding prior expectations.

Patients experienced symptom relief, such as reduced breathlessness and increased energy, enabling better management of daily activities. However, some patients remain hesitant to resume physical activity due to longstanding advice and psychological barriers. Staff identified the need for cardiac rehabilitation programs to help patients regain confidence and overcome fears related to exertion.

Psychological support is currently limited but recognized as an important area for future development to help patients adjust emotionally to improved physical health and build resilience.

Patient and Staff Experience

Patients overwhelmingly praised the clinic for personalized, responsive, and compassionate care, often describing the team as "above and beyond." Trust in the clinical scientist was high despite varying awareness of the role.

Staff expressed fulfilment from working in a committed, well-coordinated team with shared goals, emphasizing strong communication and collaborative decision-making as keys to success.

Digital Platform (Ortus) Utilization

Ortus streamlined patient outcome data collection by replacing paper questionnaires with digital forms, facilitating remote monitoring by clinical staff. Most patients (73%) preferred the digital platform, and staff valued its efficiency in tracking responses. However, some patients required paper forms due to lack of digital access or willingness, highlighting digital exclusion concerns.

Patients' engagement with Ortus was inconsistent, with variability in responsiveness to questionnaires. The coexistence of Ortus and MyChart platforms caused confusion, and there is a recommendation to consolidate functionalities into a single integrated system.

Sustainability and Scale-Up

To sustain and expand the clinic, increased staffing is needed, including additional clinical scientists or physiologists to reduce reliance on individuals and expand echocardiogram capacity. Training non-medical prescribers such as the CNS is recommended to ensure continuity during staff transitions. Securing dedicated physical space for diagnostics is also critical.

The clinic has begun expanding to additional sites, such as King's College Hospital, adopting a consultant-led model with shared multidisciplinary teams to maintain expertise. A hub-and-spoke model is proposed to improve access by using GSTT as the hub

for initiation and complex care, with local sites providing ongoing monitoring closer to patients' homes. Transitioning patients to local care requires strong communication and consistent standards to address patient concerns.

Limitations

The evaluation faced limitations including a small patient survey sample size (15 respondents), potential bias due to online survey distribution via Ortus, and lack of feedback from patients who disengaged or declined participation. Delays in Cogstack implementation prevented evaluation of patient identification objectives. Limited patient awareness of Ortus features restricted assessment of the platform's full impact.

Conclusion and Recommendations

The HCM LVOTO clinic delivers streamlined, comprehensive care with high satisfaction among patients and staff. The clinical scientist-led model, supported by the CNS and digital tools, enables effective monitoring resulting in symptom reduction and improved quality of life. Challenges include delays in blood tests and prescriptions, geographic barriers, limited clinic capacity, digital exclusion, and unmet psychological and rehabilitation needs.

Key recommendations include:

- Enhancing holistic patient support by improving access to psychological services and cardiac rehabilitation programs.
- Maintaining flexible digital engagement options to address exclusion and exploring integration of digital platforms.
- Strengthening service capacity by recruiting additional staff, expanding prescribing roles, securing diagnostic space, and preparing for new therapies.
- Expanding equitable access through a hub-and-spoke model with strong communication and consistent care standards across sites.

This evaluation supports the continued development and impact of the clinic on patient outcomes and experience across the region.