# Evaluation of the Miles Frost Fund: Phases 1 and 2, summary

## Introduction

The Miles Frost Fund and the British Heart Foundation (BHF) aimed to help establish a UK-wide cascade testing service for parents, siblings and children who could be at risk of Hypertrophic Cardiomyopathy (HCM), an inherited cardiac condition. Cascade testing means genetic testing for relatives of people who have HCM, to see if they also carry the gene that can cause HCM. If found to have the gene, they can be monitored and treated in the most timely and efficient manner.

Administered by the British Heart Foundation, the fund awarded grants to 13 sites across the UK, in two phases.

Six **phase 1** sites were awarded grants of between approximately £40,000 and £200,000 in February 2017[1]. The evaluation of these projects was completed in September 2019; except one site which was rolled into the Phase 2 evaluation due to implementation delays[2].

Seven **phase 2** sites were awarded grants of between approximately £70,000 and £160,000 in April 2018[3]. Evaluation of these projects was completed in early 2022, following a pause in evaluation activities during the Covid-19 pandemic.

Funding was awarded with the expectation that the NHS would mainstream activity into core service provision over time.

This document summarises the evaluation findings from all sites.

### Evaluation methodology

Traverse was commissioned by British Heart Foundation to:

- Evidence impact – outcomes realised for patients, staff and services
- Identify and share best practice – what has worked well and what can be learned from the experiences of the funded projects.

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[1] Belfast Health and Social Care Trust, Guy's and St Thomas' NHS Foundation Trust, Sheffield Teaching Hospitals NHS Foundation Trust, NHS Greater Glasgow and Clyde, Oxford University Hospitals NHS Foundation Trust, Swansea Bay University Health Board (formerly ABMU, prior to April 2019)

[2] Swansea Bay University Health Board

[3] University Hospitals Birmingham, University Hospitals Bristol, Leeds Teaching Hospitals, Liverpool Heart and Chest Hospital, Manchester University, University Hospital Southampton, Network for Inherited Cardiac Conditions Scotland

The evaluation applied a mixed methods approach, collecting monitoring data and qualitative insights from pilot site leads at three time points, and from staff in funded posts at the end point.

# Context

Sites used the Miles Frost funding to expand or develop their existing services and address challenges including long waiting times for patients, inconsistent standards of care, inaccessibility of services, inadequate coordination between different sites or services and lack of referrals or appropriate referrals into the service.

There was a mixture of one-unit, hub and spoke and localised models, using a range of approaches to increase cascade testing. These included video clinics, mainstreaming genetic testing, establishing parallel or joint clinics, establishing a triage process, developing a hub and spoke model and developing a local service.

Sites predominantly hired specialist nurses to undertake new duties or free up other staff, and/or non-clinical roles to support patient management and administration.

Pilot sites anticipated that their programmes would deliver a range of outcomes for patients and services, including an increase in the number of people clinically screened and offered genetic testing for HCM. This, in turn, would lead to an increase in the number of identified HCM cases.

# Outcomes

## Outcomes for patients

Across both phases, all services reported that the Miles Frost funding had increased patient access to both HCM testing and cascade genetic testing. For Phase 2, this outcome only applied prior to the Covid pandemic. This outcome was due to additional local clinics as well as improved referral routes and collaboration between services.

Increased convenience of care and improved patient experience were also reported across both phase 1 and 2 with benefits for patients including more resilient services, more personalised nurse-led care and decreased waiting times. Reduced travel times for patients due to remote appointments were noted in both phases and were said to have led to greater engagement from both patients and their families. For phase 2, it was reported that additional capacity within services had the benefit of enabling improved communication with patients, ensuring more consistent follow-ups.

## Outcomes for services and staff

Increased staff capacity due to additional staff and greater coordination of care was reported across both phases. The freeing up of time for senior professionals to provide better service delivery was emphasised and, for phase 1, it was noted that as a result services were delivered more efficiently.

During phase 2, sites also reported improved staff morale as a result of the benefits of increased capacity and improved coordination of care within services. Across both phases, there was increased knowledge of HCM amongst staff at the sites.

### Wider outcomes

In both phases, increased awareness of Inherited Cardiac Conditions (ICCs) and HCM services across regions was reported with phase 2 reporting increased referrals, particularly by GPs, as a result.

In addition, sites in phase 2 reported that lessons and outputs from activities that were part of the Miles Frost Fund had contributed to wider developments in networks across England, Wales and Scotland.

For phase 1, sites reported improved relationships and communication between key staff at different sites as well as increased equity in specialist and district general hospital patient populations as a result of new regional outreach clinics.

## Enablers

### Staffing and service models

Nurse-led care was viewed in both phase 1 and 2 as an enabler with sites noting the appropriateness of nurse-led clinics in providing a high standard of care for patients and highlighting the importance of the support given to specialist nurses in developing their skills and knowledge.

Telephone clinics were reported to be an enabler as they reduced waiting times and increased staff efficiency. The support of administrator/coordinator roles freed up the time of staff such as nurses, as well as improving patient communication.

During phase 2, sites reported that the development of patient databases for HCM or ICC patients enabled a variety of benefits in areas such as patient management, more consistent follow-up and better prognosis prediction. Similarly, the creation of Standard Operating Procedures, guidance documents and templates to outline pathways supported the development and growth of services.

### Mainstreaming of genetics within ICC services

For phase 2, the centring of genetics within ICC services was seen as another enabler due to the impact it had on improvements in service delivery such as reduced waiting times and increased awareness amongst staff.

### Improved pathways

Phase 2 sites reported that developing self-referral pathways and improving service pathways were both enablers in increasing access to care and reducing waiting times.

### Building support for new models

For phase 1, several factors enabled the building of support for new models including increasing awareness among patients and HCPs, building upon existing networks, support from the specialist centre and early engagement of spoke departments.

## Challenges

### Staffing

For phase 1, sites reported a steep learning curve for nurses that led to delays in their ability to run clinics independently as well as struggles to define roles, particularly for administrative support. For phase 2, recruitment was a challenge for some sites, with struggles to gain sign-off for recruitment and logistical issues such as a shortage of qualified applicants.

Both phases reported challenges with staff absence and turnover due to illness or long-term leave and the difficulty of covering for those absent staff. Struggles with administrative support were also noted during both phases, for example, challenges with external administrative support lacking sufficient knowledge or a broader lack of administrative support.

### Hub and spoke logistics

Across both phases, sites reported challenges with hub and spoke logistics including delivering training in this model, as this led to staffing gaps in hubs, and setting up outreach clinics because of the financial negotiations this involved. Differing systems and equipment between hub and spoke also caused challenges. For phase 1, sites reported issues accessing and sharing patient data during outreach clinics. For phase 2, sites reported variation in imaging and screening protocols as well as quality of scanning equipment between spoke and hub, that risked damaging patient confidence in the equity of services.

### Other

Phase 1 sites reported that the lack of a national, coordinated database was an ongoing challenge despite their creation of local databases. Phase 2 sites reported that changes in the provision of genetic testing on a national basis, whilst not a challenge per se, did require sites to adapt and adjust.

Two phase 2 sites noted challenges specific to their sites, including a lack of clinic space, and issues with services using different IT systems.

## Impacts of Covid-19 on delivery

During phase 2, all services were severely impacted by the Covid pandemic. There was a reduction in service capacity, as some staff were redeployed, and face to face appointments were stopped or limited. A backlog of patients therefore developed which at the time of the evaluation (early 2022) were continuing to be tackled. Staff reported that patients and families experienced increased anxiety due to waiting longer for appointments and tests.

In response to the pandemic, services moved to or accelerated their use of telephone and video appointments. Pros and cons of this were identified by staff; while some thought that patients appreciated the increased convenience, others felt that face to face interactions were more effective.

# Sustainability

## Continuation of services

For phase 1, sites that agreed ongoing funding from the beginning of the pilot were optimistic towards the end of their funding period about the sustainability of new models and activities, although some encountered challenges including gaining approval of a final business case and for the delivery of certain spoke clinics. For phase 2, all but one of the sites secured ongoing funding for posts (that one had a number of local challenges including mergers and staff redeployment).

## Future plans

Phase 2 sites were asked to comment on future plans and aspirations for the services with common themes including tackling the backlog of patients accrued during the Covid pandemic, recruitment of additional staff, resuming education and awareness-raising, development of resources for patients and clinicians and development of understanding of genetics.

# Reflections on the grant programme

## Programme support

Across both phases, sites praised communication with the BHF. Shared learning events were also viewed as a valuable source of learning and networking opportunities. During phase 2, Covid ended these face-to-face events, which staff felt was a loss.

Phase 2 sites reported that BHF had a flexible, responsive and pragmatic approach throughout the programme, particularly with regard to Covid, and that they provided valuable practical and influencing support around continuation of the services after the end of funding.

For phase 1, some sites identified challenges with the programme support such as the belief that the grant length was too short and that it was challenging without funding to carry out grant management responsibilities and evaluation requirements. Sites in phase 1 also reported that they welcomed their inclusion in the development of the core competencies although they faced challenges with the lack of a competencies framework within the pilot.

## Programme evaluation

Across both phases, staff were broadly positive regarding evaluation activities, especially interviews, noting that they were comprehensive, not burdensome, useful for self-reflection and carried out with flexibility that enabled staff participation in the context of competing demands on their time.

For phase 1, several sites reported that filling out the economic assessment tool caused difficulties as it needed wider service data (this was removed from the evaluation of phase 2 sites due to the disruption caused by Covid, which meant it was not feasible to accurately assess costs and benefits of the service).

For phase 2, the timing of the evaluation was impacted by the Covid pandemic with sites reporting that the final report was produced too late for the evaluation to have supported their business cases to commissioners. Some Phase 2 sites reported that the data monitoring requirements for the programme were demanding and queried their value. However, sites did note that the requirement to collect this data had benefits for understanding and evidencing demand and contributing to increased understanding of patients and their conditions.

## Recommendations

For sites looking to develop effective HCM services, and for BHF in relation to supporting service development, some of key enablers of success will include:

- **Supporting specialist nurses to lead** – through training and development, a supportive learning environment and dedicated administrative support
- **Bringing generalist genetics into the fold** – enabling specialist nurses to do this as part of their role, or closer working and parallel clinics with cardiologists and (generalist) geneticists alongside each other (which means patients and relatives get moved along the service pathway more quickly)
- **Establishing good infrastructure** – new (self) referral routes, effective triage, strong admin, good databases; all underpinned by SOPs and templates.

Suggestions for BHF in relation to HCM:

- Continue to support a **national conversation,** to help clinicians engage commissioners on a local level
- Support and influence around the development of a **national database for cardiomyopathies.**

Suggestions for BHF in relation to grant funding more generally:

- **Provide opportunities to share learning**, which are highly valued by clinicians
- **Supporting sites to consider funding for administrative as well as clinical roles** can make a huge difference
- **Use BHF's profile and influencing power** to support funded sites, both with external promotion of services and internal influencing with senior leaders
- **Consider how funding structures can be designed** to best ensure post-programme funding by trusts.