Enhanced cascade genetic testing for HCM

Evaluation of the Miles Frost Fund – Phase 2 pilot sites

British Heart Foundation

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Glossary and acronyms

Arrhythmia	Condition in which the heart beats with an irregular or abnormal rhythm.
Cascade test	Systematic process for identifying individuals at risk of a hereditary condition. The process starts with the identification of an individual with the condition (i.e. a proband), after which genetic testing is extended to their at-risk biological relative(s).
Hypertrophic cardiomyopathy (HCM)	Disease in which the heart muscle becomes abnormally thick (hypertrophied). The thickened heart muscle can make it harder for the heart to pump blood.
Hub-and-spoke model	Model of care where patients in district hospitals are referred to a specialist tertiary hub service. Once assessed, patient care is devolved back to the spoke.
Inherited Cardiac Condition (ICC)	Inherited cardiac conditions are passed on through families. They are also known as genetic heart conditions.
Multidisciplinary team meeting (MDT)	Meeting of a group of professionals from one or more clinical disciplines who – together – make decisions regarding recommended treatment for individual patients
One-stop-shop	Model of care that enables a patient to access a range of tests and care in a single place.
Outreach clinic	Where specialists from one hospital travel to hold clinics in another location.
Patient management pathway	The route a patient will take if they are referred for treatment by a health professional.
Proband	Person serving as the starting point for the genetic study of a family.
Tertiary	Highly specialised care in a facility that has personnel and equipment for advanced medical investigation and treatment.
Variant of unknown significance (VUS)	A variant where it is not known whether it will cause HCM or not.

Executive summary

The Miles Frost Fund and the British Heart Foundation (BHF) aimed to help establish a fully functional, 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, with the expectation that NHS trusts would mainstream project activity into core service provision over time. The evaluation of these projects was completed in September 2019.

Seven phase 2 sites were awarded grants of between approximately £70,000 and £160,000 in April 2018, again with the intention of mainstreaming into core service provision. **This executive summary presents the findings of the evaluation of the phase 2 sites**[1], in addition to one of the phase 1 sites where implementation was delayed, and therefore it was evaluated as part of phase 2[2].

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.

The evaluation applied a mixed methods approach and collected qualitative data from pilot site leads at three time points during the grant funding window, and from staff in funded posts at the end point.

Context

Sites used the 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. Phase 2 sites were a mixture of one-unit, hub and spoke and localised models, and used a range

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[1] 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

[2] Swansea Bay University Health Board (formerly ABMU, prior to April 2019) (originally part of Phase 1)

of approaches to increase cascade testing, including 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.

Outcomes

Pilot leads identified benefits for patients, as well as for service staff and the wider healthcare context within which they operate.

- Patients experienced increased access to care (because of increased service capacity) and convenience of care (for example, through being able to see genetic counsellor and cardiologist on a single visit, and through telephone/virtual appointments). There was also improved patient engagement and understanding around HCM, through the improved support provided and more consistent follow-up.
- For staff and services, outcomes included senior clinicians' time being freed up to focus on improving service delivery (made possible by the increase in capacity provided through the funded roles), and improved staff morale (staff having increased confidence in being able to provide good care; feeling better supported; taking on a more varied, interesting workload).
- There was increased awareness of ICCs and HCM services across regions, and increased appropriate referrals, amongst GPs and cardiologists.

Enablers

Where projects were felt to have worked well, pilot site leads and other staff highlighted a range of enabling factors. This included:

- Supporting specialist nurses to work at the top of their band, via training, shadowing and networking opportunities
- Mainstreaming of genetics within ICC services, by increased multidisciplinary working, parallel genetics and cardiology clinics
- Introduction of self referral pathways, removing the need for patients to seek and obtain a GP referral
- Improved service pathways and triage, enabling allocation of low risk patients to nurses for follow up
- Telephone/video clinics, enabling clinicians to fit in more calls, and reducing both travel and waiting times for patients
- Administrative support, underpinning improved communication with patients, and improved coordination of testing and records
- Databases and digitised records, enabling better patient management, and better prognosis prediction based on a larger bank of data
- Development of SOPs and templates, supporting effective and efficient running and development of services.

Challenges

The main challenges experienced by Phase 2 sites included:

- Lack of or insufficient administrative support, which led to errors such as double booking of appointments, delays in sending out letters, databases not kept up to date, and clinician time being spent on administrative tasks
- Staff absence and turnover, which was mitigated in services which had more than one person in the same role (e.g. genetic counsellor), or where key staff had broad skillsets (e.g. a nurse with genetic counselling skills)
- Changes in genetic testing provision (the introduction of national testing criteria and centralising of labs), while not a challenge as such, nevertheless required adaptation and adjustment by sites
- Recruitment challenges, including getting sign-off, agreeing banding, finding qualified applicants and hiring specialist roles on a part time basis
- Hub and spoke model logistics, such as differences in funding and systems across different sites or trusts.

Impacts of Covid-19 on delivery

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

In all but one of the sites, Trusts had taken on the funding of the posts created by the Miles Frost Fund on a permanent basis, as per the original intention behind the design of the programme. Being able to evidence demand and demonstrate alignment with wider strategic priorities were factors in making the case to commissioners.

Priorities for services going forward included: tackling backlog, recruiting additional staff, resuming education and awareness raising, expanding community outreach and engagement, continuing development of staff skills, resources and databases.

Programme support

The management of the grant progamme by BHF was praised as being proactive in giving useful advice at the application stage; for a flexible, responsive and progamatic approach throughout; and for their practical support and influencing around continuation of services post-funding. Sites appreciated the opportunity to share learning at BHF events (pre Covid). They were broadly supportive and understanding of the principles of evaluation and data monitoring, and while some felt the requirements were onerous, others noted benefits in terms of being able to understand and evidence demand.

Recommendations

For sites looking to develop effective 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
- **Funding 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.

1. Introduction

This chapter introduces the Miles Frost Fund, the British Heart Foundation Hypertrophic Cardiomyopathy Programme, and the evaluation. It describes the aims of the evaluation, as well as the purpose and structure of the report.

1.1. The Miles Frost Fund

The Miles Frost Fund and the British Heart Foundation (BHF) aimed to help establish a fully functional, UK-wide cascade testing service for parents, siblings and children who could be at risk of Hypertrophic Cardiomyopathy (HCM).

HCM is a genetic condition caused by a change or mutation in one or more genes and is passed on through families. When people are identified to have a faulty gene which causes HCM, their relatives can be offered a genetic test, to see if they have it too.

The purpose of the funding was to increase the number of people who may have HCM being identified and tested, and, if found to have the gene, monitored and treated in the most timely and efficient manner. It aimed to support the development of consistent service provision, accessible to all who may be affected across the UK.

1.2. Overview of pilot sites

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

- In Phase 1, six projects were awarded funding in February 2017
- In Phase 2, a further 7 projects were awarded funding in April 2018.

Phase 1 projects received grants of between approximately £40,000 and £200,000 over two years, Phase 2 projects received grants of between approximately £70,000 and £160,000 over two years.

NHS trusts and health boards provided 50% of funding in year 2, with the expectation that activity would be mainstreamed into core service provision over time.

1.3. Evaluation of the Miles Frost Fund

The evaluation aimed to:

- Evidence impact – what outcomes have been realised for patients, staff and services
- Identify and share best practice – what has worked well and less well, and what can be learned from the experiences of the funded projects to help the establishment of a fully functional, UK-wide cascade testing service.

The evaluation of the Phase 1 sites was completed in September 2019.

This report covers the Phase 2 projects, in addition to one of the original Phase 1 projects (Swansea Bay University Health Board), which experienced delays in starting up and so was moved into Phase 2 for evaluation purposes. Therefore this report covers the following services:

- University Hospitals Birmingham NHS Foundation Trust
- University Hospitals Bristol NHS Foundation Trust
- Leeds Teaching Hospitals NHS Foundation Trust
- Liverpool Heart and Chest Hospital NHS Foundation Trust
- Manchester University NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust
- Network for Inherited Cardiac Conditions Scotland (NICCS)
- Swansea Bay University Health Board (formerly ABMU, prior to April 2019) (originally part of Phase 1)

1.4. This evaluation report

This report is structured into the following sections:

- Methodology
- Context (about the Phase 2 sites)
- Findings – outcomes, enablers, challenges, key learning, impacts of Covid-19 on delivery, sustainability
- Reflections on the grant programme
- Conclusions and recommendations
- Case study examples

Note on Covid-19

Like all health services, HCM services were impacted by the Covid-19 pandemic. Most of the findings in this report relate to pre and post pandemic experiences, with impacts of Covid-19 being covered in a specific sub-section, within the Findings section. It is not always possible to separate these entirely from other factors affecting delivery of services; findings are reported as described to us by those delivering services.

2. Methodology

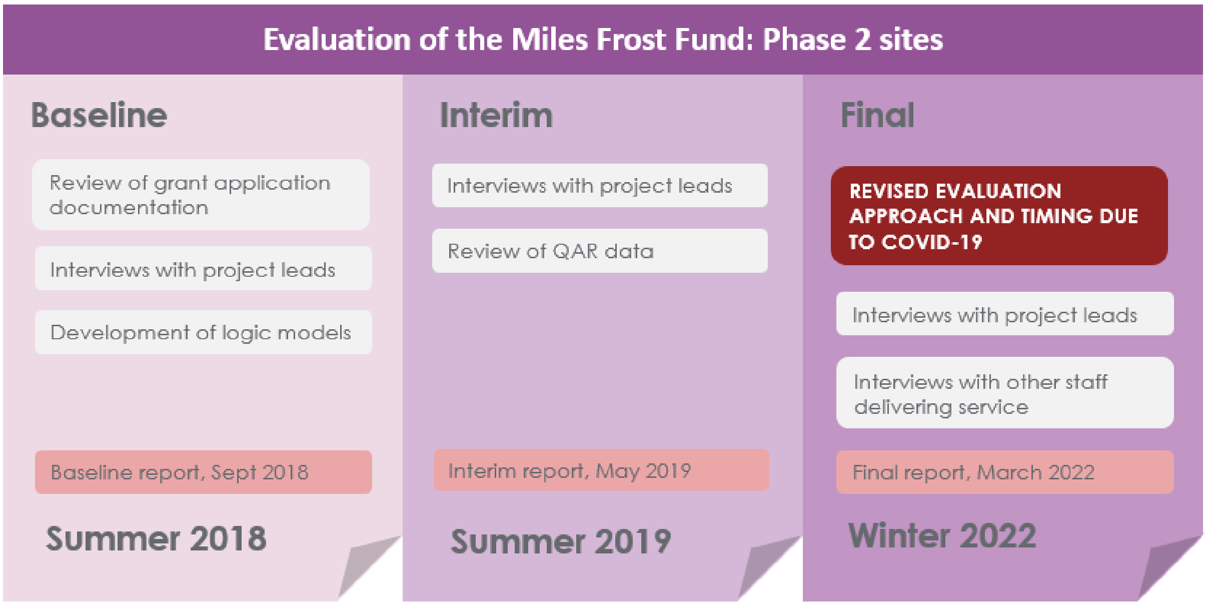
This chapter describes the evaluation methodology and data collection methods.

2.1. Methodology and data collection methods

The evaluation of the Phase 2 projects collected data at three time points across the duration of the grant funding: baseline, interim and final. Qualitative interviews were held at each time point with site leads (consultants) and at the final point, also with staff in the funded posts involved in delivering the service (specialist nurses, genetic counsellors and administrative/coordinator posts).

The evaluation methodology in Phase 1 also led analysis of quantitative data submitted by sites to BHF via GrantTracker (quarterly activity reports), economic analysis, and data collection with patients. The intention was to use the same approach in Phase 2, but due to the severe disruption to NHS services caused by the Covid-19 pandemic, the decision was taken by BHF to pause the evaluation, until January 2022, and to reduce the level of evaluation for Phase 2 at this final stage, limiting it to interviews with lead staff and funded posts only.

Figure 1. Overview of evaluation methodology



3. Context

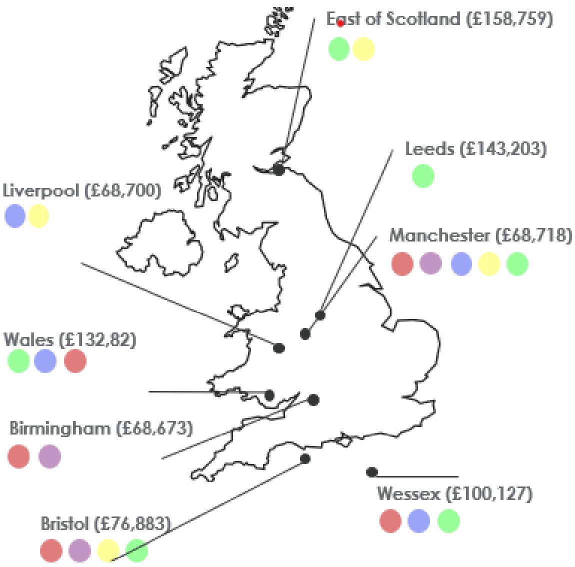
This section provides an overview of the pilot sites and key contextual factors, pilot service models and anticipated outcomes

3.1. Challenges driving service development

The majority of sites had previously offered HCM testing and used BHF funding to explore expansion or development of an existing service. Challenges faced in existing delivery of HCM testing prior to the funding award included 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.

Figure 2. Service challenges (and funding awarded)

- **Bottlenecks and long waiting times in service delivery** 🔴
- **Inconsistent or less than ideal standard of care for patients** 🟣
- **Inconvenient service arrangements for patients** 🔵
- **Insufficient coordination and communication between different sites or services** 🟡
- **Lack of referrals due to low HCM awareness among healthcare professionals** 🟢



3.2. Models and staff roles

Models

Overview of models

Phase 2 sites are a mixture of one-unit, hub and spoke and localised models, most of which have distinct approaches to make genetic testing available to all families affected by HCM using:

- Video clinics[3]

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[3] Some sites had video clinics as part of their original plans, while others introduced video or telephone clinics during Covid-19 pandemic.

- Mainstreaming genetic testing
- Establishing parallel or joint clinics
- Establishing a triage process
- Developing a hub and spoke model
- Developing a local service

As with Phase 1 sites, some projects also planned awareness raising activities including training for project staff in 'spoke' or community settings and education for cardiologists and other healthcare professionals in district hospitals and GP practices.

Sites used the funding primarily to recruit new staff to implement their delivery models. Recruitment to funded posts was intended to free up time for existing staff, or create new capacity to reshape or expand provision. Some sites also planned development activities for existing staff, such as training 'spoke' ICC Champions.

Models by site

The table provides a brief description of the model in each of the Phase 2 sites.

Figure 3. Model at each site

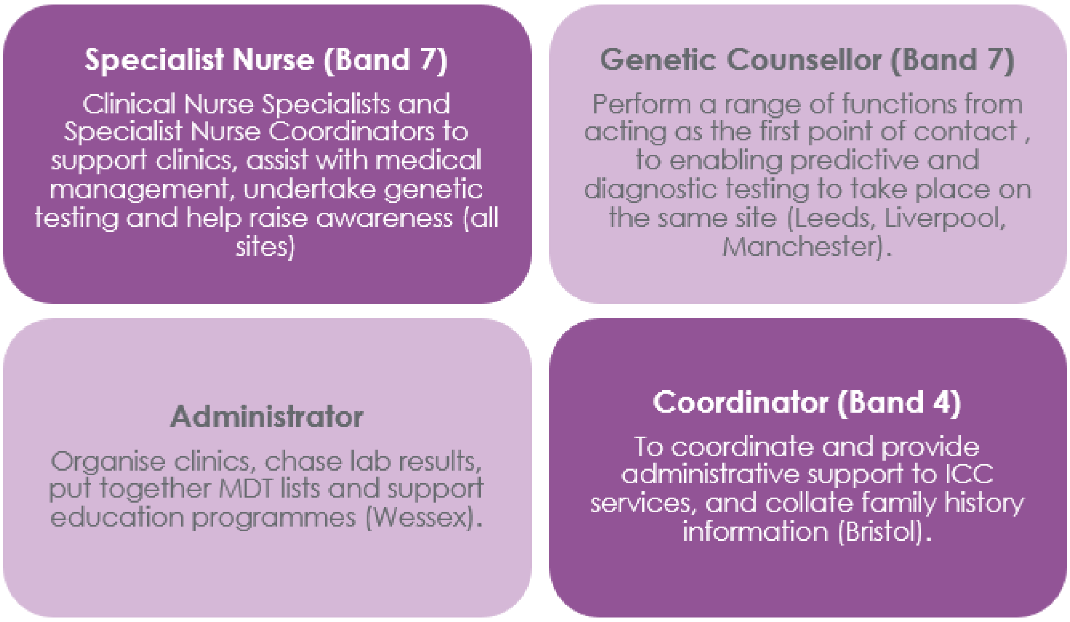
Site	Model/approach
Birmingham	*One unit model* Mainstreaming genetic testing (i.e. provided at cardiology clinic) Use of video clinics and remote testing Education and awareness raising
Bristol	*Hybrid model*: 'one stop' clinic in hub; cascade testing for spokes Online MDTs with DGHs Nurse-led clinic to see adults and children Band 4 coordinator to update and maintain database Review of database to identify untested patients Education and awareness raising: conference for non ICC specialists
Leeds	*Hub and spoke*: establish clinics and ICC champions in spokes, supported by ICC specialist nurse Mainstreaming of genetic testing Case notes review for existing patients/families Education and awareness raising: in spoke clinics and study day for coroners and pathologists
Liverpool	*One unit model* Parallel clinics for cardiology and genetic counselling Education and awareness raising: outreach via patient groups and primary care

Manchester	*Establish new triage strategy*, to direct patients on one of 4 pathways Specialist nurse and family history coordinator to implement triage Education and awareness raising: introduce new pathways to referrers
Southampton	*Hub and spoke*: roll out of joint clinic model already in Southampton, to two spoke hospitals Education and awareness raising : lectures at DGHs
East of Scotland	*Localised model*: locally appointed cardiac nurses in 5 health boards Nurses to manage patients, families and coordinate testing Testing virtual clinics Education and awareness raising: patients and staff
Wales	*Hub and spoke*: service based in Swansea and delivering satellite clinics in rural areas Education and awareness raising: public, health professionals and coroners

Funded roles

All sites recruited a specialist nurse, with some also recruiting a genetic counsellor (Liverpool, Manchester, Leeds) and/or a coordinator (Bristol) or administrator (Southampton). BHF agreed to fund administrative roles in Phase 2 sites, based on the feedback from Phase 1 sites that effective administration could free up clinicians to focus on patient care.

Figure 4. Types of post funded



Specialist Nurse (Band 7)

Clinical Nurse Specialists and Specialist Nurse Coordinators to support clinics, assist with medical management, undertake genetic testing and help raise awareness (all sites)

Genetic Counsellor (Band 7)

Perform a range of functions from acting as the first point of contact , to enabling predictive and diagnostic testing to take place on the same site (Leeds, Liverpool, Manchester).

Administrator

Organise clinics, chase lab results, put together MDT lists and support education programmes (Wessex).

Coordinator (Band 4)

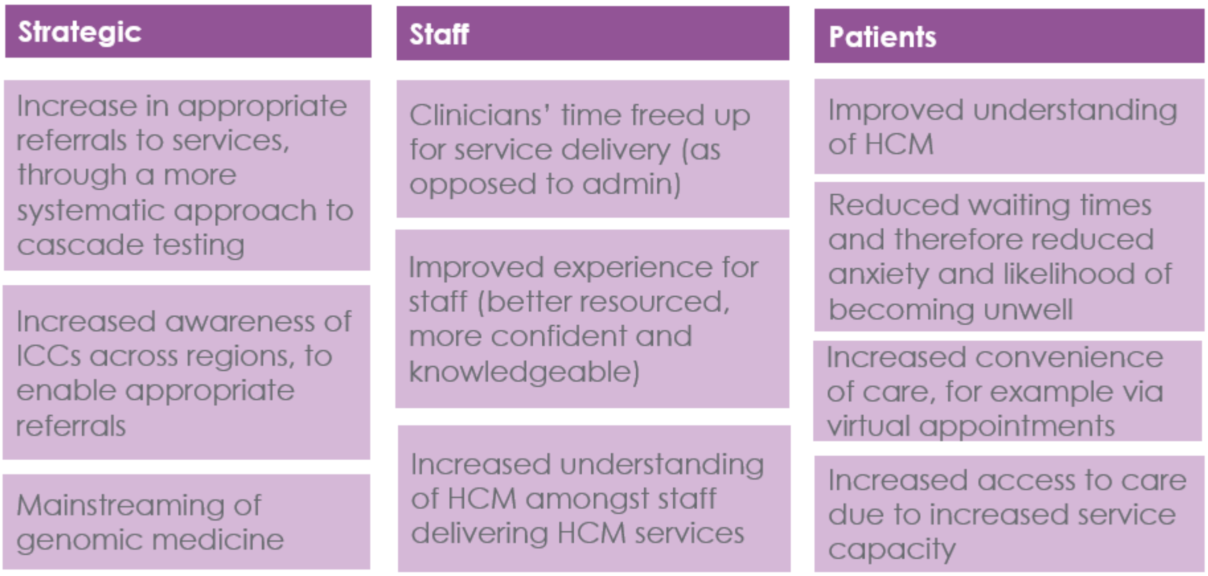
To coordinate and provide administrative support to ICC services, and collate family history information (Bristol).

3.3. Anticipated outcomes

Pilot leads were asked at baseline what outcomes they anticipated as a result of their projects. Services anticipated that they would be enabled to clinically screen and offer genetic testing to more families, which would in turn lead to an increase in the number of identified HCM cases, and appropriate treatment and monitoring of these patients.

The figure below groups together the types of outcomes for patients, staff and at strategic level, that Phase 2 sites anticipated at the outset.

Figure 5. Anticipated outcomes



Strategic	Staff	Patients
Increase in appropriate referrals to services, through a more systematic approach to cascade testing	Clinicians' time freed up for service delivery (as opposed to admin)	Improved understanding of HCM
Increased awareness of ICCs across regions, to enable appropriate referrals	Improved experience for staff (better resourced, more confident and knowledgeable)	Reduced waiting times and therefore reduced anxiety and likelihood of becoming unwell
Mainstreaming of genomic medicine	Increased understanding of HCM amongst staff delivering HCM services	Increased convenience of care, for example via virtual appointments
		Increased access to care due to increased service capacity

4. Findings

This section presents the main reported outcomes for patients, staff and services, and at a wider/strategic level. It also explores what worked well in enabling outcomes, challenges encountered and the impacts of Covid on service delivery.

4.1. Outcomes

Outcomes for patients

The new service models were anticipated to have four main benefits for patients: increased access to care; increased convenience of care; reduced waiting times; and improved patient understanding of HCM.

Increased access to care

All services reported that the Miles Frost Fund had increased patient access to HCM testing and cascade genetic testing, prior to the Covid pandemic. This was mainly a result of shorter-term changes that included:

- **Increased clinic time** – improvements in the coordination of care through the introduction of nurse-led clinics (in addition to existing consultant-led clinics) in sites such as Birmingham, Leeds, Liverpool and Wales, which meant that services could see patients quicker, freeing up space for more new patients.
- **Improved identification** – several services such as Bristol, Birmingham and East of Scotland (Grampian and Tayside) used increased capacity to review existing caseloads and gene test existing patients who had not previously received a genetic cascade test. This has since been extended to family members, which was particularly important for families with mutations capable of causing disease.

  "We have done a very intensive job in terms of getting through everyone who needed to be gene tested... we have nearly gene tested everyone we see and we are starting to expand out to relatives. We want to offer everyone who can qualify to have a gene test, to have a gene test. In people who are carrying a pathogenic mutation – finding out who else in their family is carrying it – it really changes everything" (Bristol)

- **Improved referral routes** – while several sites such as Liverpool raised awareness of referral criteria among key local healthcare professionals such as GPs, others such as Leeds, Wales and Southampton also introduced self-referral pathways that enabled relatives of patients affected by HCM to bypass GP and general cardiology appointments and access testing more easily (see "enablers – self-referral").

- **Improved collaboration** – fewer patients were reported to 'fall between the gap' of services as a result of: funded posts 'bridging' cardiology and genetics (e.g. cardiomyopathy nurse specialists); more regular Multidisciplinary Team Meetings to discuss VUS results and other patient; and pro-active efforts to strengthen links with other key departments such as paediatric cardiology.

However, while funded posts helped to increase access to care (and therefore patient caseloads) prior to the pandemic, the subsequent redeployment of staff as part of the pandemic response has meant that most services accrued a backlog of patients and now have the same or longer waiting lists for new patients than at the start of the programme (see "impacts of Covid – reduction of service capacity").

Increased convenience of care

Several sites reported that their service development had improved the convenience of testing and care for patients. This included:

- **Reduced travel** – the introduction of parallel clinics that located genetic counsellors alongside cardiologists, as well as the introduction and/or increase in telephone and virtual appointments as a result of the pandemic, saved travel time and costs for patients. This was particularly beneficial to patients living further away from hospitals, for those of working age who might prefer to take less time off work, and for rural areas in Scotland.
- **More resilient services** – additional nursing staff and extra capacity within services increased the flexibility of services, which meant that patient care was less likely to be negatively impacted by planned interruptions (e.g. annual leave) and unanticipated absence (e.g. sickness, compassionate leave, parental leave). Extra capacity also freed up consultants and specialist nurses to provide more ad hoc support to patients who were particularly struggling.
- **Timely access to specialist expertise** – patients were reported to get answers to their questions quicker, as specialist nurses and genetic counsellors had more capacity to respond than consultants. These staff felt more confident and better able to respond through training, shadowing and parallel clinics.

  "Having more confidence means that patients can have more confidence and trust in us… Compared to before when I didn't have the specialist knowledge, the information and support I could give them was more vague, or I would have say, 'I'm not sure, I'll need to ask the doctor and get back to you'. Now I have the answers to lots of questions that I didn't used to have." (Liverpool)
- **Continuity of care** – several sites such as Liverpool and Leeds started to improve collaboration with departments such as paediatric cardiology to help ease the transition between children and adult health care. One site was also, at the time of the final evaluation interviews, exploring setting up a dedicated transition/outreach service at a local children's hospital to increase uptake in screening and follow-up.

Reduced waiting times for patients

Most sites reported reduced waiting times for patients across the testing process prior to the pandemic. The main reported changes across services that underpinned this were:

- **Increased capacity** – new, funded nursing and administrative posts within ICC services, plus the introduction of nurse-led clinics, created extra capacity to run more clinics in which patients could be seen.
- **Mainstreamed genetic testing** – new or increased inhouse capacity and expertise of ICC nurses (or other staff) to record family histories and conduct genetic tests also meant that most simple investigations no longer needed to be requested from generalist genetics clinics, which often had longer waiting lists as they covered a wide range of other services.

  "Before the pandemic it was a five-month waiting list to have a genetic test, our waiting list was only six weeks, because we didn't have to wait behind other services." (Manchester)

  "We are almost in a position where we no longer need genetics for a large part of that work, it is nearly all dealt with in-house; I would say we are dealing with 90% in house which is the easier part, while the geneticists are doing the most complex 10%." (Birmingham)

- **Parallel clinics** – parallel genetic counselling clinics in Liverpool and Leeds enabled some services to offer screen and predictive tests on the same day where appropriate. Same site appointments were also reported to reduce the number of missed appointments that needed to be rearranged before patients could progress along service pathways.
- **Creation of self-referral pathways** – self-referral routes that enabled relatives of patients to bypass GP and general cardiology appointments enabled whole families to be seen much quicker and within a shorter space of time.

  "We have had whole families, eight to nine relatives, being screened within three to four months. Compared to before this service, they just dripped through gradually… Investigation is also more efficient – we don't under-investigate or over-investigate – because we know what possibilities we are looking at". (Wales)

Reduced waiting times was directly linked to improved patient experience of care, as timely diagnosis and care was reported to help patients feel more supported and reduce anxiety. However, many waiting times have since increased as a result of the pandemic (see "impacts of Covid – increased anxiety for patients and families).

Improved patient engagement and understanding of HCM

Most sites reported that patient engagement and understanding of HCM had improved within developed services. This was a result of shorter-term changes in terms of:

- **Improved support** – several sites reported that the introduction of specialist nurse-led services has improved the availability, quality and consistency of information provided to patients around HCM. This was attributed to how the role blends specialist emotional support with more rounded knowledge of cardiac conditions. Improved support included examples of where services had trained specialist nurses to deliver genetic counselling for diagnostic testing, reducing the need for separate genetic counselling services and increasing consistency of care.

“I have created a bridge between the secretary and the consultant. Our patients need a lot of emotional support, because of the anxiety of the condition. They now have a point of contact for questions that don’t need the consultant but can’t really be addressed by the secretary – emotional, personal, financial, signs and symptoms and medication.” (Birmingham)

- **More consistent follow-up** – additional capacity within services, plus the introduction of more virtual/telephone appointments, has enabled sites such as Birmingham to improve their follow-up with stable patients. These are patients who still need to be monitored but were easier to miss within stretched services as they do not regularly report having any symptoms. Additional capacity also meant that support services such as patient phone lines in Liverpool could be monitored more regularly (e.g. daily).
- **Improved communication** – several sites, such as Southampton, reported that funded administrative posts had improved communication and coordination with patients, such as ensuring that all people were telephoned before receiving letters.
- **Improved engagement in genetic counselling** – Liverpool reported that parallel genetic counselling alongside cardiology clinics (instead of at a separate women’s hospital) had helped to improve patient’s understanding of the service, the relevance of it to them and therefore their engagement.

“The diagnostic testing (i.e. patients) for the last five years has been done at the cardiology service (here) and the predictive testing (i.e. families) done at the Women’s Hospital. People wouldn’t turn up because it was, “it’s for women, why am I going there?”. Now everything is on the same site people get it and the data shows it is a lot better.” (Liverpool)

Outcomes for services and staff

Most sites reported that the Miles Frost Fund had been a critical catalyst for service development within the context of current NHS budget cuts. Without the funding it would have taken a lot longer to grow existing services, or impossible to establish new services. Improvements reported within services are as follows.

"We knew from the start that cardiologists were enthusiastic… [our] ICCs network has been around for ten years, we knew that people were keen, but there was no structure for creating the service. The Miles Frost Fund has helped develop that structure... it has facilitated and enabled things to move forwards." (East of Scotland)

Senior professionals’ time freed up for better service delivery

Most sites reported that improvements in coordination of care had freed up staff at different levels to deliver better services – including consultants. This was a result of:

- **Better management of low-risk patients** – in some sites nurses had taken on patient caseloads from consultants that were considered low-risk and not likely to develop problems. This included managing and monitoring follow-up tests and feedbacking results where relevant.
- **More organised patient records** – several sites reported that more organised patient records ensured that consultants and nurses could make the most of their clinic hours. Improvements were mainly a result of support from funded posts such as family history coordinators and administrators, as well as the creation of and/or improvements in databases as part of service development (see 'enablers – databases and digitisation of records').

Improved staff morale

Improvements in staff morale were directly linked to benefits that emerged because of increased capacity and improved coordination of care within services. This included:

- **Increased understanding of HCM among staff** – staff have increased on confidence and understanding of HCM and feel that they can provide their patients with better, more holistic care due to having time to shadow senior staff and attend external training. This was highlighted as important for specialist nurses in terms of improving their understanding of genetic testing and test results, which is not covered as part of medicine undergraduate degrees or postgraduate degrees in cardiology. In several sites this also opened up new progression opportunities for staff.
- **Improved support** – more staff within services meant more support around day-to-day work, from there being more people to answer questions (more quickly), to improved cover around planned and unanticipated absences within teams.
- **More varied workload** – greater expertise, confidence and support also meant that staff were able to take on more varied, interesting workloads, rather than only simple caseloads of patients with the same types of challenges.

  "[Extra capacity] also gives us times to do things like audits, educational work and work for families. I've joined the COA to join support groups, been able to do a lot more than that previously." (Leeds)
- **Reduced staff turnover** – better managed, more appropriate workloads relative to knowledge, capacity and contracted hours helped to improve job satisfaction and reduce turnover in key roles, such as administration. However, several services did struggle with high turnover in administrative roles.

Each of these outcomes was felt to have an indirect, positive impact on patient care, who benefited from a happier, better supported, more consistent workforce, as well as improve the overall efficiency of services.

Wider outcomes

Increased awareness of ICCs and HCM services across regions – and increased relevant referrals

Most sites reported that development of their services had helped increase awareness of ICC and HCM services among healthcare professionals. This included:

- **GPs** – raised awareness of referral pathways and criteria as a result of nurses attending network events. This was linked to an increased number of referrals from GP practices in Liverpool, though other sites highlighted the importance of also having self-referral for patients whose GP would not refer them (see 'enablers – new self-referral pathways').
- **Cardiologists** – increased awareness of the specialist service and what it covers as a result of nurses attending network meetings. This was linked to increased referrals of long-term patients from district general hospitals for more specialised care within the ICC service, as well as increased referrals of relatives for genetic cascade testing.

  > *"One of the biggest things [is in terms of] cardiologists in general… by setting up this service, they now appreciate that for the 50-year-old man with cardiomyopathy, his sons also need to be reviewed and there's a process for that. Other hospitals will now contact us to sort out." (Bristol)*

- **Hospital management** –improved understanding of how ICC services operate and why they require higher capacity than other services due to their focus on families and long-term conditions and care. This was a result of hospital managers' involvement in BHF funding applications.

  > *"As part of [the BHF application], I was making the CEO sign all of these things going into it – it put on her radar that we need to build services based on long term conditions and care. In HCM patients don't go away – they are managed for the length of their life. So the BHF funding raised the service profile and let the senior team know what was going on." (Liverpool)*

  Sites reported that this had made subsequent conversations around funding and resource allocation easier.

Wider system changes

Several sites reported that the outputs and lessons learned from Miles Frost Fund activities had contributed to broader developments within networks across England, Scotland and Wales. This included:

- Informing the development and review of screening, scanning, treatment and drug trial protocols within the Network for Inherited Cardiac Conditions Scotland (NICCS)
- Kickstarting a national review of ICC services across Wales as part of a Welsh Health Specialised Services Committee (WHSSC) commissioning review.

There was also evidence of where BHF, the Miles Frost Fund and funded services had kickstarted cultural changes at a local level. For example, where BHF's insistence on funded posts being banded at level 7 overcame a long-challenged precedent in one site that all nurses at this level had to manage junior nurses as part of their role.

4.2. Enablers

Where projects were felt to have worked well in enhancing cascade genetic testing, pilot leads and staff highlighted a range of enabling factors.

Supporting specialist nurses to work at the top of their band

Specialist nurse roles that bridged cardiology and genetics were reported to be niche roles that have extremely steep learning curves, especially in terms of their blend of knowledge and responsibilities (e.g. confidence in running clinics independently).

Particularly effective methods for helping nurses to learn rapidly and work at the top of their band included:

- **Shadowing and attendance at MDTs** – shadowing consultants and other staff provided nurses with a safe, supportive environment in which to develop skills in sites such as Liverpool, Southampton and East of Scotland. Taking part in MDTs also provided nurses with opportunities to learn from other people's cases with borderline diagnoses.
- **Co-location of nurses alongside consultant clinics**, which helped nurses to feel supported and enabled any questions that they could not answer to be resolved quickly.
- **Formal training courses** – some sites highlighted the benefits of genomics and genetic counselling courses, though it was important for these to be completed upfront as attendance was harder once services began to grow.

  "I did the genetic counselling Masters module at university… not because I wasn't confident – I had counselled patients before, I had excellent communications skills – but to get the specialist knowledge really sealed my confidence that I can do it in this [specific] area."(Southampton)
- **Networking** – BHF-supported learning events provided nurses facing similar challenges with opportunities to learn and seek support from each other early in the programme, while participation in other networks such as the Association for Inherited Cardiac Conditions (AICC) were also useful sources of support.

Mainstreaming of genetics within ICC services

Most sites reported that genetic mainstreaming had enabled a range of improvements in service delivery, including reduced waiting times, reduced anxiety and increased understanding among staff. In addition to training specialist nurses in genomics and genetic testing, sites adopted a range of approaches to mainstreaming through the Miles Frost Fund. This was typically underpinned by:

- **Multi-disciplinary teams** for example, locating nursing roles within genetics teams, which helped nurses to develop the confidence to do some genetic tests and counselling appointments themselves, as well as develop wider awareness such as a shift in mindset from focusing only on the patient, to focusing on families.

- **Parallel cardiology and genetic counselling clinics**, which meant that patients could be seen for an initial consultation and offered predictive testing or normal screening on the same day (if they wished), and that teams could more easily and quickly run questions past each other during clinics.

  "Having the genetic counsellors over here is good… you can run things past them if you come across a patient [because they are on the same site]... before I used to go over to where they were based every other month, but that meant saving all my questions up. Whereas now they are here… we have a good relationship, they are more welcoming and open to me just running things by them, it's all less formal and quicker." (Liverpool)

- **Regular multi-disciplinary team meetings** between cardiology and genetics colleagues, which provided additional insights around complex cases, as well as attendance at each other's meetings.
- **Development of shared approaches**, where cardiology and genetic department colleagues working closer together had helped to catalyse key changes such as starting to digitise notes.

  "It used to be challenging in terms of approaching screening as we didn't have the genetic information for much of the service [because it was held by genetics colleagues]. A lot of geneticists would have paper notes and they are only just catching up [with digitising of notes]. Mainstreaming has been brilliant for that – we can take ownership of those results, and provide a bit more directional screening for the patients knowing if there is a predictive test out there for them or not." (Leeds)

Self-referral pathways

Several sites including Leeds and Southampton developed self-referral pathways into their service. This helped to overcome a blockage in referrals from GPs, who would not necessarily make a referral off the back of a cascade testing letter if an initial ECG and echocardiogram returned normal results (despite lowered referral criteria).

"Because GPs did give a lot of push back and were not always making the referral… but it should be done, they should refer even if those tests are normal. Also coming into the specialty, I didn't realise at first that when there is a family history, the criteria is lowered. I will maybe change the letter to make it more clear to GPs." (Southampton)

Self-referral supported increased access to care for relatives and enabled them to be seen much faster, because they did not need a GP referral or cardiology appointment to access genetic counselling or testing. Self-referral was also reported to reduce anxiety among patients as they did not have to wait as long to be seen and had a named contact that they could immediately call in the interim.

Some sites highlighted, however, that self-referral pathways only benefited patients who lived in the same local area as the ICC service, and could not be used by relatives further afield.

Improved service pathways and triage

Most services highlighted their development of more effective triage of patients between consultants and specialist nurses as critical to their success and capacity to cope with increased referrals. The specialist nurses funded by Miles Frost Fund were band 7, autonomous practitioners who are able to manage their own caseload. This tended to involve:

- **Allocation of low-risk patients** (not likely to develop symptoms) to nurses for follow-up, who then manage and monitor tests, answer questions and return results.

  "I can look after them while [the doctor sees] all the new patients. This is good for patients, they have reduced anxiety, patients realising they have not been forgotten by us. It doesn't matter how well people are, with this condition they will always be worried to some extent that something could happen, and if they haven't been seen for a long time the risk might be greater."
  (Birmingham)

- **Regular meetings between consultants and nurses** to discuss cases where the condition might deteriorate and might need to be elevated for consultant care.
- **Adapted letters for patients** in Birmingham, which provided consultant details in line with some patients' preconceptions of seniority, but also directed initial queries towards specialist nurses (which also enabled quicker responses).

One service was also exploring an additional level of triage where low risk patients would be supported by non-nursing staff to complete a follow-up symptoms questionnaire and have an echocardiogram and blood test in the community. Specialist nurses would then return the results.

However, though triage was a key enabler from a service delivery perspective, several sites highlighted that a balanced approach was necessary to support patient and staff satisfaction. For example, sites reported incidents of where patients wanted to see consultants rather than nurses, while a nurse caseload of only low risk patients or relatives without a defined condition was not professionally satisfying.

Telephone/video clinics

All sites had implemented or expanded their use of virtual appointments during the pandemic. While this was initially out of necessity due to public health restrictions limiting face-to-face contact and clinic space, remote appointments were also reported to have a range of benefits for services.

The main benefits outlined for services and patients were:

- **Efficiencies for clinicians** for example, being able to fit in calls as and when they had time, rather than within clinic space.
- **Reduced waiting time** for patients, as results could be returned quicker than face-to-face clinics.

- **Reduced travel time** and costs for patients that live further away from the hospital, and for those of working age who might prefer to take less time out of work. This was particularly beneficial for stable patients that only needed short appointments for surveillance or standard test results.
- **Improved dynamics** between clinicians and patients, potentially because patients felt less 'pressured' to overreport symptoms to justify the time they had taken off for appointments.

  "When you phone patients in their own home, they behave and sound differently to when they are in clinic. They are more relaxed… when they take a day off work, they feel that they have to tell you things… they don't want a quick "are you alright conversation?" where they feel short-changed." (Leeds)
- **Improved engagement with some groups of patients**, such as patients in their early twenties or teenagers.

However, virtual appointments were not appropriate for all patients and scenarios and could also cause challenges within services (see 'impacts of Covid – move to or acceleration in use of video and phone appointments').

Administrative support

As noted earlier, administrative roles were not funded as part of Phase 1 but Phase 2 sites were encouraged to consider including such a role in their applications, based on feedback from Phase 1 sites. Administrative support within services was reported to underpin improved communication with patients, improved coordination of patient testing and records and, linked to this, increased capacity within clinics.

Administrative support roles varied across sites, from specialised roles such as family history coordinators to more general support from administrators or private secretaries, but was felt to be most effective when they were:

- Fully funded/recruited from **service set-up** onwards, due to the amount of initial work involved in collating and sifting through existing patient records.
- Split across **multiple administrative positions** in larger services to cope with higher volumes of administrative work compared to other health care areas, and reduce risk around unanticipated absence and turnover.
- **Dedicated to supporting specific staff members**, such as helping specialist nurses to collate information before and after clinics, as well as booking and managing appointments with patients and relatives.

  "When I started we didn't employ admin until a year into the pilot – a big delay… that was tricky, it was a long time without admin support. The figures [of patients seen/tested] since admin support has been in place have rocketed" (Southampton)
- Supported by **clear processes** and **monitoring tools and databases** that enable easy searching and indexing of patients and relatives.

Where services had struggled to recruit or retain good administrative support, sites reported a wide range of challenges that affected services and patients (see 'challenges – lack of administrative support').

Databases and digitised records

Most sites developed patient databases (or electronic patient records) for HCM or ICC patients as part of the Miles Frost Fund.

What databases looked like in practice varied between sites, ranging from the development of bespoke databases by in-house IT teams, the purchase of external software such as Kardex, or Excel sheets. Sites that developed or used database software were also able to start recording (or sort existing) digitised patient notes, which supported information sharing between different staff members (e.g. specialist nurses and genetic counsellors).

Patient databases enabled a range of benefits in terms of how services delivered care:

- **Patient management** – a clearer picture of what proportion of patients have been gene tested and predictive software to help support effective patient follow-up.

  "The Registry helps you manage your patients really easily… we input genetics, who's been tested, who has Atrial fibrillation, their ECS risk score [that predicts their likelihood of having an event in the next 5 years]. In a team, things can get overlooked, but recording everything means you can keep a track on things so they don't get lost. Because we have a lot of people who seem stable but can go downhill quickly." (Birmingham)

- **More consistent follow-up** – more organised patient records supported better patient care, such as prompting staff when they were due to follow-up with patients.
- **Better prognosis prediction** – building a bank of long-term, follow-up data for HCM patients helped consultants and nurses to have a better idea of what to say to people with the same cardiomyopathy, especially where relatives are referred in with specific mutations that are not yet fully understood.

  "It's helpful for patients, we can say don't worry too much, just because one person in your family has x, we know other relatives who don't etc." (East of Scotland)

- **Supporting advances in medical research** – comprehensive records of patients' conditions, genetic data and history enabled sites to support advances in treatment, for example responding to recent petitions regarding new clinical trials of drugs focused on obstructive HCM, or research on other ICCs in Manchester.

  "There's [a person] who wants to do a project with Lamin Cardiomyopathy… we trawled the database and hit 11 people. It was done in ten minutes, rather than screen hundreds and hundreds of notes. We have a practical solution to a problem." (Manchester)

Similar to how the Miles Frost Fund was credited as the catalyst for the development of services, funding for the development of databases was highlighted as a valuable activity as NHS funding is typically focused on directly supporting clinical care. One site felt that standardisation across databases should be a key BHF priority, as aggregation across services would create the largest database in the world. Lack of standardisation and inconsistency has made it problematic for BHF to aggregate or compare data across sites.

Development of SOPs and templates

The development of clear Standard Operating Procedures (SOPs), guidance documents and templates that clearly outlines pathways, testing and key activities underpinned the effective development and growth of services.

"We have created an SOP for nurse led clinics, one for virtual clinics, for genetic reporting, for gathering family histories, accepting referrals, requesting tests. So there was a lot of upfront work." (Birmingham)

In particular, clear referral pathways and criteria was reported to reduce previous inefficiencies around sifting through potential patients. One service also created a competencies framework to support the training and development of specialist nurses in both screening and genetic counselling.

The development of these documents was also reported to support the long-term sustainability of new services for when current leads move on.

4.3. Challenges

There were ongoing capacity challenges for all sites, due largely to Covid backlog, and described in the next section. In addition, challenges fell into a number of categories, set out below.

Lack of administrative support

By far the most common challenge was around lack of or insufficient admin support within services, due to lack of funding for admin. The impact of inadequate admin included:

- Errors, such as double-booking, and patients not knowing whether their appointment was telephone or face to face
- Impacts on patients, such as waiting around due to double booked appointments, frustration, unnecessarily travelling to appointment
- Delays, as bottlenecks develop where admin capacity is insufficient(such as delays in sending out letters)
- Patient databases not being kept up to date
- Inappropriate use of clinician time, where clinicians spend time on tasks that could be undertaken by an administrator
- Knock-on effects on all aspects of service delivery:

"We are woefully underfunded in terms of admin. It is a big issue – it becomes a chaos spiral. If things are not well organised, you spend all day on the phone dealing with patients who are trying to chase you up and you can't plan ahead. Constantly chasing your tail." (Liverpool)

In some sites, it had taken time to get admin in place, and some recognised that they had initially underestimated the amount of admin support that would be required.

Even where admin is funded, several sites identified an issue around high turnover within administrative roles, suggesting this could be due to the workload and pay.

Staff absence and turnover

Several sites had been affected by staff sickness absence and turnover. Many noted the risk inherent in having only one person in a given role – in that if that person was absent, particularly for a long period, the service would inevitably be seriously impacted. Approaches to mitigate this were:

- Where there is more than one nurse, or genetic counsellor, or administrator, this was seen to act as a buffer during absence and turnover
- Where it was not possible to have more than one person in the same role, building wider skillsets and capabilities could also enable flexibility and mitigate against absence (for example, where a specialist nurse also had genetic counselling skills, such as in Wales)

Absence of staff in administrative roles, as well as clinical ones, also had significant impacts on service delivery (as noted above).

Changes in genetic testing provision

Since the start of the programme, sites noted changes to the provision of genetic testing nationally, with the introduction of national testing criteria and the centralising of labs. This was not identified as a challenge as such, but recognised as a changing situation requiring adaptation and adjustment. Some interviewees missed the support with interpretation that they had received under the previous arrangements, where they had relationships with the lab staff, but again this was not seen to have had a significant negative impact.

Recruitment

Some sites had struggled with getting sign off for recruitment, and faced various other logistical challenges around recruitment, for example, agreeing banding for the nurses recruited, lack of suitably qualified applicants, and hiring specialist roles on a part-time basis. In several sites, including Leeds, East of Scotland and Wales, recruitment issues caused delays and took up clinical time.

Hub and spoke logistics

Establishing a hub and spoke model entailed a number of challenges, as experienced by Leeds and East of Scotland:

- **Finances**: the experience of setting up a service across different trusts and health boards was complicated; they had to put together a business case taking into account different infrastructure and reimbursement between the trusts. Different trusts and health boards also encountered challenges where spokes would not commit to funding roles at band 7 (as required by BHF funding)

- **Quality:** quality of scans was often different between the hub and spoke, and there were differences in terms of imaging and screening protocols (e.g. frequency, who is eligible for diagnostic testing). This created a risk of patient perceptions of inequitable care where families lived across different regions.
- **Systems**: different booking systems in hub and spoke led to some errors until this was spotted and resolved. Spokes often had separate patient databases that did not interface with the hub, which created extra administration as sites tracked data locally and then manually uploaded to a shared database.
- **Staffing**: sending staff out to spokes can leave a gap at the hub, so care is needed where resources are to be spread thinner in this way.

Other

Other delivery challenges experienced by Phase 2 sites were:

- Clinic space: challenges in securing space for new clinics to take place (Liverpool)
- IT: issues where cardiology and genetics were using different systems (paper vs electronic (Leeds)

4.4. Impacts of Covid

Reduction of service capacity due to redeployment of staff, leading to increased backlog of patients

All services were severely impacted by the Covid pandemic, with nurses (and genetic counsellors with nurse backgrounds) being redeployed away from the service, and face to face appointments being stopped or limited. Sites focused on urgent cases (e.g. those who are pregnant, and symptomatic patients), leaving many patients waiting. Even of those who were prioritised and invited into hospital, many did not attend due to fears around Covid. Social distancing rules applying to outpatients meant that fewer patients than usual could be seen (e.g. 6 per clinic session as compared to the usual 20, in one example).

All services reported building up a significant backlog during this period, especially coupled with ever-growing patient lists, as systems to identify relatives take effect.

With reduced capacity even for their core work of seeing patients and relatives, staff had to drop or postpone their secondary objectives of awareness-raising with wider professionals, and education via formal courses for nurses.

Set up of spoke clinics was delayed (in Leeds).

Increased anxiety for patients and families

Staff reported that patients and families experienced increased anxiety due to waiting longer for appointments and tests; with this leading to an increased volume of calls from patients, further adding to the burden on staff. Many patients were also anxious about the implications of having Covid because of their health condition, and contacted staff with questions about this and about vaccination.

Staff reported that restrictions on relatives being able to accompany patients to in-person appointments also affected patients in terms of their anxiety levels, willingness to attend appointments, and ability to absorb information during appointments.

"Even now patients are not allowed to bring a family member to clinics – which makes it a much more difficult experience for patients, it's emotionally charged, without a relative or whoever to provide support, they are stressed and they can't remember what they've been told in clinic, so that is leading to more follow up questions etc by telephone." (Liverpool)

Move to or acceleration in use of video and phone appointments

Sites that had already planned to incorporate telephone or video appointments within their service model tended to report more positive experiences of an acceleration towards this model as a result of the pandemic and public health restrictions.

However, other sites were less enthusiastic about switching to virtual channels and identified drawbacks:

- Less effective interaction than face to face, with some patients feeling less able to take in information or ask questions, and some staff feeling limited by not being able to read body language

  "I think a lot of younger patients that are working, they like the phone consultation because it's more convenient, and that has definitely helped uptake. But it is a lot of info to give on the phone – and you don't get the cues from the body language etc." (Southampton)

- Gathering of complex information on family history is more difficult, with some staff strongly preferring for this to take place in person
- Not possible to conduct physical examination, imaging/tests at the same time as the appointment, so increased admin time to arrange tests separately
- Generally lower quality of engagement with the patient, and therefore more chasing up/followup likely to be needed by clinician or admin staff to ensure next steps are taken (e.g. attend a test)

Overall, it appeared to come down to individual preference, both for staff and patients, as to whether they found virtual interactions effective. It was felt by a number of interviewees that they preferred to have initial appointments face to face, but that follow up appointments could take place remotely, once a relationship with the patient had been established. In terms of going forward, there was a general inclination towards continuing virtual appointments where appropriate, i.e. where there was no specific reason for them to be in person.

Moving physical testing out of clinics

Service efficiencies and patient experience[4] were reported to be improved by the approach adopted in Birmingham during Covid, where some types of tests were moved out of the hospital altogether, to community locations not necessarily within a healthcare setting:

"We were always keen on remote managing of people, because we have so many. Covid made this non-negotiable for the Trust – they had to make it happen that patients could do certain things outside the hospital. So now for a lot of my patients I can organise 24-hour tapes, bloods, echos etc, all to be done remotely, instead of at the same appointment with me in the hospital. People are in their houses, not taking up space in our clinics. The Trust opened lots of offsite labs – e.g. at Birmingham New Station. These off-site labs can be in any setting! It is a model that works. We can see more patients this way." (Birmingham)

4.5. Sustainability

Continuation of services, post programme funding

In the majority of sites, Trusts had taken on the funding of the posts created by the Miles Frost Fund on a permanent basis, as per the original intention behind the design of the programme (which required Trusts to part-fund the roles during the funded period).

Only in Manchester were funded posts not taken forward at the end of the programme, due to a combination of factors including the redeployment of staff during the pandemic response, the merger of two teaching hospitals and changes in internal management.

In East of Scotland, 3 of the 5 health boards that aimed to access funded posts did not ultimately receive BHF funding, due to challenges around committing to extend funding for band 7 roles (which was the minimum requirement for BHF and the role) and a moratorium on new roles during the pandemic. One board subsequently funded a Band 6 role themselves.

Making the case to commissioners

When asked about the mechanisms or drivers through which funding was secured from Trusts post-funding, interviewees noted a number of drivers for commissioners to make the funded posts substantive:

- Evidencing demand

  "I have kept a record of everything I do and the workload has demonstrated very clearly that there is a need for me!" (Birmingham)

- Demonstrating alignment with wider strategic priorities including those of integrated Care Systems and the Genomic Medicine Services Alliances

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[4] Patient views were captured via a patient focus group, held by the service in Birmingham

- Covering staff costs with available tariff.

In Wales, the support of BHF was reported to have been helpful in making the case to the commissioning body for specialist services in Wales (WHSSC).

"Jo [from BHF] helped us pull things together, identifying underspend, pulling meetings together with BHF, and it was her who helped about using our underspend to continue funding my role until the end of the financial year, before we got the permanent funding in place. With the public – we had done a few launches of the new service - BHF helped with media, getting TV and radio sorted – and helped us put our case together to WHSSC." (Wales)

While interviewees were not always clear on the specific reasons or processes involved in securing post-programme funding from Trusts, some did note that it was not straightforward, and there were instances where staff were uncertain as to the future of their post while negotiations were underway – with a negative effect on staff wellbeing during this time.

Where the Trust in Manchester did not take on the funded posts on a substantive basis, this was amid a turbulent context where two teaching hospitals merged, internal managers changed several times and new management were able to renege on the commitment to extend roles.

Future plans and aspirations for services

Sites reported a range of plans and aspirations for the continuing development and, in some cases, expansion of services. Common future-focused themes across sites were as follows:

- **Tackle backlog**: services continue to struggle with demand due to a) backlog of patients accrued during Covid pandemic, when staff were redeployed and/or a virtual service did not engage patients adequately, and b) the nature of a cascade testing service leading to the identification of more patients who need to be treated and monitored in the long term. One service (Leeds) was creating additional appointment slots, for example by reducing duration of MDTs.
- **Recruit additional staff**: a couple of services were intending to recruit an additional staff member, one of these (time limited) as part of the Sudden Unexpected Death programme (a BHF and NHS Coronial Service programme) (in Bristol), and the other an additional nurse (in Birmingham).
- **Resume education and awareness-raising** with wider professionals: this was an aspect of the pilots that had tended to be reduced because of Covid, but staff were keen to re-commence work such as attending GP meetings, regional cardiac network events etc. Some had specific plans to engage with professionals within or linked to their service, for example, in Southampton, to work with the heart failure and arrhythmia nurses to help encourage referrals
- **Expand community outreach and engagement**: sites were conscious that there are many potential probands and relatives as yet not known to services. In Birmingham, there was appetite to build community-based provision as a way of increasing identification of these:

> *"The idea is doing as much as possible locally in the community, because if you can make it easier in terms of travelling to get tests then you will get more patients doing it. And strengthen engagement because it's in the community. The challenge is how you orchestrate and manage it." (Birmingham)*

- **Further skills development of staff and refinement of pathways**: staff in funded posts were keen to continue developing both their own skills and the service more broadly, for example, in Liverpool, the genetic counsellor is working with a psychologist to a) gain knowledge and tools to better support patients in clinic and b) enable appropriate referrals for patients who need more therapeutic support.
- **Develop resources**: some sites were in the process of developing resources for patients (an information video, in Leeds) or clinicians (a learning resource to support the genetic test directory, aimed at general cardiologists, in Southampton).
- **Develop patient and family databases**: several sites talked about continuing to use and develop their patient database or registry, both as a tool to better support current patients and families, and a data source for developing better understanding of HCM variants and inheritance patterns.
- **Continue to develop understanding of genetics**: with databases as an essential supporting tool, some site leads were keen to contribute to developing the wider understanding of HCM through more joined up working across services and geographical regions.

In Leeds, future plans are developing based on a shift in the delivery model prompted by Covid, which challenged the model of nurses going out to visit and deliver within spokes. Instead, they are looking to strengthen services within spokes so that more straightforward patients can be managed locally:

"What we have traditionally done is anyone with or at risk of ICC needs to be absorbed into our service. We need to be more selective, we need strong spokes to devolve more straightforward cases to them. Going forward, we need to encourage districts to find own funding for specialist nurses and maintain our nurses working in Leeds."

In Wales, there is significant opportunity and aspiration for development of services covering other parts of Wales, thanks to 'proof of concept' in the pilot area:

"The knock-on effect has been national, across Wales, not just local to us in Swansea and south west Wales – it has highlighted that there were services that were missing, and this is a big step towards equitable access for Wales. I hope that other regions of Wales will attract permanent funding to develop a service too."

5. Reflections on the grant programme

This chapter brings together reflections on the administration of the grant programme and its evaluation.

Interviewees were invited to reflect on the level of support that the BHF provided during the funding period, as well as the independent evaluation undertaken by Traverse. These views are summarised anonymously below

5.1. Programme support

Communications and support from BHF

The management of the grant programme was praised, in terms of the support offered by BHF and communications between BHF and the funded sites. Features of this identified by interviewees included:

- Proactive in giving useful advice at the application stage, for example:

  "[BHF] encouraged us to engage with senior executives at the hospital – I hadn't foreseen how useful that would be, and it was, incredibly." (Liverpool)

- Flexible, responsive and pragmatic approach throughout, with BHF and named individuals within the programme seen to be sensitive to the challenges and context of individual sites. This was raised in relation to challenges during Covid, such as redeployment of staff, and others, such as flex in the timing of submission of data monitoring returns.
- Provided practical support (in terms of managing finances and processes) and influencing (through public promotion and meeting with Trusts) around continuation of services post-funding:

  "It definitely helped that it was high profile and BHF were supporting us and raising our profile. That applied pressure [on commissioners] around maintaining the service." (Wales)

One site (Manchester) would have liked more proactive support in helping to negotiate with internal managers after they reneged on extending funding for the substantive post. The same site also highlighted how returning evaluation findings to sites in advance of when they needed to submit business cases for continued funding may have supported them to secure the role – however, this was not possible, as the evaluation was paused during Covid to enable staff to focus on delivering services.

Opportunities to share learning

The events held by BHF for funded sites to network and share learning were widely valued, both by lead clinicians and by the nurses and genetic counsellors in funded roles. The key value of these events was in facilitating leads and staff to find out about different service delivery models, and to exchange ideas and ways of addressing challenges:

"Meeting people from other areas and talking to them about how they are setting up their service – going beyond how you are doing it, learning how people are working in a different context , or how they are approaching the same challenges differently." (Leeds)

Because of Covid-19, these events were not able to take place after early 2020. Many would have liked to have more opportunities to share learnings with other sites, and felt there would have been value in maintaining better contact with those they had established relationships with during the earlier part of the programme.

"We have kept in touch, we will send emails, but meeting in person makes such a big difference – you find that the longer it is since you have actually seen someone, the less likely you are to stay in touch." (Liverpool)

5.2. Programme evaluation

Data monitoring requirements

Interviewees were broadly supportive and understanding of the principles of evaluation and data monitoring, and felt it was entirely reasonable for BHF to require regular data returns (i.e. the figures they were asked to collate and submit to BHF on a quarterly basis). However, there was variation in how easy or difficult sites had found it to collect and provide this data. Some reflected that the specific data monitoring requirements for this programme were unduly onerous (e.g. complex or excessive), and questioned the value of the data monitoring requirements and whether the specific figures and depth of information had been necessary.

Some interviewees noted that it had been useful to be impelled to set up and reinforce the process of collecting data, and were continuing to collect and monitor data on an ongoing basis, for reasons including:

- Understanding demand and enabling better service planning
- Evidencing demand and effectiveness of the service to commissioners (as discussed under Sustainability)
- Contributing to better understanding of patients and their conditions

> *"[Reports were] Time consuming to put together – it would take a full day, and I was thinking, this isn't a good use of my time, but actually it was. It gave me an oversight of the service, it's like an audit and that's always useful. It reflected on how well the review docs etc on the EPR were being completed. I probably would not have looked at the data otherwise, or not to the same extent." (Birmingham)*

Qualitative evaluation

Staff were generally willing and able to take part in evaluation interviews, noting that this aspect of the evaluation had not been unduly burdensome (three interviews over 3 years at most) and had been beneficial for encouraging self-reflection. The production and sharing of the interim evaluation report was valued although interviewees tended to place greater value on learning directly from other sites, than on reading a written report.

Timing

Due to the evaluation being paused during the Covid-19 pandemic, the final evaluation activity (this report) was not conducted until early 2022 – long after sites had completed their funded period. Because of this, there was a missed opportunity for the evaluation to have informed and supported their business cases to commissioners.

6. Conclusions and recommendations

This chapter draws together learning from across the report to make recommendations for HCM and ICC services and for BHF in relation to grants programmes for ICC services.

Pilot sites receiving Miles Frost funding via BHF in Phase 2 reported a wide range of significant benefits to patients, families, staff and services, and generated a wealth of learning for service development applicable to HCM services and ICC services more broadly.

Some of the key impacts that sites delivered through the funding included:

- **Increased patient access to HCM testing and cascade genetic testing** prior to the pandemic and reduced waiting times – realised via increased clinic time, improved identification, and improved referral routes.
    - However subsequent redeployment of staff means that many sites have accrued a backlog of patients and now have longer waiting lists.
- **Increased convenience of care** – reduced travel requirement for patients (via parallel clinics, more care delivered in one day and use of technology for virtual appointments)
    - However, virtual clinics do not work well for everyone – patients and staff alike
- **More resilient services**, due to increased capacity to cover staff absence, timely access to specialist expertise.
- **Services functioning better**, with senior clinicians' time freed up thanks to nurse-led clinics managing low-risk patient caseloads, better administrative support and better organised and managed patient records. Many also reported that, pre pandemic, staff were enjoying greater satisfaction and confidence in their roles thanks to training and development opportunities, more varied workloads, improved support within teams and reduced turnover.

Service development and expansion has also helped raise wider awareness of ICCs, with patients directed into services and now receiving more appropriate care, while funding has kickstarted wider changes in Wales, and in some sites around band 7 requirements.

Key enablers of success identified across Phase 2 sites included:

- **Supporting specialist nurses to lead** – through strong training and development, a supportive learning environment and dedicated administrative support

- **Bringing generalist genetics into the fold** – either through 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 function, good databases; all underpinned by SOPs and templates.

All of the above represent a checklist of considerations for sites looking to develop effective services, and for BHF in relation to supporting service development.

Other areas where BHF may consider next steps in relation to HCM, suggested by participants in the evaluation, include:

1. A **national conversation to engage commissioners**: BHF should continue to support a national discussion that can help clinicians engage commissioners on a local level. Raising the profile of HCM and other ICCs and ensuring it is a national agenda helps to get the attention of commissioners, in the context of competing demands from different specialities in the wake of the pandemic.
2. A **national database for cardiomyopathies**: many clinicians expressed an appetite for this and talked about the potential benefits; there may be scope for BHF to support or influence around this, and feed it into the work with coronial services around Suddent Unexpected Death (SUD).

Recommendations for BHF in relation to grant funding more generally included:

1. **Provide opportunities to share learning**, because these are highly valued by clinicians. Many felt this was a key benefit of being part of a wider programme, and had been frustrated that it had been constrained by Covid
    - Some noted that they got the most benefit from meeting in person and were willing to travel to events to do so
    - Online platforms to support networking could also have a role
2. **Funding administrative as well as clinical roles** can make a huge difference. Inadequate admin (where admin had not been funded) was one of the biggest challenges to sites in running an effective and efficient service. BHF should encourage applicants to consider this, along with thinking about clinic space, as part of the essential infrastructure that supports clinicians to deliver care.
3. **Use BHF's profile and influencing power** to support funded sites, both with external promotion of services and internal influencing with senior leaders.
4. **Consider how funding structures can best be designed** so that post-programme, core funding can be secured more certainly/easily from trusts, and in a more timely manner so that staff are not in limbo during negotiations.

7. Case study examples

The following pages set out a selection of findings from specific pilot sites, with a key theme identified for each. This is not a complete picture of impacts and experiences at each site but intended to bring to life some of the findings from the report, within their pilot-specific context.

The examples shared are as follows:

- Birmingham: implementing and using a patient Registry
- Bristol: kickstarting wider awareness and cultural change around ICCs
- Leeds: rethinking the hub and spoke model
- Liverpool: co-locating genetic counselling and testing within the ICC service
- Manchester: building a database to make services more efficient
- East of Scotland: improved teamwork and reduced travel time through virtual communication
- Southampton: dedicated administrative support for specialist nurse
- Wales: seed funding for a regional service for ICCs

Birmingham: implementing and using a patient Registry

Overview

The funding of a specialist nurse by the Miles Frost Fund brought additional capacity into the service. This created time to for staff to make more consistent and effective use of the patient database.

Outcomes

- Identification of patients who have not been gene-tested in the past, and inviting them to take up the offer
- Efficiencies in terms of easily and quickly accessing information about individual patients
- Keeping track of patients who may have unmet needs or changing conditions

Next steps

Birmingham now has a large patient list who will need screening. They plan to recruit a second nurse to support this busy caseload and also explore whether some tasks with low-risk patients could be supported by non-nursing staff (e.g. symptoms questionnaire, ECG and blood test in the community). They also plan to target specific groups not yet engaged in the service, such as minority ethnic communities.

Implementing and using a patient registry

"The Registry helps you manage your patients really easily, for example, from just looking at a pie chart I can see what proportion of patients have been gene-tested.

We input genetics results, who's been tested, who has atrial fibrillation, ECS risk score... It shows us whether they have been discussed at MDT meetings. In a small – and even in a large – team, things can get overlooked. But recording everything means you can keep a track, so things don't get lost. Because we have a lot of people who seem stable but can go downhill quickly. If I haven't seen a patient before, I can see all their relevant information, without going trawling through notes.

[It's designed] so when you are inputting a patient, you can get it to show all the breathless people, you can triangulate that with other factors, and with their treatment. Whereas if you look at [the EPR system], you are looking at different pages for everything. Registry can generate all sorts of lists, like…one starting from the youngest patients first, so you can spot where something doesn't look right for someone in that age group and they may need to be on transplant list. It really helps to flag when, 'this person is slipping downhill and we need to do something'.

It's a big and difficult job collecting all this data but it's paying off. Both [the consultant] and I agree it makes a big difference for our team."

Bristol: kickstarting wider awareness and cultural change around ICCs

Overview

Miles Frost Fund supported a full-time Band 7 cardiomyopathy nurse and part-time administrator to assist with MDTs and cardiomyopathy clinic coordination.

This aimed to increase the service's capacity for nurse-led outpatient review, which would in turn help ensure that all patients and family members have appropriate phenotype assessment and genetic testing with cascade screening.

Outcomes

- Miles Frost funding enabled the structured creation of a developed service in a short period of time, rather than much slower, unplanned growth
- Establishment of the service has created a clear pathway for cardiologists in in terms of how you manage a patient with cardiomyopathy and undertake cascade testing. This has kickstarted a wider cultural change among cardiologists in the local area.
- Improved genetic knowledge and expertise among all team members as a result of more training and development opportunities. This has helped team members have a greater appreciation of genetic testing complexity and when to do it or not.

Next steps

The cardiomyopathy nurse and MDT coordinator have been fully adopted into the Trust. The service has since received further funding for a new ICC consultant with accompanying administrative support, and is linked to the NHS, Coronial Service and BHF's Sudden Unexpected Death (SUD) programme.

Kickstarting wider awareness and cultural change around ICCs

"From a cardiologist standpoint, the benefit has been getting a very clear pathway in terms of how you manage a patient with cardiomyopathy and cascade testing.

One of the biggest things [that has happened] is focused on cardiologists in general… [we are now in a position where] when you deal with a cardiomyopathy it is not just the patient in front of you, it's a familial disease. By setting up this service, they appreciate that for the 50-year old man with cardiomyopathy, his sons do need to be reviewed and that there is a process for that.

Other hospitals will now contact us to sort out that aspect of it. That's a huge benefit… now if you have cardiomyopathy in our region we expect you to be seen, have tests and your family assessed. We expect that to happen, whereas years ago it would have been serendipity."

Leeds: rethinking the hub and spoke model

Overview

Miles Frost Fund supported a full-time clinical nurse specialist, full-time genetics counsellor and part-time administrator.

This aimed to support a regional ICC network across Leeds and six local trusts in a hub and spoke model of care, where the six local spokes would be encouraged to refer all affected individuals with HCM to Leeds for assessment. Relatives of affected individuals requiring clinical or genetic testing would then be seen in a spoke by a specialist team, supported by the hub. However, establishment of this network was severely hindered by the pandemic and is now not as relevant and being rethought.

Outcomes

- Improved capacity for identification and follow-up in Leeds, resulting in highest overall activity ever seen with more new patients and follow-up appointments (some by telephone). Clinical nurse specialists have increased the proportion of follow-up cases that they manage
- More predictive testing and patients being seen in a timely fashion due to extra genetics counsellor capacity within service in Leeds
- Closer working established between clinical nurse specialists and genetics in Leeds, despite challenges around shared data storage

Next steps

The funded posts have been fully adopted into the Trust. Leeds' focus in the short-term is on clearing the backlog of patients that has accrued over the pandemic through extra clinics, longer clinic hours and reducing time dedicated to MDTs. They are also pulling additional video resources together for patients.

Rethinking hub and spoke models

"[The pandemic highlighted that] you have to constantly evolve... [the plan was] have a hub and follow-up devolved to the spokes, hub nurses to go out and manage follow-ups with consultant cardiologists in clinics. The pandemic has thrown that into question with telephone review… we now have new ideas that weren't being considered before.

We still need the spokes, but I don't think sending nurses out to do clinics in the spokes is going to be the right model now. That is time better spent seeing patients in Leeds. What we have traditionally done is anyone with or at risk of ICC needs to be absorbed into our service. We need to be more selective, we need strong spokes [so that we can] devolve more straightforward cases to them. Going forward, we need to encourage District General Hospitals to find their own funding for specialist nurses and maintain our nurses working in Leeds."

Liverpool: co-locating genetic counselling and testing within the ICC service

Overview

Prior to the Miles Frost funding, diagnostic testing (for patients) was done at the cardiology service at the Liverpool Heart and Chest Hospital, but predictive testing, for family members, took place at the Liverpool Women's Hospital, where the genetic counselling service was based.

Many family members did not attend their appointment at the Women's Hospital, because they did not understand why they were being sent there:

"People wouldn't turn up because it was, 'it's for women', why am I going there?"

Now, genetic counsellors are based on site within the cardiology service at the Liverpool Heart and Chest Hospital, with their clinics running in parallel with the consultant and nurse clinic sessions.

Outcomes

- Increased attendance rates at genetic counselling appointments
- Improved patient experience, in terms of a joined-up service in which the purpose of the genetic test is better understood by patients
- Increased capacity and knowledge of genetic counsellors to deliver the service to cardiac patients and families

Next steps

A business case for the roles was submitted to the hospital to continue the service, and capacity has increased to include two people in each key role: cardiologist, nurse, genetic counsellor, and clinical fellow, one of whom is working to develop a transition service for patients moving from paediatric to adult services.

Co-locating genetic counselling and testing within the ICC service

"Having genetic counsellors on site makes the service more holistic, complete, appropriate. Now everything is on the same site, people get it. Patients understand the process a lot better.

We have the paperwork in the same hospital. It felt disjointed to patients before, but now we have one electronic patient record instead of keeping information separately in the separate sites.

Patients would previously be referred into general genetic counselling clinic, so they would be on a much larger waiting list. Now the service is more specialist, and patients are only on a waiting list with other people in the cardiac service."

Manchester: building a database to make services more efficient

Overview

Manchester aimed to reconfigure their clinical ICC service with the support of the Miles Frost Fund, through adopting an effective triage strategy for new ICC referrals and recruiting a nurse specialist to initiate diagnostic genetic testing within cardiology clinics.

However, despite early successes in reaching patients, reducing waiting times and the establishment of a new cardiomyopathy database, the service struggled during the pandemic. The redeployment of staff during the pandemic response, merger of two teaching hospitals and changes in internal management meant that the Trust did not continue to support the BHF post.

Outcomes

- Mainstreaming genetic testing initially reduced waiting times for tests from around five months to six weeks
- Improved patient experience through the support of a specialist nurse
- However, loss of capacity means that capacity to see patients and do genetic testing has decreased, and backlogs have increased

Building a database to make services more efficient

"[The BHF nurse and IT team] created a database… of all patients and what their conditions are… It meant that we could link all the family members… we knew how many we were seeing; who was the pro-band; their genetic test results; any information about family members, pedigrees; their referral is on there as well, when they've been to clinic what the outcome was as well. It was easy to check and see what was happening with patients."

"If there's one legacy of this funding it's that database... there is something like 2,200+ people in there. It's useful, allows us to launch projects not from a standing start. [For example], there's a guy who wants to do a project with Lamin cardiomyopathy… we trawled the database and hit 11 people. It was done in ten minutes rather than screen hundreds and hundreds of notes. We have a practical solution to a problem.

If we were in a well-funded environment, we could build it out further…. in general the NHS doesn't support these things that sit behind services that make them more efficient and more responsive. The NHS funds the bare minimum of clinical care… it won't fund things that allow service development."

East of Scotland: improved teamwork and reduced travel time through virtual communication

Overview

East of Scotland aimed to enhance current ICC services across different health boards to meet the needs of HCM patients, and establish a Scotland wide service to improve cascade screening for HCM. This was intended to complement the previous BHF award in the West of Scotland.

The site aimed to recruit a lead in NHS Tayside and backfill specialist cardiac nurses in Lothian, Grampian, Fife and the Highlands health boards at band 7. However, challenges around committing to band 7 posts and moratorium on new hires in Fife, Lothian and the Highlands meant that roles were not recruited through BHF in these regions. Although, Highlands ultimately funded the role themselves and Lothian subsequently restructured their service.

Outcomes

- Funding catalysed the development of the service across East of Scotland, including in regions that did not receive BHF funding
- Reduced patient travel times and costs in largely rural areas following the introduction of telephone review where appropriate
- Supported wider Network for Inherited Cardiac Conditions Scotland (NICCs) development, including development of screening protocols etc.

Next steps

The BHF roles have been absorbed into Tayside and Grampian. The role has been welcomed by cardiology and the next step is to ensure that bespoke training is available to support nurses in Scotland. The service is also looking to expand its work with screening dilated cardiomyopathies.

Improved teamwork and reduced travel time through virtual communication

"In some ways the pandemic has made things easier. We cover a very big geographic area in the north of Scotland: Shetland, Orkney, Highland, Grampian. Paradoxically the need to do everything by video improved communication. Rather than travel to staff meetings, we did it digitally. I don't think the NHS would have put it into action quite so quickly were it not for the pandemic. We have staff in the highlands who we now meet with regularly… in the past they would have to come to Aberdeen, or we would go there, now with video it's every single week. All the staff know what's going on better e.g. tests available, screening available, what protocols are."

"We changed from f2f to telephone review. That worked quite nicely for my patient group – the 'well' patients that we only do surveillance on. Those are patients who don't necessarily need to come in e.g. it saves them time. However, if we felt someone was anxious, we could still easily arrange for them to come into hospital."

Southampton: dedicated administrative support for the nurse specialist

Overview

The Miles Frost funded two roles in Southampton, a nurse specialist and a dedicated administrator to support the nurse specialist. They work closely and collaboratively together to allocate tasks to make best use of the nurse's time, prioritise patients appropriately, and provide a smooth and joined up service to patients.

Outcomes

- Patients and relatives are better engaged and less likely to slip through the net; the administrator and nurse have clear systems and tools in place to keep track of patients, and the administrator calls people before appointments
- The nurse can focus on supporting patients in terms of their clinical care, without having to spend time on administrative tasks
- Administrator job satisfaction means less turnover, and a better patient service

Next steps

The roles were made permanent in January 2022. Southampton are interested in developing a database of all patients and relatives who require screening, though acknowledged that this will require funding and negotiating data permissions.

Dedicated administrative support for the nurse specialist

"We have a good working relationship, between me [admin] and the nurse. We speak to each other often, talk about things promptly and openly. There are peaks and troughs with volume of work, but the benefit of working closely with [the nurse] is I can make her aware and say, 'what should I do first?'

We have a clear process, roles and sufficient time to ensure patients don't fall off the radar. [Following referral,] I speak to the patient and I explain why I am calling, why they have been asked to come and then I send out the letter, get the appointment confirmed. [Afterwards] they get a standard letter, [the nurse] will fill in the gaps for me to send. We ask them to take a blood test form to their local hospital or GP.

We have set up a system to keep an eye on whether people gone for their blood tests yet. If I see they haven't gone, I'll contact them, and some people say, 'oh I don't want to any more'. Then the nurse will go back to them, to make sure they are making an informed decision. We have set up [a system] for chasing – with the date I last spoke to the patient, what they said they were going to do. This is so useful when someone has said they want to do the blood test, but they haven't got around to it. [The nurse] receives an email copy of blood report and I will update the spreadsheet when I see this. [It] Moves it all forward. And if someone gets ill because they didn't take up our support, then at least we can feel like we have done our best to chase. Instead of letting people slip through the net."

Wales: seed funding for a regional service for ICCs

Overview

Prior to the Miles Frost funding, there was no formally commissioned ICC service in south west Wales. ICC patients were cared for within general cardiology clinics in district hospitals, with the support of a tertiary arrhythmia service for complex or higher risk patients. Under this arrangement, different members of a family could be managed across many clinics and services, and information was not systematically shared or easy to share.

The funding of a specialist nurse post enabled the development of a structured service, predominantly designed and run by the nurse, with the support of the lead consultant, the genetics service and arrythmia nurses.

Outcomes

- Made the case for the commissioning of a **regional service for south west Wales**, with permanent funding for the specialist nurse and two assistant ICC nurses, as well as for dedicated consultant time
- Helping to secure commissioning of **ICC services across Wales**.

Next steps

The special nurse post is now fully funded. The Miles Frost Fund more broadly has been a catalyst for service development across Wales, highlighting gaps in services beyond Swansea and south west Wales. It is anticipated that other regions of Wales will likely attract permanent funding to develop services.

Seed funding for a regional service for ICCs

"The way services are commissioned in Wales is regional – long term, they have to be funded by WHSSC [the commissioning body for all the specialist services in Wales] and that crosses more than one health board. So our service, and seeking funding as part of Miles Frost, triggered an ICC service review across the whole of Wales – reviewing what type of ICC service should be expected and looking to either replicate what we have put in place, or design a service that is right for the whole of Wales. So not just in Swansea, it has impacted across Wales.

In terms of seed funding, you always have a risk reward calculation – where you are giving funding to established services to grow, that's great, but compared to us – it was a big risk for us, and it has really made a massive impact. If you can prove the concept, there is a big reward – and that's what we have done in Wales."

Appendix 1. Summary of evaluation of phase 1 sites

Six phase 1 sites were awarded grants of between approximately £40,000 and £200,000 in February 2017, with the expectation that NHS trusts would mainstream project activity into core service provision over time.

This executive summary presents the findings for five of the six phase 1 sites. One of the original six projects experienced delays in starting up and so was moved into Phase 2 for evaluation purposes. Phase 1 sites were:

- Northern Ireland Inherited Cardiac Conditions Service (Health and Social Care Trust)
- Guy's and St Thomas' NHS Foundation Trust Inherited Cardiac Conditions Clinic
- Sheffield and South Yorkshire Regional Inherited Cardiac Conditions Service (Sheffield Teaching Hospitals NHS Foundation Trust)
- West Scotland Genetic Service (NHS Greater Glasgow and Clyde)
- Oxford Regional Genetics Service (Oxford University Hospitals NHS Foundation Trust)

Phase 1 evaluation methodology

Traverse was commissioned by British Heart Foundation to:

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

In phase 1, the evaluation applied a mixed methods approach and collected qualitative data from pilot leads at three time points during the grant funding window, as well as data from pilot staff and patients.

Phase 1 context

All of the phase 1 sites had offered some form of cascade testing prior to the pilot. Services faced challenges stemming from exponential service growth without corresponding increases in staffing, and geographic inequities in care.

Across the phase 1 sites:

- Pilot sites implemented various forms of **hub-and-spoke** or **one-stop-shop** service models.

- Pilot 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 offer genetic testing for HCM. This, in turn, would lead to an increase in the number of identified HCM cases.

Phase 1 outcomes

Pilot leads identified distinct benefits for patients, as well as benefits for service staff and the wider healthcare context within which they operate.

- Phase 1 sites reported that they had **increased patient access to HCM testing and cascade genetic testing** as a result of the Miles Frost funding.
- Most sites also reported a range of other **benefits for patients**, including reduced waiting times, improved patient experience, and increased engagement of families and relatives.
- At a **service level**, phase 1 sites reported that they had increased their clinic capacity, improved efficiencies within the service and improved staff knowledge of HCM.
- At a **wider level**, the pilots were felt to have increased awareness of ICCs and specialist services and improved relationships between different centres, improving patient referrals management pathways across the system.
- Across the sites which provided cost data, **costs of the service** per new patient were similar (although there were variations in the quality and scope of data provided across sites)
- Sites that had **agreed ongoing funding at the outset** with their Trust Directorate or commissioners were optimistic about the sustainability of the new service and achievement of outcomes. Where this was not the case, other sites' future activities rest on approval of final business cases.

Phase 1 enablers

Where projects were felt to have worked well, pilot site leads and other staff highlighted a range of enabling factors. This included:

- **Nurse-led clinics** and accompanying triage were felt to provide patients with care appropriate to their level of need.
- **Coordinators** provided essential support around patient management and administrative tasks, freeing up staff to focus on clinic tasks and contributing to improved patient experience.
- Sheffield opted to employ **ICC nurses**, rather than HCM-specific nurses, which was felt to contribute to increased flexibility within the service.
- Belfast offered patients the option to attend genetic test review appointments by **telephone**, which meant results could be returned more quickly and conveniently.

- Sites secured early support for hub-and-spoke models through identifying **spoke 'champions'** who had previous experience of the specialist centre, and proactive engagement of other district general hospital departments.
- **Shadowing** was reported as one of the most effective modes of training nurses to help develop their genetics expertise.

Phase 1 challenges and key learning

The main challenges experienced by Phase 1 sites included:

- Several sites found that Miles Frost funded nurses needed a **significant amount of support** to reach a point where they could run clinics independently, which was further exacerbated within the pilot by the lack of a clear competencies framework for this new role. Sites recommended that nurses should have significant experience in cardiology, access to a supported learning environment, and be provided with a **substantial amount of lead-in time** to running clinics.
- Hub-and-spoke models **complicated staff training** as they tended to separate more experienced and newly recruited colleagues when delivering clinics, limiting shadowing opportunities. Where possible, this was mitigated through nurses and consultants working together at clinics within the hub.
- Pilot sites reported a wide range of **delivery challenges** around outreach clinics, sharing patient data and clinic administration. Sites recommended the establishment of clearly defined **relationships between consultants and support staff** in hub-and-spoke models improve patient management pathways and system efficiencies.

Phase 1 programme support

Where pilot sites reflected on the grant programme, support provided during the funding period, and independent evaluation, key themes included:

- **Shared learning events** offered Miles Frost funded nurses a valuable opportunity to share good practice and challenges encountered.
- Pilot sites welcomed their inclusion in the **development of core competencies** for the cardiac genetic nurse role.
- Positive feedback was received regarding the **evaluation's focus and flexibility.** However, sites found it challenging to participate in the BHF's monitoring procedures and evaluation requirements in the absence of funding for these activities.

Phase 1 evaluation recommendations

The following recommendations emerged from the evaluation of Phase 1 sites

Sites continuing with services

- Continue to **raise awareness** of the service at primary, secondary and tertiary care levels, to increase appropriate and timely referrals
- Further refine processes to **identify and engage with relatives**, particularly across trust/regional boundaries where data sharing is currently an issue.

- Plan corresponding increases in **coordination and administration resource** when considering further service expansion.

Other trusts looking to implement or develop services

- An **administrator/coordinator** role can support clinics and allow nurses to use their time and skills more appropriately, creating efficiencies and improving care through getting to know patients and families and booking appointments appropriately.
- New staff need **time to gain knowledge of genetics**, taking into account their previous specific experience and recognising the complexity of genetics and genetic testing.
- The service **model will impact on the ability of new staff to learn** from more experienced staff (for example, running clinics in tandem may help; having new staff based in different locations, such as spokes, may hinder learning and development opportunities.)
- With the right planning and design, service models can **enable efficiencies**, for example scheduling multiple appointments on the same day, or telephone review and family appointments.
- Development of spoke outreach clinics can be facilitated through **identifying and working with known healthcare professionals** with pre-existing expertise in specialist centres.
- Hub-and-spoke services should plan for the for spoke outreach clinics to potentially '**capture' referrals from beyond identified district general populations**; further increasing the service caseload.
- Providing and raising awareness of genetic testing will lead to **more referrals and an increased caseload**, and therefore goals such as reducing waiting times may not automatically be compatible with this; while waiting times may be reduced through greater service delivery efficiencies, waiting times may remain high due to high levels of demand.

British Heart Foundation

- Funding **administrative roles** will enable clinical roles to be deployed more effectively. There may even be a case in some services for funding only an administrative role, where clinical capacity is already high but is not being used efficiently due to administrative burden.
- Building in longer **time frames** for funding would allow for time to recruit and train staff.
- Training and upskilling can be supported through the development of **competency frameworks** for new roles; this could be anticipated and take place earlier or in advance of awarding funding.
- Grant management must take account of the additional **complexity** and potential ambiguity associated with genetic testing for HCM. For example, early involvement of experts in genetic testing would help to design appropriate and meaningful monitoring tools.

- **Learn and share** opportunities are greatly valued by grantees and should be maximised.
- Support **awareness raising** through media activity, for example highlighting the launch of services or showcasing specific patient cases involving cascade testing.
- Provide **core funding** to pilot site leads to help support participation in grant management and evaluation activities.

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