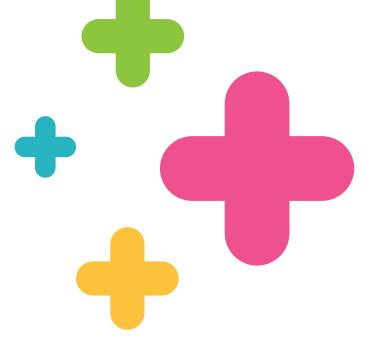


A STORY ABOUT THINKING DIFFERENTLY



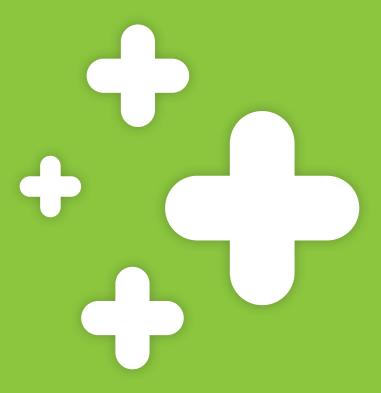
READ ON TO ABDUCT SOME KNOWLEDGE ABOUT HEART FAILURE!

#ThoughtsWorthExploring



CONTENTS

FOREWORD04
BID HIGHLIGHTS
THE COST OF HEART FAILURE IN THE UK
WHAT IS HAPPENING IN GREATER MANCHESTER?07
SETTING THE SCENE
WHAT THE COMMUNITY HAS TO SAY
RAISING AWARENESS
WHAT DID OUR PRE-SURVEY TELL US?
CREATION OF THE PROGRAMME
EVALUATION OF THE MARVELLOUS MENTORS EVENT16
FEEDBACK
WHAT HAVE WE MISSED?20
RESOURCES21
RECOMMENDATIONS
VALUABLE INSIGHTS23
TACTICAL SHORT-TERM (18 MONTHS)24
STRATEGIC MEDIUM / LONG-TERM (24-36 MONTHS)25



FOREWORD

We have pleasure in presenting the final report into the Marvellous Mentors programme which was a partnership between the Pumping Marvellous Foundation and Greater Manchester Health and Social Care Partnership.

of heart failure and its significance within Greater Manchester; secondly, how to promote the prompt diagnosis of heart failure, along with managing patients appropriately in Primary Care and the Community via NICE Guidelines, recently published in September 2018. The programme created Marvellous Mentors

The aim of the project was two-fold; firstly, to raise the profile of heart failure and its significance within Greater Manchester; promoting joint learning and support via a diverse range of secondly, how to promote the promot diagnosis of heart failure educational tools and events.

We would like to take this opportunity to thank all the Clinicians, patients and their carers of Greater Manchester who gave their time, energy and belief in the programme.

Nick Hartshorne-Evans

CEO, Pumping Marvellous Foundation

Angela Graves

Clinical Lead, Pumping Marvellous Foundation

BID HIGHLIGHTS

The original bid for the Marvellous Mentor programme wished to address the following:

- The National Heart Failure Nurse Audit 2018 completed by the Foundation across the UK identified a disparity of provisioning of Specialist Heart Failure Nurse services across the GM footprint.
- A scooping exercise carried out by the Foundation into the skills gap within the Community and Primary Care nursing teams, identifying a need to raise heart failure awareness across all teams, and the commissioners of GM and its cause-effect, everincreasing demand on healthcare services and budgets. The idea of creating mentors that could be healthcare professionals or patients was conceived.

The following areas were critical to the concept of producing a programme that responded to all the identified needs

- Develop and design a brand for Marvellous Mentors
- Multi-branded programme with GMHSCP
- Three major educational events to be held across the GM footprint
- The event to be open to NHS teams across all CCGs and Acute Trusts
- Invitation to be open to non-NHS teams to address equity of access
- · Collection of quantitative and qualitative data from pre/post-events
- Events to be supported by Cardiology teams from community and acute sectors
- · A range of tools and resources to be made available to teams to support the education process
- A social media campaign to promote the project
- Evaluation of the project, and how to scope out and develop a Marvellous Mentors Kitemark programme





- There are approximately 920,000 people in the UK who have heart failure (NICE 2018 NG106 Chronic Heart Failure in Adults)
- Heart failure is expensive, accounting for a million inpatient bed days, 2% of all hospital admissions, 5% of all hospital admissions (All-Party Parliamentary Group on Heart Disease (2016) Focus on Heart Failure)
- It is the main cause of admissions to A&E in over 65 years (NICE 2014 Acute Heart Failure: Diagnosis & Management)
- Hospital admissions for heart failure have a long length of stay, median of 6 to 9 bed stays
 (NICE 2018 NG106 Chronic Heart Failure in Adults)

- Cost of GP consultations is estimated to be £50 million (NICE 2018 NG106 Chronic Heart Failure in Adults)
- An average 10,000 list size practice will have between 100-200 patients with heart failure (NICE 2018 NG106 Chronic Heart Failure in Adults)
- 20-25 new cases would be diagnosed in a practice per year (NICE 2018 NG106 Chronic Heart Failure in Adults)
- The UK in-hospital mortality is 8.9% (NICE 2018 NG106 Chronic Heart Failure in Adults)
- 26.7% mortality in 1 year in the UK (NICE 2018 NG106 Chronic Heart Failure in Adults)

WHAT IS HAPPENING IN GREATER MANCHESTER?



The programme that was eventually created aimed to meet core objectives

- What is happening in the Greater Manchester Health and Social Care Partnership?
- The implications of heart failure in Greater Manchester
- · What is heart failure?
- Sign and symptoms of heart failure
- The diagnostic pathway across GM
- How to treat heart failure
- Who are the Clinicians dealing with heart failure, with representatives from across Primary, Secondary and Community Care?
- Innovation in practice-group consultation
- The patient's and carer's voice, patient symposium
- Workshops, what are we taking back to our practice?
- Generating a movement within the clinical community to raise awareness of heart failure

Creation of the programme

The Pumping Marvellous Foundation was keen to rise to the challenge of delivering a multi-event programme. The Foundation wished to deliver a varied, informative and diverse programme on heart failure, that was able to meet the requirements of a diverse range of Clinicians whose knowledge and experience of heart failure would be extremely

different. Our first step was to ascertain the opinions of our two steering groups, the first group constituted patients with heart failure and their carers, and the second group a number of Clinicians from across the healthcare interface. On the plus side, we had Clinicians and patients who believed strongly in what we were trying to achieve.

- In 2015-2016 there were 4,334 acute heart failure admissions across GM (National Heart Failure Audit 2015-2016)
- This accounts for 34,000 39,000 bed days (National Heart Failure Audit 2015-2016)
- The cost to CCGs is £16.4 million (tariff £3796 as of 2015/2016)







SETTING THE SCENE

The Foundation believed that it was imperative to hear the patient's voice in order to gain an insight into their experiences of the care that they have received in Greater Manchester and the challenges of living with the condition locally in order to steer and give direction to the programme. Therefore, a patient steering group was created comprising of patients and carers from across Greater Manchester. It became apparent that there was a huge variation of people's experiences on being diagnosed, treated, and the supportive services that they were able to access. As a consequence, it became apparent that the issue of access and equity of care needed to be addressed. The programme needed to ensure that access was open to the voluntary sector, acute sector, community services and Primary Care.

We approached all the CCG and Acute Trust communication teams. Many of the communication teams helped disseminate our invitation to the target groups and these areas were demonstrated proportionately in the level of attendees. Where the communication team didn't initially support the dissemination there was poor uptake, but as soon as we managed to demonstrate the Marvellous Mentors programme was GM-wide then the uptake in that area increased. All in all, there were some pockets of non-collaboration but mainly the communication teams were helpful.

In total, 78 voluntary services and public sector support services were invited to the three mentor events; invites also went to the Prison Service and community teams working with the homeless, Homes for the Elderly, North West Ambulance Service, and all City and Borough Councils who provide services to cardiovascular patients. The voluntary sector was also offered the opportunity to showcase their services at the events. Despite a repeated invitation, and social media marketing, there was a poor uptake of voluntary services at the events.

There was a strong representation from the majority of CCGs, predominately Clinicians but also commissioners. The Acute

Trusts were represented from Cardiology, elderly and frailty teams. There was a diverse representation from community services and a high representation from Primary Care, including GPs but predominately Practice Nurses and Community Nurses which were the programme's main focus.

Above all, we had the engagement of Cardiologists and the Heart Failure Specialist Nurse Community. This was achieved by engaging the Clinicians early in the programme, identifying their area of practice, gaps in services, any concerns, success and their hopes for the future. It also ensured that the cardiac community were engaged and happy to support the events, leading to presentations form Cardiologists and Heart Failure Specialist Nurses.

There were a significant number of Nurses from Practice Nursing. With support from Louise Brady, Lead Nurse for Primary and Community Care, the Foundation was able to present to the Practice Nursing Community at various meetings and events and were able to draw together an educational programme based on their needs.





GETTING CLINICIANS AND PATIENTS TOGETHER!

The Pumping Marvellous Foundation believed that to have a true understanding of the current landscape in Greater Manchester of heart failure provision, it needed to talk to healthcare professionals from across all sectors of healthcare delivery. With that in mind, a variety of meetings were held whereby the Foundation met Clinicians from Primary, Community and Acute Care. It was a rare opportunity to meet

colleagues from different sectors, where they were able to discuss issues, problems, and solutions to the provision of heart failure care that they face on a day-to-day basis. What's more, it was also an opportunity for patients and Clinicians to come together in an informal social setting with clear discussion points focusing on solutions to allow them to form a 360-degree viewpoint.

RAISING THE PROFILE IN PRIMARY CARE

The Foundation attended events in local practices, talking to Clinicians and their patients, raising awareness of heart failure and gaining an insight into the challenges of Primary Care.

"Building local insights helps drive the right activities for the local population." Nick, Pumping Marvellous

CLINICIANS MEETING PATIENTS

One of the most insightful gatherings informal setting, barriers were broken was bringing a variety of Clinicians and patients together for dinner. In such an

down and friendships formed.



WHAT THE COMMUNITY HAS TO SAY

"I was not sure what to expect; I am a natural sceptic. But I was very much enthused by the interactions, especially with a heart failure patient, as I don't think I have ever really interacted with patients like this before (only in direct clinical environments)."

Consultant Cardiologist

"It's exciting to be working across sectors and to be so patient-focused."

Primary Care Nurse

"I have learnt how important it is to have the patient experience in planning new services."

Primary Care Nurse





Consultant Cardiologist

"It was great to just sit and chat with a Cardiologist with no barriers, just sitting and chatting about heart failure."

Patient



RAISING **AWARENESS**

Raising awareness, supporting Clinicians, putting heart failure at the top of the agenda

gain further insights into heart failure care in the Greater and influenced the agenda, getting heart failure as a priority when the Foundation partnered with Clinicians presenting a the power of an engaged patient group and powerful clinical case through a staged presentation of what the challenges evidence to clearly underpin the patient's needs.

delivered at a Clinical Network event where we supported

"We are committed to scope/deliver work plans for key areas of improvement for the heart failure pathway." Catherine Cain, Programme Lead GM & Eastern Cheshire (GMEC) Cardiac & Stroke Strategic Clinical Network



HEART FAILURE **SPECIALIST NURSES (HFSN)**

Pumping Marvellous has long highlighted the significant role that the Heart Failure Specialist Nurse plays in the life of patients and carers. Therefore, we felt it was a priority to meet with the various teams from across the GM footprint. We gathered together HFSNs

who shared experiences, current difficulties (especially in the recruitment of Nurses), success and ambitions for their teams. The Nurses were extremely supportive of the Marvellous Mentors programme agreeing to present at the various planned events.

"It is a great opportunity to explain the crucial role in the provision of evidence-based and individual care which shows a reduction of mortality, reduction in hospital admission and costs and improvements of the quality of life of patients with heart failure." **Caroline, Heart Failure Specialist Nurse**



HEART FAILURE PATIENTS OF GREATER MANCHESTER

A high priority for the Pumping Marvellous Foundation was to care that they have received from all sectors of healthcare. gain the views of the patients of GM. We met with a diverse mix of patients and carers who shared with us their experiences of

Their experiences varied considerably and raised the issue of equity of care across GM.

"It's good to share our experience of how you live your lives with heart failure on a daily basis, the programme is a fantastic idea." Carer



WHAT DID OUR PRE-SURVEY TELL US?



90.5% of respondents correctly identified heart failure as a condition whereby the heart fails to pump efficiently. 87% of delegates believed that the prognosis of heart failure was that the condition could be managed with only 7.5% feeling it could not be cured. Significantly all responders believed that heart failure was not a condition of the elderly.

46.6% of delegates believed that heart failure patients should be managed by a Specialist Nurse, 26.5% under the care of a Cardiologist, with 22.3% believing it should be the GP. There appeared to be a general awareness of the most common symptoms of heart failure with 96.8% believing that breathlessness on doing anything, 95.7% swollen ankles, and 87.2% of recognising significant fatigue.

When asked what is the incidence of heart failure across the UK, NICE 2018 have estimated that there are up to 920,000 people with heart failure, 43.5% of our responders believed that the figure is unknown, 25.5% believed it was between 750,000 to one million, 18% stated that it was 500,000 to 750,000.









The Pumping Marvellous Foundation was keen to rise to the challenge of delivering a multi-event programme.

The programme that was eventually created aimed to meet core objectives.

- What is happening in the Greater Manchester Health and Social Care Partnership?
- The implications of heart failure in Greater Manchester
- · What is heart failure?
- Sign and symptoms of heart failure

- The diagnostic pathway across GM
- How to treat heart failure
- Who are the Clinicians dealing with heart failure, with representatives from across Primary, Secondary and Community Care?
- Innovation in practice-group consultation
- The patient's and carer's voice patient symposium
- Workshops what are we taking back to our practice?
- Generating a movement within the clinical community to raise awareness of heart failure

Social Media

The conversation was driven across three platforms including

- Pumpingmarvellous.org The website was used as the lead content point for all conversations. This included attractive and engaging branded imagery, content around what the purpose was of the programme, programme content and a registration page for the three planned events
- Facebook (Heart Failure Aware, Marvellous Mentors Page and Marvellous Mentors Closed Group) With Heart Failure Aware, the Pumping Marvellous Foundation main Facebook page anchoring the social media conversation driving interest through to the two Marvellous Mentor pages

Creating a social media movement is very difficult within the confines of a short programme and we found that Twitter excelled when it came to showcasing our programme to strong community of "Twitterati" across the GMHSCP footprint.

interested parties. Activity to our dedicated lead content point on our website was amplified by Twitter. This suggests a very





EVALUATION OF THE MARVELLOUS MENTORS EVENT

We decided to undertake a pre-event evaluation entitled - "What Do You Know" - these questions were different from our pre-survey questionnaire and focused on five areas.

- 1. Who is the responsible healthcare professional for patients with heart failure?
- 2. Which age group does heart failure affect the most?
- 3. What is the approximate cost of heart failure across Greater Manchester?
- 4. Approximately how many heart failure patients live across Greater Manchester?
- 5. How many full-time Heart Failure Specialist Nurses are there in Greater Manchester?

We were keen to understand attendees' knowledge of heart failure in Greater Manchester prior to our events.

This would enable the Foundation to fine-tune the programme, to attendees' gaps in knowledge. (Results pertain to all three events.)



FEEDBACK

Who is the responsible healthcare professional for patients with heart failure?

The result reflected an almost equal split between Cardiologists (27%) and Heart Failure Specialist Nurses (26%). Although not listed as an option, 19% of attendees believed that it was the responsibility of all healthcare professionals.

Correct Answer: All

Which age group does heart failure affect the most?

0-18 19-35 36-50 51-65 65-75 75+

26.5% of attendees felt it was is the 51-56 age group that heart failure mostly affects, 40% that it is the 65-67-year olds. 39% believed it is the over 75s.

Correct Answer: 75+

What is the approximate cost of heart failure across Greater Manchester?

Over half (53.7%) believed that the cost to GM is £32 million, 26.5% felt it was £64 million.

Correct Answer: £16 Million

Approximately how many heart failure patients live across Greater Manchester?

42% of attendees believed that up to 30,000 patients live with heart failure in GM, 37% believed that the figure was 40.000.

Correct Answer: Up to 40,000

How many full-time Heart Failure Specialist Nurses work across Greater Manchester?

11% of attendees believed that there were up to 30 HFSN in Greater Manchester with an approximate spilt with the other sections.

Correct Answer: Up to 25



FEEDBACK FROM THE BREAKOUT SESSIONS

Pumping Marvellous believed it was crucial that as part of the educational events, the attendees were able to demonstrate what they had learnt, how this would affect their practice and what they believed should be the next steps to the programme. Breakout sessions were held and five areas of development were identified.

RESOURCES

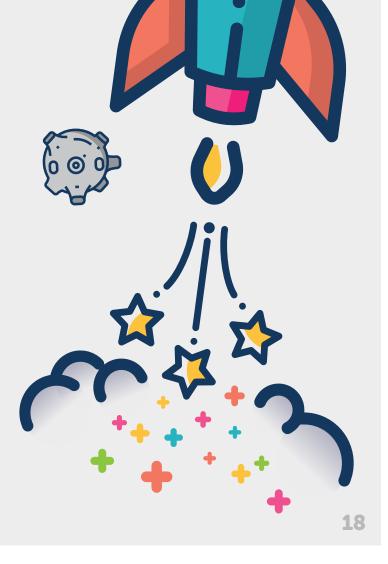
- Build awareness of heart failure across Primary Care and community services
- Advertise resources in Practices/Surgeries: PMF, BHF, support lines regarding heart failure
- Promotion of self-care resources and their value
- Clinical meetings in practices raising the significance of heart failure

MANAGEMENT

- Need to get heart failure on the highest agendas particularly in relation to cost and resource implications
- That there should be a lead GP for heart failure
- Need to address health inequalities in service provision
- Mapping of services in GM across the entire workforce
- Identify wraparound services that support or could support heart failure patients

EDUCATION AND TRAINING

- · Continuing education for Practice Nurses, putting heart failure on their agenda
- Primary Care online education module
- · Make heart failure training mandatory
- · Need to raise red flags for triaging of heart failure patients





EDUCATION AND TRAINING

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DIAGNOSIS

- Ensure natriuretic peptide testing available for all
- · Don't ask to test, just do it
- · A simple message of symptoms, history, test

TELL US HOW YOU FEEL NOW

The feedback from the sessions was highly positive.

Have we changed your opinion about heart failure? YES/NO 87% of responders believed their opinion of heart failure had changed by attending the events.

Are you positive about the future of heart failure across GM? YES/NO

Approximately 90% of people felt positive about the future of heart failure care across

Greater Manchester through the Marvellous Mentors programme.

Do you feel more equipped to deal with heart failure? YES/NO 98% felt that they were more equipped to deal with heart failure.

COMMUNICATION

- It should be both micro and macro
- GMHSCP wide campaign as well as a national campaign
- Need to raise awareness of cost implications
- Practice Nurse direct referral to Heart Failure Specialist Nurse
- Raise awareness of heart failure to all, including clinical and non-clinical teams
- Improve communications to GPs regarding the significance of heart failure
- A link between Primary and Secondary Care and how best to get advice from specialists
- Need to get the patient story out there including patient isolation
- Need to engage with HFE





Individual sessions were ranked in order of usefulness, 5 being the most useful and 1 being the least to you.

What to do in heart failure

78.20% rated the session 5 18.20% rated the session 4

The role of the Heart Failure Specialist Nurse

69% rated the session 5 18.4% rated the session 4 Group Consultation

57% rated the session 5 26% rated the session 4 Patient Symposium -Living with heart failure

79% rated the session 5 16.4% rated the session 4

What shall we take back to our workplace?

43.5% rated the session 5 42% rated the session 4



WHAT HAVE WE MISSED?

Many of the attendees took the opportunity to give a general opinion of the events, repeated words and phrases were:

Amazing, informative, patient-focused, wonderful, excellent, thought-provoking, really good training, good materials.

Attendees also expressed an interest in:

End of life and supportive conservations, more structured time for networking, pharmacology, how to engage with the elderly especially in homes for the elderly, hearing patient stories, online training tools, active case management, cardiac rehabilitation, format for an annual review, template and protocols for across GM.

"I have never been to an NHS event where people have queued to get their take-home bags, there is no rushing, it's as though people want to stay and learn more..."

 $^{'}$ A phrase picked up by the team at the Bolton event summed up the embracing attitude towards the programme.





RESOURCES

The Pumping Marvellous Foundation has provided a range of resources to support the Marvellous Mentor Programme. As well as access to all PDF and social media resources produced by PMF, teams have also had the following individually designed and tailored for the project.

Steering Group

 Patients with heart failure and their carers from GM to support and focus the project

Marvellous Mentor Programme - on the day individuals received

- Poster Journey of discovery, Heart Failure Needs You (x3)
- Poster Being Aware of Heart Failure Signs and Symptoms
- Poster My Marvellous Symptom Checker
- Marvellous Map of Heart Failure fold-up tool

- My Marvellous Symptom Checker fold-up tool
- Post-it notes
- Residential Home advice for patients with heart failure and Marvellous Symptom Checker
- NICE Chronic Heart Failure Guidelines in Adults 2018 guidance for Primary and Community Care
- Pumping Marvellous Contact Card
- Pumping Marvellous Foundation Marvellous Mentors linen bag for life

Online/Social Media Resources

- Marvellous Mentors Facebook Group
- A dedicated phone number for access to Marvellous Mentors
- . Primary Care online education tool on the management of heart failure for Clinicians, via the Pumping Marvellous website
- Telephone conference facilities available free to support beneficiaries









Since the inception of the Pumping Marvellous Foundation working partnership with the GMHSCP, the insights gathered to conceptualise, design, develop and deliver the Marvellous Mentors programme have elevated the challenges of heart failure and the expected quality standards of managing the condition across the GM footprint.

It is very important to understand that even before the start through a patient/healthcare professional presentation and of the programme, the inclusion of the Pumping Marvellous Foundation in the wider GM community helped elevate the heart failure conversation so that the Greater Manchester and Eastern Cheshire Strategic Clinical Network adopted heart failure in its cardiac workstream as a priority, especially around the adoption of the new NICE Chronic Heart Failure Guidelines for adults published in 2018. The Foundation, along with Dr Fozia Ahmed and Dr Colin Cunnington, secured the priority

dialogue with the Clinical Network.

It is imperative to understand what the Marvellous Mentors programme is trying to achieve. After the Pumping Marvellous Foundation's completion of the first National Heart Failure Nurse Audit in 2018, insights focused on some of the challenges that were appearing around the provisioning of services within the GM footprint.

- The inconsistency of access to NP testing for diagnosis
- The inequity of access to Heart Failure Speciaist Nurses across GM
- Teams employed by Acute Trusts, lack of consistent community provisioning





VALUABLE INSIGHTS

Awareness of heart failure outside of the "Acute" setting is poor. Across the UK, 80% of people are diagnosed in the hospital, however we have had access to NP testing since 2010 through the 2010 NICE Chronic Heart Failure Guidelines in adults. There is not equity of access to NP testing across GM and whether it is used appropriately is questionable. NP testing has been emphasised heavily in the new NICE guidelines of 2018.

Access to Heart Failure Specialist Nurses (HFSNs) in community settings is poor with multiple CCGs with no HFSNs or poor provisioning in the community. The new NICE Chronic Heart Failure Guidelines emphasise the importance of a specialist Multi-Disciplinary Team (MDT) where the HFSN is at the core of the team's ability to effectively manage the patient. Even if GM was sufficiently staffed with appropriate numbers of HFSNs the management of optimised, relatively stable patients being discharged from the specialist MDTs falls into the hands of Primary Care and Community

Care. This is where patients present late, decompensate and get into trouble, this is where people become hospitalised where the median stay of a heart failure patient is 10 days with a tariff of just under £4,000 in GM. Patients should be managed well in Primary Care and the community. They should have access back onto the specialist MDT when they decompensate, and their symptoms need specialist intervention. If there are no Heart Failure Specialist Nurses in the community to accept back into a specialist MDT, this then becomes an Acute problem. MDTs and the "recycling" of patient

access to them, along with access to HFSNs, is a core focus of the new NICE 2018 Chronic Heart Failure Guidelines for adults.

We needed to look at this differently and understand how in the short-term we could utilise the resource in a different and innovative way. We opened up a conversation with Louise Brady, Nurse Lead Primary and Community for the GMHSCP, and Helen Barlow, Director of Nursing for the GMHSCP, to discuss how we could start to put some solutions in place to arrest the effects of lack of provisioning in the short-term.

A funding plan was drawn up for the Pumping Marvellous Foundation with its resources to invest and mentor Nurses, particularly in primary care and community-based Nurses around the following

- Identification of a potential heart failure diagnosis through signs, symptoms, history and initiation of NP testing
- Where to refer patients to with elevated NP test results
- How to best manage heart failure patients in the community

The challenge was to elevate the awareness of heart failure across the GM footprint to try to counteract some of the challenges.

As detailed, we ran three events across the GM footprint and with the pre/post-feedback from the events, from our knowledge of the provisioning and anecdotal qualitative commentary from people and teams in the system, these are our recommendations.





TACTICAL SHORT-TERM (18 MONTHS)

- 1. Continuing the Marvellous Mentors programme of education to Practice Nurses and Community Nurses.
- 2. Ensure provisioning and usage of NP testing in accordance with the NICE Chronic Heart Failure Guidelines 2018. Readdress the imbalance where an effective and swift diagnosis in Primary Care with direct access to heart failure specialists is not only embedded in the clinical pathways but elevated to the same awareness around cancer diagnosis. All evidence suggests the quicker you get patients to the specialists the better the prognosis.
- 3. Develop a care plan for heart failure patients to drive quality and consistency of care and access to treatment and patient self-management tools. This featured highly in the NICE Chronic Heart Failure Guidelines. If this was developed by GMHSCP and the Pumping Marvellous Foundation this would be a first in class programme. The care plan would be a partnership development satisfying the clinical and quality of life needs of patients. Access to the care plan must be available to the patient and family.



STRATEGIC MEDIUM / LONG-TERM (24-36 MONTHS)

- 1. Build an awareness campaign to secure grassroots support for the elevation of awareness of heart failure to the public and healthcare professionals alike. Promote resource to Primary and Community Care.
- 2. Develop a Kitemark system to drive quality and learning across GP surgeries confirming their alignment with national guidelines and local clinical pathways. If developed by GMHSCP and the Pumping Marvellous Foundation this would be a first in class programme and a very public identifiable indication of investment in heart failure care by the GMHSCP.
- 3. Identify a GP lead for heart failure and create a working group to identify service gaps at a local level. Working group lead by GP to champion the continued focus both at the coal face and the strategic and political level.

We are making heart failure clearer for everyone

To learn more please visit **pumpingmarvellous.org**Find your local Heart Failure Specialist Nurse team at **justheartfailure.org**