

Terms of Reference for the Clinical Board of the Pumping Marvellous Foundation

The terms of reference for the Clinical Board of the Pumping Marvellous Foundation are in place to ensure a clear understanding, way of working and engagement with the registered charity the Pumping Marvellous Foundation referred hereafter as PMF and the Clinical Board and it's members referred hereafter as CB.

The Charity

The Pumping Marvellous Foundation is a registered non-profit company (company no 08370761) with charitable status (charity no 1151848)

Registered Address

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Website – pumpingmarvellous.org

Facebook – HeartFailureAware – community page / Help for Hearts – closed group

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Structure and Governance

Trustees

- The Pumping Marvellous Foundation (PMF) has a voluntary trustee board that meet twice yearly and convene for tele-conference calls every two months (6 per year).
- The Trustees govern the charity through its “Governance Documents and the Articles of Association.”
- The current board of Trustees do not have pecuniary interest and receive no payment from the charity other than out of pocket expenses.
- The trustee board is currently recruited by recommendation. This may change with the needs of the charity.
- The 3 administrative trustees are nominated and voted in by the trustees via a postal vote every 2 yrs.

Executive Team

The Pumping Marvellous Foundation has an executive team with administrative support that manages the strategic direction and is responsible for the delivery of the charities operational activities.

Patient Board

The Pumping Marvellous Foundation is a beneficiary led charity and has an initially selected patient board comprising of a minimum of 10 patients / carers who set the strategic direction of the charity as well as supporting the tactical initiatives of the charity. They give the charity the voice and focus.

Membership

The charity does not have a membership and is all inclusive in line with the charity objects

The State of Heart Failure

Heart Failure (HF) continues to be a complex syndrome of both a clinical nature and social and psychological burden on those that are diagnosed along with their families and wider population. Heart Failure continues to have poor outcomes and has a worse prognosis than most forms of common cancer. There is an estimated 800,000 – 1,000,000 people suffering from heart failure in the UK where 30-40% of those diagnosed will die within one year of diagnosis.

Although the HF population is predominantly elderly there is evidence to show that a quick diagnosis with intervention by heart failure specialists and on discharge support from a strong multi-disciplinary team (MDT) wrapped around the patient can result in improved outcomes. The multi-disciplinary team is an under resourced element of the pathway that struggles with cohesive interlock ensuring the patient has all the support they need.

The Pumping Marvellous Foundation was founded to demonstrate leadership around the patient voice working in partnership with all stakeholders to ensure the patient and their families have the best quality of life that is achievable.

Aims and Objectives

PMF has four primary goals that act as a cohesive multi-disciplinary approach to heart failure care.

1. To support patients, carers and their families on how to self-manage the psychological, socio-economic, and physical, impacts on their lives that the condition imposes
2. To improve timescales to diagnose heart failure at primary care gateways
3. To increase the number of patients receiving specialist heart failure care and support
4. To influence government, regulators and the pharmaceutical industry policies to reflect patient needs.

PMF carries out the following activities to achieve these goals

- a) Working in partnership with clinicians, commissioners and a range of associated agencies and guided by PMF to create patient-driven initiatives.
- b) Building a digital heart failure patient community by interlocking our website, social media and publications to ensure our services are accessible to patients, carers and their family. Create a representative voice of a community of heart failure patients to act as one voice, influencing awareness, perception and the MDT, refocusing on what matters which is the QOL for patients and their families.
- c) Providing advocacy services to beneficiaries at a local, regional and national level via a network of regional volunteers who participate in campaigns, publications, distributing literature and building local relationships.
- d) Lobbying MP's and government officers to gain their support to increase awareness of the ever-increasing cost of heart failure to the health economy.
- e) Using peer-to-peer coaching and support of patients to promote, self-care, self-education and self-intervention and to increase early diagnosis and treatment of heart failure.

Public Benefit

The goal of the Pumping Marvellous Foundation is to ensure that patients receive the optimal treatment and care leading to an improvement in the quality of life of patients and their families.

The Pumping Marvellous Foundation aim is to ensure that patients receive the optimal diagnosis, clinical intervention and support from an MDT both in the acute setting and community setting ensuring an optimal quality of life. The Pumping Marvellous Foundation looks to collaborate in partnership with other organisations

and individuals to facilitate the development of heart failure services to enable a clear and defined pathway from diagnosis through to palliative, secondary and community care settings.

Objectives

- Create the patient voice in all stakeholder channels
- Maintain and strengthen the patient voice in all stakeholder channels
- Create a community of patients who offer peer to peer support
- Increase awareness of what heart failure is across all stakeholder channels
- Increase awareness of 3 basic symptoms of heart failure across all stakeholder channels
- Move the charity operations to a permanent office, scale operational capability
- Develop the operational team
- Increase and develop our digital presence
- Develop further patient resource
- Develop a sustainability model to ensure the charity is able to keep 12 months of reserves
- Raise the awareness of the importance of the multi-disciplinary team
- Encourage partnerships with stakeholders within the health system
- Re-design governance documentation
- Plan for capability organisational restructure in line with demands

Interlock:

Charity – Trustee Board and the Executive Team

Advisory Boards – Innovation, Clinical and Patient

The trustee board and the executive team now have interlock with three boards that are independent from the charity but act as advisory boards to the charity by making recommendations as to the initiatives, activities and strategy of the charity. They have no responsibility and cannot be held to account for their advice. However they play a valuable role to enable the charity to have unsurpassed insight into the formation of its strategy and activities.

Each board is composed of members, the membership is voluntary and terms of membership are individual to each of the boards.

This Section is particular to the Clinical Board

Ways of Working

- The innovation board, clinical board and the patient board are independent.
- The charity will act as a secretariat for all three boards

- The relationship between the charity and 3 advisory boards will be transparent where meeting minutes will be circulated amongst the boards to aid transfer of knowledge
- It is the charity's executive team's responsibility to circulate minutes between the advisory boards
- Each advisory board will set its own parameters as to frequency of meetings whether face to face or via tele-conference
- With prior notification a representative from each board can sit on other boards in an observing capacity

Travel expenses will be paid in line with the charity's expenses policy. This is available on request.

Clinical Board

Role

The role of the Clinical Board is to act as an independent advisory board with no responsibility or accountability as to the actions of the charity.

Purpose

The purpose of the Clinical Board is to guide the charity in making the right decisions around the health and wellbeing of heart failure patients across the United Kingdom - offering factual and real world experience from the clinical and payer perspective.

The Clinical Board will have access to all of the charity's resource and will also act to create new opportunities for the charity.

The Clinical Board's role is advisory and is not binding on the Charity.

The Charity will indemnify the Clinical Board against legal claims based on its advice, provided the members of the Clinical Board have acted in good faith and have given advice in keeping with the conduct of their professional positions.

Capacity

The Clinical Board comprises of a steering committee that will determine the Board's agenda in consultation with the Executive Team.

The Clinical Board will consist of a four person steering committee with a Chair, Vice Chair and two other participants.

The initial membership and Chair have been determined by mutual consent between the Executive Team and the members of the clinical Board. Additions to, or replacement of, the members of the Clinical Board will be by majority decision of the Clinical Board, in consultation with the Executive Team, and relate to the needs of the Charity.

It is anticipated that membership of the Clinical Board will be for an initial term of 2

years, subject to extension by mutual agreement of the member of the Clinical Board and the Executive Team of the Charity, and subject to majority vote from the Clinical Board.

Frequency of face-to-face or Skype/teleconference meetings will be determined initially by the steering committee but is expected to be at least annually. The Executive Team will use the skills of the Clinical Board at other times, where appropriate.

The role, purpose and capacity of the Clinical Board will be reviewed at least every 2 years by the Executive Team and changes made where appropriate, and after discussion with the Clinical Board. In the case of dispute that cannot be resolved by discussion, the decision of the Executive Team will be final.