The Martin House Research Centre's Public Involvement and Engagement Strategy: November 2019 – December 2021.

INTRODUCTION

The Martin House Research Centre was established in January 2017 as a multi-disciplinary centre for research on the care and support of children and young people with life-limiting conditions or medical complexity, their families and the workforce that care for them. From the outset it has been committed to involving children and young people, their families and those who support them as partners in the processes by which our research is identified, prioritised, designed, conducted, implemented, disseminated and evaluated. Such activities and partnerships are often called 'patient and public involvement' (PPI). The Centre is also committed to ensuring the wider public knows about its research and research findings. This is usually referred to as 'public engagement' (PE).

This document sets out the Centre's PPI-E work and activities to date, and its strategy going forward. Its primary purpose is for internal use as opposed to public facing.

PPI-E WORK AND ACTIVITIES UNDERTAKEN TO DATE

Work already undertaken by the Centre to fulfil its commitment to PPI-E include:

- Parents and a young person attended and spoke at the MHRC launch event.
- In its first year, consultation with young people, parents and professionals regarding the Centre's research priorities.
- A PPI-E lead for the Centre has been appointed.
- The establishment of a Family Advisory Board (FAB) to provide oversight and scrutiny of the Centre's PPI-E activities and to act as a forum to consult about on-going research and to develop and fine-tune ideas for future research.
- The appointment of two members of the FAB to the Centre's Advisory Board.
- All MHRC studies have a specific PPI-E advisory group or are utilising the FAB.
- Development work with a group of young adults regarding their involvement in the Centre's research.
- The implementation of at least bi-annual meetings with Martin House staff.
- The creation, and on-going maintenance, of a comprehensive Centre website.
- Where possible, using plain English in all webpage text and, where not possible, providing plain English summaries alongside.
- A single system for logging all PPI-E activities (MHRC PPI-E log) undertaken by and for MHRC and its research has been created.
- All project advisory/steering groups include PPI representation and/or the project has a parallel PPI group.

OUR VISION

Our vision is to build on PPI-E work already undertaken and extend and fully embed PPI-E in the work of the MHRC, both throughout the research cycle and across all projects. We aspire to a model of co-production and co-creation of research in which our research teams include representation of all the necessary views, experiences, skills and knowledge.[1]

AIMS OF THE STRATEGY

In order to achieve this vision, our PPI-E strategy will continue to be underwritten by what are understood to be core principles[2] of PPI-E:

i. Diversity:
    - We will seek to ensure children, young people and families (and others who represent them) involved in PPI work for MHRC (referred to herein as our 'PPI partners') represent the diversity of experience in children and young people with life-limiting conditions and medical complexity and their families.

ii. Inclusivity:
    - We will seek to ensure issues of access, communication difference, and information/training needs associated with participating in PPI-E do not act as barriers to PPI-E.

iii. Early and continuous:
    - We will seek to involve PPI partners as early as possible in the research process (e.g. prioritising topics, identifying research questions) and to continue that involvement throughout the research process.

iv. Transparency:
    - We will work hard to ensure those involved in PPI work will be able to see and understand how decisions are made. More widely, information about MHRC and its research will always be made available in a Plain English version as well as other formats.

v. Clarity of purpose:
    - We will take care to ensure all involvement activities have the clear aim to enhance the relevance, quality and/or impact of the Centre's research. We will take care to ensure that the aims of each PPI activity are understood by those being invited to contribute.

vi. Feedback:
    - We will make sure the outcomes of all PPI activities will be fed back to PPI partners.

vii. Monitoring, learning and sharing:
    - We will regularly and critically review the implementation of our PPI-E strategy, and seek to learn from and share our experiences with the wider community.

The MHRC Management Team (CMT) is responsible for: i) supporting the Centre's PPI-E lead to implement this strategy, and ii) ensuring it is implemented. Oversight of its implementation will sit with the governing and advisory bodies for MHRC; namely: the MHRC Partnership Committee, the MHRC Advisory Board and the MHRC Family Advisory Board (FAB). An update on PPI-E activities and progress towards implementing the PPI-E strategy will be provided at meetings for each of these bodies.

DELIVERY OF THE PPI-E STRATEGY

The following action plan sets out how the CMT intends to achieve the aims and objectives of the strategy. There are five core areas of work:

1. Further embedding of PPI-E within MHRC
2. Extending MHRC's PPI-E work and activities
3. Broadening the diversity of MHRC's PPI partners in terms of representation of 'hard to reach groups' and diversity of experience.
4. Implementing an evaluation process
5. Sharing learning

1. Actions to further embed PPI-E within MHRC

1.1 The Centre's PPI-E lead will develop a 'Project PPI-E assessment and action checklist' for use by the Centre from initial development of project proposals/funding applications going forwards. This will be a 'live' document and will facilitate the planning, implementation and evaluation of PPI-E activities for individual projects. The Lead Applicant/Chief Investigator will be responsible for ensuring timely completion and review. [*Developed and implemented by end February 2020*]

1.2 PPI-E will be a standing item on all relevant Centre meetings (e.g. MHRC team meetings; MHRC CMT; MHRC Advisory Board; MHRC Partnership Committee). Where required/appropriate, the Centre's PPI-E lead will attend meetings for this item. [*Implement immediately*]

1.3 The Centre's PPI-E lead will prepare a report for inclusion in interim and annual reports submitted to the Centre's Partnership Committee. [*Implement immediately*]

1.4 On at least an annual basis, CMT will review research activities and future plans of the Centre against the research priorities identified during the 2017 consultation exercise.[3] [*Implement immediately*]

1.5 The Centre will implement the following training and development strategy:

- induction process for new MHRC staff (including PhD students) which includes face-to-face meeting with the Centre's PPI-E lead. [*Implement immediately*]

- all MHRC staff will attend at least one FAB or project-specific PPI-E meeting every twelve months. The Centre's Administrator will develop and maintain a log recording this. [*Implement immediately*]
- the Centre will implement bi-annual, half day PPI-E learning and development workshops for Centre staff (and PhD students), attendance at which is expected. The Centre's PPI-E lead will be responsible for designing the programmes for these sessions. [*First session to be held by May 2020*]

1.6 The MHRC website will be reviewed on a six-monthly basis by the Centre's PPI-E lead with respect to PPI-E 'compliance'. Where appropriate, FAB members (and hopefully in the future, young adult PPI partners) will be involved in this review process. [*Implement immediately*]

2. Actions to extend MHRC's PPI-E work and activities

2.1 The PPI-E lead will continue to lead development work with the new young adults group, with the aim of co-producing a research bid/project. *[Proposal for project funding submitted by December 2020]*

2.2 The PPI-E lead will extend involvement to include children and young people (under 18) in the Centre's research. *[Implement April 2020]*

2.3 The PPI-E lead will work with senior MH staff to review current processes by which they and 'frontline' staff are involved in the work of the Centre. [*Completed by February 2020*]

2.4 The PPI-E lead, working with the CMT, will consider the need for and feasibility of forming an additional PPI group comprising 'frontline staff' closely involved in the care of children and young people with life-limiting conditions or medical complexity. [*Decision taken by end March 2020 at the latest*]

3. Actions to broaden the diversity of MHRC's PPI partners

3.1 The Centre will establish infrastructure to facilitate virtual involvement in the FAB and other MHRC PPI groups for those who may not otherwise get involved. For example, promoting virtual membership; supporting remote participation in meetings (e.g. via Skype) and virtual group discussions (e.g. closed Facebook page); designing virtual PPI activities. [*Begin implementation immediately*]

3.2 The Centre will proactively disseminate information about the FAB and other Centre PPI groups and opportunities via the following:

  - The MHRC website and social media channels (Twitter, Facebook)
  - The newsletters, websites, social media channels, and events of organisations or groups that support or represent children and young people with life-limiting conditions or medical complexity and their families (e.g. Martin House, Yorkshire and Humber Children's Palliative Care Network, Together for Short Lives)
  - where appropriate (and when consent to on-going contact has been obtained), to study participants or PPI partners of completed MHRC projects. [*Implement immediately*]

4 Actions to implement an evaluation process

4.1 The Centre's PPI-E lead will create tools by which researchers and PPI partners self-report the impact of PPI-E within individual studies and, on an annual basis the PPI activities within the Centre. The tool is likely to cover five main domains: engagement/attendance; impact on the study / Centre; impact on researchers and PPI partners; factors which facilitate and hinder participation; and costs. [*Developed and implemented by April 2020*]

4.2 The Centre's PPI-E lead will review and synthesise all PPI-E evaluation data on an annual basis and present findings to the CMT. Findings will be used to inform: staff training and development and the Centre's PPI-E strategy and practices. [*Implement immediately*]

5 Actions to support sharing of learning

5.1 Co-production of research will be a key theme at the 2020 MHRC conference. [*Implement immediately*]

5.2 Overseen by the Centre's PPI-E led, the Centre will continue to seek opportunities to contribute to regional and national PPI-E networks, guideline and standards development and impact evaluation. [*Implement immediately*]

References

[1] INVOLVE (2019) UK Standards for Public Involvement. https://www.invo.org.uk/wp-content/uploads/2019/11/UK-standards-for-public-involvement-v6.pdf

[2] Baines et al. (2017) Optimizing patient and public involvement (PPI): Identifying its "essential" and "desirable" principles using a systematic review and modified Delphi methodology, Health Expectations, DOI: 10.1111/hex.12618

[3] Martin House Research Centre Prioritisation Exercise website and reports: https://www.york.ac.uk/healthsciences/research/public-health/projects/martinhouse/research/prior-exercise/