Managing chronic conditions in Irish primary care: Priority Setting Partnership Protocol November 2022

1. Purpose of the PSP and background

The purpose of this protocol is to clearly set out the aims, objectives and commitments of the Managing Chronic Conditions in Irish Primary Care Priority Setting Partnership (PSP) in line with James Lind Alliance (JLA) principles. The Protocol is a JLA requirement and will be published on the PSP's page of the JLA website. The Steering Group will review the Protocol regularly and any updated version will be sent to the JLA.

The JLA is a non-profit making initiative, established in 2004. It brings patients, carers and health care professionals together in PSPs. These PSPs identify and prioritise the evidence uncertainties, or 'unanswered questions', that they agree are the most important for research in their topic area. Traditionally PSPs have focused on uncertainties about the effects of treatments, but some PSPs have chosen to broaden their scope beyond that. The aim of a PSP is to help ensure that those who fund health research are aware of what really matters to patients, carers and clinicians. The National Institute for Health and Care Research, (England) www.nihr.ac.uk coordinates the infrastructure of the JLA to oversee the processes for PSPs, based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), University of Southampton, England.

Contributing to a research agenda for primary care research is a key priority for the HRB Primary Care Clinical Trials Network in their plan for 2021-2026, and this PSP will be the basis for continuing work in this area. The network, funded by the Health Research Board, is a collaborative network of clinicians and researchers supporting high quality clinical trials in primary care. Ensuring new research addresses the priorities of those most affected is a key factor in achieving this high quality, and we hope that this PSP will form a basis for future research addressing the most important needs for people with chronic conditions, their carers and clinicians in primary care settings.

Building on a strong history of patient and public involvement work, the network is aiming to have strong representation of diverse patient and carer perspectives in the steering group and selection of partner organisations, as well as perspectives from key primary care clinical groups like GPs, nurses, and allied health professionals

2. Aims, objectives and scope of the PSP

The aim of the 'Managing Chronic Conditions in Irish Primary Care PSP' is to identify the unanswered questions about the management of chronic illnesses in primary care from patient, carer and clinical perspectives and then prioritise those that people with chronic conditions, their carers and clinicians agree are the most important for research to address.

The objectives of the PSP are to:

- work with people with chronic conditions, their carers/ family members and healthcare professionals to identify uncertainties about the management of chronic illnesses in primary care settings
- to agree by consensus a prioritised list of those uncertainties, for research
- to publicise the results of the PSP and process
- to engage with funders and other research support bodies to encourage research in the priority areas

The scope of the Managing Chronic Conditions in Irish Primary Care PSP is defined as:

- Questions about the role of primary care in managing an ongoing chronic condition or supporting the self-management of such conditions or symptoms
  - **Chronic condition**: any condition or symptom that has long-term effects on a person, needs ongoing management, and which may impact the activities of daily life.
  - **Management**: the ongoing treatment, coordination, monitoring and support undertaken by people with chronic conditions and healthcare professionals to improve health outcomes.
  - **Primary care**: treatment and support that is available in the community and involves a sustained relationship or degree of continuity between people with chronic conditions and healthcare professionals. This includes "first contact" practitioners such as general practitioners (GPs), general practice nurses, community and public health nurses, and other community based professionals (eg physiotherapists, occupational therapists etc.).
- Focused on Ireland (ROI)
- Concerning adults (18+)

The PSP will exclude from its scope:

- Services outside of Ireland
- Under 18 years
- Focus on specific conditions and/or treatments (e.g. "which is the best drug to treat X" will be out of scope)
- Conditions that are cared for or treatments that are mostly provided in secondary or tertiary care (i.e. specialist care by consultants or other specialised health professionals, hospital based care).

The above scope has been developed through discussion with the steering group, and they will be involved in assessing whether uncertainties are in or out of scope during data gathering and processing. Submissions deemed out of scope for this PSP will be recorded separately, and decisions will be made with the steering group about appropriate ways to pass these on to relevant organisations or research groups.

3. The Steering Group

The Steering Group includes membership of people with chronic conditions, carers and clinicians working in primary care, as individuals or representatives from a relevant group. The steering group was convened in July 2022.

The PSP will be led and managed by a Steering Group involving the following:

- Karen Cowap, Patient & Member of Collaborative Doctoral Award in Multimorbidity PPI Group
- Sarah Delaney, Research support Co-ordinator, Health Research Charities Ireland
- Michelle Hanlon, independent patient representative
- Peter Hayes, GP (Limerick)
- Mary Jordan, GP Nurse/ prescriber & Chair of Irish GP Nurses Educational Association
- Mick Metcalfe, Patient & Member of Collaborative Doctoral Award in Multimorbidity PPI Group
- Caroline McCarthy, GP (Dublin City)
- Brian McGuire, Clinical psychologist and Psychological Society of Ireland/ Heads of Psychology Services Ireland nominee
- Denis Mockler, Patient & Member of the Primary Care PPI Group

- Maryrose Tarpey – James Lind Alliance Adviser, Steering Group Chair
- Susan Smith – PSP Team Lead (overall responsibility for successful delivery of the PSP)
- Laura O'Connor – PSP Team Coordinator (responsible for the day-to-day running of the PSP)

The Steering Group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process, with input and advice from the JLA.

4. Partners

Organisations and individuals will be invited to be involved with the PSP as partners *[this section will be updated as partners are confirmed].* Partners are organisations or groups who will commit to supporting the PSP, promoting the process and encouraging their represented groups or members to participate. Organisations which can reach and advocate for these groups will be invited to become involved in the PSP. Partners represent the following groups:

- people who have or have had chronic health conditions
- carers of people with chronic health conditions
- health and social care professionals - with experience of managing chronic health conditions in primary care settings

Exclusion criteria
Some organisations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to potentially cause unacceptable bias as a member of the Steering Group. As this is likely to affect the ultimate findings of the PSP, those organisations will not be invited to participate. It is possible, however, that interested parties may participate in a purely observational capacity when the Steering Group considers it may be helpful.

5. The methods the PSP will use

This section describes a schedule of proposed steps through which the PSP aims to meet its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods used in any step will be agreed through consultation between the Steering Group members, guided by the PSP's aims and objectives. More details of the method are in the Guidebook section of the JLA website at www.jla.nihr.ac.uk where examples of the work of other JLA PSPs can be seen.

Step 1: Identification and invitation of potential partners

Potential partner organisations will be identified through a process of peer knowledge and consultation, through the Steering Group members' networks. Potential partners will be contacted and informed of the establishment and aims of the Managing Chronic Conditions in Irish Primary Care PSP.

Step 2: Awareness raising

PSPs will need to raise awareness of their proposed activity among their patient, carer and clinician communities, in order to secure support and participation. Depending on budget, this may be done by a face-to-face meeting, or there may be other ways in which the process can be launched, e.g. via social media. It may be carried out as part of steps 1 and/or 3. The Steering Group should advise on when to do this. Awareness raising has several key objectives:

- to present the proposed plan for the PSP
- to generate support for the process
- to encourage participation in the process
- to initiate discussion, answer questions and address concerns.

Step 3: Identifying evidence uncertainties

The Managing Chronic Conditions in Irish Primary Care PSP will carry out a consultation to gather uncertainties from patients, carers and clinicians. A period of 2-3 months will be given to complete this exercise (which may be revised by the Steering Group if required).

The Managing Chronic Conditions in Irish Primary Care PSP recognises that the following groups may require additional consideration:

- *age – young, middle aged, older adults will all need to be accessed in different ways*
- *minority groups will require targeted communications*
- *healthcare professionals – time and access*

The Steering Group will use the following methods to reach the target groups

- online survey(s) primarily
- interviews or focus groups could be deployed with steering group input/consideration

Existing sources of evidence uncertainties may also be searched.

- Reviewing research is underway
- Partner orgs could be surveyed to ask for lists of FAQs they get contacted with

Step 4: Refining questions and uncertainties

The consultation process will produce ‘raw’ questions and comments indicating patients’, carers’ and clinicians’ areas of uncertainty. These raw questions will be categorised and refined into summary questions which are clear, addressable by research, and understandable to all. Similar or duplicate questions will be combined where appropriate. Out-of-scope and ‘answered’ submissions will be compiled separately. The Steering Group will have oversight of this process to ensure that the raw data is being interpreted appropriately and that the summary questions are being worded in a way that is understandable to all audiences. The JLA Adviser will observe to ensure accountability and transparency.

This will result in a long list of in-scope summary questions. These are not research questions and to try and word them as such may make them too technical for a non-research audience. They will be framed as researchable questions that capture the themes and topics that people have suggested.

The summary questions will then be checked against evidence to determine whether they have already been answered by research. The PSP will complete the JLA Question Verification Form, which clearly describes the process used to verify the uncertainty of the questions, before starting prioritisation. The Question Verification

Form includes details of the types and sources of evidence used to check uncertainty. The Question Verification Form should be published on the JLA website as soon as it has been agreed to enable researchers and other stakeholders to understand how the PSP has decided that its questions are unanswered, and any limitations of this.

Questions that are not adequately addressed by previous research will be collated and recorded on a standard JLA template. This will show the checking undertaken to make sure that the uncertainties have not already been answered. The data should be submitted to the JLA for publication on its website on completion of the priority setting exercise, taking into account any changes made at the final workshop, in order to ensure that PSP results are publicly available.

The Steering Group will also consider how it will deal with submitted questions that have been answered, and questions that are out of scope.

Step 5: Prioritisation – interim and final stages

The aim of the final stage of the priority setting process is to prioritise through consensus the identified uncertainties about managing chronic conditions in primary care. This will involve input from patients, carers and clinicians. The JLA encourages PSPs to involve as wide a range of people as possible, including those who did and did not contribute to the first consultation. There are usually two stages of prioritisation.

1. Interim prioritisation is the stage where the long list of questions is reduced to a shorter list that can be taken to the final priority setting workshop. This is aimed at a wide audience, and is done using similar methods to the first consultation. With the JLA's guidance, the Steering Group will agree the method and consider how best to reach and engage patients, carers and clinicians in the process. The most highly ranked questions (around 25) will be taken to a final priority setting workshop. Where the interim prioritisation does not produce a clear ranking or cut off point, the Steering Group will decide which questions are taken forwards to the final prioritisation.

2. The final priority setting stage is generally a one-day workshop facilitated by the JLA. With guidance from the JLA and input from the Steering Group, up to 30 patients, carers and clinicians will be recruited to participate in a day of discussion and ranking, to determine the top 10 questions for research. All participants will declare their interests. The Steering Group will advise on any adaptations needed to ensure that the process is inclusive and accessible.

6. Dissemination of results

The Steering Group will identify audiences with which it wants to engage when disseminating the results of the priority setting process, such as researchers, funders and the patient and clinical communities. They will need to determine how best to communicate the results and who will take responsibility for this. Previous PSPs' outputs have included academic papers, lay reports, infographics, conference presentations and videos for social media.

It should be noted that the priorities are not worded as research questions. The Steering Group should discuss how they will work with researchers and funders to establish how to address the priorities and to work out what the research questions are that will address the issues that people have prioritised. The dissemination of the results of the PSP will be led by the HRB Primary Care Clinical Trials Network.

The JLA encourages PSPs to report back about any activities that have come about because of the PSP, including funded research. Please send any details to jla@soton.ac.uk.

7. Agreement of the Steering Group

The Managing Chronic Conditions in Irish Primary Care PSP Steering Group agreed the content and direction of this Protocol on 28th October 2022