Appendix: Identifying research priorities for chronic disease management in primary care: results of an Irish James Lind Alliance Priority Setting Partnership

Contents

1. REPRISE checklist

No	Item	Descriptor and/or examples	Text	Section
A	Context and scope			
1	Define geographical scope	Global, regional, national, city, local area, institutional/organizational level, health service	anyone living in Ireland with one or more chronic condition(s), caring for someone with one or more chronic condition(s), or working in a primary healthcare role was eligible to participate in the activities of this PSP	Methods, 2. Gathering submissions
2	Define health area, field, focus	Disease or condition specific, interventions, healthcare delivery, health system	The main area of focus was decided at the outset by the Primary Care CTNI as chronic disease management in primary care	Methods, 1. Project initiation
3	Define the intended beneficiaries	This may include the general population or a specific population based on demographic (age, gender), clinical (disease, condition), or other characteristics who may benefit from the research	In doing so, we hope to offer funders and researchers a guide to align future projects with the priorities of those most affected by the outcomes; the patients, carers, and clinicians interacting in primary care every day	Introduction
4	Define the target audience of the priorities	Policy makers, funders, researchers, industry or others who have the potential to implement the priorities identified	In doing so, we hope to offer funders and researchers a guide to align future projects with the priorities of those most affected by the outcomes; the patients, carers, and clinicians interacting in primary care every day	Introduction
5	Identify the research area	Public health, health services research, clinical research, basic science	Our aim in this project was to develop a list of the top research priorities to inform policy and management of chronic conditions in primary care	Introduction

No	Item	Descriptor and/or examples	Text	Section
6	Identify the type of research questions	Etiology, diagnosis, prevention, treatment (interventions), prognosis, health services, psychosocial, behavioral and social science, economic evaluation, implementation; this may not be pre-defined	Exclusion criteria were decided to guide future decisions regarding who could submit suggestions and what submissions could be considered within scope. The steering group agreed that the focus of the PSP would be adults in Ireland, and on excluding input that concerned overly specific conditions or treatments, or input that focused on secondary or tertiary care alone	Methods, 1. Project initiation
7	Define the time frame	Interim, short-term, long-term priorities, plans to revise and update	Our aim in this project was to develop a list of the top research priorities to inform policy and management of chronic conditions in primary care. In doing so, we hope to offer funders and researchers a guide to align future projects with the priorities of those most affected	Introduction
B	Governance and Team			
8	Describe the selection and structure of the leadership and management team	Those responsible for initiating, developing, and guiding the process for priority setting, and examples of structures include; Steering Committee, Advisory Group, Technical Experts	The Primary Care CTNI led the project as part of its core network funding received from the HRB. The JLA assigned an independent adviser, who chaired the steering group and final workshop and advised on methods throughout. a steering group with relevant stakeholder representation was established	Methods
9	Describe the characteristics of the team	Stakeholder group or role, institutional affiliations, country or region, demographics (e.g. age sex), discipline, experience, expertise	Table provided of all members in appendix.	Appendix

No	Item	Descriptor and/or examples	Text	Section
10	Describe any training or experience relevant to conducting priority setting	Consultants or advisors, members with experience or skills relevant to the conducting priority-setting e.g. qualitative methods, surveys, facilitation	The JLA assigned an independent adviser, who chaired the steering group and final workshop and advised on methods throughout.	Methods
C	Framework for priority setting			
11	State the framework used (if any)	James Lind Alliance, COHRED, CHNRI, Dialogue Model, no framework (general research priority setting)	The James Lind Alliance (JLA) Priority Setting Partnership (PSP) method was chosen to realise this aim, due to its focus on the involvement of stakeholders outside of the traditional research space.	Introduction
D	Stakeholders or participants			
12	Define the inclusion criteria for stakeholders involved in priority-setting	Patients, caregivers, general community, health professionals, researchers, policy makers, non-governmental organizations, government, industry; specific groups including vulnerable and marginalized populations	‘Stakeholders’ in this case refers to patients, carers, and healthcare professionals, all with first-hand experience of the topic at hand. Researchers and academics may observe but not take part.	Methods
13	State the strategy or method for identifying and engaging stakeholders	Partnership with organizations, social media, recruitment through hospitals	Traditional and social media were used to share a press release about the project and the survey, and this was also sent to community and charitable organisations with relevant memberships.	Methods, 2. Gathering submissions (first survey)

No	Item	Descriptor and/or examples	Text	Section
14	Indicate the number of participants and/or organizations involved	Number of individuals and organizations, include number by stakeholder group	Table 3, Demographic details of participants This workshop gathered 16 stakeholders and included seven patients and carers, three GPs, three physiotherapists, two pharmacists and an optometrist. Two James Lind Alliance advisers and the project coordinator facilitated the priority setting discussions.	Results, Survey responses/Final workshop
15	Describe the characteristics of stakeholders	Stakeholder group, demographic characteristics, areas of interest and expertise, discipline, affiliations	Item 2 in appendix	Appendix
16	State if reimbursement for participation was provided	Cash, vouchers, certificates, acknowledgement; what purpose e.g. travel, accommodation, honorarium	For patient and carer members of the steering group, participation was reimbursed using gift vouchers. Like the steering group, patient and carer attendees received gift vouchers as reimbursement for their time, and travel and accommodation expenses were covered for all attendees travelling to the workshop.	Methods, Project initiation and Final workshop
E	Identification and collection of research priorities			
17	Describe methods for collecting initial priorities	Methods e.g. Delphi survey, surveys, nominal group technique, interviews, focus groups, meetings, workshops; prioritization e.g. voting, ranking; mode e.g. face-to-face, online; may be informed by evidence e.g. systematic reviews, reviews of guidelines/other documents, health technology assessment	The questionnaire was shared in March 2023, primarily using (Microsoft Forms)[16], with paper versions provided on request	Methods, Gathering submissions

No	Item	Descriptor and/or examples	Text	Section
18	Describe methods for collating and categorizing priorities	Taxonomy or other framework used to organize, summarise, and aggregate topics or questions	researchers then reviewed… developed an initial set of categories based on the scope as outlined in the protocol. Summary questions were formed by grouping statements, first by their broad category, then sub-category, and finally by looking for any overlap between statements in each subcategory	Methods, Processing responses
19	Describe methods and reasons for modifying (removing, adding, reframing) priorities	Based on scope, clarity, definition, duplication, other criteria	marking anything deemed out of scope (as determined at project initiation)	Methods, Processing responses
20	Describe methods for refining or translating priorities into research topics or questions	Reviewed by Steering Committee or project team	Summary questions were formed by grouping statements, first by their broad category, then sub-category, and finally by looking for any overlap between statements in each subcategory. The resulting list of summary questions was then sent to the steering group for comment while the evidence checking protocol was finalised	Methods, Processing responses
21	Describe methods for checking whether research questions or topics have been answered	Systematic reviews, evidence mapping, consultation with experts	Each summary question was checked against the existing literature using question-specific and primary care keywords in both the Cochrane Library and the Gov.ie repository of clinical guidelines.[19,20] Supplementary searches were conducted using PubMed, Google Scholar, and guideline repositories of relevant bodies and professional organisations (e.g. Irish College of General Practitioners, Nursing and Midwifery Board of Ireland, HSE Health Protection Surveillance Centre) when appropriate to the individual question.	Methods, Checking the evidence

No	Item	Descriptor and/or examples	Text	Section
22	Describe number of research questions or topics	Number of priorities at each stage of the process	The remaining 323 statements were processed as described above, resulting in the formation of 30 summary questions. The other 29 questions were found to have insufficient evidence to allow them to be considered answered. The interim ranking second survey resulted in 20 questions being identified for discussion at the final workshop	Throughout Results
F	Prioritization of research topics/questions			
23	Describe methods and criteria for prioritizing research topics or questions	Methods e.g. Delphi survey, surveys, nominal group technique, interviews, focus groups, meetings, workshops; Prioritization e.g. voting, ranking; Mode e.g. face-to-face, online; Criteria e.g. need, feasibility, novelty, equity	A top twenty was then made up of the top ten ranked questions of each of these two groups, to allow for a manageable twenty unanswered questions to go forward for final ranking in the workshop The final priority setting took place at an in-person workshop in Galway in January 2024.	Methods, Interim Priority setting and Final workshop
24	State the method or threshold for excluding research topics/questions	Thresholds for ranking scores, proportions, votes; other criteria	Once the second session concluded with a ranking agreed by consensus in each room, facilitators combined the scores to create a single ranked list for discussion in the afternoon sessions. For these final sessions, group allocations were changed to mix the participants with others while retaining balance. These new groups agreed upon any further revisions to the order. The final ranking was decided by combining the rankings of the three groups following this session. At this point, all participants gathered in a single group to review the final ranking of the 20 items and confirm their agreement.	Methods, Final workshop

No	Item	Descriptor and/or examples	Text	Section
G	Output			
25	State the approach to formulating the research priorities	Area, topic, questions, PICO (population, intervention, comparator, outcome)	Summary questions were formed by grouping statements, first by their broad category, then sub-category, and finally by looking for any overlap between statements in each subcategory. The resulting list of summary questions was then sent to the steering group for comment while the evidence checking protocol was finalised	Methods, Processing responses
H	Evaluation and feedback			
26	Describe how the process of prioritization was evaluated	Survey, workshop	Following the workshop, a survey was shared by the JLA with workshop attendees to gather feedback on the ranking producing a Top Ten list. Attendees were also asked to report back on their experience in the workshop.	Methods, Final workshop
27	Describe how priorities were fed back to stakeholders and/or to the public; and how feedback (if received) was addressed and integrated	Public meetings or workshop, newsletters, website, email, online presentations	N/A	Beyond the scope of this article
I	Implementation			

No	Item	Descriptor and/or examples	Text	Section
28	Outline the strategy or action plans for implementing priorities	Communication with target audience, via policies and funding	N/A	Beyond the scope of this article
29	Describe plans, strategies, or suggestions to evaluate impact	Integration in decision-making, funding allocation, review of relevant documents	N/A	Beyond the scope of this article
J	Funding and conflict of interest			
30	State sources of funding	Name sources of funding for the priority-setting exercise; if relevant include the budget and/or cost	This work is funded by the Health Research Board as part of their funding of the HRB Primary Care CTNI (grant reference CTN-2021-002).	Methods, role of funding source
31	Declare any conflicts or competing interests	State any conflicts of interest that may be at an individual level and/or at a contextual level (e.g. political issues, controversies) that may affect the process, output or implementation.		Declaration of Interests

2. Steering group membership

Prof Susan Smith	PSP Lead, Associate Director HRB Primary Care CTNI
Maryrose Tarpey	PSP Chair, JLA independent adviser
Laura O'Connor	PSP coordinator, researcher HRB Primary Care CTNI
Karen Cowap	Independent patient representative
Dr Sarah Delaney	Health Research Charities of Ireland representative
Michelle Hanlon	Independent patient representative
Dr Peter Hayes	GP
Mary Jordan	Practice nurse (chair of Irish GP Nurses Educational Association at outset of PSP)
Dr Caroline McCarthy	GP
Prof Brian McGuire	Clinical psychologist (nominated by Psychological Society of Ireland)
Denis Mockler	Independent patient representative
Mick Metcalfe	Independent patient representative

The steering group and PSP were also supported by organisational partners: The Alzheimer Society of Ireland, Asthma Society of Ireland, Chronic Pain Ireland, and the Irish General Practice Nurses Educational Association. As partners, these groups supported the PSP by sharing information with their members and assisted with promoting the surveys and workshop. As partners, these groups supported the PSP by sharing information with their members and assisted with promoting the surveys and workshop.

3. Survey 1 – Submission Gathering

HEALTH RESEARCH BOARD
Primary Care CTNI
CLINICAL TRIALS NETWORK IRELAND

James Lind Alliance
Priority Setting Partnerships

Your priorities for research in the management of chronic conditions in primary care

Who should take part in this survey?

You should consider taking part in this survey if you are an adult (18+) in Ireland living with a chronic condition or conditions; a family member, friend, or carer of someone with a chronic condition; or a healthcare professional who works in primary care treating people with chronic conditions.

What is the purpose of this survey?

We want to know what you think researchers should be focusing on so we can promote a list of your top priorities, to encourage and support researchers to start projects that will answer those questions.

What is this survey asking me?

We are asking all people affected by chronic conditions (those managing their own conditions, health professionals treating them, family and/or friends caring for a person with chronic conditions) to share with us their questions about managing chronic conditions in primary care. We specifically want to know what unanswered questions you have about the role of primary care in managing chronic conditions.

You can write as much or as little as you like. Your response will be anonymous; while we do ask you for some optional information to help us see who we are reaching, and to contact you with updates, this will not be linked to your response in any way. We will keep this survey open for submissions until Wednesday 12th of April.

Who are we?

The HRB Primary Care Clinical Trials Network are leading this project. As a group that supports high quality clinical trials in primary care, we want to ensure that the research we support reflects the needs and interests of the people most affected; the patients and healthcare professionals in primary care.

We are working with the James Lind Alliance (https://www.jla.nihr.ac.uk/about-the-jameslind-alliance/) who are leaders in this method of identifying research questions which are of direct relevance and potential benefit to patients and the clinicians who treat them. The first step in this process was to set up a diverse, committed steering group of people with lived experience of having chronic conditions, supporting loved ones with chronic conditions, and treating chronic conditions in primary care. This survey has been designed with their input.

To complete the survey, please scan the QR code to the right, or visit primarycaretrials.ie/psp

If you have any questions, please contact our coordinator Laura at laura.l.oconnor@universityofgalway.ie

HRB Health Research Board

Ollscoil na Gaillimhe University of Galway

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

How can primary care help people with chronic conditions to manage their conditions and live as well as possible?

We want to help researchers prioritise the questions and areas that mean the most to you. This is your chance to add your own questions or comments about your experience as a healthcare professional in primary care.

Your question may relate to:

- How medications, treatments, appointments and other forms of support from health professionals, carers, family and friends work in primary care for those with chronic conditions
- The health system and questions or comments about continuity of care with a named professional, the role of different types of healthcare professionals and their communications with patients and the people who care for them, communication between hospitals and the community
- Information you feel is important for people with chronic conditions, those caring for them, and primary care health professionals to know to best manage chronic conditions any other question or comment relevant to you

You may have other important questions about chronic conditions that research could answer, but that this process can't focus on. If we get a submission that is out of our scope, we will pass it on to relevant groups who can use the information in their work. Some examples of topics that are beyond our scope are:

- Questions about your specific situation and supports available to you
- Questions about specific conditions and/or treatments
- Questions about specialist care
- Questions concerning the biological causes of conditions
-

1. What question(s) or comment(s) do you have about managing chronic conditions in primary care in Ireland?

4. Question Verification Form

James Lind Alliance Priority Setting Partnership Question Verification Form

The purpose of this Question Verification Form is to enable Priority Setting Partnerships (PSPs) to describe clearly how they checked that their questions were unanswered, before starting the interim prioritisation stage of the process.

The JLA requires PSPs to be transparent and accountable in defining their own scope and evidence checking process. This will enable researchers and other stakeholders to understand how individual PSPs decided that their questions were unanswered, and any limitations of their evidence checking. For an example of this form completed by a PSP, please see http://www.jla.nihr.ac.uk/priority-setting-partnerships/hyperacusis/downloads/Hyperacusis-PSP-question-verification-form.pdf

Name of the PSP
Managing chronic conditions in Irish primary care
Please describe the 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 o 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. o Management: the ongoing treatment, coordination, monitoring and support undertaken by people with chronic conditions and healthcare professionals to improve health outcomes. o 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).
Please provide a brief overview of your approach to checking whether the questions were unanswered
Our search focused on finding evidence syntheses (systematic reviews and meta analyses) and/or clinical guidelines with relevance to individual questions.

Questions were determined to be unanswered when no systematic review or clinical guidelines could be found, or where relevant syntheses determined that there was insufficient or low quality evidence in the area.

Please list the type(s) of evidence you used to verify your questions as unanswered

- Evidence syntheses – systematic reviews, meta-analyses
- Clinical guidelines
- (in the case of provision of care/policy questions only) HSE and/or Department of Health reports

Please list the sources that you searched in order to identify that evidence

Main sources

- The Cochrane Library
- Gov.ie repository of clinical guidelines

Other sources

- PubMed
- Google Scholar
- ICGP clinical guidelines (access restricted to GPs) and guidelines of other professional organisations where appropriate

What search terms did you use?

The following terms were used in combination to best represent the question being investigated (formatted as appropriate for each source's searching interface to allow for close matches and synonyms):

Review; meta-analysis; synthesis
Primary care; general practice; community care; primary healthcare; GP
Chronic; chronic condition; chronic disease; lifelong
Managing; treating; self-management; monitoring;

Topic specific search terms combined with the above included:
referral; outpatients; hospital; consultant; specialist; access; utilization; cost; burden; education; training; CPD; pain; fatigue; medically unexplained symptoms; waiting list; delay; medication; polypharmacy; data management; patient information; disease management programmes; resourcing; planning; mental health; continuity;

Please describe the parameters of the search (eg time limits, excluded sources, country/language) and the rationale for any limitations

- Searches were limited to title/abstract/keywords rather than fulltext
- Searches included publications between January 2010 and October 2023
- English only articles

Results that focused on healthcare systems radically different from the Irish system, or that focused on aspects of health systems that were not comparable to the Irish context were not possible to systematically screen out, and as such were identified while reviewing returned results and discounted on a case-by-case basis.

Names of individuals who undertook the evidence checking

Laura O'Connor
Louise O'Grady
Razan Alkhabbaz

On what date was the question verification process completed?

August – October 2023

Any other relevant information

Version 2 Date 19.12.2023

5. Survey 2 – Interim Priority Setting

Priorities for research in the management of chronic conditions in primary care

Managing chronic conditions in primary care - A priority setting partnership

The HRB Primary Care Clinical Trials Network have established this Priority Setting Partnership (PSP), with the support of the James Lind Alliance, to decide the top priorities for research about the management of chronic conditions in primary care. The following survey includes a longlist of priorities for future research, submitted by people with chronic conditions, those who care for them, and healthcare providers who treat them. We are now asking that people, who may or may not have taken part in that first phase, choose their top priorities from that longlist.

You should take part if you are someone who manages a chronic condition, if you care for someone who does, or if you are a healthcare provider working in primary care.

This survey will ask you to tell us how you describe your relationship with chronic condition management, choose your top priorities for research from our list, and then to tell us a bit more about yourself so we can ensure a broad range of people take part.
It won't ask you to identify yourself, and should only take about **5-10 minutes** to complete.
If you have an interest in taking part in the next in-person stage of this project, you can leave your email at the end, but otherwise you do not have to give any contact information.

This survey will run until the **20th December**.

For the full background on this project, please visit https://primarycaretrials.ie/psp/

* From the following options, please select the one that best describes you.

- ○ Person with a chronic condition or multiple chronic conditions
- ○ Healthcare professional working in primary care
- ○ Person caring for (or who has cared for) someone with one or more chronic conditions
- ○ Individual submitting a response on behalf of an organisation

* **Which of these questions do you think are important to answer? Choose all that are important to you.**

You may find the following definitions helpful:

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.).

- ☐ What is the best way to ensure **appropriate and timely access** to Irish primary care services for people managing chronic conditions?
- ☐ How can primary care services best manage the complexities of caring for people with **multiple chronic conditions** (across the lifespan)?
- ☐ In what ways can the **financial implications (inc. direct and indirect costs)** faced by people with chronic conditions and their families be recognised and addressed?

- [ ] What information and/or interventions would help people with chronic conditions to **manage their medications** effectively and confidently?
- [ ] How could **primary care consultations/appointments be best structured** (e.g. short vs long consultations, in-person vs remote) to meet the needs and improve the experience of people managing chronic conditions?
- [ ] How could the **experience of referral from primary care to specialist/hospital services** be improved for both people with chronic conditions and healthcare professionals in primary care?
- [ ] How can the general **exchange of information** be improved from specialist/hospital services and primary care for both people with chronic conditions and healthcare professionals?
- [ ] How can primary care better support people with chronic conditions **after being discharged from specialist or inpatient care**, including the transfer of their records and prescriptions?
- [ ] How can a **multidisciplinary approach** (e.g. the involvement of a mix of health care professionals) be implemented when managing chronic conditions in primary care?
- [ ] How can **primary health care data be used** to inform chronic condition management, both in the care of individual patients and in the delivery of services more broadly?
- [ ] How effectively do **disease management programmes** (e.g. the HSE chronic disease management programme or CDM) meet the needs of people with chronic conditions, and do they provide a good experience of care?
- [ ] In what ways can **primary care healthcare professionals be supported** to provide patient centered disease management programmes and procedures to ensure effective delivery of care (e.g. resources, guidelines, organisational changes)?
- [ ] What is the best way to support **continuity of care within primary care** for people with chronic conditions, including continuity in their relationships with primary care professionals and in the management and coordination of their care?
- [ ] What **education, training, or continuing professional development** could be provided to health care professionals working in primary care to help better understand and meet the needs of people with chronic conditions?
- [ ] How can people with chronic conditions be best supported to **engage with and navigate health and social care information and services**?
- [ ] How can **social services and supports** (e.g. social prescribing, or referring people to non-medical supports in the community) be made available to people with chronic conditions within or through primary care?

- [ ] How has **technology (e.g. online information and search engines, social media, apps, wearable devices) affected the management of chronic conditions** in primary care, particularly the dynamic between the patient and the healthcare professional in relation to knowledge about treatment?
- [ ] What **non-drug treatments for managing chronic conditions** (e.g., exercise and other lifestyle changes, physical therapies, talk therapies) could be integrated into primary care services instead of or in addition to medications?
- [ ] How can up to date best evidence and patient priorities be used to **identify and integrate potential new treatments** for chronic conditions (including but not limited to medications) into primary care?
- [ ] What is the best approach to **developing future national policies** (e.g. policies affecting equitable access to care and medications, funding and delivery of resources, and other governmental level decisions) for chronic condition management in primary care ensuring input from all stakeholders?
- [ ] How can **newly developed or improved medications for chronic conditions** be integrated into primary care chronic condition management in a timely, accessible and equitable way?
- [ ] How can primary care services **support good mental health and wellbeing** for people managing chronic conditions and symptoms?
- [ ] What are the **best ways for primary healthcare professionals to communicate**, to ensure that people with chronic conditions feel understood and heard in primary care?
- [ ] In what ways can primary care **understand and address patient and family/carer treatment burden**, i.e., the work people have to do to manage chronic conditions and the impact that has?
- [ ] What are the best ways for primary care to ensure that **patient centred care plans** to manage chronic conditions are developed with input from people with chronic conditions and their family and carers?
- [ ] How can **the needs of people and/or groups often overlooked or ignored by mainstream society** (including people with disabilities, migrants and refugees, people from the LGBTQI+ community, people who face financial, geographical, or other barriers to accessing care) who are managing chronic conditions be addressed and integrated into primary care policy and services?
- [ ] What are the best ways for people with chronic conditions to be supported by primary care services in the **self-management and monitoring** of their conditions?
- [ ] What is the best approach to **workforce planning and resourcing** in primary care that avoids understaffing and/or overloading staff's ability to treat people with chronic conditions?
- [ ] What are the best approaches in primary care services for the management of chronic and **medically unexplained symptoms?**

- [ ] How can **patient safety** in primary care be ensured in the management of chronic conditions?

* You've marked all of the questions below as important to you. Please now select which 10 are the **most** important to you (if you have less than 10 choices below, choose the ones you'd most like to see answered, even if that is all of them.) .

- [ ] What is the best way to ensure appropriate and timely access to Irish primary care services for people managing chronic conditions?
- [ ] How can primary care services best manage the complexities of caring for people with multiple chronic conditions (across the lifespan)?
- [ ] In what ways can the financial implications (inc. direct and indirect costs) faced by people with chronic conditions and their families be recognised and addressed?
- [ ] What information and/or interventions would help people with chronic conditions to manage their medications effectively and confidently?
- [ ] How could primary care consultations/appointments be best structured (e.g. short vs long consultations, in-person vs remote) to meet the needs and improve the experience of people managing chronic conditions?
- [ ] How could the experience of being referred from primary care to specialist/hospital services be improved for both people with chronic conditions and healthcare professionals in primary care?
- [ ] How can exchange of information be improved between specialist/hospital services and primary care for both people with chronic conditions and healthcare professionals?
- [ ] How can primary care better support people with chronic conditions after being discharged from specialist or inpatient care, including the transfer of their records and prescriptions?
- [ ] How can a multidisciplinary approach (e.g. the involvement of a mix of health care professionals) be implemented when managing chronic conditions in primary care?
- [ ] How can primary health care data be used to inform chronic condition management, both in the care of individual patients and in the delivery of services more broadly?
- [ ] How effectively do disease management programmes (e.g. the HSE chronic disease management programme or CDM) meet the needs of people with chronic conditions, and do they provide a good experience of care?
- [ ] In what ways can primary care centred disease management programmes, procedures, and guidelines incorporate the input of healthcare professionals (e.g. on scope of practice, new guidelines needed, gaps observed in care programmes) to ensure effective delivery of care?

- [ ] What is the best way to support continuity of care for people with chronic conditions within primary care, including continuity in their relationships with primary care professionals and in the management and coordination of their care?
- [ ] What education, training, or continuing professional development could be provided to health care professionals working in primary care to help better understand and meet the needs of people with chronic conditions?
- [ ] How can people with chronic conditions be best supported to engage with and navigate health and social care information and services?
- [ ] How can social services and supports (e.g. social prescribing, or referring people to non-medical supports in the community) be made available to people with chronic conditions within or through primary care?
- [ ] How has technology (e.g. online information and search engines, social media, apps, wearable devices) affected the management of chronic conditions in primary care, particularly the dynamic between the patient and the healthcare professional in relation to knowledge about treatment?
- [ ] What non-drug treatments for managing chronic conditions (e.g., exercise and other lifestyle changes, physical therapies, talk therapies) could be integrated into primary care services instead of or in addition to medications?
- [ ] How can up to date best evidence and patient priorities be used to identify and integrate potential new treatments for chronic conditions (including but not limited to medications) into primary care?
- [ ] What is the best approach to developing future national policies (e.g. policies affecting equitable access to care and medications, funding and delivery of resources, and other governmental level decisions) for chronic condition management in primary care ensuring input from all stakeholders?
- [ ] How can newly developed or improved medications for chronic conditions be integrated into primary care chronic condition management in a timely, accessible and equitable way?
- [ ] How can primary care services support good mental health and wellbeing for people managing chronic conditions and symptoms?
- [ ] What are the best ways for primary healthcare professionals to communicate, to ensure that people with chronic conditions feel understood and heard in primary care?
- [ ] In what ways can primary care understand and address patient and family/carer treatment burden, i.e., the work people have to do to manage chronic conditions and the impact that has?
- [ ] What are the best ways for primary care to ensure that patient centred care plans to manage chronic conditions are developed with input from people with chronic conditions and their family and carers?

- [ ] How can primary care acknowledge and address the needs of people and/or groups often overlooked or ignored by mainstream society (including people with disabilities, migrants and refugees, people from the LGBTQI+ community, people who face financial, geographical, or other barriers to accessing care) in the management of chronic conditions?
- [ ] What are the best ways for people with chronic conditions to be supported by primary care services in the self-management and monitoring of their conditions?
- [ ] What is the best approach to workforce planning and resourcing in primary care that avoids understaffing and/or overloading staff's ability to treat people with chronic conditions?
- [ ] What are the best approaches in primary care services for the management of chronic and medically unexplained symptoms?
- [ ] How can patient safety in primary care be ensured in the management of chronic conditions?

* Where are you located?

- ○ Republic of Ireland
- ○ Northern Ireland
- ○ Outside the island of Ireland

* What is your profession/role in primary care?

* Which condition or conditions do you have, or does the person you care for have?

* Which organisation are you submitting on behalf of?

*

Which age group do you belong to?

- ◯ Prefer not to say
- ◯ 18-24
- ◯ 25-34
- ◯ 35-44
- ◯ 45-54
- ◯ 55-64
- ◯ 65-74
- ◯ 75 years or older

* Which gender do you most identify with?

- ◯ Prefer not to say
- ◯ Man
- ◯ Woman
- ◯ Other

Next steps

The final part of this project involves an in-person workshop in Galway on the 22nd of January.
We will be inviting a mix of people with chronic conditions, carers, and healthcare professionals to participate, which involves attending on the day and taking part in discussions about the items deemed most important by the people who did this survey.

If you think you might be interested in taking part in this workshop, please enter your email before closing this survey.

6. Data management sheet

PSP Name	Total number of verified uncertainties identified by the PSP	Uncertainty (PICO formatted indicative uncertainty where possible. Advised minimum requirements are 'Population' and 'Intervention'. Not all submissions may be suitable for PICO structure, but they should be in a format that will ultimately be of value to the research community)	Explanatory note (a plain language summary of up to 150 words, explaining key points of the uncertainty and why it is important, for research funders to begin working on. PSPs may wish to include examples of the original survey submissions here)	Example statement from survey submission (deidentified where necessary)	Note on available evidence	Date of the priority setting workshop	Rank of the uncertainty at the final workshop. (If no rank was agreed, please indicate)	Evidence (reference, and weblink where available, to the most recent relevant systematic review identified by the PSP, plus a maximum of 2 other systematic reviews, including protocols for future systematic reviews, that the PSP considers relevant.)
Managing chronic conditions in Irish primary care	*30*	What is the best way to ensure **appropriate and timely access** to Irish primary care services for people managing chronic conditions?	Delays, inability to access services in local areas, and shortages of key services in primary care were mentioned in the statements contributing to this question. Cost and difficulty in contacting services or booking appointments were also important parts of this question.	How do you get prompt appointments when you are suffering due to a specific condition and GP has no available appointment for days or weeks at a time.	Some research shows individual interventions having limited effects, but no reviews or guidelines exist for broad access to care questions.	*22-Jan-24*	*6*	*2021 COPD clinical guidelines - https://www.gov.ie/en/publication/5df41-national-clinical-guideline-no27-management-of-chronic-obstructive-pulmonary-disease-copd/*
		How can primary care services best manage the complexities of caring for people with **multiple chronic conditions** (across the lifespan)?	Submissions relating to people managing multiple conditions noted the complexity involved when conditions increase, including needing to involve more HCPs, attend more appointments in more locations, investigations of symptom changes taking longer, medication management being more complex. Despite recent progress in research there is still uncertainty around best approaches to this complexity.	Not sure how you would do it but some kind of research might be interesting about the lack of general physicians to whom to refer people with complex multimorbidity (eg managing a patient early 60s with gout, heart failure and advanced renal impairment). Even when old enough for med elderly they seem mainly interested in mobility and falls……having to get advice from multiple specialists is very draining for patients	2021 Cochrane review reports mixed evidence and calls for clearer definitions and higher quality research	*22-Jan-24*	7	Smith et al - https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD004910.pub3/full#CD004910-abs-0004
		In what ways can the **financial implications (inc. direct and indirect costs) faced by** people with chronic conditions and their families be recognised and addressed**?**	Submissions contributing to this question mentioned specifics from the Irish context (i.e. medical card elibility, CDM accessibility, other government schemes) but cumulatively focused on the problem of people incurring costs and losing income when managing chronic conditions. Key to note is the aim of looking at the whole picture for individuals and families, not just direct costs, and the associated question that implies about costs to the state (illustrated in the example statement to the right)	My chronic condition is primarily managed (well) by specialists in a hospital out-patient clinic, and since diagnosis I have had no need to attend primary care. This turns out to be cost saving for me as visits to GP are costly (€60) and outpatient visits free and I get expert advice of specialist team which I value. However, I am acutely aware that these costs are taken up by the state and the way in which my condition is managed is at odds with goals of Slaintecare and government policy.	No reviews focusing on financial burden, related reviews call for targeted cost effectiveness research	*22-Jan-24*	17	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD010398/full - extending pharmacist scope could affect costs of accessing care
		What information and/or interventions would help people with chronic conditions to manage **their medications** effectively and confidently?	The focus of this statement is on the medication management of individuals, supported by their primary care practitioners. Statements on this included mentions of ensuring adherance, understanding medications prescribed, avoiding polypharmacy, changes between branded and generic items.	Changing prescription medication for generic tablets for elderly patients can be very confusing especially if tablets are a different colour or packaging	Only relevant Cochrane review (2018) focused on clinician feedback, reports poor evidence of effect	*22-Jan-24*	Did not go forward to workshop	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD012042.pub2/full
		How could **primary care consultations/appointments be best structured** (e.g. short vs long consultations, in-person vs remote) to meet the needs and improve the experience of people managing chronic conditions?	This question reflects statements feeling the current process does not fit all needs for chronic condition management, including times where multiple issues need to be covered, or times where someone is seeking information rather than treatment.	I don't feel I have easy access just to an advice clinic. Sometimes I just want to be able to call and ask a question. I don't need to have a full appointment with a doctor or nurse. It all feels very disjointed between hse staff and then the gp surgery.	No joined up research available around format of appointments - Cochrane reviews report some promise for automated telephone communication, insufficient evidence for altering appointment length.	*22-Jan-24*	20	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009921.pub2/full#CD009921-sec-0332 https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD003540.pub3/full
		How could the experience of **being referred from primary care to specialist/hospital services** be improved for both people with chronic conditions and healthcare professionals in primary care?	Referrals were a huge point of frustration in many submissions, with specifics including long waiting lists, lack of communication, HCPs lack of knowledge on available services or pathways, patient's inability to access referral letters or other documentation.	People with chronic conditions are bounced offwaitig lists too easily.They are often discharged into the community for non attendance when a little work on logistics would keep them on the system.	2014 systematic review suggests more research in whole system approaches to improve referrals, evidence lacking	*22-Jan-24*	18	https://pubmed.ncbi.nlm.nih.gov/25452541/

		How can **exchange of information** be improved between specialist/hospital services and primary care for both people with chronic conditions and healthcare professionals?	Where information has to move between services/practitioners, an uncertainty was identified in how this could meet the needs of patients and of healthcare professionals. Specific issues to be addressed included the lack of any one "record", the difficulties in balancing swift and easy information exchange with privacy rights, and what level of access or control patients should have to such information	My main concern in the way people are treated in the healthcare system is that when there is a diagnosis on one chronic condition other health matters are often not included or forgotten. There isn't one definite database where your GP can access all your health data, so the person and the body does not get treated as a whole.	General research on info exchange is lacking - some evidence in a CR of having a consultation liason to support mental health care, but nothing more general	*22-Jan-24*	1	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD007193.pub2/full#CD007193-abs-0002
		How can primary care better support people with chronic conditions **after being discharged from specialist or inpatient care**, including the transfer of their records and prescriptions?	Discharge from secondary care back home was noted as a pain point in the process, with records and medications specified in submissions. Statements contributing to this question included statements from family/careres, who noted additional interest in exploring this transition from that perspective	There is a huge issue with patient safety in relation to transition from secondary care with prescriptions for multiple items. Quantifying this if possible might trigger change towards a universal process for discharge prescriptions	No relevant syntheses found - some pockets of evidence in specific areas but conclusions weak and not aligned with Irish context	*22-Jan-24*	Did not go forward to workshop	
		How can a **multidisciplinary approach** (e.g. the involvement of a mix of health care professionals) be implemented when managing chronic conditions in primary care?	Submissions on this topic came from many perspectives, including patients who would like to see greater communication between HCPs they already attend, HCPs speaking to collaboration with colleagues, and submissions also specifying certain professions and interested in potential impacts of expanding the scope of certain roles to include more multidisciplinary focus	Incomplete teams in the community and a lack of standardisation nationwide make it very difficult to figure out the best services for a patient.	Existing research focuses on expansion of specific roles - cochrance review of nurse role lacks specific evidence around how to implement, review of non-medical prescribing calls for further cost-effectiveness and quality research.	*22-Jan-24*	3	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011227.pub2/full#CD011227-abs-0003 https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD001271.pub3/full
		How can **primary health care data be used** to inform chronic condition management, both in the care of individual patients and in the delivery of services more broadly?	This questions reflects an interest from both healthcare professionals and patients in efficient use of already routinely collected data for individual management and research purposes.	How can health care workers in primary care share local research data and clinical outcomes so the best practice of managing chronic disease can be established	Cochrane review regarding individual access to own records was inconclusive, not totally aligned with irish context. Further research is needed, and specific work focusing on Irish setting	*22-Jan-24*	4	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD012707.pub2/full#CD012707-abs-0002
		How effectively do **disease management programmes** (e.g. the HSE chronic disease management programme or CDM) meet the needs of people with chronic conditions, and do they provide a good experience of care?	Many submissions specified the HSE CDM in asking about structured disease management programmes, asking questions about current effectiveness, potential expansion to new conditions/new patient groups, HCP involvement in development of services, and in accessibility of related information and training.	Why is there no free access to G.P. for most chronic conditions, which can affect how often you can see your doctor?	Some reporting available regarding rollout of CDM, but nothing focusing on effectiveness from patient perspective/satisfaction. Cochrane review on shared care between primary and secondary services for depression has some overlap but also calls for further research	*22-Jan-24*	11	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD004910.pub3/full#CD004910-abs-0004
		In what ways can primary care centred disease management programmes, procedures, and guidelines **incorporate the input of healthcare professionals** (e.g. on scope of practice, new guidelines needed, gaps observed in care programmes) to ensure effective delivery of care?	Submissions in this area, mainly from HCPs, included questions about how involved HCPS could or should be in the development of practice and programmes, and uncertainty around how much their input was sought after or incorporated in such development currently	New system is very good (structured care in GP practices). But I'm really struggling to se how the new CDM hubs fit in and how are they different from hospital clinics. We have a diabetes HSE nurse visiting our practice. Since she started we have referred no diabetics to the hospital. We work in a deep end practice so having this access is brilliant. The patients much more likely to attend. But now they want to take her out and locate her in the CDm hub to which many of our patients will not go . So you could look at the functioning (or not)of these hubs in areas of disadvantage	There is little research on guideline/process development relevant to the Irish setting, and research that does have overlap suggests primary care professionals are rarely involved in development	*22-Jan-24*	15	https://www.cfp.ca/content/cfp/61/1/52.full.pdf
		What is the best way to support **continuity of care** for people with chronic conditions **within primary care**, including continuity in their relationships with primary care professionals and in the management and coordination of their care?	Continuity was a common theme in submissions from patients and carers, including both continuity with the same HCPs as well as with local services generally. Continuity of approach across services also featured, and in times of transition between settings (residential and home, or young adult to adult care)	would like to be looked after by same team of healthcare personnel when possible.when you have a chronic illness it helps to have familiar people treating you.	The benefits of continuity are well documented but research calls for more exploration of how best to approach that benefit in terms of resource allocation and interventions to promore continuity.	*22-Jan-24*	9	https://bjgp.org/content/70/698/e600.short https://link.springer.com/article/10.1186/s12913-023-09718-8

		What **education, training, or continuing professional development could be provided to health care professionals** working in primary care to help better understand and meet the needs of people with chronic conditions?	HCPs had interest in how they could best be supported in their roles by education and continued training, while patients and carers were keen to see research into how HCP education could incorporate their priority areas (like patient centered approaches, communication skills, condition knowledge)	Training for practice nurses to implement this CDM is poor. Educational resources on patient conditions are not readily available and you have to search for everything. Discovering new elements yourself as opposed to being informed.	No broader research into education around chronic condition management - overlap with cochrane review in COPD education for HCPs, which found inconclusive evidence	*22-Jan-24*	13	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD012652.pub2/full#CD012652-abs-0002
		How can people with chronic conditions be best supported to **engage with and navigate health and social care information and services**?	Submissions, mainly from patients/carers, in this area spoke about feeling lost or overburdened trying to navigate between different services, particularly when new diagnoses were made.	Often patients feel lost & abandoned after diagnosis. What plans are there to explain the PROCESS & pathways available to the patient & carer.	No relevant syntheses in Irish context or similar - some encouraging outcomes for group educations with veterans in US synthesis but relevant overlap is small	*22-Jan-24*	8	https://pubmed.ncbi.nlm.nih.gov/24501785/
		How can **social services and supports** (e.g. social prescribing, or referring people to non-medical supports in the community) be made available to people with chronic conditions within or through primary care?	This question summarises interest in investigating interventions including social prescribing, and greater integration of social services into primary care disease management (e.g. referrals to support groups, exercise options)	I would like to see the roll out of social prescribing aligned and more available to all areas.	Some specific evidence regarding support for screening approaches in certain settings but little looking at broad integration	*22-Jan-24*	19	https://bjgpopen.org/content/bjgpoa/early/2023/09/06/BJGPO.2023.0155.full.pdf
		How has **technology (e.g. online information and search engines, social media, apps, wearable devices)** affected the management of chronic conditions in primary care, particularly the dynamic between the patient and the healthcare professional in relation to knowledge about treatment?	Note - added by core PSP team during review of longlist. This question was composed to include the topic of technology, touched on in some submissions. The aim of this question was to reflect growing interest in the integration of technology into daily life including health, rather than technologies specifically designed for primary care applications.	Role of technology to make care more convenient.	No relevant syntheses found, some single studies and hypotheses only	*22-Jan-24*	Did not go forward to workshop	
		What **non-drug treatments** for managing chronic conditions (e.g., exercise and other lifestyle changes, physical therapies, talk therapies) could be integrated into primary care services instead of or in addition to medications?	Statements from patients contributed to this question, in particular mentioning a desire for more research into common conditions and opportunities for non-drug treatments to be developed/tested, and greater insight into what existing non-drug treatments could be made more accessible through primary care and provide benefits.	I would like to know, if my condition were to be managed in primary care, would there be a greater focus on non-pharmacological treatments, which I would like to see and would I have a greater say in my treatment? I expect this could be cost saving for me and the state, as costs of medications are very high, greater than €80 per month, and I worry about the longer term side effects.	Existing evidence is focused on certain conditions/states (mental health, multimorbidity), some promise suggested for complex interventions in care delivery	*22-Jan-24*	2	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD006560.pub4
		How can newly developed or improved medications for chronic conditions be integrated into primary care chronic condition management in a timely, accessible and equitable way?	this question intended to reflect interest in some submissions in development of brand new treatments, especially for conditions with few current treatments available. Submissions showed interest in how patient priorities could influence what is devleoped, and what is then integrated into primary care (versus specialist care)	If new drug is available how does people get it do they need to ask for it themselves ? People with Alzheimer's may have issues remembering their name leave alone tracking progress on new development	Using perspective of evidence based primary care: strong evidence based mindset already, keeping up to date with guidelines and recommendations, however relevant syntheses are based in US so system incomparable	*22-Jan-24*	14	
		What is the best approach to **developing future national policies** (e.g. policies affecting equitable access to care and medications, funding and delivery of resources, and other governmental level decisions) for chronic condition management in primary care ensuring input from all stakeholders?	Note - added by core PSP team during review of longlist. This question was added by the team in recognition of how many submissions overlapped research interests with suggestions or queries about policy decisions, and submissions reflecting on what evidence would be needed to influence such decision making	How can we create a system which puts the person at the centre, not bureaucratic needs.		*22-Jan-24*	Did not go forward to workshop	
		How can primary care services **support good mental health and wellbeing** for people managing chronic conditions and symptoms?	Submissions querying the role of primary care in supporting good mental health generally while addressing specific complaints contributed to this question. This includes the treatment of specific mental health conditions but is not limited to that, instead taking a holistic wellbeing view so as to include maintaining good mental health while treating other chronic issues.	Should mental health practitioners be assigned to primary care teams to bring some expertise to the area of mental health care , along with the appropriate use of both pharmacological and non pharmacological care approaches required in the community ?	Cochrane review of primary care centred approach for management of certain disorders showed promise - too narrow to answer this question	*22-Jan-24*	10	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD007193.pub2/full#CD007193-abs-0002

		What are the best ways for primary healthcare professionals to **communicate,** to ensure that people with chronic conditions feel understood and heard in primary care?	Statements mentioning communication between patients (and carers) and healthcare professionals were emotive, often feeling there were issues arising from training or lack of. Submissions about communication included questions and statements about soft communication skills, as well as use of different communication channels	I think one of the biggest issues I face in primary care, especially as a young woman with a complex illness, is not being taken seriously or listened to. It's a very common experience for self reported symptoms to be labelled anxiety or dismissed. What can be done to undo such entrenched and wide spread unconscious bias?	Mixed results in related Cochrane review on patient centred consultations, conclusions suggest more exploration of communication based interventions needed	*22-Jan-24*	Did not go forward to workshop	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD003267.pub2/full
		In what ways can primary care understand and address patient and family/carer **treatment burden**, i.e., the work people have to do to manage chronic conditions and the impact that has?	The concept of treatment burden was used in this question to encompass questions asked about all of the efforts associated with accessing and organising care, such as arranging appointment, transferring information between HCPs, making lifestyle changes, travelling between care settings and so on. While financial concerns were split out into another question, there is some overlap in that this burden could exacerbate financial concerns and financial management could add to burden	Why is the burden or organisation, planning, coherence, communication invariably on the patient or carer (unless it is in the psychiatric system)?	Scoping review of person centred integrated care to tackle non-disease related burdens called for more research, evidence points to competencies that should be present in primary care but more work needed on how that could be operationalised	*22-Jan-24*	5	https://pubmed.ncbi.nlm.nih.gov/37046190/
		What are the best ways for primary care to ensure that **patient centred care plans** to manage chronic conditions are developed with input from people with chronic conditions and their family and carers?	While the language in this question can have specific meanings in some settings, this question refers to the broadest possible concept - plans being made between HCPs and the patient (and carers) where the patient and their desires and needs are at the centre of the decision making. This is based on submissions regarding the individual's role in decision making about their own care, the role of carers in these decisions, and how primary care can balance best care with keeping the patient centred	How can we take a more patient-centred approach to chronic condition management?	Reasonable evidence that personalised care is promising presented in Cochrane review - Coulter et al 2015 Very little evidence for any interventions to involve patients with multiple conditions in decision makingin primary care (Butterworth et al)	*22-Jan-24*	16	Coulter https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD010523.pub2/full Butterworth https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD013124.pub2/full
		How can primary care acknowledge and address **the needs of people and/or groups often overlooked or ignored by mainstream society** (including people with disabilities, migrants and refugees, people from the LGBTQI+ community, people who face financial, geographical, or other barriers to accessing care) in the management of chronic conditions?	Note - added by core PSP team during review of longlist. This question was added after reflection that our survey was likely to not have reached people equally, and that different groups will have different needs and practices relating to how they engage with primary care.	How do I know what are the best services to meet specific needs of specific chronic conditions?	Syntheses available on interventions for a condition or specific target group, however no evidence found around general use of primary care for ongoing management needsthrough an EDI lens. Linked cochrane review calls for more cultural awareness training research for HCPs noting lack of robust evidence.	*22-Jan-24*	Did not go forward to workshop	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009405.pub2/full
		What are the best ways for people with chronic conditions to be supported by primary care services in the **self-management** and monitoring of their conditions?	Self-management and supports for self-maangement activities were a theme evident in submissions, often acknowledging it as part of the bigger picture when managing a chronic condition rather than focusing on it alone	What psychosocial input would be beneficial for self management of chronic disease?	Research available focuses on condition specific programmes - e.g. integrated programmes showing promise in COPD management	*22-Jan-24*	Did not go forward to workshop	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009437.pub3/full#CD009437-abs-0002
		What is the best approach to **workforce planning and resourcing** in primary care that avoids understaffing and/or overloading staff's ability to treat people with chronic conditions?	Submissions on the workforce in priamry care were sent in by patients, carers, and HCps, many acknowledging the current shortages in key areas. This question aims to include those who asked about resourcing more generally in a high-level sense (resourcing primary care) as well as those who asked specifically about managing employment in specific roles	A review of staff numbers/ what quantity and quality workforce is required for effective delivery of care.	Very little available on workforce planning specifically for primary care. Related Cochrane review of medical vs non medical prescribing noted promise of change to prescribing practices which would impact staffing, but called for further more rigorous research	*22-Jan-24*	12	https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011227.pub2/full#CD011227-abs-0003

		What are the best approaches in primary care services for the management of chronic and **medically unexplained symptoms**?	Note - added by core PSP team during review of longlist. This question draws on statements made where people mentioned specific unexplained symptoms as examples of the condition they were managing (primarily chronic pain, fatigue, and post-viral symptoms). It aims ot acknowledge the specific situation of managing a chronic issue without a diagnosis and the uncertainty this can create	The services offered for chronically ill patients are poor to put it mildly… They'll come back and say great news your bloods are clear, and send you home..well great my bloods are clear that doesn't magically make my symptoms resolve i still need help	IASP and BPS offer evidence based resources for HCPs regarding pain, some research into functional somatic symptoms (and other phrases) but no real consensus on recommendations for primary care Most relevant Cochrane review (Rosendal) concludes that current evidence for enhanced care in primary care is insufficient	*22-Jan-24*	Did not go forward to workshop	Rosendal https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD008142.pub2/full
		How can **patient safety** in primary care be ensured in the management of chronic conditions?	Note - added by core PSP team during review of longlist This questions reflects a theme seen in the submissions around identifying and reducing risks to patients	There is a huge issue with patient safety in relation to transition from secondary care with prescriptions for multiple items. Quantifying this if possible might trigger change towards a universal process for discharge prescriptions	Meta-review of measuring and monitoring safety in primary care concludes more development of methods needed, and further work on integrating methods into practice	*22-Jan-24*	Did not go forward to workshop	https://pubmed.ncbi.nlm.nih.gov/34405231/