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

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Abstract

Background Chronic conditions are extremely common, with approximately 1 million people in Ireland currently affected by the four most common chronic conditions alone. This is expected to significantly increase in the near future due to Ireland's aging population. Identifying the priorities of patients, carers, and healthcare professionals for primary care research in chronic condition management could ensure future work is relevant and that resulting service changes and policy decisions align with the needs of those most affected.

Methods An initial survey to collect potential research questions about the management of all chronic diseases was shared with patients, carers, and healthcare professionals from March to May 2023. Submissions were sorted and checked against existing evidence resulting in a list of 30 unanswered questions. An interim priority setting survey was shared in late 2023, and a final workshop to rank the top ten research priorities took place in January 2024.

Findings The first survey resulted in 350 individual statements ($n = 185$ participants). Seventy-three respondents had a chronic disease and 72 were primary healthcare professionals. Rankings were informed by an initial priority setting survey ($n = 108$), followed by an in-person workshop ($n = 16$) to decide the final order.

Interpretation The resulting top ten research priorities offer a starting point for funding bodies and researchers to ensure that future primary care research in chronic condition management is relevant, meaningful, and impactful. The top ten priorities reflect current Irish and global challenges in healthcare, with top items including communication, non-pharmacological treatments, and multidisciplinary care.

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Keywords Chronic conditions, Research priorities, Priority setting partnership, Consensus, Co-production, Patient and public involvement

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Introduction

Primary care is defined as the first point-of-contact healthcare available in the community, with aims of continuous, comprehensive and coordinated patient-centred care [1]. In many countries, including Ireland, it is the main gateway to accessing health services [2], with data collected in February 2020 showing general practitioners (GPs) completing 29 consultations per day on average, totalling an estimated 21.4 million GP consultations a year across Ireland [3]. Primary healthcare extends past GPs, including general practice nurses, community and public health nurses, and other community-based professionals (e.g. physiotherapists, occupational therapists etc.). Irish investment in primary care centres (which centrally locate multidisciplinary teams) is aligned with growing recognition that "the current hospital-centric configuration is not suited to the changing demographic profile and health needs of the country" [4].

With approximately a quarter of people in Ireland living with the four most common chronic conditions alone (diabetes, asthma, chronic obstructive pulmonary disease, cardiovascular disease) [5], the management of chronic conditions is a major focus of primary care. The introduction of the General Practice Chronic Disease Management Programme (CDM) has increased provision for the subset of eligible patients with these four most common chronic conditions, while also providing a rich source of data on those who have taken part since its introduction in 2020 ($n = 186{,}210$) [6]. CDM is a key component of the Sláintecare improvement strategy; Ireland's national health reform program aimed at providing universal healthcare, ensuring timely access to care, and improving overall health outcomes. One of Sláintecare's main aims is to deliver more integrated care, with primary and community care at the centre and CDM is at the core of this process. While CDM is still only available to a subset of primary care patients with specific conditions (see context highlight below), it has proved popular, with uptake estimated at 55% of all eligible adults and up to as high as 83% of eligible adults over 65. With longitudinal data beginning to become available, there are promising signs of success in terms of tackling modifiable risk factors, with 43% of patients who had presented with hypertension at their first visit reducing their blood pressure by their third visit [6].

Despite the continual need for up-to-date evidence to inform CDM delivery and expansion and improve patient outcomes, doing research in primary care presents unique challenges in trial design and delivery. The nature of the processes and setting of primary care make the recruitment of sites and participants into trials difficult and time consuming [7]. Participation in primary care research often relies on patients and practitioners seeing research as relevant to them [7].

The Primary Care Clinical Trials Network (CTNI), established in 2015 with funding from the Health Research Board (HRB), has a vision of supporting the creation of high-quality clinical evidence which improves patient outcomes in Irish primary care. One of the network's aims for 2021–2026 is to develop an agenda for Irish primary care clinical trials research. 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.

The JLA was established in 2004 to address the mismatch observed between the research carried out by industry and academia and the priority areas of clinicians and patients [8]. A not-for-profit initiative, the JLA supports organisations and researchers to develop PSPs which bring patients, carers, and clinicians together to identify and rank the most important unanswered research questions in their areas of interest. This process involves working in partnership with stakeholders, following a series of pre-defined steps resulting in a top ten list, and promoting that list as a prioritised research agenda [9].

Our aim in this project was to develop a list of the top research priorities to inform policy and management of all 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 by the outcomes; the patients, carers, and clinicians interacting in primary care every day.

Context:

Primary care in Ireland – Ireland has a two-tier healthcare system, with a Medical Card system providing free at the point of care access to primary care and other services to those eligible, based on income and age thresholds. Approximately 60% of GP patients do not have a Medical Card and have to pay per consultation (approx. €50–60) [10]. In 2020, 31% of patients were entitled to a Medical Card based on income and received healthcare without a charge, and a further 11% had a Doctor Visit Card, based on a higher income threshold and age (up to age 8 and over age 70), which gives them free GP care but they pay for medicines. As well as means-tested eligibility, there are a range of other ways to qualify for a discretionary or emergency medical card

All citizens are covered by a Drugs Payment Scheme which caps expenditure on medicines to a payment of approx. €80 per family per month. These schemes have extended eligibility in recent years, in a move towards realising Sláintecare recommendations of implementing universal healthcare

CDM – The Chronic Disease Management Programme has been available to patients with a Medical or Doctor Visit Card since 2020 who are entitled to free visits at the point of care. Previously, care was delivered predominantly through secondary care, with ad hoc or sporadic input from GPs. The programme covers adults with type 2 diabetes, asthma, chronic obstructive pulmonary disorder (COPD), TIA/Stroke or cardiovascular disease (CVD) and involves twice yearly reviews with GP practice teams. These reviews result in a care plan to help support effective self-management of the condition(s). The related CDM Prevention programme extends this model to offer yearly reviews to those with certain risk factors for CVD or diabetes

Methods

The JLA PSP is a multi-stage process which is well-documented in JLA resources and in the publications of other PSP teams [9, 11, 12]. The process involves initiating the partnership with a team of stakeholders, gathering submissions, processing those submissions into statements, checking those statements against the existing evidence to identify unanswered questions, performing some interim ranking, and deciding the final order in a workshop (see Fig. 1). We utilised the REporting guideline for PRIority SEtting of health research (REPRISE) to ensure transparency in reporting on this process (see Appendix item 1) [13].

'Stakeholders' in this case referred to patients, carers, and healthcare professionals, all with first-hand experience of the topic at hand. Researchers and academics could observe but could not take part. The following sections will go through each of the stages and how this PSP approached them using the JLA guidance.

The Primary Care CTNI led the project as part of its core network funding received from the HRB. The JLA assigned an independent adviser (MT), who chaired the steering group and final workshop and advised on methods throughout.

Project initiation

The main area of focus was decided at the outset by the Primary Care CTNI as chronic disease management in primary care, in alignment with network supported research and current efforts in healthcare in Ireland. With that in mind, a steering group with relevant stakeholder representation was established (see Appendix item 2). In line with JLA guidance, those with only research experience of the topic were not considered for full membership of the steering group (or later involvement in other stages); only those with first-hand knowledge of living with, caring for, or treating chronic conditions in primary care were eligible. For patient and carer members of the steering group, participation was reimbursed using gift vouchers. To further support the PSP, relevant organisations were named as partners; these were organisations with an interest in the PSP who committed to championing the PSP to their membership and to contributing their expertise where needed.

The steering group was tasked with overseeing the project and making decisions at key stages. During initial meetings, the scope of the project was decided and key terms defined to ensure that the scope was clearly understandable (see Table 1 for definitions). In addition, 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 to exclude input that concerned overly specific conditions or treatments, or input that focused on secondary or tertiary care alone.

These definitions and specifications about the scope of the PSP were used along with the JLA template to create the protocol document used to guide the PSP. This living document could be updated to reflect later decisions, and was available on the Primary Care CTNI and JLA websites throughout the PSP [14, 15].

With these decisions made, the protocol was confirmed by the steering group and made available on the Primary Care CTNI and JLA websites throughout the PSP [14, 15].

Gathering submissions (first survey)

Following the scope of the PSP and guidance from the JLA, 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.

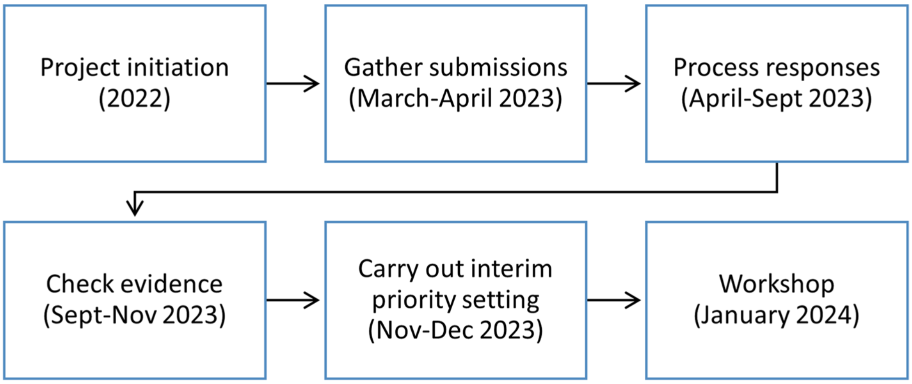

Fig. 1 Timeline

Table 1 Defined terms

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)/family practitioners, general practice nurses, community and public health nurses, and other community-based professionals (e.g. physiotherapists, occupational therapists etc.)

To avoid confusion regarding the term carer, which could be interpreted as only including those in defined caring employment or in receipt of carer benefits, we used language like "a family member, friend, or carer of someone with a chronic condition" in explanatory text on survey materials.

A questionnaire was designed to target people likely to fulfil those criteria, with a single open-ended question of "What question or comment do you have about managing chronic conditions in primary care in Ireland?" (see Appendix item 3). Accompanying information explained the PSP and the definitions being used and linked back to the Primary Care CTNI website [15] for further information.

The questionnaire was shared in March 2023, primarily using MS Forms (Microsoft Forms) [16], with paper versions provided on request. Respondents were asked some optional demographic questions so that reach in terms of age, gender, type of area (e.g. urban/rural), and respondent type could be checked in real time and promotion altered to gather as diverse a response as possible. The Primary Care CTNI, steering group members and partner organisations all assisted in promoting the questionnaire. 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. For example, organisations like Men's Sheds were targeted for sharing to address a lack of submissions from men, and student unions and youth groups targeted to increase numbers of younger people submitting.

Processing responses

The survey closed to responses in early April 2023. The first stage of processing responses involved cleaning the submissions, to create a collection of individual sortable statements. Many respondents had replied to the prompt in a conversational way, covering multiple topics in a single paragraph submission. Each individual statement was separated out and identified by a unique code to aid in sorting and tracking. Following JLA guidance, two researchers then reviewed each statement, marking anything deemed out of scope (as determined at project initiation, see above), and developed an initial set of categories based on the scope as outlined in the protocol (see Table 2). 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.

Checking the evidence

Evidence checking commenced in September 2023 following the below searching procedure, based on guidance provided in the JLA Guidebook and following the example of other published PSP processes regarding the appropriate choice of search tools and repositories [9, 17, 18].

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 Service Executive] Health Protection Surveillance Centre) when appropriate to the individual question. Questions were considered answered if a recent (published since 2010) evidence synthesis concluded there was sufficient relevant evidence on the topic to give certainty.

Examples of search terms used can be found in the question verification form (see Appendix item 4).

Interim priority setting (second survey)

The remaining longlist of 30 unanswered questions were reviewed by the core team (authors LOC, MT, SS, AM) and refined to maximise clarity and standardise language. Interim priority setting [9] then followed, where consultation with wider stakeholders was used to reduce the list to a more manageable number for discussion at the final workshop.

A second online survey was designed using QuestionPro (which allowed user's choices to be displayed back

Table 2 Categories identified from stakeholder questionnaire

Category	Subcategory	Explanation
Condition	Condition	Relating to specific knowledge, training or management of conditions
	Diagnostics	Access to resources, knowledge around early and efficient diagnosis
Management	Treatment	Including pharmaceutical, medical, lifestyle and self-management recommendations
	Coordination	The communication between patient and their HCPs (healthcare professionals), and the aligning of different elements of care (including communications between primary and secondary care)
	Monitoring	Repeated appointments for monitoring of conditions, e.g. blood tests, not to add/change treatments
	Support	The supportive relationship between the patient and their HCPs
Primary Care	Community	Availability of necessary resources within the community, including equitable access to services
	Continuity	Sustained relationships between the patient and HCPs
Other	Patient experience	Aspects of being a patient managing chronic conditions that are not addressed above
	HCP experience	Aspects of working in primary care that are not directly included in the above activities
	Provision of care	Larger questions about resource allocation, economic or policy level decision making

to them, unlike MS Forms) [21]. This survey, administered in November 2023, presented the 30 unanswered questions and asked participants to indicate their top ten questions (see Appendix item 5). Responses were dichotomised; patient, carer and supporting organisation responses were grouped together, as were responses from healthcare professionals. A top twenty was then created using the top ten ranked questions of each of these two groups, to allow for a balanced and manageable twenty unanswered questions to go forward for final ranking in the workshop.

Final workshop

The final priority setting took place at an in-person workshop in Galway in January 2024. The workshop included people with chronic conditions, people caring for family or loved ones with chronic needs, and healthcare professionals, with some people belonging to more than one of these groups. Some members of the steering group took part, with other participants being identified through direct expressions of interest, partner organisations, professional organisations and other networks. 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.

The workshop followed the JLA format and involved multiple sessions of small group discussion, bookended by an introduction to the project and the day, and a session discussing the decided Top Ten and next steps. The workshop was chaired by the JLA adviser MT, who also facilitated small group sessions alongside an additional JLA adviser and the PSP coordinator, allowing for three small group discussions to be held simultaneously. Following advice from the JLA adviser, it was decided to put forward 20 questions for ranking at the workshop to allow participants latitude to consider as many priorities as possible while ensuring manageable workload and time commitment.

Following the introduction, as per JLA processes, participants were assigned to predetermined groups, to ensure balance between stakeholder types. Members within each group discussed their most and least important questions, before taking a short break. During this break, facilitators in each room prepared a ranking of the 20 questions based on that initial discussion, which was then the topic for the second session. 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. 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.

Results

Survey responses

There were 185 respondents to the first submission gathering survey (Table 3). One hundred and thirteen patients, carers, and organisational representatives and

76 healthcare professionals completed the questionnaire, with some individuals indicating they belonged to multiple categories. The vast majority completed the questionnaire online, with only 8 respondents returning hard copies.

In the second interim priority setting survey, 108 people responded: 78 patients, carers, and organisational representatives and 45 healthcare professionals.

Processing responses

The 185 submissions to the first survey were broken down into 350 individual statements, 27 of which were identified as being out of scope during this process.

The remaining 323 statements were processed as described above, resulting in the formation of 30 summary questions.

Evidence checking

Evidence checking resulted in one summary question being deemed answered; the evidence search for the question "Does the primary care setting adequately prevent transmission of infection?" returned a 2023 guideline published by the Department of Health which listed primary care settings as generally low risk for infection transmission [22].

The other 29 questions were found to have insufficient evidence to allow them to be considered answered. In most cases, no syntheses were found that directly related to the question being considered. Where relevant syntheses were found, they invariably only addressed part of the

Table 3 Demographic details of survey participants

Category	Gathering submissions – first survey	Interim priority setting – second survey
Age	***n*** **= 185**	***n*** **= 108**
18–24 years old	1	2
25–34 years old	11	8
35–44 years old	47	23
45–54 years old	53	35
55–64 years old	45	28
65–74 years old	12	8
75 years or older	7	0
Declined to answer	9	
Gender	***n*** **= 176**	***n*** **= 108**
Woman	146	31
Man	26	75
Other	3	2
Prefer not to say	1	
Stakeholder category	***n*** **= 185**	***n*** **= 108**
Person with one or more chronic condition(s)	73	57
Primary care healthcare professional	72	45
Carer/family member/friend	30	11
Organisation representative	1	10
Carer and organisation representative	1	
Carer with chronic condition(s)	4	
Carer and HCP	2	
All three	2	
Healthcare worker area of practice	**(*n* = 67)**	
Mixed	31	
Urban	19	
Rural	17	
Other stakeholder area of residence	**(*n* = 116)**	
Countryside	34	
Town	24	
City	58	

question and almost always reported a need for further research before reaching a conclusion.

At this stage, a data management sheet was prepared. This detailed all verified unanswered questions, explanatory notes and example statements to show their development, and notes on the available evidence returned by the evidence checking process (see Appendix item 6).

Interim priority setting

The interim ranking second survey (demographics of respondents available in Table 3) resulted in 20 questions being identified for discussion at the final workshop, comprised of the top ten ranked by healthcare professionals, and the top ten ranked by the combination of the other categories of respondents.

Final workshop

The final workshop took place in Galway in January 2024. 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. Other team members observed the workshop and had no input to conversation or decision making. The Top Ten questions (and subsequent question rankings from 11–20) were confirmed by group discussion. Of note, items 11–20 are not discarded and are reported in the paper and may also be used to generate research questions where appropriate (Table 4).

Table 4 Final ranking of research questions

Final rank	Question
1	How can exchange of information be improved between specialist/hospital services and primary care for both people with chronic conditions and healthcare professionals?
2	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?
3	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?
4	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?
5	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?
6	What is the best way to ensure appropriate and timely access to Irish primary care services for people managing chronic conditions?
7	How can primary care services best manage the complexities of caring for people with multiple chronic conditions (across the lifespan)?
8	How can people with chronic conditions be best supported to engage with and navigate health and social care information and services?
9	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?
10	How can primary care services support good mental health and wellbeing for people managing chronic conditions and symptoms?
11	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?
12	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?
13	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?
14	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?
15	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?
16	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?
17	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?
18	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?
19	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?
20	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?

In a post-workshop survey administered by the James Lind Alliance, 14 attendees responded to the statement "I felt able to talk about my thoughts and opinions on the questions that we were looking at" with Strongly Agree ($n = 12$) or Agree ($n = 2$) and "The workshop facilitators were fair and independent" with Strongly Agree ($n = 13$) and Agree ($n = 1$). The survey also asked "At the workshop you prioritised the questions in small groups then came together as a larger group to agree the final order of priority of the questions. How much do you agree that this process was useful in helping to agree a Top 10 list of questions?" to which attendees responded Strongly Agree (11), Agree (2) and Strongly Disagree (1). Seven text comments were appended to this question, all of which included positive feedback on the process.

Discussion

This is the first time that research priorities for the management of chronic conditions in primary care have been established using a formal priority setting partnership approach.

This project, unlike most PSPs [23], focuses on a broad topic rather than a defined condition. The steps followed echo those of previous PSPs, many of which have influenced research in the years after they released their Top Ten lists [24]. In this case, while the PSP was based in Ireland, the relevance of the priorities identified and ranked have potential for international adaption and application. The key themes represented in the top ten (Table 4) were, in order, information exchange or communication, non-pharmacological treatments, multidisciplinary care, use of healthcare data, treatment burden, timely and accessible care, multimorbidity, access to information and wayfinding, continuity of care, and mental health and wellbeing. They reflect the major challenges facing not just Irish primary care, but also healthcare more broadly. Ireland is experiencing overburdened primary care [25], slow national development and integration of digital health records and communication tools [26], an aging population where multimorbidity is the norm [27], and low levels of satisfaction with the healthcare system [28], none of which are unique in the global context [29]. While the order or presentation of these topics could vary in other countries, their appearance in a priority list is not surprising. Indeed, many items overlap with lists produced by other PSPs, such as those focusing on multiple chronic conditions in later life [30], patient safety in primary care [12], and medically unexplained symptoms [18], and with those produced by a 2018 modified Delphi exercise focusing on research priorities for global primary care research [31].

Reflecting on the evidence checking phase, it is striking that only one summary question could be deemed answered based on the existing evidence. In similar PSPs also focusing on broader health topics (as opposed to single diseases), like physiotherapy [17] and adult social work [32], this is not uncommon. The searching of evidence and ability to compare to other PSPs highlights the disparity between the questions that are being answered currently by research and the questions that patients and front-line clinicians would prioritise. Research in primary care has long been considered as lagging behind other health topics, and calls for increased focus [33], more funding [34], and more strategic planning [35] have all been echoed across jurisdictions.

Strengths and limitations

A clear strength of this project has been the successful stakeholder involvement throughout, which was scaffolded by the robust JLA guidance on their PSP process [9]. This is firstly unique in the involvement of stakeholders beyond patients and the public, especially given the level of partnership and shared decision making that permeates all stages of the process. Secondly, the opening of this stage of research, idea generation and the planning of future research, to those other than principal investigators and research team members is noteworthy. For example, a 2018 review of patient and public involvement (PPI) in primary care research in the UK found that PPI is still inconsistently planned and executed across the various stages of research projects, but particularly so in developing plans for future research [36].

By following the rigorous PSP process, clear gaps in existing evidence have been identified, and the resulting Top Ten questions, if answered, could help address the most urgent concerns of people with chronic conditions, their carers, and the clinicians who treat them. The ability to rank up to 20 questions further broadens the potential of this process to influence future research and resource allocation.

A limitation of the project is the representativeness of those involved, in terms of diversity of demographics and the implications that may have for the generalisability of the findings to the broader Irish and global context. Members of the steering group and participants in the workshop were selected to bring differing experiences to the table, but the nature of the commitments resulted in biases, like some HCPs also having academic/research roles (which allowed them the time to participate but could introduce bias due to academic interests). Considering the large numbers of people who would have been eligible to take part, the relatively small proportion of responses in both surveys and gender and age skews in responses should be noted. The JLA are clear in their guidance that demographic information is not collected for analysis purposes but rather for allowing targeting of survey sharing, reflecting the ethos that a PSP should strive for diversity of submissions and inclusion of minority and underserved populations rather than statistical representativeness [9]. The alignment of our resulting priorities with those of other PSPs carried out in other jurisdictions support their validity.

Conclusion

Following the JLA PSP process has resulted in the first prioritised top ten list of unanswered questions for research in managing chronic conditions in primary care, aligning with current Irish and global challenges in healthcare and with the results of other complementary PSPs. This list is an opportunity for funders, who could use this list to aim funds at areas of high priority, and researchers, who could use it to inform meaningful and impactful work. The successful involvement of a broad group of stakeholders throughout the project shows the potential for subsequent research to address topics that patients, carers, and healthcare workers value highly, which bodes well for both the delivery of such projects and for future evidence-based care and service delivery.

Abbreviations

GP	General practitioner (primary care doctor)
CDM	Chronic Disease Management Programme
CTNI	Primary Care Clinical Trials Network
JLA	James Lind Alliance
PSP	Priority Setting Partnership
COPD	Chronic obstructive pulmonary disease
CVD	Cardiovascular disease
REPRISE	REporting guideline for PRIority SEtting of health research
HSE	Health Service Executive
HRB	Health Research Board
MS Forms	Microsoft Forms
HCP	Healthcare professional
PPI	Patient and public involvement

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12875-025-02822-0.

Supplementary Material 1

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Authors' contributions

AM and SS obtained funding for this work. LOC, MT, AM, and SS conceptualised the study. All authors (LOC, SD, MH, PH, CMC, BMG, DM, PM, LOG, MT, AM, SS) contributed to the design. LOC, MT, and LOG analysed submissions. LOC, MT, AM and SS wrote the initial manuscript and all authors (LOC, SD, MH, PH, CMC, BMG, DM, PM, LOG, MT, AM, SS) reviewed and approved the final manuscript.

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Data availability

Materials from the PSP are available in supplementary material and on the James Lind Alliance repository of PSPs (https://www.jla.nihr.ac.uk/priority-setting-partnerships/managing-chronic-conditions-in-irish-primary-care). Statements submitted to the PSP have not been made publicly available as despite the survey being anonymous, statements may contain identifying information.

Declarations

Ethics approval and consent to participate

Not applicable as a priority setting partnership is considered a service evaluation and development exercise, which does not require ethical approval. This was confirmed with the University of Galway Research Ethics Committee.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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