


# BMJ Open Research priority setting related to older adults: a scoping review to inform the Cochrane-Campbell Global Ageing Partnership work programme

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## ABSTRACT

**Objective** To explore and map the findings of prior research priority-setting initiatives related to improving the health and well-being of older adults.

**Design** Scoping review.

**Data sources** Searched MEDLINE, EMBASE, AgeLine, CINAHL and PsycINFO databases from January 2014 to 26 April 2021, and the James Lind Alliance top 10 priorities.

**Eligibility criteria** We included primary studies reporting research priorities gathered from stakeholders that focused on ageing or the health of older adults (≥60 years). There were no restrictions by setting, but language was limited to English and French.

**Data extraction and synthesis** We used a modified Reporting Guideline for Priority Setting of Health Research (REPRISE) guideline to assess the transparency of the reported methods. Population–intervention–control–outcome (PICO) priorities were categorised according to their associated International Classification of Health Interventions (ICHI) and International Classification of Functioning (ICF) outcomes. Broad research topics were categorised thematically.

**Results** Sixty-four studies met our inclusion criteria. The studies gathered opinions from various stakeholder groups, including clinicians (n=56 studies) and older adults (n=35), and caregivers (n=24), with 75% of the initiatives involving multiple groups. None of the included priority-setting initiatives reported gathering opinions from stakeholders located in low-income or middle-income countries. Of the priorities extracted, 272 were identified as broad research topics, while 217 were identified as PICO priorities. PICO priorities that involved clinical outcomes (n=165 priorities) and interventions concerning health-related behaviours (n=59) were identified most often. Broad research topics on health services and systems were identified most often (n=60). Across all these included studies, the reporting of six REPRISE elements was deemed to be critically low.

**Conclusion** Future priority setting initiatives should focus on documenting a more detailed methodology with all initiatives eliciting opinions from caregivers and older adults to ensure priorities reflect the opinions of all key stakeholder groups.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Utilised the Reporting Guideline for Priority Setting of Health Research (REPRISE) criteria to assess the quality of reporting in the included studies.
- ⇒ An advisory board composed of both patients and practitioners was used when developing the methods and writing this review.
- ⇒ All priority-setting initiatives were carried out in high-income countries, and therefore, the priorities collected do not encompass the opinions of key stakeholder groups in low-income and middle-income countries.

## INTRODUCTION

The global demographic shift of an ageing population will put pressure on social, economic and health systems over the next 20 years. This global population ageing has led the World Health Organization (WHO) and United Nations (UN) to declare the Decade of Healthy Ageing from 2021 to 2030.<sup>1</sup> The aim of this decade is to improve the lives of older people and their families as well as the communities in which they reside. To foster healthy ageing, WHO has stated that we must take action through ‘changing how we think, feel and act towards age and ageing; ensuring that communities foster the abilities of older people; delivering person-centred integrated care and primary health services responsive to older people; and providing access to long-term care for older people who need it’.<sup>2</sup>

The Cochrane Campbell Global Ageing Partnership is a part of the WHO international consortium on metrics and evidence for healthy ageing. The partnership was established in 2019 to collaborate on priority-setting, dissemination, knowledge translation and evidence synthesis focused on healthy



ageing<sup>3</sup> in collaboration with key stakeholders. Key stakeholders are defined as any person or party who either provides, receives, manages or funds the intervention of interest and can include patients, caregivers, advocacy organisations, health and social care professionals, researchers, research funders, policy-makers, community organisations, health and social care providers, and health and social care procurers.<sup>4 5</sup> In order to build the evidence-base, there is a need to understand key evidence gaps and needs from the perspective of these stakeholders.<sup>6</sup>

Priority-setting for research is an explicit process to gather diverse stakeholder opinions and rank them according to importance.<sup>7</sup> There are numerous methods, such as nominal group technique, surveys and Delphi processes. Several organisations, professional associations, charities and advocacy groups have conducted priority-setting initiatives related to ageing and older adults, such as the James Lind Alliance (JLA) Priority Setting Partnerships (PSP) in the UK. JLA is a British non-profit making initiative that believes in bringing together patients, caregivers and clinicians to identify and rank research priorities in need of attention.<sup>8</sup> However, there is no systematic summary of priorities for older adults or healthy ageing.

The Cochrane Campbell Global Ageing Partnership has decided to focus on topics relevant to adding life to later years. Thus, in this study, we focus on identifying unresolved research priorities related to improving the health and well-being of older adults. The identified priorities will highlight gaps in a broad scope of ageing research and inform a 5-year work plan being developed by the Cochrane Campbell Global Ageing Partnership. The findings of this study will be discussed with our ageing research partners such as WHO, HelpAge and the Canadian Red Cross. It will also inform priority-setting, knowledge mobilisation and brokerage activities within the UN Decade of Healthy Ageing.

## OBJECTIVE

This study aims to identify and map the findings of prior research priority-setting initiatives related to improving the lives of older adults.

The scoping review questions include:

1. What methods have been used in priority-setting initiatives for older adults? How comprehensive was the reporting of these methods?
2. Which stakeholders were involved in the priority-setting processes?
3. What types of research priorities for older adults have been reported?

## METHODS

We followed the JBI methodological guidance for conducting scoping reviews.<sup>9</sup> We reported our scoping review according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for

scoping reviews and the checklist can be found in online supplemental file 5.<sup>10</sup> The methodology used by this scoping review was also reviewed with an advisory board of consumers and research experts.

## Eligibility criteria

### Population

Studies had to specify priorities were only collected from people 60+ years old or had to mention the priorities were collected with the intention to expand ageing research in either the background or methods. Older adults were defined as being 60+ years of age since this is the cut-off used in the WHO baseline report to describe the effects of population ageing.<sup>1</sup> Studies focusing on conditions associated with older age, such as cancer, old age and palliative care were excluded if they didn't meet this criterion.

### Concept

Any study that involved a priority-setting process in gathering opinions from stakeholders (eg, patients, caregivers, advocacy organisations, health and social care professionals, researchers, research funders, policy-makers, health and social care providers, health, and social care procurers) and that focused on ageing, or the health of older adults was included.

### Context

We only considered studies published from 2014 to 26 April 2021, for recency and relevance of priority topics. Studies were not limited by the setting (eg, geographical location, care setting). Studies were limited to those in English and French.

### Types of evidence sources

We included primary research studies of priority setting with stakeholders. We excluded systematic reviews, literature reviews, policy documents, opinion pieces and guidelines because these documents did not seek or gather stakeholder opinions.

## Search strategy

We searched the following databases for studies on priority-setting for research related to older adults:

- ▶ Ovid Medline (R) ALL (1946 to present).
- ▶ Embase Classic + Embase Ovid (1947 to present).
- ▶ PsycInfo Ovid (1806 to present).
- ▶ CINAHL EBSCO (1984 to present).
- ▶ AgeLine EBSCO (1984 to present).

The search strategy was developed by an experienced information specialist (DB). It included terms for ageing and older adults from a search designed for a Campbell Evidence and gap map on ageing.<sup>11</sup> We used terms for priority-setting from prior search strategies.<sup>12</sup> Complete search strategies can be found in online appendix A.

We also asked our advisory board and research team to suggest relevant articles that fit our inclusion criteria.

Lastly, we reviewed PSP on the JLA website and the Ludwig Boltzmann Gesellschaft Priority Setting Project

Database to identify additional initiatives focused on older adults that were not captured in the database searches.

### Screening and selection

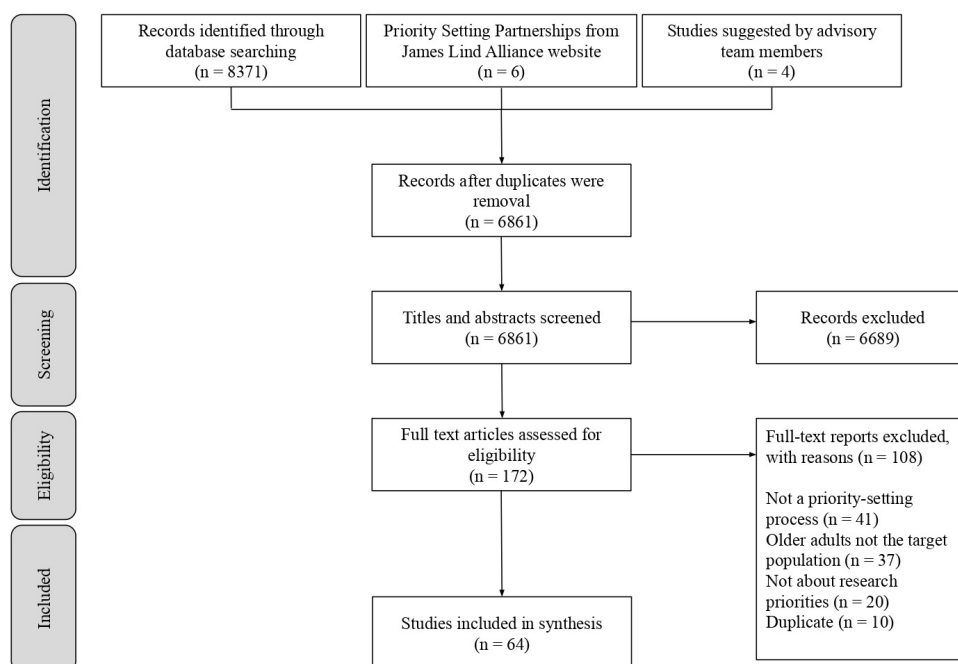
Study selection was based on the eligibility criteria. The title and abstracts were screened independently by five authors (VIB, LM, AAA, VAW and ETG) in duplicate using Covidence, and conflicts were discussed until a consensus was reached. Full texts of the relevant studies were obtained and screened independently by three authors (VIB, LM and AAA) in duplicate using Covidence. Conflicts were discussed until a consensus was reached.

### Data collection

We developed three data collection forms to collect details on the study methods, focus, funding and identified priorities. The first form, displayed in online appendix B, focused on study characteristics such as the types stakeholder groups involved (eg, clinicians, older adults, caregivers, personal support workers), how opinions were collected (eg, survey or consensus or both), the geographic location of participants, what happened to the priorities, for example, how were they disseminated and to whom and any evidence that these have been addressed (ie, IMPACT), and if the priorities relate to any of the top 10 causes of disability-adjusted life-years (DALY) in older adults.<sup>13</sup> Data extraction of the study characteristics was performed independently by five authors (VIB, LM, AAA, VAW and ETG) in duplicate using Covidence. Conflicts were discussed until a consensus was reached.

The priorities identified by each of the initiatives were then categorised as either population–intervention–control–outcome (PICO) priorities or broad research topics so that the characteristics of the priorities could

be extracted using one of the two final extraction sheets. Only the top 10 were recorded in the data collection form for studies that identified more than 10 ranked priorities. For studies with unranked priorities and more than 10 priorities, the categories were collected instead if provided, otherwise, all priorities were collected. The extraction sheet for the PICO priorities was used to capture the population of focus, the interventions as classified by the International Classification of Health Interventions,<sup>14</sup> the general outcomes of interest (eg, social, health, caregiver, well-being) and the International Classification of Functioning, Disability and Health (ICF) outcomes<sup>15</sup> found in online appendix C. Regarding the ICF categories outcomes, they were also then grouped into the three main categories included in the WHO Healthy Ageing framework.<sup>13</sup> PICO priorities and their associated characteristics were extracted from four studies in triplicate as a training set to ensure coding consistency across authors. After the training set, data extraction of the priorities and their characteristics was performed independently by one of three authors (VIB, LM and AAA) using Excel and 15% of the priorities were checked at random for accuracy by one of two senior authors (VAW and ETG). The third and final extraction sheet was used to categorise the broad research topics. Five authors (VIB, LM, AAA, VAW and ETG) met to categorise all the broad topics using the categories from a scoping review on priority setting for musculoskeletal research as a starting point.<sup>12</sup> Categories were merged, and new categories were created as the team deemed necessary. For topics that related to more than one category, only the most specific and relevant one was selected. All data collection forms can be found



**Figure 1** Flow diagram of the study selection following the PRISMA template. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

**Table 1** Methods, participants and funding sources of the included studies (n=64)

Category	Subcategory	N (%)
Method/s used to collect initial priorities	Survey (only)	21 (33)
	Consultation (only)*	18 (28)
	Evidence (only)	2 (3)
	Mixed methods†	23 (36)
Method/s used to prioritise priorities	Consensus (only)‡	24 (38)
	Survey (only)	20 (31)
	Survey and consensus	16 (25)
	Not described	4 (6)
Framework	JLA	12 (19)
	Delphi	11 (17)
	Nominal group	9 (14)
	CITRA	5 (8)
	World Café	2 (3)
	No established framework used	25 (39)
	Geographical location of participants	USA
UK		13 (20)
Canada		9 (14)
Europe§		6 (11)
Australia		1 (2)
Japan		1 (2)
Multiple continents		9 (14)
Not specified		2 (3)
Participant types	Clinicians	56 (88)
	Older adults	35 (55)
	Caregivers	24 (38)
	Personal support workers	17 (27)
	Range of stakeholders¶	49 (77)
Funding	Government	13 (20)
	University/Institute	10 (16)
	Not for profit	5 (8)
	Professional association	2 (3)
	Industry	1 (2)
	Multiple	18 (28)
	No funding	3 (5)
	Not reported	12 (19)

\*Consultation methods were classified as methods involving collecting research priorities through face-to-face interactions with key stakeholder groups and could have included interviews, workshops, expert panels and focus groups.

†Study design involved multiple methods (eg, survey and consensus).

‡Consensus methods were classified as methods involving prioritisations through face-to-face group discussion between key stakeholder groups and could have included workshops, expert panels and focus groups.

§The European priority settings involved participants from Austria, Belgium, Bosnia Herzegovina, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, The Netherlands, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden, Switzerland and Turkey.

¶Range of stakeholders: 2+ types of stakeholders from the following list: clinicians, patients, caregivers, government, industry, researchers, educators, managers, administrators and funding agencies.

JLA, James Lind Alliance; CITRA, Cornell Institute for Translational Research on Ageing Model.

in online appendix D. Due to time constraints, we did not contact investigators for missing information.

A modified version of the Reporting Guideline for Priority Setting of Health Research (REPRISSE) criteria was used to examine the transparency of reporting.<sup>7</sup> The REPRISSE guideline was chosen as it can be used to guide a range of different methodological approaches to priority setting. Each of the 31 elements on the guideline was modified into yes or no questions to identify which methodological aspects were described or not. The goal of REPRISSE is not to appraise the quality of the studies; therefore, no formal assessment of methodological quality was performed in this scoping review.<sup>7</sup>

### Patient and public involvement

This scoping review was guided by an advisory board composed of six practitioners and two consumer representatives. The two consumer representatives (MS and RM) were recruited from the Cochrane Consumer Network to contribute as coauthors in addition to being members of the advisory board. The advisory board met twice throughout the project; first to discuss and provide feedback on the methods of this study and the second meeting was to discuss how the data should be synthesised. The advisory board also suggested relevant papers to be considered for inclusion in this review and provided written feedback on both the protocol and manuscript drafts.

### Practitioner involvement

The six remaining advisory board members (MC, TH, SM, HM, MN and JTC) were recruited due to their practice and expertise in dimensions related to priority setting and ageing research topics (eg, rehabilitation, oncology, cognition).

### Analysis

Data were summarised in tables and figures to describe the characteristics of the priority-setting initiatives, stakeholders and the population, interventions and outcomes of identified priorities.

## RESULTS

### Search results

We retrieved 6851 non-duplicate records from our database searches, and a further 6 from the JLA website and 4 suggested by our advisory team. Of these records, 6689 were excluded during title and abstract screening, leaving 172 potentially eligible studies. Of these studies, 108 were excluded leaving us with 64 eligible records. The reasons for exclusion are summarised in figure 1.

### Included studies

Sixty-four records fulfilled our inclusion criteria.<sup>16–79</sup> Of these records, 51 were full-text studies, 12 were conference abstracts and 1 was a poster. The characteristics of the priority-setting processes of these included studies are



summarised in [table 1](#) and full datasets can be viewed on the Open Science Framework (OSF) repository.<sup>80</sup>

### Approach and framework

The most common methods of collecting the initial lists of priorities were by using surveys only (n=21, 33%) or a mixed-methods approach (n=23, 36%) which involved the following combinations: surveys and consultations (n=9), consultations and evidence (n=6), surveys and evidence (n=5), and surveys, consultations and evidence (n=3). In terms of the methods used to condense and rank the priorities, using only consensus methods were the most common (n=24, 38%), followed by only surveys (n=20, 31%) and lastly, mixed methods involving both surveys and consensus (n=16, 25%). Twenty-five studies did not use a previously published framework that had been used in a prior priority-setting exercise. Of the studies that cited an established framework, the most common was JLA (n=12, 19%).

### Participants

Of the studies that reported the total number of participants, the numbers ranged from 8 to 2200. Most of the included studies involved gathering clinicians' opinions (n=56, 88%) and around half of the studies involved gathering the views of older adults (n=35, 55%). Priority-setting initiatives involving caregivers (n=24, 38%) and personal support workers (n=17, 27%) were less common. Personal support workers were defined as unregulated care providers who provided help with household tasks, personal care and in some cases clinical care in either long term care or community settings.<sup>81–83</sup> Eliciting the opinions of a range of different stakeholder groups was common among the included priority-setting initiatives (n=49, 77%). Regarding the participants' geographical locations, only nine initiatives involved stakeholders from multiple continents (14%). The initiatives with a more targeted location were most often conducted in the USA (n=22, 34%), the UK (n=13, 20%) or Canada (n=9, 14%). None of the included priority-setting initiatives reported gathering the opinions of stakeholders located in low-income or middle-income countries.

### Funding

The majority of the included studies reported their sources of funding (n=52, 81%). The most common funding sources were the government (n=13, 20%) and universities (n=10, 16%). The least common funding sources were industry (n=1, 2%) and professional associations (n=2, 3%). Three of the studies reported that they received no funding. Of the 12 studies that did not report if funding was received or not, more than half of these were conference abstracts (n=9, 75%).

### Methodology reporting

The transparency of reporting was assessed using the REPRISSE criteria (7). All 51 included full-text studies meet the REPRISSE criteria for reporting the health area, intended beneficiaries, research area, type of research

questions and methods for collecting initial priorities. Conversely, the reporting of the time frame (n=1, 2%), relevant training and experience of the governing team (n=14, 28%), reimbursement for participation (n=2, 4%), methods for checking whether priorities have been previously answered (n=15, 29%), the process by which the priority setting was evaluated (n=8, 16%) and how the priorities were fed back to stakeholders and the public (n=14, 28%) were all deemed to be critically low. Percentages of the full-text studies for all elements of the REPRISSE criteria are displayed in [table 2](#).

### Identified research priorities and themes

#### PICO priorities

Twenty-nine articles identified 217 priorities that followed the PICO framework. Of these PICO priorities, 209 were presented as specific research questions. Eight priorities were not phrased as questions; however, they were grouped with the PICO priorities as they possessed all the PICO elements. The characteristics of the PICO priorities are summarised in [table 3](#).

The top 10 causes of DALY identified most frequently as the focus of the PICO priorities were Alzheimer's disease and other dementias (n=24). The least common burdens of disease were chronic obstructive pulmonary disease (COPD) and lower respiratory infections (both n=0). Sixty-two priorities had a condition of focus that was not captured by the top 10 causes of DALY and involved but were not limited to conditions such as frailty, delirium, gout and visual impairment. Seventy-five priorities had reported older adults in general as the population of focus and not older adults with a specific condition. The complete list of the top 10 causes of DALY is displayed in [table 3](#) in the order of prevalence determined by WHO in 2020.<sup>13</sup>

In terms of the outcomes of the PICO priorities, just over three-quarters (n=165, 76%) were associated with clinical outcomes. One-third (n=74, 34%) of the research priorities were related to social and psychosocial outcomes for older adults. Of the PICO priorities, 51 (24%) were associated with outcomes for the caregivers of older adults.

The PICO priorities were most commonly related to multiple interventions (n=69, 32%) across all outcome categories. Out of the 145 priorities focused on a specific intervention, those relating to health-related behaviours (n=59, 41%) were the most prevalent, followed by interventions on activities and participation domains (n=40, 28%), environmental interventions (n=33, 23%) and lastly, interventions on body systems and functions (n=28, 9%). Among the ICF outcome categories that make up the WHO Healthy Ageing framework, environmental was the most common (n=161, 74%), followed by intrinsic capacity (n=140, 65%) and lastly functional ability (n=110, 51%). Of the environmental outcomes, the priorities were most commonly related to services, systems and policy (n=134, 62%) and support and relationships (n=41, 19%). Among the intrinsic capacity outcomes, physiological body function outcomes (n=96, 44%) and mental

outcomes (n=71, 33%) were most common. In terms of the functional ability outcomes basic needs (n=73, 66%) and mobility (n=36, 33%) were the most frequent. The most common types of priorities were those focused on interventions relating to health-related behaviours with environmental (n=55, 25%) and functional ability (n=35, 16%) outcomes. The least common priorities were those focused on environmental interventions and interventions on body systems with functional ability outcomes

(both n=7, 3%). The full matrix of priorities as classified by the intervention and outcome categories is displayed in [figure 2](#).

#### Broad research topics

Thirty-seven articles identified 272 priorities that were presented as broad topic areas or statements. Most of these broad research topics identified as priorities were focused on health services and systems (n=60, 22%) and

**Table 2** Percentages of full-text studies that meet each of the REPRISE criteria

Category	REPRISE criteria	Percentage of studies (n=51)
Context and scope	1.Geographical scope defined	65
	2.Health area, field, focus described	100
	3.Intended beneficiaries defined	100
	4.Target audience of the priorities defined	98
	5.Research area was stated	100
	6.Type of research questions described	100
	7.Time frame defined	2
Governance and team	8.Selection and structure of the leadership and management team described	47
	9.Characteristics of the team described	39
	10.Training or experience relevant to conducting priority setting described	28
Framework for priority setting	11.Was an established framework used	63
Stakeholders or participants	12.Inclusion criteria for stakeholders involved in priority-setting defined	94
	13.Strategy or method for identifying and engaging stakeholders reported	78
	14.No of participants and/or organisations involved indicated	90
	15.Characteristics of stakeholders described	98
	16.Stated if reimbursement for participation was provided	4
Identification and collection of research priorities	17.Methods for collecting initial priorities described	100
	18.Methods for collating and categorising priorities described	86
	19.Methods and reasons for modifying (removing, adding, reframing) priorities described	69
	20.Methods for refining or translating priorities into research topics or questions	71
	21.Methods for checking whether research questions or topics have been answered	29
	22.No of research questions or topics reported at each stage of the process	90
Prioritisation of research questions or topics	23.Methods for prioritising research topics or questions reported	98
	24.Method or threshold for excluding research topics/questions stated	71
Output	25.Approach to formulating the research priorities stated	77
Evaluation and feedback	26.How the process of prioritisation was evaluated described	16
	27.How priorities were fed back to stakeholders and/or to the public; and how feedback (if received) was addressed and integrated was described	28
Implementation	28.Strategy or action plans for implementing priorities described	41
	29.Plans, strategies or suggestions to evaluate impact described	39
Funding and conflict of interest	30.Sources of funding declared	96
	31.Conflicts or competing interests declared	82

Colours are used for clarity (0%–33% red, 34%–66% amber and 67%–100% green).  
REPRISE, Reporting Guideline for Priority Setting of Health Research.

**Table 3** Characteristics of the PICO priorities (n=217)

Category	Subcategory	N (%)
Condition*	Ischaemic heart disease	10 (5)
	Stroke	2 (1)
	COPD	0
	Alzheimer's diseases and other dementias	24 (11)
	Diabetes mellitus type 2	5 (2)
	Tracheal, bronchus and lung cancer	10 (5)
	Low back pain	3 (1)
	Lower respiratory infections	0
	Age-related hearing loss	1 (1)
	Falls	16 (7)
	Other†	71 (29)
	No condition specified	75 (33)
Outcomes	Social/psychosocial	74 (34)
	Medical/clinical	165 (76)
	Caregiver focused	51 (24)

\*The top 10 causes of burden of disease are displayed in the order of prevalence in older adults globally, as reported by WHO.

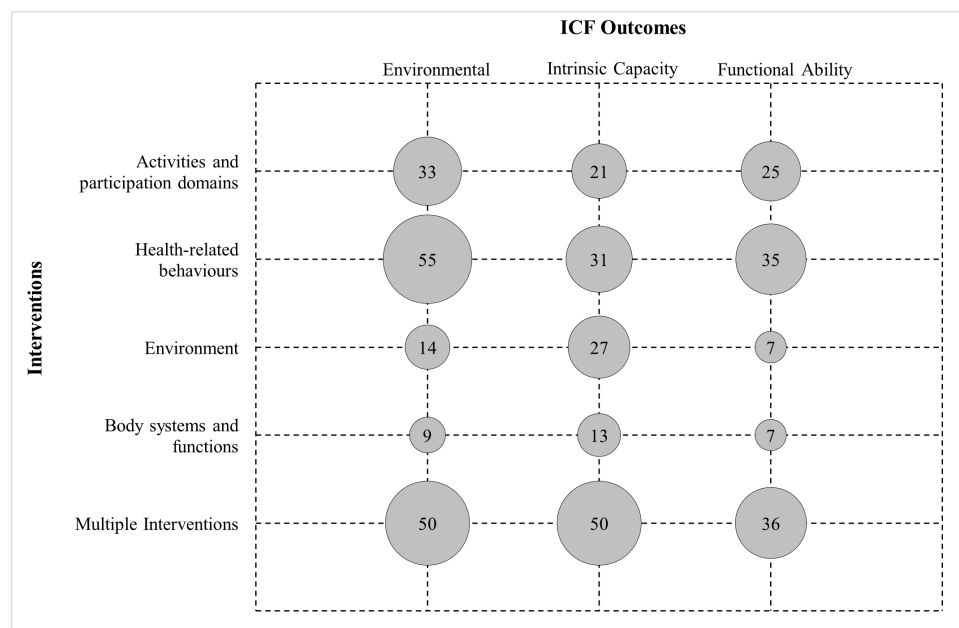
†Conditions of focus that are not captured by the top 10 list of burden diseases (eg, frailty, delirium, gout and visual impairment). COPD, chronic obstructive pulmonary disease; PICO, population–intervention–control–outcome.

epidemiology/aetiology (n=41, 15%). The three least common themes of interest were economic evaluation, prevention, and social services and systems (all n=5, 2%). A slightly greater emphasis was placed on screening and diagnosis, natural history and digital technologies

in priority settings involving older adults. The complete list of research themes used to categorise all the broad research topics is displayed in [table 4](#).

## DISCUSSION

Using health research priority-setting processes is an effective way for researchers and policy-makers to target key areas for future research. While established comprehensive approaches such as the JLA method exist to guide researchers, there is no global consensus on a standardised methodology for health research prioritisation.<sup>8 84</sup> We identified 64 priority-setting initiatives that gathered research priorities aimed at improving the health of older adults. It can be seen from our results that while more than half of the studies reported using a previously published methodology, there were 25 studies (39%) in which an established framework was not reported as being used. It is important to note that following an established methodology or framework does not ensure complete reporting transparency. By employing a modified REPRISSE criteria, we concluded that the reporting of methods was lacking in several critical areas. Only around half of the studies reported if they had used an advisory or steering group to guide and oversee the priority-setting initiatives. While involving an experienced multidisciplinary advisory group to guide the priority-setting initiative is not required for it to be successful, it has been suggested that using one can improve the relevancy and feasibility of the identified priorities.<sup>85</sup> Stakeholder involvement is a dynamic process; therefore, to continuously improve the quality and acceptability of these priority-setting processes, the methods should be evaluated by the participants involved.<sup>86</sup> Despite this, only 16% of the included



**Figure 2** Matrix of PICO priorities as classified by their associated ICHI interventions and who healthy ageing framework ICF outcomes. The size of the circles corresponds to the number of priorities (n=217). ICF, International Classification of Functioning; ICHI, International Classification of Health Interventions; PICO, population–intervention–control–outcome.

**Table 4** Types of the broad research topics

Category	N (%)		
	No older adults* (n=151)	Older adults (n=121)	All broad topics (n=272)
Health services and systems	35 (23)	25 (21)	60 (22)
Epidemiology and aetiology	33 (22)	8 (7)	41 (15)
Treatment	21 (14)	17 (14)	38 (14)
Screening, diagnosis, and assessment	11 (7)	22 (18)	33 (12)
Caregiver needs and support	20 (13)	1 (1)	21 (8)
Natural history, prognosis, and outcomes	7 (5)	14 (12)	21 (8)
Digital technologies	3 (2)	15 (12)	18 (7)
Outcome measurement	5 (3)	4 (3)	9 (3)
Patient and caregiver perspectives	5 (3)	3 (2)	8 (3)
Research capacity build	3 (2)	5 (4)	8 (3)
Economic evaluation	4 (2)	1 (1)	5 (2)
Social services and systems	3 (2)	2 (2)	5 (2)
Prevention	1 (1)	4 (3)	5 (2)

\*Topics gathered from priority-setting initiatives that did not include older adults.

articles reported if they evaluated their methods, and only 28% reported gathering feedback from stakeholders or the general public. Additionally, only around 40% described an implementation plan for using the identified priorities in the future. This is essential so that the readers understand the scope of the project and how the authors intend the priorities to be used.<sup>87</sup> As the purpose of conducting a priority-setting exercise is to identify gaps to fill with future research, it is crucial to ensure that the priorities are areas lacking evidence. Despite this, only around one-third of the included studies reported methods for identifying if enough existing evidence to answer the research priorities. A globally standardised checklist for conducting PSPs could be used to minimise discrepancies in reporting and to ensure reproducibility in future priority-setting research.<sup>86</sup>

In addition to there being discrepancies in reporting, there were also discrepancies in format of the priorities. Of the 64 included initiatives, there were 37 studies which collected broad topics that will require further engagement and analysis to obtain systematic review questions. Of these broad topics, most were categorised as having a focus on epidemiology and aetiology, or health services and systems. Conversely, social services and systems

were only the focus of five broad research topics. A similar pattern can be observed with the PICO priorities, whereby 76% have a clinical focus while only 34% have a social focus. With the current COVID-19 pandemic, social topics like loneliness, social isolation and psychosocial well-being have become problems among older adults now more than ever.<sup>13 88</sup> To meet the needs of older adults, future priority-setting initiatives should be conducted with a focus on gaps in evidence surrounding social and psychosocial conditions as well as the participation of older adults in society.

Engaging relevant stakeholder groups is an essential part of priority-setting processes and is one of the aims for the UN Decade of Healthy Ageing.<sup>1</sup> More than three-quarters of the studies included in this review involved a range of stakeholders which is considerably more than what has been seen in previous systematic reviews on research priority-setting.<sup>12 89</sup> The frequency of specific broad topics varied depending on whether older adults were involved in the research priority setting or not. Priorities associated with screening and digital technology were second and fourth in terms of prevalence when older adults were involved in the process. In priority-setting initiatives without the involvement of older adults, screening and digital technology were ranked 6th and 10th out of 13 categories. Involving multiple relevant stakeholder groups such as older adults, caregivers, social support workers and clinicians is essential for incorporating differing views on what is important and for facilitating crucial discussions.<sup>90</sup>

To examine the relevancy of the priorities on the general population of older adults, the priorities were mapped against the Global Burden of Disease's top 10 DALYs.<sup>13</sup> Of the PICO priorities focused on a specific condition, only around half focused on the top 10 burden diseases. No identified priorities were specific to COPD and lower respiratory infections despite these conditions being prevalent enough to be in the top 10 DALYs among older adults globally. Ischaemic heart disease, the leading cause of burden disease in older adults, only had 10 targeted priorities. As these conditions remain highly prevalent among older adults, it may be beneficial to perform targeted priority-setting initiatives for older adults with these conditions.

This scoping review has several strengths and weaknesses. First, a comprehensive and structured search of multiple electronic databases was used to maximise the capture of relevant studies. All screening of the studies was performed in duplicate following a specific inclusion criterion to minimise selection bias. Another strength was that the REPRISSE criteria was used to evaluate the quality of reporting in the included studies. Additionally, an advisory board composed of both patients and practitioners was used when developing the methods and writing this review. Collaborating with a diverse advisory board improves the relevancy and quality of research through eliciting feedback and open discussions between patients and experts with different specialisations and perspectives.



Included studies were limited to those in either English or French so relevant studies in other languages may have been missed. Additionally, all included priority-setting initiatives only reported gathering stakeholder opinions in high-income countries and therefore, the results might not be applicable to low-income or middle-income settings.

In conclusion, future priority-setting initiatives should focus on ensuring comprehensive and reproducible reporting. These methods should ideally involve a multi-disciplinary advisory committee including older adults and caregivers, implementation plans and some type of literature search for each of the identified priorities. Future PSPs for older adults should focus on priorities related to priorities with social outcomes. These future PSPs should also aim to collect the opinions of diverse populations including older adults and caregivers from low-income or middle-income countries. Based on the priority topics identified, future ageing research should focus on gathering research concerning care setting interventions and outcomes related to services, systems and policy.

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**Appendix A: Search Strategies**

Database: Ovid MEDLINE(R) ALL &lt;1946 to present&gt;

Search Strategy:  
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1. \*Adult/
2. Frail elderly/
3. \*Aged/
4. Middle Aged/
5. (ageing or aging or ager).ab,ti.
6. centenarian.ab,ti.
7. elder\*.ab,ti.
8. geriatric\*.ab,ti.
9. nonagenarian\*.ab,ti.
10. sexagenarian\*.ab,ti.
11. septuagenarian\*.ab,ti.
12. senescence\*.ab,ti.
13. pensioner\*.ab,ti.
14. (resident\* and (old\* or home\* or retirement\* or nursing\*)).ab,ti.
15. (veteran\* and (old\* or home\* or retire\*)).ab,ti.
16. (old\* and (people or adult\* or men or women or age)).ab,ti.
17. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18. exp Health Priorities/
19. Health Services Research/
20. consensus/
21. consensus development conference/
22. (research adj2 agenda).ab,ti.
23. (funding adj2 priorit\*).ab,ti.
24. (priorit\* adj2 setting).ab,ti.
25. (agenda adj2 setting).ab,ti.
26. (research adj2 priorit\*).ab,ti.
27. (research adj2 setting).ab,ti.
28. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27
29. 17 and 28
30. limit 29 to yr="2014" - current



Database: Embase Classic + Embase <1974 to present>

Search Strategy:

---

1. (research adj2 setting).ab,ti.
2. exp Health Priorities/
3. \*health services research/
4. \*consensus/
5. (research adj2 agenda).ab,ti.
6. (funding adj2 priorit\*).ab,ti.
7. (priorit\* adj2 setting).ab,ti.
8. (agenda adj2 setting).ab,ti.
9. (research adj2 priorit\*).ab,ti.
10. 1 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11. \*adult/
12. frail elderly/
13. \*aged/
14. \*middle aged/
15. (ageing or aging or ager).ab,ti.
16. centenarian\*.ab,ti.
17. "elder\*".ab,ti.
18. "geriatric\*".ab,ti.
19. "nonagenarian\*".ab,ti.
20. "sexagenarian\*".ab,ti.
21. "septuagenarian\*".ab,ti.
22. "senescence\*".ab,ti.
23. "pensioner\*".ab,ti.
24. (resident\* and (older or home\* or retirement or nursing)).ab,ti.
25. (veteran\* and (old\* or home\* or retire\*)).ab,ti.
26. (old\* and (people or adult\* or men or women or age)).ab,ti.
27. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26
28. 10 and 27
29. limit 28 to yr="2014 -Current"

Database: APA PsycInfo 1806 to present

Search Strategy:

---

1. (ageing or aging or ager).ab,ti.
2. centenarian.ab,ti.
3. elder\*.ab,ti.
4. geriatric\*.ab,ti.
5. nonagenarian\*.ab,ti.
6. sexagenarian\*.ab,ti.
7. septuagenarian\*.ab,ti.
8. senescence\*.ab,ti.
9. pensioner\*.ab,ti.
10. (resident\* and (old\* or home\* or retirement\* or nursing\*)).ab,ti.
11. (veteran\* and (old\* or home\* or retire\*)).ab,ti.
12. (old\* and (people or adult\* or men or women or age)).ab,ti.
13. older adulthood/
14. healthy aging/
15. \*aging/
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. (research adj2 agenda).ab,ti.
18. (funding adj2 priorit\*).ab,ti.
19. (priorit\* adj2 setting).ab,ti.
20. (agenda adj2 setting).ab,ti.
21. (research adj2 priorit\*).ab,ti.
22. (research adj2 setting).ab,ti.
23. research setting/
24. older americans act/
25. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26. 16 and 25
27. limit 26 to yr="2014 -Current"

Database: CINAHL & Ageline EBSCO (1984 to present)

Search Strategy:

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S26	S15 AND S25
S25	(S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24)
S24	AB research setting OR TI research setting
S23	AB research priorities OR TI research priorities
S22	AB agenda setting OR TI agenda setting
S21	AB priority setting* OR TI priority setting*
S20	AB funding priorities OR TI funding priorities
S19	AB research agenda OR TI research agenda
S18	(MM "Consensus")
S17	(MM "Health Services Research")
S16	(MM "Health Priorities")
S15	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14
S14	TI old* AND TI ( people OR adult* OR men OR women OR age )
S13	AB old* AND AB ( people OR adult* OR men OR women OR age )
S12	AB veteran* AND AB ( old* OR home* OR retire* )
S11	TI veteran* AND TI ( old* OR home* OR retire* )
S10	TI resident* AND TI ( old* OR home* OR retirement* OR nursing )
S9	AB resident* AND AB ( old* OR home* OR retirement* OR nursing )
S8	AB pensioner* OR TI pensioner*
S7	AB ( nonagenarian* OR sexagenarian* OR septuagenarian* or senescence* ) OR TI ( nonagenarian* OR sexagenarian* OR septuagenarian* or senescence* )
S6	AB ( centenarian OR elder* OR geriatric* ) OR TI ( centenarian OR elder* OR geriatric* )

- S5 AB ( ageing OR aging OR ager ) OR TI ( ageing OR aging OR ager )
- S4 (MH "Adult")
- S3 (MM "Middle Age")
- S2 (MM "Aged") OR (MH "Centenarians") OR (MH "Aged, 80 and Over")
- S1 (MM "Frail Elderly")

\*\*\*\*\*



**Appendix B: Top 10 causes of burden diseases**

No.	Causes of DALYs
1	Ischaemic heart disease
2	Stroke
3	Chronic obstructive pulmonary disease
4	Alzheimer's diseases and other dementias
5	Diabetes Mellitus type 2
6	Tracheal, bronchus and lung cancer
7	Low back pain
8	Lower respiratory infections
9	Age-related hearing loss
10	Falls

**Appendix C: ICF Outcomes**

Outcome Category	Measure/construct
Environment	<ul style="list-style-type: none"> <li>• Attitudes</li> <li>• Products and technology</li> <li>• Support and relationships</li> <li>• Natural environment and human-made changes to the environment</li> <li>• Services, systems and policy</li> </ul>
Intrinsic capacity	<ul style="list-style-type: none"> <li>• Mental</li> <li>• Physiological body functions*</li> </ul>
Functional Ability	<ul style="list-style-type: none"> <li>• Basic needs</li> <li>• Learning and applying knowledge</li> <li>• Social contribution/participation</li> <li>• Mobility</li> <li>• Communication</li> <li>• Relationships</li> </ul>

\*Includes sensory functions and pain, neuromusculoskeletal function, voice and speech, cardiovascular, haematology, immune, respiratory, digestive, endocrine, metabolic functions, genitourinary reproductive system, and integumentary system function.

**Appendix D: Extraction Sheets**

## Methodology

	Field	Description	Source
<b>Context and Scope</b>	1. Geographical scope defined? (Y/N)	Global, regional, national, city, local area, institutional/organizational level, health service	REPRISE
	2. Health area, field, focus described? (Y/N)	Disease or condition-specific, interventions, healthcare delivery, health system	REPRISE
	3. Intended beneficiaries defined? (Y/N)	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	REPRISE
	4. Target audience of the priorities defined? (Y/N)	Policymakers, funders, researchers, industry, or others who have the potential to implement the priorities identified	REPRISE
	5. Research area was stated? (Y/N)	Public health, health services research, clinical research, basic science	REPRISE
	6. Type of research questions described? (Y/N)	Etiology, diagnosis, prevention, treatment (interventions), prognosis, health services, psychosocial, behavioral, and social science, economic evaluation, implementation; this may not be pre-defined	REPRISE
	7. Time frame defined? (Y/N)	Interim, short-term, long-term priorities, plans to revise and update	REPRISE
<b>Team and Governance</b>	8. Selection and structure of the leadership and management team described? (Y/N)	Those responsible for initiating, developing, and guiding the process for priority setting, and examples of structures include: Steering Committee, Advisory Group, Technical Experts	REPRISE
	9. Characteristics of the team described? (Y/N)	Stakeholder group or role, institutional affiliations, country or region, demographics (e.g. age sex), discipline, experience, expertise	REPRISE
	10. Training or experience relevant to conducting priority setting described? (Y/N)	Consultants or advisors, members with experience or skills relevant to the conducting priority-setting e.g. qualitative methods, surveys, facilitation	REPRISE
<b>Priority Setting Approach</b>	11. Was an established framework used? described? (Y/N)	A cited methodology that has been previously validated/used for other studies	REPRISE

	Field	Description	Source
	Describe the established framework that was used	e.g. JLA approach, expert panel, survey, Delphi, evidence mapping	Bourne, 2018
<b>Identification and collection of initial research priorities</b>	17. Methods for collecting initial priorities described? (Y/N)	Methods e.g. Delphi survey, surveys, nominal group technique, interviews, focus groups, meetings, workshops; mode e.g. face-to-face, online; may be informed by evidence e.g. systematic reviews, reviews of guidelines/other documents, health technology assessment	REPRISE
	Survey used? (Y/N)	Survey used to collect initial questions/research priorities	
	Consultation used? (Y/N)	Consensus used to collect initial questions/research priorities e.g. nominal group technique, interviews, focus groups, meetings, workshops	
	Evidence used? (Y/N)	Evidence used to collect initial questions/research priorities e.g. systematic reviews, reviews of guidelines/other documents, health technology assessment	
	Search strategy of literature review (if performed) reported explicitly? (Y/N)	If the answer for 'Evidence used?' was no then select N/A	Bourne, 2018
	18. Methods for collating and categorizing priorities described? (Y/N)	Taxonomy or other framework used to organize, summarise, and aggregate topics or questions	REPRISE
	19. Methods and reasons for modifying (removing, adding, reframing) priorities described? (Y/N)	Based on scope, clarity, definition, duplication, other criteria	REPRISE
	20. Methods for refining or translating priorities into research topics or questions described? (Y/N)	Reviewed by Steering Committee or project team	REPRISE
	21. Methods for checking whether research questions or topics have been answered reported? (Y/N)	Systematic reviews, evidence mapping, consultation with experts	REPRISE
<b>Prioritization of research topics/questions</b>	23. Methods for prioritizing research topics or questions reported? (Y/N)	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;	REPRISE
	Method(s) for prioritizing research topics or questions	Survey (only), Consensus (only), Survey and Consensus, If 'No' was selected for REPRISE 23 then select N/A	Bourne, 2018
	24. Method or threshold for excluding research topics/questions stated? (Y/N)	Thresholds for ranking scores, proportions, votes; other criteria	REPRISE



	Field	Description	Source
	25. Approach to formulating the research priorities stated? (Y/N)	Area, topic, questions, PICO (population, intervention, comparator, outcome)	REPRISE
	22. Number of research questions or topics reported at each stage of the process? (Y/N)		REPRISE
	Number of priorities at the end of the process	After the final prioritization	
	Are the final research priorities framed as answerable questions? (Y/N)	e.g. PICO (population, intervention, comparator, outcome) format	
<b>Evaluation and feedback</b>	26. How the process of prioritization was evaluated described? (Y/N)	Survey, workshop	REPRISE
	27. How priorities were fed back to stakeholders and/or to the public; and how feedback (if received) was addressed and integrated was described? (Y/N)	Public meetings or workshop, newsletters, website, email, online presentations	REPRISE
<b>Implementation</b>	Was this an update or reassessment of an earlier priority-setting activity? (Y/N)		Bourne, 2018
	28. Strategy or action plans for implementing priorities described? (Y/N)	Communication with target audience, via policies and funding	REPRISE
	29. Plans, strategies, or suggestions to evaluate impact described? (Y/N)	Integration in decision-making, funding allocation, review of relevant documents	REPRISE
<b>Participants</b>	12. Inclusion criteria for stakeholders involved in priority-setting defined? (Y/N)	e.g. Patients, caregivers, general community, health professionals, researchers, policy makers, non-governmental organizations, government, industry; specific groups including vulnerable and marginalized populations	REPRISE
	13. Strategy or method for identifying and engaging stakeholders reported? (Y/N)	e.g. Partnership with organizations, social media, recruitment through hospitals	REPRISE
	14. Number of participants and/or organizations involved indicated? (Y/N)	Number of individuals and organizations; include the number per stakeholder group	REPRISE
	Indicate the number of participants involved		
	15. Characteristics of stakeholders described? (Y/N)	e.g. Stakeholder group, demographic characteristics, areas of interest and expertise, discipline, affiliations	REPRISE
	Geographic Location	Where were the included stakeholders from? (Participants from multiple continents, UK, USA, Canada, Europe, Australia, Japan, Other)	

Field	Description	Source	
Low/middle income country (Y/N)	Were stakeholders from low/middle income countries included in the priority setting process (use the World Bank Classifications: <a href="https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups">https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups</a> )		
Clinicians involved? (Y/N)	Were clinicians included as a stakeholder in the priority setting process? Clinicians are all types of health and social care professionals with experience of caring for people with the health problem, including organizations or groups who represent them	JLA	
Patients involved? (Y/N)	Were patients included as a stakeholder in the priority setting process? Individuals with experience of the health problem and those who represent them, including relatives and charities	JLA	
Caregivers involved? (Y/N)	Were caregivers included as a stakeholder in the priority setting process? This includes informal and unpaid caregivers such as family members.	JLA	
Personal support workers involved? (Y/N)	Were personal support workers included as a stakeholder in the priority setting process?		
Range of stakeholders involved? (Y/N)	2+ types of stakeholders from the following list: clinicians, patients, caregivers, government, industry, researchers, educators, managers, administrators, and funding agencies?	Bourne, 2018	
Older adults involved? (Y/N)	Were older adults included as a stakeholder in the priority setting process?		
16. Stated if reimbursement for participation was provided? (Y/N)	e.g. Cash, vouchers, certificates, acknowledgement; what purpose e.g. travel, accommodation, honorarium?	REPRISE	
<b>Causes of disability-adjusted life years (DALY) in older adults</b>	Ischaemic heart disease (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10
	Stroke (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10
	COPD (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10
	Alzheimer's diseases and other dementias (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10

	<b>Field</b>	<b>Description</b>	<b>Source</b>
	Diabetes Mellitus type 2 (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10
	Tracheal, bronchus and lung cancer (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10
	Low back pain (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10
	Lower respiratory infections (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10
	Age related hearing loss (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10
	Falls (Y/N)	Were there research priorities identified that are related to this condition?	DALY top 10
	Multiple comorbidities (Y/N)	The answer is yes if yes was answered for >1 of the DALYs or the study reported a focus on multiple comorbidities.	
<b>Funding and Conflict of Interest</b>	30. Sources of funding declared? (Y/N)	Name sources of funding for the priority-setting exercise, if relevant include the budget and/or cost	REPRISE
	State sources of funding	Choose one of the following: government, professional association, university/institute, hospital, industry, professional association, consumer group etc.	
	31. Conflicts or competing interests declared? (Y/N)	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.	REPRISE
	Describe conflicts of interest		
<b>PICO Questions</b>			
	<b>Field</b>	<b>Description</b>	<b>Source</b>
<b>Priorities</b>	Priority	Copy and paste one research questions/priority per line from the study	
<b>Intervention</b>	Type of Intervention	Choose one the following: interventions on body systems and functions, interventions of activities and participation	ICHI

	Field	Description	Source
		domains, interventions on the environment, interventions on health-related behaviours.	
<b>Population</b>	Who carries out the intervention?	e.g. Health sector, social care sector and voluntary sectors	
	Who benefits from the intervention?	Target population whose health will benefit from that specific research priority e.g. older adults with multiple conditions	
<b>General Outcomes</b>	Social/Psychosocial Outcome (Y/N)		
	Clinical/Medical Outcome (Y/N)		
	Caregiver Outcome (Y/N)		
	Wellbeing Outcome (Y/N)	If the priority mentions general health, patient satisfaction, quality of life or wellbeing it is considered to have a wellbeing outcome	
<b>Environmental Outcomes</b>	Attitudes (Y/N)	Is this an outcome of this research priority? The attitudes classified are those of people external to the person whose situation is being described. e.g., individual attitudes of immediate family members, friends, caregivers, health professionals; societal attitudes; social norms, practices and ideologies	ICF
	Products and technology (Y/N)	e.g., accessibility of products for personal consumption, use in daily living, indoor/outdoor mobility and transportation, communication	ICF
	Support and Relationships (Y/N)	Being able to provide practical physical or emotional support, nurturing, protection, assistance, and relationships to other persons, in their home, place of work, school or at play or in other aspects of their daily activities. The environmental factor being described is not the person or animal, but the amount of physical and emotional support the person or animal provides.	ICF

Field	Description	Source	
	e.g., Accessible medical and social services that provide individualized information		
Natural environment and human-made changes to the environment (Y/N)	Animate and inanimate elements of the natural or physical environment, and components of that environment that have been modified by people, as well as characteristics of human populations within that environment e.g., age-friendly cities, Transport	ICF	
Services, systems, and policies (Y/N)	Services that provide benefits, structured programs, and operations, in various sectors of society, designed to meet the needs of individuals (Included in services are the people who provide them). e.g., Health services, systems, and policies	ICF	
<b>Intrinsic Capacity Outcomes</b>	Mental (Y/N)	e.g., depression, sleep, vitality, memory	ICF
	Physiological body functions (Y/N)	e.g., sensory functions and pain, neuromusculoskeletal function, voice and speech, cardiovascular, haematology, immune, respiratory, digestive, endocrine, metabolic functions, genitourinary reproductive system, and integumentary system function	ICF
<b>Functional Ability Outcomes</b>	Basic needs (Y/N)	e.g., self-care, acquisition of goods and services	ICF
	Learning and applying knowledge (Y/N)	e.g., applying knowledge	ICF
	Social contribution/participation (Y/N)	e.g., community life, employment	ICF
	Mobility (Y/N)	e.g., walking; using transportation; moving around using equipment (i.e., wheelchair)	ICF
	Communication (Y/N)	Communicating by language, signs, and symbols, including receiving and producing messages, carrying on conversations, and using communication devices and techniques. e.g., digital literacy	ICF



Field	Description	Source
Relationships (Y/N)	Carrying out the actions and tasks required for basic and complex interactions with people (strangers, friends, relatives, family members and lovers) in a contextually and socially appropriate manner. e.g., interpersonal interactions	ICF

## Broad Research Topics

Field	Description	Source
<b>Priorities</b>		
Priority	Copy and paste one research questions/priority per line from the study	
Type	Choose the most relevant category from the following: Health services and systems; Research capacity build; Treatment; Screening, diagnosis, and assessment; Epidemiology and aetiology; Natural history, prognosis, and outcomes; Digital technologies; Caregiver needs and support; Caregiver needs and support; Outcome measurement; Patient and caregiver perspectives; Social services and systems; Prevention; Economic evaluation	Bourne. 2020

## Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
<b>TITLE</b>			
Title	1	Identify the report as a scoping review.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	'Abstract'
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	'Introduction'
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	'Objective'
<b>METHODS</b>			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	'Eligibility Criteria'
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	'Search Strategy'
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix A
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	'Screening and Selection'
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	'Data Collection'
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	'Data Collection'
Critical appraisal of individual sources of	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was	N/A



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
evidence§		used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	'Analysis'
<b>RESULTS</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	'Search Results'
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	'Included Studies' and 'Published Data (on OSF)'
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	'Identified Research Priorities and Themes', and 'Published Data (on OSF)'
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	'Included Studies' and 'Identified Research Priorities and Themes'
<b>DISCUSSION</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	'Discussion'
Limitations	20	Discuss the limitations of the scoping review process.	'Discussion'
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	'Discussion'
<b>FUNDING</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	'Funding'

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).



From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA ScR): Checklist and Explanation. *Ann Intern Med*. 2018;169:467–473. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850).



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