

Comparing research priority setting partnerships for older adults across international healthcare systems: a systematic review

Supplementary File

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Table S1. PRISMA checklist

| Section and Topic | Item # | Checklist item | Location where item is reported |
|-------------------------------|--------|--|---------------------------------|
| TITLE | | | |
| Title | 1 | Identify the report as a systematic review. | Page 1 |
| ABSTRACT | | | |
| Abstract | 2 | See the PRISMA 2020 for Abstracts checklist. | Page 1 |
| INTRODUCTION | | | |
| Rationale | 3 | Describe the rationale for the review in the context of existing knowledge. | Page 2 |
| Objectives | 4 | Provide an explicit statement of the objective(s) or question(s) the review addresses. | Page 2 |
| METHODS | | | |
| Eligibility criteria | 5 | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses. | Page 3 |
| Information sources | 6 | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted. | Page 3 |
| Search strategy | 7 | Present the full search strategies for all databases, registers, and websites, including any filters and limits used. | Table S2 |
| Selection process | 8 | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process. | Pages 3 and 4 |
| Data collection process | 9 | Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process. | Pages 4 and 5 |
| Data items | 10a | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g., for all measures, time points, analyses), and if not, the methods used to decide which results to collect. | Not applicable |
| | 10b | List and define all other variables for which data were sought (e.g., participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information. | Not applicable |
| Study risk of bias assessment | 11 | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process. | Page 5 |
| Effect measures | 12 | Specify for each outcome the effect measure(s) (e.g., risk ratio, mean difference) used in the synthesis or presentation of results. | Not applicable |
| Synthesis methods | 13a | Describe the processes used to decide which studies were eligible for each synthesis (e.g., tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)). | Page 5 |
| | 13b | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions. | Page 5 |
| | 13c | Describe any methods used to tabulate or visually display results of individual studies and syntheses. | Page 5 |
| | 13d | Describe any methods used to synthesise results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used. | Not applicable |
| | 13e | Describe any methods used to explore possible causes of heterogeneity among study results (e.g., subgroup analysis, meta-regression). | Not applicable |
| | 13f | Describe any sensitivity analyses conducted to assess robustness of the synthesised results. | Not applicable |
| Reporting bias assessment | 14 | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases). | Not applicable |
| Certainty assessment | 15 | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. | Not applicable |
| RESULTS | | | |
| Study selection | 16a | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram. | Page 5 |
| | 16b | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded. | Not applicable |
| Study characteristics | 17 | Cite each included study and present its characteristics. | Pages 6 and 7 |
| Risk of bias in studies | 18 | Present assessments of risk of bias for each included study. | Page 8 |
| Results of individual studies | 19 | For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. | Not applicable |
| Results of | 20a | For each synthesis, briefly summarise the characteristics and risk of bias among | Page 8 |

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|--------|---|---------------------------------|
| syntheses | | contributing studies. | |
| | 20b | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g., confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | Not applicable |
| | 20c | Present results of all investigations of possible causes of heterogeneity among study results. | Not applicable |
| | 20d | Present results of all sensitivity analyses conducted to assess the robustness of the synthesised results. | Not applicable |
| Reporting biases | 21 | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. | Not applicable |
| Certainty of evidence | 22 | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. | Not applicable |
| DISCUSSION | | | |
| Discussion | 23a | Provide a general interpretation of the results in the context of other evidence. | Pages 8 and 9 |
| | 23b | Discuss any limitations of the evidence included in the review. | Pages 10 and 11 |
| | 23c | Discuss any limitations of the review processes used. | Pages 10 and 11 |
| | 23d | Discuss implications of the results for practice, policy, and future research. | Page 10 |
| OTHER INFORMATION | | | |
| Registration and protocol | 24a | Provide registration information for the review, including register name and registration number, or state that the review was not registered. | Page 3 |
| | 24b | Indicate where the review protocol can be accessed, or state that a protocol was not prepared. | Page 3 |
| | 24c | Describe and explain any amendments to information provided at registration or in the protocol. | Page 3 |
| Support | 25 | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review. | Title page |
| Competing interests | 26 | Declare any competing interests of review authors. | Page 12 |
| Availability of data, code, and other materials | 27 | Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | Page 12 |

Table S2. Search strategies for Medline and Embase

| Medline (Ovid): 1946 to present (for studies in the United Kingdom) | |
|--|--|
| # | Query |
| 1 | (research priority setting\$ or research agenda\$ or priority setting\$).tw. |
| 2 | (Health Priorities/ and research*.tw.) or (Health Priorities/ and evidence.tw.) |
| 3 | ((research* or health*) adj3 prioriti*).tw. |
| 4 | (research adj2 (agenda or quest* or initiative*).tw. |
| 5 | (priority areas of research or priority setting partnership\$).tw. |
| 6 | service* priorit*.tw. |
| 7 | (priorit* adj3 (survey* or partner*).tw. |
| 8 | (uncertain* adj3 research*).tw. |
| 9 | or/1-8 |
| 10 | aged.mp. or Aged/ |
| 11 | geriatrics.ti.ab. or Geriatrics/ |
| 12 | (elder* or old*).ti.ab. |
| 13 | Aging/ or (aging or ageing).ti.ab. |
| 14 | frail elderly.ti.ab. or Frail Elderly/ |
| 15 | or/10-14 |
| 16 | 9 and 15 |
| 17 | exp United Kingdom/ |
| 18 | (national health service* or nhs*).ti.ab.in. |
| 19 | (english not ((published or publicati on* or transl* or written or language* or speak* or literature or citation*) adj5 english)).ti.ab. |
| 20 | (gb or "g.b." or britain* or british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti.ab.jw.in. |
| 21 | (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's orleeds*" or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or "norwich or norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worchester not (massachusetts* or boston* or harvard*)) or ("worchester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york* or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti.ab.in. |
| 22 | (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti.ab.in. |
| 23 | (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*)) or stirling or "stirling's").ti.ab.in. |
| 24 | (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti.ab.in. |
| 25 | or/17-24 |
| 26 | (exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp United Kingdom/ or europe/) |
| 27 | 25 not 26 |
| 28 | 16 and 27 |
| 29 | limit 28 to yr="2021 -Current" |
| 30 | (case reports or comments or commentary or editorial or letters).mp. |
| 31 | 29 not 30 |
| 32 | child/ or infant/ or adolescent/ or maternal health service/ |
| 33 | (child* or infant* or adolescen* or matern* health service*).mp. |
| 34 | or/32-33 |
| 35 | 31 not 34 |
| Embase (Ovid): 1974 to present (for studies in the United Kingdom) | |
| # | Query |
| 1 | (research priority setting\$ or research agenda\$ or priority setting\$).tw. |
| 2 | (Health Priorities adj3 (research* or evidence)).tw. |
| 3 | ((research* or health*) adj3 prioriti*).tw. |

| | |
|---|--|
| 4 | (research adj2 (agenda or quest* or initiative*).tw. |
| 5 | (priority areas of research or priority setting partnership\$.tw. |
| 6 | service* priorit*.tw. |
| 7 | (priorit* adj3 (survey* or partner*).tw. |
| 8 | (uncertain* adj3 research*).tw. |
| 9 | or/1-8 |
| 10 | exp United Kingdom/ |
| 11 | (national health service* or nhs*).ti,ab,in,ad. |
| 12 | (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab. |
| 13 | (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad. |
| 14 | (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or Carlisle* or "Carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))).ti,ab,in,ad. |
| 15 | (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad. |
| 16 | (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad. |
| 17 | (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad. |
| 18 | or/10-17 |
| 19 | (exp "arctic and antarctic"/ or exp oceanic regins/ or exp western hemisphere/ or exp africa/ or exp asia/ or exp "australia and new zealand"/) not (exp United Kingdom/ or europe/) |
| 20 | 18 not 19 |
| 21 | 9 and 20 |
| 22 | (case reports or comments or commentary or editorial or letters).mp. |
| 23 | 21 not 22 |
| 24 | child/ or infant/ or adolescent/ or maternal health service/ |
| 25 | (child* or infant* or adolescen* or matern* health service*).mp. |
| 26 | or/24-25 |
| 27 | 23 not 26 |
| 28 | limit 27 to yr="2021 -Current" |
| 29 | aged.mp. or Aged/ |
| 30 | elderly.mp. |
| 31 | old*.mp. |
| 32 | geriatric.mp. or Geriatrics/ |
| 33 | frail*.mp. |
| 34 | 29 or 30 or 31 or 32 or 33 |
| 35 | 28 and 34 |
| Medline (Ovid): 1946 to present (for studies in the United States, South Korea, and countries in Africa) | |
| # | Query |
| 1 | (research priority setting\$ or research agenda\$ or priority setting\$.tw. |
| 2 | (Health Priorities/ and research*.tw.) or (Health Priorities/ and evidence.tw.) |
| 3 | ((research* or health*) adj3 priorit*).tw. |
| 4 | (research adj2 (agenda or quest* or initiative*).tw. |
| 5 | (priority areas of research or priority setting partnership\$.tw. |
| 6 | service* priorit*.tw. |
| 7 | (priorit* adj3 (survey* or partner*).tw. |
| 8 | (uncertain* adj3 research*).tw. |
| 9 | or/1-8 |

| | |
|--|---|
| 10 | aged.mp. or Aged/ |
| 11 | geriatrics.ti.ab. or Geriatrics/ |
| 12 | (elder* or old*).ti.ab. |
| 13 | Aging/ or (aging or ageing).ti.ab. |
| 14 | frail elderly.ti.ab. or Frail Elderly/ |
| 15 | or/10-14 |
| 16 | 9 and 15 |
| 17 | exp United States/ |
| 18 | exp Korea/ |
| 19 | exp Africa/ or (Africa* or Algeria or Angola or Benin or Botswana or "Burkina Faso" or Burundi or "Cabo Verde" or "Cape Verde" or Cameroon or "Central African Republic" or Chad or Comoros or Congo or "Cote d'Ivoire" or "Ivory Coast" or Djibouti or Egypt or "Equatorial Guinea" or Eritrea or Eswatini or Ethiopia or Gabon or Gambia or Ghana or Guinea or "Guinea-Bissau" or Kenya or Lesotho or Liberia or Libya or Madagascar or Malawi or Mali or Mauritania or Mauritius or Morocco or Mozambique or Namibia or Niger or Nigeria or Rwanda or "Sao Tome" or Principe or Senegal or Seychelles or "Sierra Leone" or Somalia or "South Africa" or Sudan or Tanzania or Togo or Tunisia or Uganda or Zambia or Zimbabwe).mp. |
| 20 | 17 or 18 or 19 |
| 21 | 16 and 20 |
| 22 | limit 21 to yr="2011 -Current" |
| 23 | (case reports or comments or commentary or editorial or letters).mp. |
| 24 | 22 not 23 |
| 25 | child/ or infant/ or adolescent/ or maternal health service/ |
| 26 | (child* or infant* or adolescen* or matern* health service*).mp. |
| 27 | 25 or 26 |
| 28 | 24 not 27 |
| Embase (Ovid): 1974 to present (for studies in the United States, South Korea, and countries in Africa) | |
| # | Query |
| 1 | (research priority setting\$ or research agenda\$ or priority setting\$).tw. |
| 2 | (Health Priorities adj3 (research* or evidence)).tw. |
| 3 | ((research* or health*) adj3 prioriti*).tw. |
| 4 | (research adj2 (agenda or quest* or initiative*)).tw. |
| 5 | (priority areas of research or priority setting partnership\$).tw. |
| 6 | service* priorit*.tw. |
| 7 | (priorit* adj3 (survey* or partner*)).tw. |
| 8 | (uncertain* adj3 research*).tw. |
| 9 | or/1-8 |
| 10 | exp United States/ |
| 11 | exp Korea/ |
| 12 | exp Africa/ or (Africa* or Algeria or Angola or Benin or Botswana or "Burkina Faso" or Burundi or "Cabo Verde" or "Cape Verde" or Cameroon or Central African Republic or Chad or Comoros or Congo or "Cote d'Ivoire" or "Ivory Coast" or Djibouti or Egypt or "Equatorial Guinea" or Eritrea or Eswatini or Ethiopia or Gabon or Gambia or Ghana or Guinea or "Guinea-Bissau" or Kenya or Lesotho or Liberia or Libya or Madagascar or Malawi or Mali or Mauritania or Mauritius or Morocco or Mozambique or Namibia or Niger or Nigeria or "Nile Valley" or Rwanda or "Sao Tome" or Principe or Senegal or Seychelles or "Sierra Leone" or Somalia or "South Africa" or "Sub Saharan" or Sudan or Tanzania or Togo or Tunisia or Uganda or Zambia or Zimbabwe).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word] |
| 13 | 10 or 11 or 12 |
| 14 | 9 and 13 |
| 15 | (case reports or comments or commentary or editorial or letters).mp. |
| 16 | 14 not 15 |
| 17 | child/ or infant/ or adolescent/ or maternal health service/ |
| 18 | (child* or infant* or adolescen* or matern* health service*).mp. |
| 19 | 17 and 18 |
| 20 | 16 not 19 |
| 21 | limit 20 to yr="2011 -Current" |
| 22 | aged.mp. or Aged/ |
| 23 | elderly.mp. |
| 24 | old*.mp. |
| 25 | geriatric.mp. or Geriatrics/ |
| 26 | frail*.mp. |
| 27 | 22 or 23 or 24 or 25 or 26 |
| 28 | 21 and 27 |

Table S3. Description of common priority setting partnerships

| Priority setting partnership | Background | Patient and public involvement | Major steps |
|---|--|---|---|
| James Lind Alliance approach | This approach was established by the James Lind Alliance for engaging patients, carers, and the public in identifying research priorities. | Patient and public involvement is essential to this approach, with patients, caregivers, patient advocates, and/or the public presenting in the steering group. They also involve in the priority setting survey(s) and the prioritisation workshop as key stakeholders. | <ol style="list-style-type: none"> 1. Setting up a steering group of stakeholder representatives and confirming the action plan 2. Gathering evidence uncertainties (i.e., research gaps) from stakeholders via surveys and searching existing literature to find evidence gaps 3. Summarising the responses gathered and checking if they are true uncertainties 4. Conducting an interim priority setting survey with stakeholders to reduce the list of research questions 5. Convening a prioritisation workshop for stakeholders to discuss the “Top 10” list of research questions 6. Disseminating results |
| Nominal group technique | This approach was established to encourage all participants to share their own opinions, while considering others’, before reaching consensus by voting or ranking exercises. | Patient and public involvement is essential to this approach, with patients, caregivers, patient advocates, and/or the public helping generate research questions and attending and voting in the group discussion. | <ol style="list-style-type: none"> 1. Gathering research questions from individual stakeholder representatives without group discussion 2. Stakeholder representatives taking turns to read aloud their research questions to the group 3. Discussing and clarifying the research questions among stakeholder representatives and exploring underlying rationales 4. Arranging voting(s) for stakeholder representatives to finalise the list of research questions 5. Disseminating results |
| Delphi process | This approach was established to reach consensus among experts using repeated rounds of anonymous feedback. It has been adapted for research priority setting exercises. | Patient and public involvement is essential to this approach, with patients, caregivers, patient advocates, and/or the public helping generate research questions anonymously. They also involve in prioritising and re-prioritising research questions via anonymous questionnaires. | <ol style="list-style-type: none"> 1. Gathering research questions from stakeholders or stakeholder representatives 2. Stakeholder representatives prioritising research questions and providing opinions via an anonymous questionnaire 3. Summarising the questionnaire results and reducing the list of research questions 4. Presenting the results to the stakeholder representatives 5. Stakeholder representatives re-prioritising the research questions on the list (and providing opinions) via an anonymous questionnaire to finalise the research questions 6. (Steps 3 to 5 can be repeated if extra rounds are necessary) 7. Disseminating results |
| Cornell Institute for Translational Research on Aging model | This approach was established by the Cornell Institute for Translational Research on Aging for creating meaningful dialogue and equal-status contact between researchers and practitioners, to bridge the gap between research-based knowledge and practice-based insights. It has been extended to consider patients’ (and caregivers’) expectations. | Patient and public involvement is becoming essential to this approach. Patients, caregivers, patient advocates, and/or the public may involve in the representative advisory group for topic selection. They may also participate in meetings for generating and confirming research questions. | <ol style="list-style-type: none"> 1. Selecting a topic by a representative advisory group of stakeholders via meetings 2. Selecting a panel of expert researchers and expert practitioners on the topic to produce an up-to-date review that summarises relevant research in nontechnical language 3. Convening a larger group of stakeholders to discuss the review and achieve initial consensus on research questions that are more relevant to practice 4. Convening a follow-up roundtable meeting for stakeholder representatives to reach final consensus 5. Disseminating results |

Table S4. Nine Common Themes of Good Clinical Practice

| Theme of Good Clinical Practice | Criteria for good practice |
|--|--|
| Context | Resources |
| | Focus/scope |
| | Values/principles |
| | Environment |
| Use of a comprehensive approach | Decide if use of a comprehensive approach is appropriate, or if development of own methods is the preferred choice |
| Inclusiveness | Identify which stakeholders need to be involved in the research priority setting exercise, why their opinions need to be sought, and what role they should play in the process |
| Information gathering | Consideration should be made on which types of information are necessary to inform the priority setting process |
| Planning for implementation | Planning for implementation should be a priority during the initial phase of a research priority setting exercise (and not be left till after priorities are established) |
| Criteria | Define criteria for the exercise |
| Methods for deciding on priorities | Define method used to identify priorities |
| Evaluation | Plans to evaluate priorities after they have been set |
| Transparency | The report should not be limited to stating a list of priorities, but should also explain how those priorities were established, and by who |

Table S5. Definitions of themes used in grouping research priorities

| Theme | Definition |
|--|---|
| Diagnosis & Recognition | Research priorities related to the diagnosis or recognition (identification) of the medical condition. |
| Treatment & Intervention | Research priorities related to any pharmacological or non-pharmacological treatment(s) or intervention(s) of the medical condition. |
| Prevention | Research priorities related to any level of prevention of the medical condition. |
| Prognostic/Predictive factors | Research priorities related to the prognosis or prediction of the medical condition. |
| Aetiology | Research priorities related to the cause(s) or pathophysiology of the medical condition. |
| Caregivers & Support | Research priorities related to the impact of the medical condition on caregivers, healthcare professionals, or social services |
| Service development | Research priorities related to the development or improvement of healthcare services for managing the medical condition. |
| Patient knowledge, experience, education, and engagement | Research priorities related to the improvement of patient knowledge, experience, education, or engagement of the medical condition. |
| Other | Research priorities not related to any of the other defined themes. |