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Patient Experiences of Co-Designed Rehabilitation Interventions: Protocol for a Rapid Review

Authors

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ABSTRACT

Introduction: Patient-centred care can be facilitated by co-design, which refers to collaboration between healthcare professionals and consumers in producing and implementing healthcare. Systematic reviews on co-design have mainly focused on the effectiveness of co-produced healthcare interventions. Less attention has been directed towards the experiences of patients in co-designed interventions. This rapid review aims to explore patient experiences of co-designed rehabilitation interventions and inform rehabilitation decision-making.

Methods and analysis: A rapid review will expedite timely information on co-design experiences for stakeholders. Four electronic databases, including Cochrane CENTRAL, MEDLINE, Embase, and CINAHL, will be searched from 1 January 2000 to 1 July 2021. The Cochrane Risk of Bias tool will be used for randomised trials. Critical appraisal checklists from The Joanna Briggs Institute shall evaluate the risk of bias of non-randomised trials and qualitative studies. A narrative synthesis will be provided for the quantitative studies. Thematic synthesis will be conducted on qualitative findings. The overall strength evidence will be measured using the GRADE framework for quantitative investigations and the GRADE-CERQual for qualitative studies. The results will be presented textually, with flow charts, summary tables, statistical analysis, narrative summaries and identified themes.

Ethics and dissemination: Ethics approval is not required for the review. The protocol and rapid review will be submitted to a peer-reviewed journal for publication. The review findings will be rapidly translated to consumers, clinicians, healthcare leaders, organisations, researchers and policy makers via publications, evidence summaries, conferences, workshops, websites, social media, and online events.

1.• Your submission should include a title page (embedded in the main document) which must contain the following information:

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Article Summary

Registration details: This protocol has been published on PROSPERO: CRD42021264547.

Strengths and limitations of this study:

- Timely evidence generated on the relationships between co-designed rehabilitation interventions and patient experiences will inform policies and rehabilitation practice.
- Co-production and co-authorship with consumers are strengths of this study.
- Rapid knowledge synthesis will accelerate the translation of evidence into rehabilitation practice.
- Risk of bias may be introduced by rapid methods and will be controlled for by *a priori* recommended methods and transparent reporting of the results.

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INTRODUCTION

Patient-centred care is integral to the delivery of high-quality healthcare and positive patient experiences.[1] Facilitating patient participation across all levels of health service ecosystems is key for safe and effective patient-centred care.[2] Wolfe et al. (2014) defined patient experiences as "…the sum of all interactions, shaped by the organisation's culture, that influence patient perceptions, across the continuum of care."[3] Consumer participation is the gold-standard for person-centred care.[4]

Rehabilitation is a person-centred approach which tailors interventions to the individual and involves an interdisciplinary team.[5] Rehabilitation interventions are designed to improve mobility and independence, minimise pain, and to improve a person's ability to adapt to changes in circumstances.[5] Rehabilitation also aims to optimise movement, strength, function, upper limb control, balance and to facilitate timely discharge.[6] Various methods can be used to improve patient experiences of rehabilitation.[7] One approach is co-design, which refers to collaboration between healthcare professionals and consumers to design and implement therapies and services.[8] Rehabilitation designed in partnership with patients is more likely to meet their needs and preferences.[9] The National Institute for Health Research (NIHR) in the United Kingdom, and similar agencies, have advocated co-design.[9-12]

Previous reviews of co-design in healthcare have centred around consumer needs;[1,8,10,13,14] implementing co-designed interventions to influence health professional behaviour;[8] evaluation of how co-design facilitates clinical and service outcomes in acute healthcare settings;[14] and outcomes for different co-designed hospitals tools, therapies and services.[10]

The primary aim of this review is to explore patient experiences of co-designed interventions

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in rehabilitation hospitals. Secondary aims will be to understand (i) the methods used to co-design rehabilitation interventions; (ii) the ways in which co-designed rehabilitation interventions are implemented; and (iii) the barriers and facilitators to implementing co-designed rehabilitation therapies.

METHODS AND ANALYSIS

Systematic reviews provide high-quality evidence syntheses to appraise policy and clinical practice.[15,16] A rapid review is an evidence synthesis that provides information to decision makers in a timely manner, allowing for rapid communication of research findings to end-users.[17] Components of a standard systematic review are streamlined in a rapid review.[18] Rapid reviews are particularly valuable when stakeholders and policy makers have a short deadline for evidence and advice.[16,17] It is noteworthy that rapid reviews are rigorous and are not less systematic than standard systematic reviews.[19] The Cochrane Rapid Review Methods Group gives recommendations on the methodology supporting rapid reviews. [17,18] These include a reduced number of reviewers for screening, streamlining data extraction, and method quality appraisal processes, and restricting the inclusion criteria to a defined date range.[17] They also recommend limiting databases searched and minimising grey literature and supplemental searching.[18]

The current protocol has been published on the international prospective register of systematic reviews (PROSPERO: CRD42021264547) for registration, in compliance with the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) recommendations.[20] In the absence of a published reporting guideline for rapid reviews,[15] the protocol will be informed by the PRISMA-P guidelines and the Cochrane Rapid Review methods.[18,20] The review methods will also be guided by the Cochrane Rapid Review

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Methods Group best practice recommendations and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[18,21] The Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) guideline will be used to apprise the reporting of qualitative elements of the evidence synthesis. [22]

Patient and public involvement

This protocol has been co-designed and co-authored with two consumer representatives. Consumers offer an authentic lived-experience contribution, and the consumer representatives assisted in the conceptualisation of the protocol, the refinement of the research question, and the editing of the manuscript. The consumers will also provide input into the evidence synthesis and assist in writing the final manuscript for the rapid review.

Eligibility criteria

Studies are to be included when they meet the following criteria: participants who are adults older than 18 years; rehabilitation interventions co-designed with patients; patient experiences of co-designed rehabilitation interventions are reported; inpatient hospital settings; empirical study design reported in English. Publications will be excluded if they are protocols, book chapters, theses, editorials, conference abstracts or studies that include participants in a paediatric population or patient groups that require a third party to participate in the co-design process (e.g., individuals with severe cognitive impairment).

Identification and selection of included papers

A health services librarian will develop the search strategies and run the electronic database searches. Four online databases (Cochrane CENTRAL, MEDLINE, Embase, and CINAHL) will be searched from 1 January 2000 to 1 October 2021. Search terms for the following key concepts will be used: co-design; rehabilitation interventions; consumers and patients; patient

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experience; hospitals and acute health care settings. An example search is in the supplementary file (appendix 1).

The search results will be downloaded to EndNote X9.3.1.[23] The combined yield will be uploaded into Covidence to sort and select the studies against the eligibility criteria.[24] Initially the duplicates will be deleted in Covidence then titles alone will be screened for eligibility. The remaining titles with abstracts will then be screened in Covidence. At least one quarter of the titles with abstracts will be screened by two reviewers through applying the eligibility criteria.[17] The remaining titles with abstracts will be screened by one reviewer. After reaching consensus on the yield, the full texts will be obtained for the remaining abstracts. The full texts will be saved in Covidence, read in full by at least one reviewer and screened using the eligibility criteria. A second reviewer will screen the excluded abstracts and full text studies and the two reviewers will meet to reach consensus.[17] Reasons for exclusions will be noted in Covidence. Any discrepancies or disagreements that arise during this process will be resolved by consultation and consensus with a third author. A PRISMA-compliant flow chart (online supplementary appendix 2) generated through Covidence, will record the selection process for the included studies.

Method quality assessment

The Cochrane Risk of Bias tool will be used to appraise the method quality for the randomised controlled clinical trials.[25] Critical appraisal checklists from The Joanna Briggs Institute (JBI) critical appraisal tools will be completed to assess the risk of bias, matched to the quantitative or qualitative designs of the included studies.[26,27] Two reviewers will assess the included studies using the Cochrane Risk of Bias tool or relevant JBI critical appraisal checklist to independently assess the trustworthiness of included studies.[25,26] The checklists include a series of questions which will help the reviewers to determine the risk of bias and

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the trustworthiness of the reported results. Each checklist has a comprehensive guide for each item.[26,28]

Data extraction and management

Two reviewers will independently extract the data into spreadsheets using headings such as: study design, country, first author, year, setting, sample size, participant characteristics, intervention characteristics (content, who delivered, dosage etc.), co-design strategies used, description of co-design implementation, primary and secondary outcome measures such as patient experience and effects of co-production, outcome data and results, themes, co-design barriers, and co-design facilitators. The data extraction spreadsheets will be evaluated for consistency and any disagreements will be discussed and agreed upon. The spreadsheets will then be combined for the data synthesis stage.

Data analysis/synthesis

Data analysis will be independently completed by two reviewers. For the quantitative data, a narrative synthesis will be used and reported according to the Synthesis without Meta-Analysis (SWiM).[29] Two reviewers will independently summarise and interpret the reported results for the included studies. A textual description will be provided for each study to give details on the setting, participants, intervention, and findings such as effect sizes or mean changes.[26]

For the qualitative data, a thematic synthesis will be used within a theoretical framework of meta-synthesis and an analytical framework of thematic analysis.[30] The three stages of thematic synthesis recommended by Harden and Thomas (2008) will be used for combined analysis of the primary studies.[31] This includes coding the findings of the included studies

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and developing descriptive themes for the combined coding; identifying relationships between the descriptive themes; and generating analytical themes which transcend the content of each original study.[31] This synthesis approach is supported by the Cochrane Qualitative and Implementation Methods Group recommendations. They advise descriptive themes often inform policy and analytical themes inform theory. Two reviewers will independently read the included studies to code and extract the themes reported by the authors of each paper. The reviewers will then group themes according to their similarities, forming representative themes. From the consolidated themes, analytical themes will be developed independently by each reviewer and finalised by consensus.[31] Summary tables will be used for the qualitative findings. Any discrepancies between the two reviewers will be settled by a third author.

Confidence in cumulative evidence

PRIMSA-P recommends that the overall strength of included studies be assessed.[20] For randomised controlled clinical trials and observational studies, the Grading of Recommendations Assessment, Development and Evaluation (GRADE) framework will be utilised.[32] This provides a quality of evidence rating system for each review outcome. The results will be displayed in a table summarising the findings.[32]

Where the included studies are of a qualitative design, the strength of the findings will be measured using the GRADE-CERQual (Confidence in Evidence from Reviews of Qualitative Research).[33] The GRADE-CERQual is a framework for reviewers to assess the amount of confidence they can have in the review results from qualitative syntheses.[33] Two reviewers (JPM, SCS) will independently perform a GRADE-CERQual assessment of the findings of each review.

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RESULTS

The quantitative results will be presented textually, with flow charts, summary tables, statistical analysis and narrative summaries. The qualitative results will be presented as themes and subthemes and summary tables linked to the data.

DISCUSSION

The rationale and design of a rapid review of patient experiences of co-design of rehabilitations interventions has been described. The review will identify important factors in co-production and inform optimum intervention design for rehabilitation.

ETHICS AND DISSEMINATION

Ethics approval will not be required for the protocol and rapid review. The protocol and accompanying review will be submitted to an international peer-reviewed journal for publication. The findings will be rapidly translated to consumers, clinicians, healthcare leaders, organisations, and the research community and policy makers via publications, evidence summaries, conferences, workshops, websites, social media, and online events.

Acknowledgements

We thank Elizabeth Lawrence, La Trobe University librarian, for developing and conducting the search of the literature.

Author Contribution

JPM, SCS, JJ, and MEM contributed to the conceptualisation of the study, research question and study design. JPM wrote the first draft of the protocol manuscript. JPM, SCS, and MEM contributed to the subsequent drafts of the manuscript. The final draft was edited and approved by all authors prior to submission (JPM, SCS, JJ, AH, MK, JG, JW and MEM).

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Competing interests: None declared

Data statement: Data sharing is not applicable as no participant datasets will be generated and/or analysed for this study.

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REFERENCE LIST

1. Bombard Y, Baker GR, Orlando E, et al. Engaging patients to improve quality of care: a systematic review. *Implementation Science.* 2018;13(1):98.
2. Merner B, Hill S, Colombo C, et al. Consumers and health providers working in partnership for the promotion of person-centred health services: a co-produced qualitative evidence synthesis. *Cochrane Database of Systematic Reviews.* 2019(2).
3. Wolfe JA, Niederhauser V, Marshburn D, LaVela S. Defining patient experience. *Patient Experience Journal.* 2014;1(1).
4. (ACSQHC) ACoSaQihC. Partnering with consumers standard. https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard. Published 2019. Accessed 28 August 2021.
5. Wade DT. What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clinical Rehabilitation.* 2020;34(5):571-583.
6. Rehabilitation in health systems. In: Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.
7. Luxford K, Piper D, Dunbar N, Poole N. *Patient-centred care: Improving quality and safety by focusing care on patients and consumers.* 2010.
8. Oakman J, Cahill LS, Clune S, et al. Effectiveness of health consumer representative involvement in implementation of interventions to change health professional behaviour. *International Journal for Quality in Health Care.* 2020;33(1).
9. A Guide to Build Co-design Capability. In: 2019: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0013/502240/Guide-Build-Codesign-Capability.pdf.

1-9-21

10. Lim S, Morris H, Pizzirani B, Kajewski D, Lee WK, Skouteris H. Evaluating hospital tools and services that were co-produced with patients: A rapid review. *Int J Qual Health Care.* 2020;32(4):231-239.

11. Wolstenholme D, Grindell C, Dearden A. A co-design approach to service improvement resulted in teams exhibiting characteristics that support innovation. *Design for health (Abingdon, England).* 2017;1(1):42-58.

12. Pelton L, Knihtila M. Experience-Based Co-Design of Health Care Services - Implementation Guide. Institute for Healthcare Improvement. http://www.ihi.org/. Published 2018. Accessed. 29 August 2021.

13. Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview of reviews. *Health Research Policy and Systems.* 2020;18(1):17.

14. Clarke D, Jones F, Harris R, Robert G. What outcomes are associated with developing and implementing co-produced interventions in acute healthcare settings? A rapid evidence synthesis. *BMJ Open.* 2017;7(7):e014650.

15. Stevens A, Garritty C, Hersi M, Moher D. Developing PRISMA-RR, a reporting guideline for rapid reviews of primary studies (Protocol). 2018.

16. Higgins J, Green S, Cochrane C, Wiley I, NetLibrary I. *Cochrane handbook for systematic reviews of interventions.* Chichester, England; Hoboken, NJ: Wiley-Blackwell; 2008.

17. Garritty C, Gartlehner G, Nussbaumer-Streit B, et al. Cochrane Rapid Reviews Methods Group offers evidence-informed guidance to conduct rapid reviews. *J Clin Epidemiol.* 2021;130:13-22.

18. Garritty C, Gartlehner G, Kamel C, et al. Cochrane Rapid Reviews. Interim Guidance from the Cochrane Rapid Reviews Methods Group. In: March 2020: https://methods.cochrane.org/rapidreviews/sites/methods.cochrane.org.rapidreviews/files/public/uploads/cochrane_rr_-_guidance-23mar2020-final.pdf.

1-9-21

19. Moons P, Goossens E, Thompson DR. Rapid reviews: the pros and cons of an accelerated review process. *European Journal of Cardiovascular Nursing.* 2021;20(5):515-519.

20. Moher D, Shamseer L, Clarke M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews.* 2015;4(1):1.

21. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ.* 2021;372:n71.

22. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol.* 2012;12(1):181-181.

23. Endnote reference management software, Clarivate Analytics. www.endnote.com. Accessed. 29 August 2021.

24. Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia. www.covidence.org. Accessed.

25. Sterne JAC, Hernán MA, Reeves BC, et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. *BMJ.* 2016;355:i4919.

26. Aromataris E, Munn Z (Editors). JBI Manual for Evidence Synthesis. In: *JBI.*2020: https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-01.

27. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc.* 2015;13(3):179-187.

28. Higgins J, Savović J, Page M, Elbers R, Sterne J. Chapter 8: Assessing risk of bias in a randomized trial. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). In: Cochrane Handbook for Systematic Reviews of Interventions version 6.2 (updated February 2021). Cochrane, 2021.

1-9-21

29. Campbell M, McKenzie JE, Sowden A, et al. Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. *BMJ.* 2020;368:l6890.

30. Noyes J, Booth A, Cargo M, et al. Chapter 21: Qualitative evidence. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). Cochrane Handbook for Systematic Reviews of Interventions version 6.2 (updated February 2021). Cochrane, 2021. In.

31. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol.* 2008;8(1):45-45.

32. Guyatt G, Oxman AD, Akl EA, et al. GRADE guidelines: 1. Introduction—GRADE evidence profiles and summary of findings tables. *J Clin Epidemiol.* 2011;64(4):383-394.

33. Lewin S, Booth A, Glenton C, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. *Implementation Science.* 2018;13(1):2.

Appendix 1: Search Strategy:

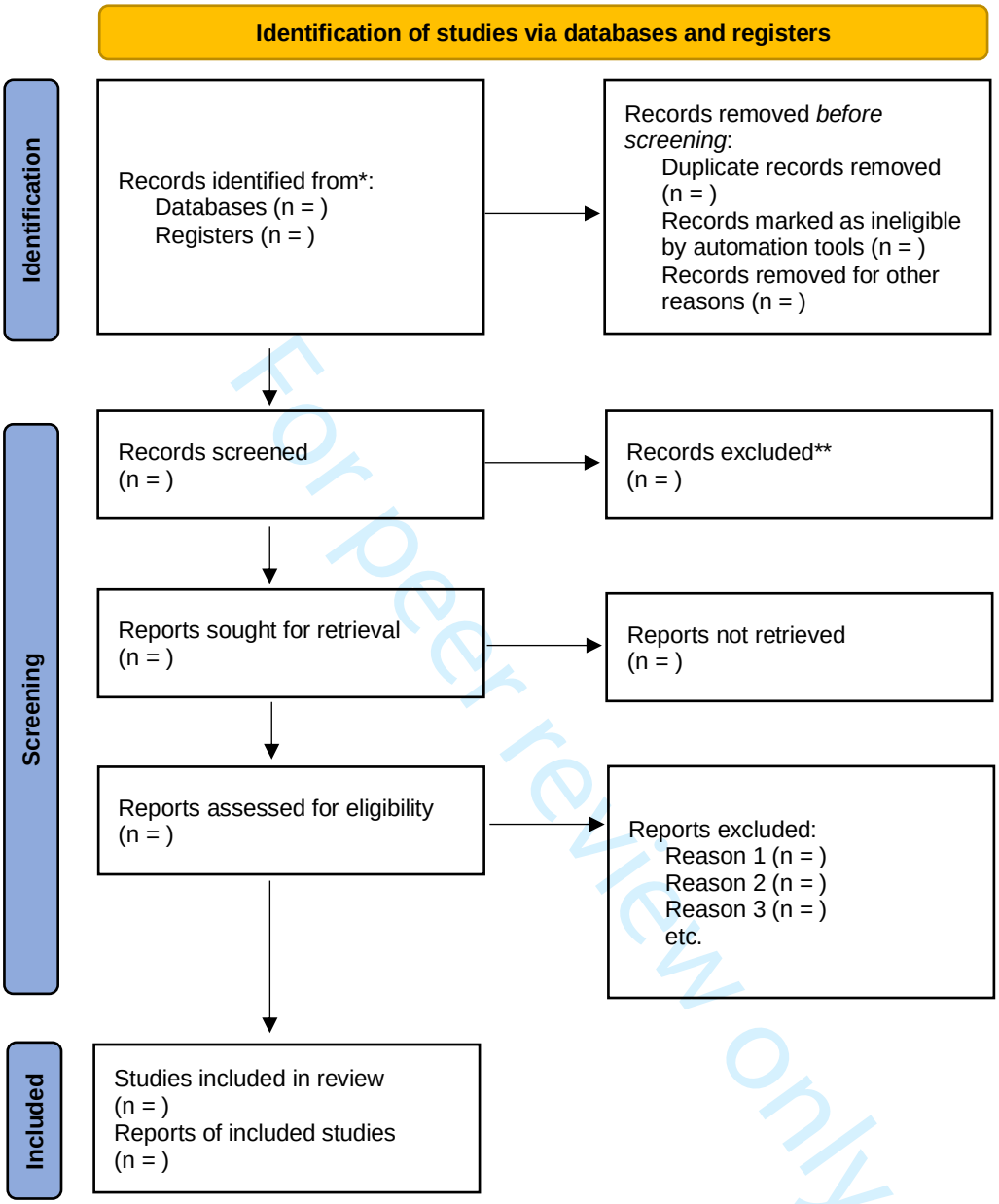
Database(s): **Ovid MEDLINE(R) ALL** 1946 to June 2021

Search ID#	Search Terms	Search Notes	Results
1	(co-design* or codesign*).mp.		1614
2	(co-produc* or coproduc*).mp.		5418
3	(codevise* or cocreate* or co-create* or co-invent* or cogenerate* or co-found*).mp.		914
4	participatory design*.mp.		623
5	collaborative design*.mp.		138
6	("Experience based" adj2 design*).mp.		99
7	Decision Making, Shared/		1005
8	(share* adj2 "decision making").mp.		10869
9	or/1-8		19259
10	patient engagement.mp.		3550
11	patient involvement.mp.		2896
12	patient consultation.mp.		560
13	Patient Participation/		27250
14	patient participation.mp.		29017
15	patient input*.mp.		419
16	Stakeholder Participation/		1578
17	stakeholder participation.mp.		1906
18	consumer engagement.mp.		253
19	consumer involvement.mp.		357
20	consumer participation.mp.		414
21	consumer input.mp.		99
22	or/10-21		36540
23	design*.mp.		2282168
24	22 and 23	more general co-design terms AND "design"	7842
25	9 or 24	Co-design terms	26095
26	exp Hospitals/		287515
27	hospital*.tw.		1381782
28	Critical Care/		55257

29	Inpatients/		24172
30	inpatient*.mp.		128467
31	Hospitalization/		117596
32	hospitali?ation.mp.		234243
33	exp Hospital Units/		119558
34	ward*.tw,kw.		64380
35	((acute or subacute or sub-acute) adj3 (clinic* or care or department* or unit* or centre* or center*)).mp.		60190
36	Subacute Care/		1211
37	or/26-36	Hospital terms	1722776
38	(patient* adj2 (experience* or perception* or belief* or believe* or participat*)).mp.		170925
39	(consumer* adj2 (experience* or perception* or belief* or believe* or participat*)).mp.		2655
40	lived experience*.mp.		7501
41	38 or 39 or 40	Outcomes terms	180025
42	25 and 37 and 41		1790
43	limit 42 to (english language and yr="2000 -Current")		1592

NOTE: [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

Appendix 2: PRISMA flow Diagram:



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

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- Risk of bias can sometimes be introduced by rapid methods and will be controlled for by *a priori* recommended methods and transparent reporting of the results.

INTRODUCTION

Patient-centred care is integral to the delivery of high-quality healthcare and positive patient experiences.[1] Facilitating patient participation across health service ecosystems is key for safe and effective patient-centred care.[2] Wolfe et al. (2014) defined patient experiences as "…the sum of all interactions, shaped by the organisation's culture, that influence patient perceptions, across the continuum of care."[3] Consumer participation is the gold-standard for person-centred care, and can include co-design.[4] Co-design refers to collaboration between stakeholders such as patients, healthcare professionals, carers, or families to design and implement therapies and services in partnership.[5] Rehabilitation interventions are considered to be co-designed if a patient has participated in planning, design, or delivery, including the re-design of interventions to meet individual needs and preferences.

Rehabilitation is a person-centred approach that tailors interventions to the individual and their goals, and involves an interdisciplinary team.[6] Movement rehabilitation interventions can be designed to improve mobility and independence, minimise pain, and to improve a person's ability to adapt to changes in circumstances.[6] Movement rehabilitation also aims to optimise movement, strength, function, upper limb control, balance and to facilitate timely discharge.[7] Various methods can be used to improve patient experiences of movement rehabilitation.[8] One approach is co-design, which refers to collaboration between healthcare professionals and consumers to design and implement therapies and services.[5] Rehabilitation designed in partnership with patients is more likely to meet their needs and preferences.[9] The National Institute for Health Research (NIHR) and other agencies across the globe have advocated co-design.[9-12]

Previous reviews of co-design in healthcare have centred around consumer needs;[1, 5, 10, 13, 14]

implementing co-designed interventions to influence health professional behaviours;[5] evaluation of how co-design facilitates clinical and service outcomes in acute healthcare settings;[14] and outcomes for different co-designed hospitals tools, therapies and services.[10] A new area of research has been the use of co-design of mobile health (mHealth) interventions, also known as digital health.[15] For example, one trial showed that a co-designed mHealth system supported stroke rehabilitation by improving communication of health advice and patient engagement.[16] A systematic literature review by Noorbergen et al. [15] showed that co-designed strategies were of benefit to some rehabilitation patients. The literature emphasises early co-design and there is a paucity of research on the post-design phase.[15] A focus on post-design implementation may elucidate how users experience the product, service, or therapy environment.[17]

The primary aim of this review is to explore patient experiences of co-designed interventions in rehabilitation hospitals. Secondary aims will be to understand (i) the methods used to co-design rehabilitation interventions; (ii) the ways in which co-designed rehabilitation interventions are implemented; and (iii) the barriers and facilitators to implementing co-designed rehabilitation therapies. Our analysis will clarify patient experiences during both the co-design and implementation phases of rehabilitation.

METHODS AND ANALYSIS

Systematic reviews provide high-quality evidence syntheses to enable appraisal of policies and clinical practice.[18, 19] A rapid review is an evidence synthesis that provides information to decision makers in a timely manner, allowing for rapid communication of research findings to end-users.[20] Components of a standard systematic review are streamlined in a rapid review, to enable fast completion and dissemination.[21] Rapid reviews are particularly

valuable when stakeholders have a short deadline for evidence and advice.[19, 20] It is noteworthy that rapid reviews are rigorous and are not less systematic than standard systematic reviews.[22] The Cochrane Rapid Review Methods Group gives recommendations on the methodology supporting rapid reviews. [20, 21] These include a reduced number of reviewers for screening, streamlining data extraction, and method quality appraisal processes, and restricting the inclusion criteria to a defined date range.[20] They also recommend limiting the number of databases searched and minimising grey literature and supplemental searching.[21]

The current protocol has been published on the international prospective register of systematic reviews (PROSPERO: CRD42021264547) for registration, in compliance with the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) recommendations.[23] In the absence of a published reporting guideline for rapid reviews,[18] the protocol will be informed by the PRISMA-P guidelines and the Cochrane Rapid Review methods.[21, 23] The review methods will also be guided by the Cochrane Rapid Review Methods Group best practice recommendations and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[21, 24] The Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) guideline will enable reporting of qualitative elements of the evidence synthesis. [25]

Patient and public involvement

This protocol has been co-designed and co-authored with two consumer representatives. Consumers offer an authentic lived-experience contribution, and the consumer representatives assisted in the conceptualisation of the protocol, the refinement of the research question, and the editing of the manuscript. The consumers will also provide input into the evidence synthesis and assist in writing the final manuscript for the rapid review.

Eligibility criteria

Studies are to be included when they meet the following criteria: published papers in journals or conference proceedings; inclusion of participants who are adults older than 18 years; conducted in a physical rehabilitation setting, such as neuro-rehabilitation, musculoskeletal rehabilitation or cardiorespiratory rehabilitation, acute, sub-acute or slow stream rehabilitation; include rehabilitation interventions that are co-designed with patients; report patient experiences of co-designed rehabilitation interventions; inpatient hospital settings; empirical study design reported in English. Any study design will be included, such as randomised controlled clinical trials (RCT), non-randomised trials, cohort studies, pilot studies, feasibility analyses, single case designs, surveys, and qualitative investigations.

Publications will be excluded if they pertain to drug, alcohol, vocational or psychiatric rehabilitation; relate to rehabilitation in the home or outpatient settings; are protocols, book chapters, theses, editorials, conference abstracts without an accompanying paper; are solely on paediatric or maternity participants; or if they are on patient groups that require a third party to participate in the co-design process (e.g., individuals with severe cognitive impairment, dementia or delirium or those in intensive care).

Identification and selection of included papers

A health services librarian will develop the search strategies and run the electronic database searches. Four online databases (Cochrane CENTRAL, MEDLINE, Embase, and CINAHL) will be searched for papers published from 1 January 2000 to 1 January 2022. Search terms for the following key concepts will be used: co-design; rehabilitation interventions; consumers and patients; patient experience; hospitals and acute health care settings. A draft example of the search strategy is given in Supplementary File 1.

The search results will be downloaded to EndNote X9.3.1.[26] The combined yield will be uploaded into Covidence® to sort and select the studies against the eligibility criteria.[27] Initially the duplicates will be deleted in Covidence then titles alone will be screened for eligibility. The remaining titles with abstracts will then be screened in Covidence. At least one quarter of the titles with abstracts will be screened by two reviewers through applying the eligibility criteria.[20] The remaining titles with abstracts will be screened by one reviewer. After reaching consensus on the yield, the full texts will be obtained for the remaining abstracts. The full texts will be saved in Covidence, read in full by at least one reviewer and screened using the eligibility criteria. A second reviewer will screen the excluded abstracts and full text studies and the two reviewers will meet to reach consensus.[20] Reasons for exclusions will be noted. Any discrepancies or disagreements that arise during this process will be resolved by consultation and consensus with a third author. A PRISMA-compliant flow chart (Supplementary File 2) will record the selection process for the included studies.

Method quality assessment

Summary tables will document key elements for each investigation, such as the setting, co-design strategy, co-designed interventions and evaluation. The Cochrane Risk of Bias tool will be used to appraise the method quality for the RCTs.[28] For the non-randomised trials, checklists from The Joanna Briggs Institute (JBI) critical appraisal tools will be completed to assess method quality and the risk of bias, matched to different quantitative or qualitative designs.[29, 30] This includes for survey and interview data, which will be summarised, tabulated and analysed for themes.

Two reviewers will assess the included studies using the Cochrane Risk of Bias tool or relevant JBI critical appraisal checklist to independently assess the trustworthiness of the

included studies.[28, 29] The checklists include a series of questions which will help the reviewers to determine the risk of bias and the trustworthiness of the results. Each checklist has a comprehensive guide for each item.[29, 31]

Data extraction and management

Two reviewers will independently extract the data into spreadsheets using headings such as: study design, country, first author, year, setting, sample size, participant characteristics, intervention characteristics (content, who delivered, dosage etc.), co-design strategies used, description of co-design implementation, primary and secondary outcome measures such as patient experience and effects of co-production, outcome data and results, themes, co-design barriers, and co-design facilitators. The data extraction spreadsheets will be evaluated for consistency and any disagreements will be discussed and agreed upon. The spreadsheets will then be combined for the data synthesis stage.

Data analysis/synthesis

Data analysis will be independently completed by two reviewers. The quantitative data will be reported according to the Synthesis without Meta-Analysis (SWiM).[32] Two reviewers will independently summarise and interpret the reported results for the included studies. A textual description will be provided for each study to give details on the setting, participants, intervention, and findings such as effect sizes or mean changes.[29]

For the qualitative data, a thematic synthesis will be used within a theoretical framework of meta-synthesis and an analytical framework of thematic analysis.[33] The three stages of thematic synthesis recommended by Harden and Thomas (2008) will be used for combined analysis of the primary studies.[34] This includes coding the findings of the included studies

and developing descriptive themes for the combined coding; identifying relationships between the descriptive themes; and generating analytical themes which transcend the content of each original study.[34] This synthesis approach is supported by the Cochrane Qualitative and Implementation Methods Group recommendations. They advise descriptive themes often inform policy and analytical themes inform theory. Two reviewers will independently read the included studies to code and extract the themes reported by the authors of each paper. The reviewers will then group themes according to their similarities, forming representative themes. From the consolidated themes, analytical themes will be developed independently by each reviewer and finalised by consensus.[34] Summary tables will be used for the qualitative findings. Discrepancies between the two reviewers will be resolved by a third author.

Confidence in cumulative evidence

PRIMSA-P recommends that the overall strength of included studies be assessed.[23] For randomised controlled clinical trials and observational studies, the Grading of Recommendations Assessment, Development and Evaluation (GRADE) framework will be utilised.[35] This provides a quality of evidence rating system for each review outcome. The results will be displayed in a table summarising the findings.[35]

Where the included studies are of a qualitative design, the strength of the findings will be measured using the GRADE-CERQual (Confidence in Evidence from Reviews of Qualitative Research).[36] The GRADE-CERQual is a framework for reviewers to assess the amount of confidence they can have in the review results from qualitative syntheses.[36] Two reviewers (JPM, SCS) will independently perform a GRADE-CERQual assessment of the findings of each review.

RESULTS

The quantitative results will be presented as statistical analyses, summary tables, flow charts, and narrative summaries. The qualitative results will be presented as themes and subthemes and summary tables linked to the data.

DISCUSSION

The rationale and design of a rapid review of patient experiences of co-design of rehabilitations interventions has been described. The review will identify important factors in co-production and inform optimum intervention design for movement rehabilitation.

ETHICS AND DISSEMINATION

Ethics approval will not be required for the protocol and rapid review. The protocol and accompanying review will be submitted to an international peer-reviewed journal for publication. The evidence will be rapidly translated to the research community, policy makers, consumers, health professionals and healthcare organisations using a range of implementation science methods.[37, 38] We shall hold a series of consumer workshops online and face-to-face, to share the results with end users. A series of digital health seminars will be conducted on the results using the Academic and Research Collaborative in Health (ARCH) online platform. The findings will also be presented at workshops and conferences and disseminated to health professionals at in professional development seminars. An evidence summary will be posted online via social media, and on websites, to ensure that the findings have wide reach.

Acknowledgements

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Author Contribution

JPM, SCS, JJ, and MEM contributed to the concept and design of the study, research question and acquisition of data and resources. JPM, SCS, JJ, AH, MK, JG, JW and MEM contributed to the planning, conduct and reporting of the work in this paper. JPM wrote the first draft of the protocol manuscript. All authors contributed to the subsequent drafts of the manuscript. The final draft was edited and approved by all authors prior to submission (JPM, SCS, JJ, AH, MK, JG, JW and MEM).

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Competing interests: None declared

Data statement: Data sharing is not applicable as no participant datasets will be generated and/or analysed for this study.

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REFERENCE LIST

1. Bombard Y, Baker GR, Orlando E, et al. Engaging patients to improve quality of care: a systematic review. Implementation Science. 2018;13(1):98.
2. Merner B, Hill S, Colombo C, et al. Consumers and health providers working in partnership for the promotion of person-centred health services: a co-produced qualitative evidence synthesis. Cochrane Database of Systematic Reviews. 2019(2).
3. Wolfe JA, Niederhauser V, Marshburn D, et al. Defining Patient Experience. Patient Experience Journal. 2014;1(1).
4. ACSQHC. Partnering with consumers standard. 2019 Available from: https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard.
5. Oakman J, Cahill LS, Clune S, et al. Effectiveness of health consumer representative involvement in implementation of interventions to change health professional behaviour. International Journal for Quality in Health Care. 2020;33(1).
6. Wade DT. What is rehabilitation? An empirical investigation leading to an evidence-based description. Clinical Rehabilitation. 2020;34(5):571-83.
7. Rehabilitation in health systems. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.
8. Luxford K, Piper D, Dunbar N, et al. Patient-centred care: Improving quality and safety by focusing care on patients and consumers. 2010.
9. https://aci.health.nsw.gov.au/__data/assets/pdf_file/0013/502240/Guide-Build-Codesign-Capability.pdf.
10. Lim S, Morris H, Pizzirani B, et al. Evaluating hospital tools and services that were co-produced with patients: A rapid review. Int J Qual Health Care. 2020;32(4):231-9.

11. Wolstenholme D, Grindell C, Dearden A. A co-design approach to service improvement resulted in teams exhibiting characteristics that support innovation. Design for health (Abingdon, England). 2017;1(1):42-58.

12. Pelton L, Knihtila M. Experience-Based Co-Design of Health Care Services Implementation Guide. Boston, Massachusetts: Institute for Healthcare Improvement; 2018 Available from: http://www.ihi.org/.

13. Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview of reviews. Health Research Policy and Systems. 2020;18(1):17.

14. Clarke D, Jones F, Harris R, et al. What outcomes are associated with developing and implementing co-produced interventions in acute healthcare settings? A rapid evidence synthesis. BMJ Open. 2017;7(7):e014650.

15. Noorbergen TJ, Adam MTP, Roxburgh M, et al. Co-design in mHealth Systems Development: Insights from a systematic literature review. Association for Information Systems transactions on human-computer interaction. 2021;13(2):175-205.

16. Aljaroodi HM, Adam M, Chiong R, et al. Empathic Avatars in Stroke Rehabilitation: A Co-designed mHealth Artifact for Stroke Survivors2017. 73-89 p.

17. Sanders EBN, Stappers PJ. Probes, toolkits and prototypes: three approaches to making in codesigning. CoDesign. 2014;10(1):5-14.

18. Stevens A, Garritty C, Hersi M, et al. Developing PRISMA-RR, a reporting guideline for rapid reviews of primary studies (Protocol). 2018.

19. Higgins J, Green S, Cochrane C, et al. Cochrane handbook for systematic reviews of interventions. Chichester, England; Hoboken, NJ: Wiley-Blackwell; 2008.

20. Garritty C, Gartlehner G, Nussbaumer-Streit B, et al. Cochrane Rapid Reviews Methods Group offers evidence-informed guidance to conduct rapid reviews. J Clin Epidemiol. 2021;130:13-22.

21. Garritty C, Gartlehner G, Kamel C, et al. Cochrane Rapid Reviews. Interim Guidance from the Cochrane Rapid Reviews Methods Group March 2020. Available from: https://methods.cochrane.org/rapidreviews/sites/methods.cochrane.org.rapidreviews/files/public/uploads/cochrane_rr_-_guidance-23mar2020-final.pdf.

22. Moons P, Goossens E, Thompson DR. Rapid reviews: the pros and cons of an accelerated review process. European Journal of Cardiovascular Nursing. 2021;20(5):515-9.

23. Moher D, Shamseer L, Clarke M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. Systematic Reviews. 2015;4(1):1.

24. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021;372:n71.

25. Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Med Res Methodol. 2012;12(1):181-.

26. Endnote reference management software, Clarivate Analytics [Available from: www.endnote.com.

27. Covidence systematic review software. Available from: www.covidence.org.

28. Sterne JAC, Hernán MA, Reeves BC, et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. BMJ. 2016;355:i4919.

29. Aromataris E, Munn Z (Editors). JBI Manual for Evidence Synthesis 2020. Available from: https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-01.

30. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. Int J Evid Based Healthc. 2015;13(3):179-87.

31. Higgins J, Savović J, Page M, et al. Chapter 8: Assessing risk of bias in a randomized trial. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA

(editors). Cochrane Handbook for Systematic Reviews of Interventions version 6.2 (updated February 2021). Cochrane, 2021. Available from: www.training.cochrane.org/handbook.

32. Campbell M, McKenzie JE, Sowden A, et al. Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. BMJ. 2020;368:l6890.

33. Noyes J, Booth A, Cargo M, et al. Chapter 21: Qualitative evidence. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). Cochrane Handbook for Systematic Reviews of Interventions version 6.2 (updated February 2021). Cochrane, 2021.

34. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol. 2008;8(1):45-.

35. Guyatt G, Oxman AD, Akl EA, et al. GRADE guidelines. J Clin Epidemiol. 2011;64(4):383-94.

36. Lewin S, Booth A, Glenton C, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. Implementation Science. 2018;13(1):2.

37. Greenhalgh T, Papoutsi C. Spreading and scaling up innovation and improvement. BMJ. 2019;365:l2068.

38. Sarkies MN, Robins LM, Jepson M, et al. Effectiveness of knowledge brokering and recommendation dissemination for influencing healthcare resource allocation decisions: A cluster randomised controlled implementation trial. PLOS Medicine. 2021;18(10):e1003833.

Draft of Medline Search Strategy

(with example interim results)

Database(s): **Ovid MEDLINE(R) ALL**

Search ID#	Search Terms	Search Notes	Results
1	(co-design* or codesign*).mp.		1614
2	(co-produc* or coproduc*).mp.		5418
3	(codevise* or cocreate* or co-create* or co-invent* or cogenerate* or co-found*).mp.		914
4	participatory design*.mp.		623
5	collaborative design*.mp.		138
6	("Experience based" adj2 design*).mp.		99
7	Decision Making, Shared/		1005
8	(share* adj2 "decision making").mp.		10869
9	or/1-8		19259
10	patient engagement.mp.		3550
11	patient involvement.mp.		2896
12	patient consultation.mp.		560
13	Patient Participation/		27250
14	patient participation.mp.		29017
15	patient input*.mp.		419
16	Stakeholder Participation/		1578
17	stakeholder participation.mp.		1906
18	consumer engagement.mp.		253
19	consumer involvement.mp.		357
20	consumer participation.mp.		414
21	consumer input.mp.		99
22	or/10-21		36540
23	design*.mp.		2282168
24	22 and 23	more general co-design terms AND "design"	7842
25	9 or 24	Co-design terms	26095
26	exp Hospitals/		287515
27	hospital*.tw.		1381782

28	Critical Care/		55257
29	Inpatients/		24172
30	inpatient*.mp.		128467
31	Hospitalization/		117596
32	hospitali?ation.mp.		234243
33	exp Hospital Units/		119558
34	ward*.tw,kw.		64380
35	((acute or subacute or sub-acute) adj3 (clinic* or care or department* or unit* or centre* or center*)).mp.		60190
36	Subacute Care/		1211
37	or/26-36	Hospital terms	1722776
38	(patient* adj2 (experience* or perception* or belief* or believe* or participat*)).mp.		170925
39	(consumer* adj2 (experience* or perception* or belief* or believe* or participat*)).mp.		2655
40	lived experience*.mp.		7501
41	38 or 39 or 40	Outcomes terms	180025
42	25 and 37 and 41		1790
43	limit 42 to (english language and yr="2000 -Current")		1592

NOTE: [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

Draft of Embase Search Strategy

(with example interim results)

Database(s): **Embase Classic+Embase**

Search ID#	Search Terms	Search Notes	Results
1	(co-design* or codesign*).mp.		2011
2	(co-produc* or coproduc*).mp.		6311
3	(codevise* or cocreate* or co-create* or co-invent* or cogenerate* or co-found*).mp.		1316
4	participatory design*.mp.		658
5	collaborative design*.mp.		185
6	("Experience based" adj2 design*).mp.		156
7	shared decision making/		9161
8	(share* adj2 "decision making").mp.		17648
9	or/1-8		27744
10	patient engagement.mp.		5154
11	patient involvement.mp.		4006
12	patient consultation.mp.		905
13	patient participation/		29537
14	patient participation.mp.		31308
15	patient input*.mp.		882
16	stakeholder engagement/		3763
17	stakeholder participation.mp.		424
18	consumer engagement.mp.		377
19	consumer involvement.mp.		521
20	consumer participation.mp.		674
21	consumer input.mp.		158
22	or/10-21		43839
23	design*.mp.		2618705
24	22 and 23		8921
25	9 or 24		35753
26	exp hospital/		1309237
27	hospital*.tw.		2200888
28	intensive care/		131889
29	hospital patient/		194627

30	inpatient*.mp.		201483
31	hospitalization/		424891
32	hospitali?ation.mp.		527240
33	exp "hospital subdivisions and components"/		631311
34	ward*.tw,kw.		104585
35	((acute or subacute or sub-acute) adj3 (clinic* or care or department* or unit* or centre* or center*)).mp.		90253
36	subacute care/		1177
37	or/26-36		3091932
38	(patient* adj2 (experience* or perception* or belief* or believe* or participat*)).mp.		265842
39	(consumer* adj2 (experience* or perception* or belief* or believe* or participat*)).mp.		3293
40	lived experience*.mp.		9078
41	38 or 39 or 40		276832
42	25 and 37 and 41		2366
43	limit 42 to (english language and yr="2000 -Current")		2255

NOTE: [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

Draft of CINAHL Search Strategy

(with example interim results)

Search ID#	Search Terms	Search Notes	Results
S1	co-design* or codesign*		948
S2	co-produc* or coproduc*		1,084
S3	codevise* or cocreate* or co-create* or co-invent* or cogenerate* or co-found*		1,026
S4	"participatory design*"		330
S5	"collaborative design*"		81
S6	"Experience based" N2 design*		79
S7	(MH "Decision Making, Shared")		2,159
S8	share* N2 "decision making"		7,201
S9	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8		10,509
S10	"patient engagement"		2,133
S11	"patient involvement"		1,602
S12	"patient consultation"		217
S13	"patient participation"		1,532
S14	"patient input*"		199
S15	(MH "Stakeholder Participation")		1,435
S16	"stakeholder participation"		1,527
S17	"consumer engagement"		208
S18	"consumer involvement"		228
S19	(MH "Consumer Participation")		21,333
S20	"consumer participation"		21,416
S21	"consumer input"		72
S22	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21		26,691
S23	design*		871,880
S24	S22 AND S23		5,274
S25	S9 OR S24		15,237
S26	(MH "Hospitals+")		122,030

S27	TI hospital* OR AB hospital*		484,543
S28	(MH "Critical Care")		24,037
S29	(MH "Inpatients")		84,408
S30	inpatient*		123,011
S31	(MH "Hospitalization")		39,453
S32	hospitalization or hospitalisation		83,875
S33	(MH "Hospital Units+")		101,055
S34	TI ward* OR AB ward*		29,373
S35	(acute or subacute or sub-acute) N3 (clinic* or care or department* or unit* or centre* or center*)		41,004
S36	(MH "Subacute Care")		1,780
S37	S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36		710,289
S38	patient* N2 (experience* or perception* or belief* or believe* or participat*)		72,462
S39	consumer* N2 (experience* or perception* or belief* or believe* or participat*)		22,773
S40	"lived experience"		5,252
S41	S38 OR S39 OR S40		97,797
S42	S25 AND S37 AND S41		1,177
S43	S25 AND S37 AND S41	Limiters - English Language; Published Date: 20000101-20211231	1,107

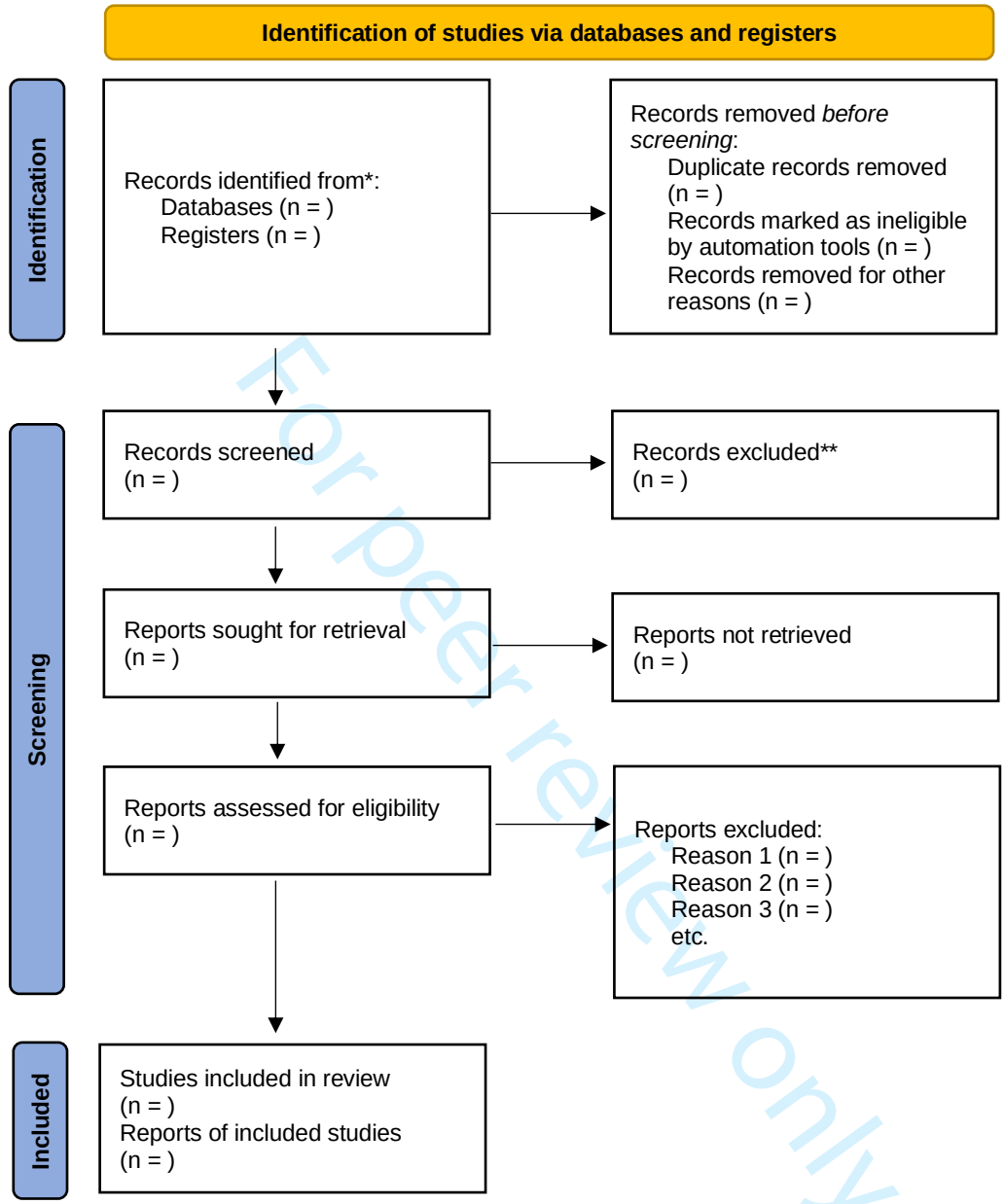
Draft of Cochrane Search Strategy

(with example interim results)

Search ID#	Search Terms	Search Notes	Results
#1	co-design* OR codesign*		194
#2	co-produc* or coproduc*		120
#3	codevise* or cocreate* or co-create* or co-invent* or cogenerate* or co-found*		119
#4	participatory NEXT design*		47
#5	collaborative NEXT design*		12
#6	Experience based NEAR/2 design		12
#7	MeSH descriptor: [Decision Making, Shared] this term only		36
#8	share* NEAR/2 "decision making"		1657
#9	{OR #1-#8}		2125
#10	patient engagement		587
#11	patient involvement		462
#12	patient consultation		142
#13	MeSH descriptor: [Patient Participation] this term only		1427
#14	patient participation		2979
#15	patient NEXT input*		56
#16	MeSH descriptor: [Stakeholder Participation] this term only		19
#17	stakeholder participation		31
#18	consumer engagement		26
#19	consumer involvement		75
#20	consumer participation		150
#21	consumer input		31
#22	{OR #10-#21}		4107
#23	design*		295537
#24	#22 AND #23		1718
#25	#9 OR #24		3634
#26	MeSH descriptor: [Hospitals] explode all trees		3713
#27	hospital*:ti,ab		170151
#28	MeSH descriptor: [Critical Care] this term only		1773
#29	MeSH descriptor: [Inpatients] this term only		987

#30	inpatient*		21072
#31	MeSH descriptor: [Hospitalization] this term only		5397
#32	hospitalization OR hospitalisation		44727
#33	MeSH descriptor: [Hospital Units] explode all trees		4254
#34	ward*:ti,ab,kw		13937
#35	(acute or subacute or sub-acute) NEAR/3 (clinic* or care or department* or unit* or centre* or center*)		8705
#36	MeSH descriptor: [Subacute Care] this term only		19
#37	{OR #26-#36}		199880
#38	patient* NEAR/2 (experience* or perception* or belief* or believe* or participat*)		32637
#39	consumer* NEAR/2 (experience* or perception* or belief* or believe* or participat*)		316
#40	lived NEXT experience*		237
#41	{OR #38-#40}		33076
#42	#25 AND #37 AND #41		499
		Central (Trials only)	378

Appendix 2: PRISMA flow Diagram:



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

PRISMA-P 2015 checklist: recommended items to address in a systematic review protocol

Section & topic	Item no:	Checklist item	Page & Line
ADMINISTRATIVE INFORMATION			
Title:			
Identification	1a	Identify the report as a protocol of a systematic review	Page 1, line 2
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	N/A
Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number	Page 3, line 4
Authors:			
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	Page 1, lines 8-11
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	Page 1, lines 4-5,
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	N/A
Support			
Sources	5a	Indicate sources of financial or other support for the review	Page 12, lines 18-19
Sponsor	5b	Provide name for the review funder and/or sponsor	Page 12, lines 18-19
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	Page 12, lines 18-19
INTRODUCTION			
Rationale	6	Describe the rationale for the review in the context of what is already known	Page 5, lines 2-13
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	Page 5, lines 15-20
METHODS			
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	Page 7, lines 4-19
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	Page 7 lines 23-24
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	Supplemental file 1
Study records:			
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	Page 8, lines 5-

			6. Page 9, line 11.
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)	Page 8, lines 5-18
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	Page 9, lines 11-18
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications	Page 7, lines 4-19
Outcomes & prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	Page 7, lines 8-9
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	Page 8, lines 22-25. Page 9, lines 1-8
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised	Page 9, lines 21-24
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I^2, Kendall's τ)	Page 9, lines 21-24
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	Page 9, lines 21-24
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	Page 10, lines 4-18
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	Page 10, lines 21-25. Page 11, lines 2-7
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)	Page 10, lines 21-25. Page 11, lines 2-7