



Review Article

Patient-reported outcome and experience measures in post-ECMO follow-up: a scoping review

Paulo Costa^{a,b,*}, Amélia Ferreira^{a,c}, Luís Sá^a^a Faculdade de Ciências de Enfermagem e da Saúde, Universidade Católica Portuguesa, Porto, Portugal^b ICU Department - ULS São João, Porto, Portugal^c ICU Department - ULS Matosinhos, Matosinhos, Portugal

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ABSTRACT

Objectives: To map the use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in adult follow-up after extracorporeal membrane oxygenation (ECMO), and to identify measurement gaps relevant to critical care nursing practice.

Methods: This scoping review was conducted in accordance with the Joanna Briggs Institute methodology and reported in accordance with the PRISMA-ScR guideline. MEDLINE/PubMed, Web of Science and CINAHL Complete were searched, supplemented by reference-list screening. Eligible studies included adults treated with ECMO or extracorporeal life support and assessed after ICU or hospital discharge. Quantitative, qualitative, and mixed-methods studies published between 2016 and 2026 in English or Portuguese were included. Data were charted on study characteristics, instruments, domains, follow-up timing, and measurement gaps. Critical Appraisal Skills Programme-informed appraisal supported interpretive weighting.

Results: The MEDLINE/PubMed, Web of Science, and CINAHL Complete searches retrieved 2357 records. After removal of 86 duplicates, 2271 records were screened. The final review included 32 studies. PROM-focused evidence predominated: 25 studies assessed health-related quality of life, physical or functional recovery, mental health, respiratory burden, disability, cognition, return to work, or social participation. No formal PREM instrument was identified. Seven primary studies provided PREM-like evidence, mainly through qualitative or mixed-methods exploration of survivor and family experience, communication, support needs, decision-making, care transition, and follow-up experience.

Conclusions: Post-ECMO follow-up literature measures patient-reported outcomes more consistently than patient-reported experiences. No formal PREM instrument was identified; however, qualitative and mixed-methods PREM-like evidence provides important insight into survivor and family experience.

Implications for Clinical Practice: Critical care follow-up after ECMO should integrate PROMs, PREMs, and family perspectives within structured person- and family-centred pathways.

Introduction

Extracorporeal membrane oxygenation (ECMO) is increasingly used as rescue support for patients with severe, potentially reversible respiratory or circulatory failure [1–3]. Improvements in ECMO technology, patient selection, and intensive care management have contributed to increased survival among critically ill patients who previously had limited treatment options. However, survival after ECMO should not be equated with recovery. In this review, survivorship refers to survival beyond the acute ECMO episode and critical illness, whereas recovery refers to the multidimensional process through which survivors regain,

adapt, or reconstruct physical, psychological, cognitive, functional, social, and occupational roles after discharge [4–9].

Post-ECMO recovery overlaps with broader post-ICU survivorship but also has specific features that justify focused attention. ECMO survivors may have experienced severe respiratory or circulatory failure, prolonged organ support, deep sedation, delirium, invasive cannulation, vascular or neurological complications, and complex rehabilitation needs. In addition, families are often deeply involved in decision-making, communication with clinicians, and post-discharge support, particularly when survivors have fragmented memories of the ICU and ECMO experience [7,10–14].

* Corresponding author at: Faculdade de Ciências de Enfermagem e da Saúde, Universidade Católica Portuguesa, Porto, Portugal.

E-mail address: s-pjrcosta@ucp.pt (P. Costa).

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Patient-reported outcome measures (PROMs) capture the patient's perspective on health status, symptoms, functioning, quality of life, disability, psychological burden, cognition, social participation, or return to work. Patient-reported experience measures (PREMs) capture how patients or families experience care processes, including communication, decision-making, preparation for discharge, continuity, support, and follow-up. Because validated ECMO-specific PREMs are rarely available, this review also uses the term PREM-like evidence to describe qualitative or mixed-methods evidence that addresses patient or family experience of care and recovery without using a formal PREM instrument [15–25].

For critical care nursing, integrating PROMs, PREMs, and PREM-like evidence into post-ECMO follow-up is directly connected to person- and family-centred care, continuity after ICU or hospital discharge, symptom surveillance, psychological support, patient education, family involvement, and coordination between critical care, rehabilitation, community services, and specialist follow-up clinics [24,26–32]. Critical care nurses are well positioned to identify unmet needs, monitor recovery, support self-management, facilitate communication, and advocate for care models that reflect outcomes and experiences that matter to survivors and families.

Existing studies have assessed a range of outcomes after ECMO, including health-related quality of life, physical function, psychological morbidity, respiratory symptoms, cognition, and return to work [1–3,6,8–10,12,16,17,19–23]. However, the extent to which these studies integrate formal PREMs, patient experience, family experience, and care transition remains unclear. Accordingly, this scoping review aimed to map the use of PROMs, PREMs, and PREM-like evidence in adult post-ECMO follow-up, identify the instruments and approaches used, and describe measurement gaps relevant to post-ECMO survivorship and critical care nursing practice.

Methods

Review design

This scoping review was conducted in accordance with the Joanna Briggs Institute methodology for scoping reviews and reported in accordance with the PRISMA-ScR guideline [33]. A scoping review design was selected because the evidence base is heterogeneous in terms of study design, ECMO modality or indication, follow-up timing, outcome instruments, and approaches to patient and family experience. The purpose was to map measurement approaches and identify domains that were represented, underrepresented, or absent in the literature, rather than to pool outcome effects.

An internal a priori protocol was developed to guide the review question, eligibility criteria, search strategy, study selection, data charting, and synthesis. The protocol was not registered or published, and this is acknowledged as a limitation.

Review questions

The primary question was: which PROMs and PREMs are used in the follow-up of adults treated with ECMO after ICU discharge? A secondary question was: which outcome and experience domains are represented, underrepresented, or absent in the post-ECMO follow-up literature? PROMs were defined as measures directly capturing the patient's perspective on health status, symptoms, functioning, quality of life, disability, psychological burden, cognition, or social participation. Formal PREMs were defined as standardised instruments designed to capture patient or family experience of care processes. PREM-like evidence was defined a priori as qualitative, mixed-methods, or survey-based evidence addressing experience-related domains such as communication, decision-making, discharge preparation, continuity, support needs, or follow-up experience without using a formal PREM instrument.

Population–concept–context framework

The review was structured according to the JBI Population–Concept–Context framework. The population comprised adults treated with ECMO or extracorporeal life support (ECLS), irrespective of modality or indication, including veno-venous ECMO, veno-arterial ECMO, and extracorporeal cardiopulmonary resuscitation. The concept was the use of PROMs, PREMs, or PREM-like evidence to assess outcomes or experiences after ECMO. The context was post-ECMO follow-up after ICU or hospital discharge, including outpatient, telephone, survey-based, rehabilitation, or qualitative follow-up contexts (Table 1).

Eligibility criteria

Eligible studies included adults treated with ECMO or ECLS and reporting post-discharge or follow-up data relevant to PROMs, PREMs, or PREM-like evidence. Studies involving family members or caregivers were eligible when they explored experience, support needs, decision-making, or transition after ECMO. Quantitative, qualitative, and mixed-methods studies were considered. Reviews, editorials, commentaries, paediatric-only studies, conference abstracts without sufficient outcome detail, and studies focused only on in-hospital mortality, technical management, complications, or physiological outcomes were excluded from the final mapping set. Studies published between 2016 and 2026 in English or Portuguese were considered. This timeframe was selected to capture contemporary ECMO survivorship evidence, reflecting recent developments in ECMO technology, patient selection, critical care survivorship practice, PROM/PREM reporting, and post-ICU follow-up models, while also capturing evidence before, during, and after the COVID-19 pandemic.

Search strategy and information sources

A structured search was conducted in MEDLINE/PubMed, Web of Science and CINAHL Complete, supplemented by manual screening of reference lists. The final search was updated in July 2026.

Search terms combined ECMO-related terms (extracorporeal membrane oxygenation ECMO ECLS extracorporeal life support) critical care and follow-up terms (ICU intensive care critical care discharge survivorship post-ICU follow-up recovery rehabilitation long-term) and PROM/PREM terms (patient-reported outcome PROM quality of life HRQoL patient-reported experience PREM patient experience family experience qualitative interview care transition transition of care continuity of care). Full database strategies are provided in Supplementary Appendix A

The search strategy was developed by the author team and refined using clinical ECMO and research expertise. It was not formally peer-reviewed by an information specialist or medical librarian.

Study selection

Records were exported to Microsoft Excel spreadsheets, deduplicated electronically, and manually checked. Titles and abstracts were screened

Table 1
Population–concept–context framework.

PCC element	Definition used in this review
Population	Adults treated with ECMO or ECLS, irrespective of modality or indication, including VV-ECMO, VA-ECMO, and ECPR contexts.
Concept	Use of PROMs, PREMs, or PREM-like evidence to assess outcomes or experiences after ECMO.
Context	Post-ECMO follow-up after ICU or hospital discharge, including outpatient, telephone, survey-based, rehabilitation, or qualitative follow-up contexts.

by PC and verified by AF. The verification process was not blinded and did not use an independent screening platform. Full texts were assessed for eligibility using the same criteria. Disagreements or uncertain cases were resolved through discussion between PC and AF and, when necessary, with LS until consensus was reached. Reasons for full-text exclusion were recorded by category, and the selection process was documented using a PRISMA flow diagram (Supplementary Tables – Appendix B).

Data extraction and charting

A structured charting form was developed to capture author, year, country, design, ECMO population and modality, sample size, follow-up timing, PROMs used, PREMs or PREM-like approaches, domains assessed, family involvement, main findings relevant to survivorship, and implications for follow-up and critical care nursing. Data charting was performed by PC using the structured charting form and reviewed by AF with access to PC's charting decisions. This process represented verification of charted data rather than blinded independent duplicate extraction. Uncertainties were resolved through discussion between PC and AF and, when necessary, with LS until consensus was reached.

PROM domains included health-related quality of life, physical function, disability, activities of daily living, respiratory symptoms, psychological morbidity, cognition, return to work, and social participation. PREM and PREM-like domains included survivor experience, family experience, communication, decision-making, care transition, discharge needs, follow-up needs, continuity of care, and perceived support.

Methodological appraisal

Critical Appraisal Skills Programme (CASP) informed appraisal was undertaken to support interpretive weighting rather than to exclude studies. Cohort studies were assessed using the CASP Cohort Study Checklist, qualitative studies using the CASP Qualitative Checklist, and cross-sectional or mixed-methods studies using CASP-informed criteria adapted to design characteristics. Each study was assigned an overall judgement of high, moderate-high, or moderate, considering clarity of aims, design appropriateness, recruitment, outcome measurement, confounding or reflexivity, follow-up completeness, analytical rigour, and relevance to the review question (Supplementary Tables – Appendix F).

Data synthesis

A descriptive and narrative synthesis was undertaken. Studies were grouped as quantitative PROM-focused studies, mixed-methods studies, formal PREM studies, or qualitative PREM-like studies, and then mapped across outcome and experience domains. Classification of individual studies as PROM-focused, formal PREM, or PREM-like evidence was performed during data charting by PC and reviewed by AF against the predefined operational definitions. AF reviewed the classification with access to PC's decisions. Uncertain classifications were discussed among the authors, including LS when required, until consensus was reached. Consistency was checked by comparing each study-level classification with the domain definitions and the study-by-study matrix. Domains were classified as represented when they appeared in multiple studies or were assessed through explicit instruments or qualitative themes; underrepresented when they appeared in few studies, inconsistently, or mainly through indirect evidence; and absent when no eligible study provided relevant data. These classifications were used for evidence mapping rather than quantitative grading.

Results

Search results and study selection

The database searches identified 2357 records. After removal of 86 duplicates, 2271 records were screened by title and abstract. Of these, 2214 records were excluded because they did not meet the eligibility criteria or were not relevant to post-ECMO PROM/PREM mapping. A total of 57 full-text reports were retrieved and assessed for eligibility. No reports were unavailable for retrieval. After full-text assessment, 25 reports were excluded. The principal exclusion categories were wrong population, wrong concept or absence of PROM, PREM, or PREM-like data, in-hospital or physiological outcomes only, wrong publication type, and insufficient outcome detail. The final review included 32 studies. The study selection process is summarised in the PRISMA flow diagram (Supplementary Tables – Appendix B).

Characteristics of included studies

The 32 included studies comprised 23 quantitative studies, 7 qualitative studies and 2 mixed-methods studies. Quantitative studies included prospective and retrospective cohort studies, cross-sectional surveys, registry-based follow-up studies, and longitudinal follow-up studies. Qualitative studies explored the lived experience of ECMO survivors and family members, including recovery, psychological burden, communication, decision-making, and post-discharge needs. Mixed-methods studies combined structured outcome assessment with qualitative or experiential data (Table 2).

Studies included adults treated with VV-ECMO, VA-ECMO, ECPR, or mixed ECMO/ECLS populations where modality-specific results were not always reported separately. Follow-up timing varied substantially, ranging from early post-discharge assessment to long-term follow-up at 1, 2, 3, 5 years or longer. A condensed overview of study characteristics is provided in Table 3, with detailed charting in Supplementary Tables – Appendix C.

PROM domains mapped

PROM-focused evidence predominated. Of the 32 included studies, 25 studies directly assessed at least one patient-reported outcome domain, including health-related quality of life, physical or functional recovery, mental health, respiratory symptoms, disability, cognition, return to work, or social participation.

The most frequently represented PROM domains were health-related quality of life and mental health; each identified in 20 studies. Health-related quality of life was assessed using instruments such as EuroQol

Table 2
Characteristics of included studies.

Characteristic	Number of studies	Comment
Quantitative studies	23	Prospective/retrospective cohorts, cross-sectional surveys, registry-based and longitudinal follow-up studies.
Mixed-methods studies	2	Combined structured outcomes with qualitative or experiential data.
Qualitative studies	7	Explored survivor and/or family experience, decision-making, recovery, support needs, and care transition.
PROM-focused evidence	25	Assessed at least one patient-reported outcome domain.
PREM-like evidence	7 primary studies; additional mixed/survey contributions	Mainly qualitative or mixed-methods exploration of patient/family experience; formal PREMs were rare.

Table 3
Domains of included studies.

Domain	Representation in included literature	Interpretation
Health-related quality of life	20 studies	Most consistently mapped PROM domain.
Mental health	20 studies	Commonly assessed through anxiety, depression, PTSD, or distress measures and qualitative accounts.
Physical/functional recovery	13 studies	Assessed through disability, mobility, activities of daily living, or functional status.
Return to work/social participation	12 studies	Used as an indicator of reintegration and longer-term recovery.
Cognition/memory	10 studies	Less frequent than HRQoL or mental health; included formal screening and qualitative accounts.
Respiratory burden/pulmonary functioning	7 studies	Relevant particularly for VV-ECMO/ARDS but inconsistently measured.
Patient/family experience and care transition	Underrepresented; mainly PREM-like evidence	Communication, decision-making, discharge preparation, continuity, family support, and follow-up needs require standardisation.

five-dimension questionnaire (EQ-5D), EuroQol visual analogue scale (EQ-VAS), 36-item Short Form Health Survey (SF-36), SF-36 version 2 (SF-36v2), St George's Respiratory Questionnaire (SGRQ), and the Minnesota Living with Heart Failure Questionnaire (MLHFQ).

Mental health was represented in 20 studies using instruments including the Hospital Anxiety and Depression Scale (HADS), Beck Depression Inventory-II (BDI-II), Patient Health Questionnaire-9 (PHQ-9), Impact of Event Scale-Revised (IES-R), Impact of Event Scale-6 (IES-6), and post-traumatic stress disorder symptom scales (Supplementary Tables – Appendix E – Table 4). Mental health outcomes were also prominent in qualitative studies, where survivors and families described fear, uncertainty, intrusive memories, emotional distress, and the psychological consequences of critical illness and ECMO (Supplementary Tables – Appendix E – Tables 7 and 8).

Physical function, disability, mobility, and activities of daily living were mapped in 13 studies (Supplementary Tables – Appendix E – Table 2). Measures included the modified Rankin Scale (mRS), World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0), Barthel Index, Instrumental Activities of Daily Living (IADL), and structured clinical or symptom-based assessments. Return to work, occupational role, and social participation were reported in 12 studies and were commonly used as indicators of social reintegration and longer-term functional recovery (Supplementary Tables – Appendix E – Table 6).

Cognitive outcomes and memory were mapped in 10 studies (Supplementary Tables – Appendix E – Table 5). Formal cognitive screening was less frequent than health-related quality of life (HRQoL) or mental health assessment and included tools such as the Montreal Cognitive Assessment (MoCA) and telephone-based cognitive assessment. Respiratory symptoms and pulmonary functioning were represented in 7 studies using dyspnoea scales, respiratory questionnaires, spirometry, lung function tests, and symptom review (Supplementary Tables – Appendix E – Table 3).

PREM and PREM-like domains mapped

No study used a formal or validated PREM instrument. Seven primary studies were classified as providing PREM-like evidence because they used qualitative or mixed-methods approaches to explore patient or

family experience without applying a formal PREM instrument. In addition, experience-related domains overlapped across the included studies; therefore, the domain counts reported below are not mutually exclusive, because the same study could contribute to more than one experience-related domain.

Patient experience and survivor PREM-like evidence were mapped in 9 studies (Supplementary Tables – Appendix E – Table 7). These studies explored how survivors experienced acute illness, ECMO treatment, ICU care, recovery, psychological distress, loss of independence, memory disturbance, uncertainty, and adaptation to a “new normal”. Family experience and caregiver PREM-like evidence were mapped in 5 studies (Supplementary Tables – Appendix E – Table 8), including emotional burden, uncertainty, communication needs, witnessing ECMO treatment, decision-making involvement, and responsibility for supporting recovery after discharge.

Care transition, discharge needs, follow-up needs, and decision-making were represented in 12 studies (Supplementary Tables – Appendix E – Table 9). This domain included preparation for discharge, continuity of care, coordination between hospital and community services, perceived gaps in follow-up, information needs, communication quality, decision support, and family involvement. These findings were not captured through formal PREM instruments but emerged repeatedly in qualitative and mixed-methods evidence.

Evidence gaps in post-ECMO follow-up measurement

The final domain mapping revealed a clear asymmetry between PROMs and experience-related evidence. The literature measured patient-reported outcomes more consistently than patient-reported experiences. Health-related quality of life and mental health were the most frequently assessed domains, whereas no formal PREM instrument was identified and family-centred experience measures were particularly underdeveloped (Supplementary Tables – Appendix D and E).

Several measurement gaps were identified. First, there was limited standardisation of instruments. Second, follow-up timing was highly variable, reducing comparability and limiting understanding of recovery trajectories. Third, cognitive outcomes, respiratory-specific burden, family experience, and care transition were less consistently measured than global HRQoL and psychological symptoms. Fourth, PREM-related domains were mostly captured through qualitative or mixed-methods studies rather than standardised instruments, limiting benchmarking and routine integration into clinical follow-up pathways.

Taken together, the findings indicate that post-ECMO follow-up research has developed a stronger measurement tradition around outcomes than around experience. This gap is important for critical care nursing because follow-up after ECMO requires attention not only to survival, function, and symptoms, but also to communication, continuity, family support, and the patient's experience of recovery.

Discussion

Principal findings

This scoping review mapped the use of PROMs, formal PREMs, and PREM-like evidence in post-ECMO follow-up. The main finding is that the literature is weighted towards patient-reported outcomes, particularly health-related quality of life, mental health, physical/functional recovery, respiratory burden, disability, cognition, return to work, and social participation. In contrast, no formal PREM instrument was identified, and patient-reported experience was more often represented through qualitative or mixed-methods evidence than through standardised experience instruments.

This imbalance is clinically important because recovery after ECMO is not only a question of functional status or symptom burden, but also of how patients and families experience communication, decision-making, discharge preparation, continuity of care, and follow-up support.

Predominance of PROMs over PREMs

The predominance of PROMs reflects the broader trajectory of critical care survivorship research, where post-ICU recovery has often been assessed through health-related quality of life, psychological morbidity, physical function, and return to work. In this review, structured measures such as EQ-5D, SF-36, HADS, SGRQ, WHODAS 2.0, MoCA, Barthel Index, and return-to-work assessments provided ways of identifying persistent burden after ECMO. These measures can support clinical follow-up, risk stratification, patient counselling, rehabilitation planning, and evaluation of survivorship services [34–40].

However, PROM use was not harmonised. Similar domains were assessed using different instruments, at different time points, and in different ECMO populations [41–46]. This limits comparability between studies and makes it difficult to define standardised outcome measurement in post-ECMO follow-up.

The fact that no formal PREM instrument was identified does not mean that experience-related evidence is absent. Qualitative and mixed-methods studies provided rich PREM-like evidence on survivor and family experience, including fear, uncertainty, fragmented memories, delirium-related recollections, emotional burden, family witnessing, decision-making pressure, communication needs, and the challenge of rebuilding life after ECMO. These studies reveal domains that formal PROMs do not fully capture and that future PREMs should address [5,7,27–29,42–46,49].

ECMO-specific relevance within broader critical care survivorship

The candidate domains identified in this review overlap with broader post-ICU survivorship domains, but post-ECMO follow-up requires specific application and interpretation. ECMO survivors may differ from general ICU survivors because of the severity and reversibility of the underlying respiratory or circulatory failure, ECMO modality or indication, cannulation-related complications, prolonged critical illness, rehabilitation needs, and specialist follow-up requirements. Family experience may also be particularly salient because relatives often participate in high-stakes treatment decisions and help reconstruct the survivor's ICU narrative.

The contribution of this review is therefore not to replace established post-ICU follow-up models, but to identify how PROMs, PREMs, and PREM-like evidence are currently used in the ECMO survivorship context and to identify candidate domains for future standardisation.

Implications for post-ECMO follow-up and critical care nursing

The findings suggest that post-ECMO follow-up should integrate both outcome and experience assessment. Candidate outcome domains for future standardisation include health-related quality of life, physical or functional recovery, mental health, cognitive status, and social participation or return to work. Respiratory symptoms and pulmonary function should also be considered, particularly in VV-ECMO and ARDS populations. Candidate experience domains include communication, preparation for discharge, continuity of care, family involvement, decision-making support, perceived usefulness of follow-up, and unmet needs after discharge.

These findings are highly relevant to critical care nursing. Critical care nurses are central to the patient and family journey across the ECMO trajectory: during critical illness, at ICU discharge, during ward transition, and in post-ICU or specialist follow-up services [47–50]. Experience-related domains such as communication, discharge preparation, family support, continuity, education, and perceived preparedness are closely linked to nursing practice. If these domains are not measured, they may remain invisible in service evaluation and quality improvement.

Limitations

This review has limitations. First, included studies were methodologically heterogeneous, which is appropriate for a scoping review but limits direct comparison and prevents quantitative synthesis. Second, follow-up timing varied substantially, which may influence the prevalence and severity of reported symptoms, disability, psychological burden, and experience-related needs. Third, no formal PREM instrument was identified; therefore, qualitative and mixed-methods studies were used as PREM-like evidence. This approach supports mapping of experience-related domains but prevents standardised comparison of experience across studies. Fourth, studies included mixed ECMO populations and clinical contexts, including VV-ECMO, VA-ECMO, ECPR, ARDS, COVID-19, cardiogenic shock, and broader ECLS. Fifth, CASP-informed appraisal supported interpretive weighting but was not used as an exclusion criterion, consistent with scoping review methodology. Sixth, the review focused on studies from 2016 to 2026 in English or Portuguese, which may have excluded relevant evidence outside these parameters. Seventh, although MEDLINE/PubMed, Web of Science, and CINAHL Complete were searched, Embase and other databases were not searched; this may have resulted in the omission of some relevant rehabilitation, biomedical, or conference-indexed literature. Eighth, the search strategy was not formally peer-reviewed by an information specialist or medical librarian. Finally, an internal a priori protocol guided the review, but the protocol was not registered or published.

Conclusion

This scoping review shows that post-ECMO follow-up literature measures patient-reported outcomes more consistently than patient-reported experiences. Health-related quality of life, mental health, physical function, disability, respiratory symptoms, cognition, and return to work are increasingly represented through PROMs, but instruments and follow-up timings remain heterogeneous.

No formal PREM instrument was identified in post-ECMO survivorship. Patient and family experience is captured mainly through qualitative or mixed-methods PREM-like evidence. This is an important gap because recovery after ECMO is shaped not only by symptoms and functional limitations, but also by communication, discharge preparation, continuity of care, family involvement, decision-making, and perceived support after ICU discharge.

Future post-ECMO follow-up should integrate outcome measurement, experience-related assessment, and family perspectives within structured person- and family-centred pathways. The candidate domains identified in this review may support future standardisation, clinical decision-making, and quality improvement in critical care nursing practice.

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CRediT authorship contribution statement

Paulo Costa: Writing – original draft, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Amélia Ferreira:** Writing – review & editing, Validation, Supervision, Project administration, Conceptualization. **Luís Sá:** Writing – review & editing, Validation, Supervision.

Ethics statement

This study is a review of published literature and did not involve human participants or identifiable data; ethics approval and consent were not required.

Ethics in publishing

1. Does your research involve experimentation on animals?: No.
2. Does your study include human subjects?: No.
3. Does your study include a clinical trial?: No.
4. Are all data shown in the figures and tables also shown in the text of the Results section and discussed in the Conclusions?: Yes.

Declaration of competing interest

The authors declare no competing interests.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.iccn.2026.104518>.

References

- [1] Peperstraete H, Vandewiele K, Wille E, Vandenbroucke B, Meuser A, Herck I, et al. Epidemiology, outcomes, and three-year quality of life in patients supported with VV-ECMO for critical COVID-19 infection. *Minerva Anesthesiol* 2025;91(11): 1041–54. <https://doi.org/10.23736/S0375-9393.25.19256-0>.
- [2] Turgeon J, Venkatamaran V, Englesakis M, Fan E. Long-term outcomes of patients supported with extracorporeal membrane oxygenation for acute respiratory distress syndrome: a systematic review and meta-analysis. *Intensive Care Med* 2024;50(3):350–70. <https://doi.org/10.1007/s00134-023-07301-7>.
- [3] Burrell A, Kim J, Alliegro P, Romero L, Serpa Neto A, Mariajoseph F, et al. Extracorporeal membrane oxygenation for critically ill adults. *Cochrane Database Syst Rev* 2023;2023(9):CD010381. <https://doi.org/10.1002/14651858.CD010381.pub3>.
- [4] Berger R, Nemeth A, Boburg RS, Vöhringer L, Lausberg HF, Acharya M, et al. Long-term follow-up of survivors of extracorporeal life support therapy for cardiogenic shock: are they really survivors? *Medicina (Kaunas)* 2022;58(3):427. <https://doi.org/10.3390/medicina58030427>.
- [5] Zhang M, Sun A, Yu A, Deng J, Wang Y, Cheng X, et al. Lived experience of extracorporeal membrane oxygenation survivors: a phenomenological study. *Nurs Crit Care* 2026;31(2). <https://doi.org/10.1111/nicc.70341>.
- [6] Zeng X, Yang F, Luo X, Li J, Lan Y, Zeng F, et al. Long-term health related quality of life in adult extracorporeal membrane oxygenation survivors: a single-Centre, cross-sectional study. *BMC Public Health* 2024;24(1). <https://doi.org/10.1186/s12889-024-20782-5>.
- [7] Knudson KA, Funk M, Redeker NS, Andrews LK, Whittemore R, Mangi AA, et al. An unbelievable ordeal: the experiences of adult survivors treated with extracorporeal membrane oxygenation. *Aust Crit Care* 2022;35(4):391–401. <https://doi.org/10.1016/j.aucc.2021.06.010>.
- [8] Kalra A, Kang JK, Khanduja S, Menta AK, Ahmad SA, Liu O, et al. Long-term neuropsychiatric, neurocognitive, and functional outcomes of patients receiving ECMO. *Neurology* 2024;102(3). <https://doi.org/10.1212/WNL.0000000000208081>.
- [9] Hodgson CL, Hayes K, Everard T, Nichol A, Davies AR, Bailey MJ, et al. Long-term quality of life in patients with acute respiratory distress syndrome requiring extracorporeal membrane oxygenation for refractory hypoxaemia. *Crit Care* 2012; 16(5):R202. <https://doi.org/10.1186/CC11811>.
- [10] Oude Lansink-Hartgring A, Miranda DDR, Mandigers L, Delnoij T, Lorusso R, Maas JJ, et al. Health-related quality of life, one-year costs and economic evaluation in extracorporeal membrane oxygenation in critically ill adults. *J Crit Care* 2023;73:154215. <https://doi.org/10.1016/j.jccr.2022.154215>.
- [11] Mikkelsen ME, Still M, Anderson BJ, Bienvenu OJ, Brodsky MB, Brummel N, et al. Society of Critical Care Medicine's international consensus conference on prediction and identification of long-term impairments after critical illness. *Crit Care Med* 2020;48(11):1670–9. <https://doi.org/10.1097/CCM.0000000000004586>.
- [12] Tramm R, Ilic D, Sheldrake J, Pellegrino V, Hodgson C. Recovery, risks, and adverse health outcomes in year 1 after extracorporeal membrane oxygenation. *Am J Crit Care* 2017;26(4):311–9. <https://doi.org/10.4037/ajcc2017707>.
- [13] Haines KJ, Berney S, Warrillow S, Denehy L. Long-term recovery following critical illness in an Australian cohort. *J Intensive Care* 2018;6:8. <https://doi.org/10.1186/s40560-018-0276-x>.
- [14] Higa KC, Mayer K, Quinn C, Jubina L, Suarez-Pierre A, Colborn K, et al. Sounding the alarm: what clinicians need to know about physical, emotional, and cognitive recovery after venoarterial extracorporeal membrane oxygenation. *Crit Care Med* 2023;51(9):1234–45. <https://doi.org/10.1097/CCM.0000000000005900>.
- [15] Taylor LJ, Jolley SE, Ramani C, Mayer KP, Etchill EW, Mart MF, et al. Early posthospitalization recovery after extracorporeal membrane oxygenation in survivors of COVID-19. *J Thorac Cardiovasc Surg* 2023;165(2):842–851.e1. <https://doi.org/10.1016/j.jtcvs.2021.11.099>.
- [16] Fernando SM, Scott M, Talarico R, Fan E, McIsaac DI, Sood MM, et al. Association of extracorporeal membrane oxygenation with new mental health diagnoses in adult survivors of critical illness. *JAMA* 2022;328(18):1827–36. <https://doi.org/10.1001/jama.2022.17714>.
- [17] Cho HW, Song IA, Oh TK. Quality of life and long-term mortality among survivors of extracorporeal membrane oxygenation: a nationwide cohort study in South Korea. *Crit Care Med* 2021;49(8):e771–80. <https://doi.org/10.1097/CCM.0000000000005015>.
- [18] IJsselstijn H, Schiller RM, Holder C, Shappley RKH, Wray J, Hoskote A. Extracorporeal life support organization (ELSO) guidelines for follow-up after neonatal and pediatric extracorporeal membrane oxygenation. *ASAIO J* 2021;67(9):955–63. <https://doi.org/10.1097/MAT.0000000000001525>.
- [19] IJsselstijn H, Hunfeld M, Schiller RM, Houmes RJ, Hoskote A, Tibboel D, et al. Improving long-term outcomes after extracorporeal membrane oxygenation: from observational follow-up programs toward risk stratification. *Front Pediatr* 2018;6: 177. <https://doi.org/10.3389/fped.2018.00177>.
- [20] Lucchini A, Villa M, Giani M, Andreossi M, Alessandra V, Vigo V, et al. Long-term outcome in patients treated with veno-venous extracorporeal membrane oxygenation: a prospective observational study. *Intensive Crit Care Nurs* 2024;82: 103631. <https://doi.org/10.1016/j.iccn.2024.103631>.
- [21] Neto AS, Higgins AM, Bailey MJ, Anderson S, Bernard S, Fulcher BJ, et al. Long-term functional outcomes in the first 12 months after VA-ECMO in adult patients: a prospective, multicenter study. *Circ Heart Fail* 2025;18(6). <https://doi.org/10.1161/CIRCHEARTFAILURE.124.012476>.
- [22] Jolink FEJ, Onrust M, Dos Reis Miranda D, Mandigers L, Delnoij T, Maas JJ, et al. Five years after extracorporeal membrane oxygenation: a prospective cohort study of health-related quality of life and patient outcomes. *Crit Care Med* 2025;53(12): e2487–96. <https://doi.org/10.1097/CCM.0000000000006900>.
- [23] Norkiene I, Jovaisa T, Scupakova N, Janusauskas V, Rucinskas K, Serpytis P, et al. Long-term quality of life in patients treated with extracorporeal membrane oxygenation for postcardiotomy cardiogenic shock. *Perfusion* 2019;34(4):285–9. <https://doi.org/10.1177/0267659118815291>.
- [24] Ramsey S, Shehata AL, Ramanathan K, Shekar K, Brodie D, Diaz R, et al. Extracorporeal life support organization 2024 guideline for early rehabilitation or mobilization of adult patients on extracorporeal membrane oxygenation. *ASAIO J* 2025;71(3):187–99. <https://doi.org/10.1097/MAT.0000000000002375>.
- [25] Tonna JE, Abrams D, Brodie D, Greenwood JC, Rubio Mateo-Sidron JA, Usman A, et al. Management of adult patients supported with venovenous extracorporeal membrane oxygenation (VV ECMO): guideline from the extracorporeal life support organization (ELSO). *ASAIO J* 2021;67(6):601–10. <https://doi.org/10.1097/MAT.0000000000001432>.
- [26] Polastri M, Eden A, Swol J. Rehabilitation for adult patients undergoing extracorporeal membrane oxygenation. *Perfusion* 2024;39(1_suppl):115S–26S. <https://doi.org/10.1177/02676591231226289>.
- [27] Tramm R, Ilic D, Murphy K, Sheldrake J, Pellegrino V, Hodgson C. Experience and needs of family members of patients treated with extracorporeal membrane oxygenation. *J Clin Nurs* 2017;26(11–12):1657–68. <https://doi.org/10.1111/jocn.13566>.
- [28] Minion JT, Mastikhina L, Dowsett L, Egunsola O, Farkas B, Flanagan J, et al. The lived experience by patients and family members of extracorporeal membrane oxygenation: a qualitative study. *Intensive Crit Care Nurs* 2022;73:103307. <https://doi.org/10.1016/j.iccn.2022.103307>.
- [29] Yang X, Lin Y, Tang A, Zeng X, Dai W, Zhang Q, et al. Tough choices: the experience of family members of critically ill patients participating in ECMO treatment decision-making: a descriptive qualitative study. *BMC Med Inform Decis Mak* 2025;25(1). <https://doi.org/10.1186/s12911-025-02876-1>.
- [30] Costa P, Ferreira A, Roncon-Albuquerque R. Mapping transitional care models after ICU discharge for ECMO survivors: a scoping review. *Enferm Intensiva* 2026;37(2): 500598. <https://doi.org/10.1016/j.enfi.2026.500598>.
- [31] McPeake J, Hirshberg EL, Christie LM, Drumright K, Haines K, Hough CL, et al. Models of peer support to remediate post-intensive care syndrome: a report developed by the Society of Critical Care Medicine thrive international peer support collaborative. *Crit Care Med* 2019;47(1):e21–7. <https://doi.org/10.1097/CCM.0000000000003497>.
- [32] Dimopoulos S, Leggett NE, Deane AM, Haines KJ, Abdelhamid YA. Models of intensive care unit follow-up care and feasibility of intervention delivery: a systematic review. *Aust Crit Care* 2024;37(3):508–16. <https://doi.org/10.1016/j.aucc.2023.04.005>.
- [33] 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(7):467–73. <https://doi.org/10.7326/M18-0850>.
- [34] Hodgson CL, Fulcher B, Mariajoseph FP, Burrell AJC, Pellegrino V, Brodie D, et al. A core outcome set for research in patients on extracorporeal membrane oxygenation. *Crit Care Med* 2021;49(12):e1252–4. <https://doi.org/10.1097/CCM.0000000000005110>.
- [35] McDonald MD, Sandsmark DK, Palakshappa JA, Mikkelsen ME, Anderson BJ, Gutsche JT. Long-term outcomes after extracorporeal life support for acute respiratory failure. *J Cardiothorac Vasc Anesth* 2019;33(1):72–9. <https://doi.org/10.1053/j.jvca.2018.05.023>.
- [36] Gray EL, Forrest P, Southwood TJ, Totaro RJ, Plunkett BT, Torzillo PJ. Long-term outcomes of adults with acute respiratory failure treated with veno-venous

- extracorporeal membrane oxygenation. *Anaesth Intensive Care* 2021;49(6): 477–85. <https://doi.org/10.1177/0310057X211042386>.
- [37] Ortuno S, Bachelet D, Varnet O, Tridon C, de Montmollin E, Dessajan J, et al. Long-term functional and quality-of-life outcomes in survivors of refractory cardiogenic shock treated with venoarterial extracorporeal membrane oxygenation. *Crit Care Explor* 2025;7(12):e1359. <https://doi.org/10.1097/cce.0000000000001359>.
- [38] Dinglas VD, Cherukuri SPS, Needham DM. Core outcomes sets for studies evaluating critical illness and patient recovery. *Curr Opin Crit Care* 2020;26(5): 489–99. <https://doi.org/10.1097/MCC.0000000000000750>.
- [39] Hodgson CL, Burrell AJC, Engeler DM, Pellegrino VA, Brodie D, Fan E. Core outcome measures for research in critically ill patients receiving extracorporeal membrane oxygenation for acute respiratory or cardiac failure: an international, multidisciplinary, modified Delphi consensus study. *Crit Care Med* 2019;47(11): 1557–63. <https://doi.org/10.1097/CCM.0000000000003954>.
- [40] Robinson KA, Davis WE, Dinglas VD, Mendez-Tellez PA, Rabiee A, Sukrithan V, et al. A systematic review finds limited data on measurement properties of instruments measuring outcomes in adult intensive care unit survivors. *J Clin Epidemiol* 2017;82:37–46. <https://doi.org/10.1016/j.jclinepi.2016.08.014>.
- [41] Ho MH, Lee JJ, Lai PCK, Li PWC. Prevalence of delirium among critically ill patients who received extracorporeal membrane oxygenation therapy: a systematic review and proportional meta-analysis. *Intensive Crit Care Nurs* 2023;79:103498. <https://doi.org/10.1016/j.iccn.2023.103498>.
- [42] Tramm R, Ilic D, Murphy K, Sheldrake J, Pellegrino V, Hodgson C. A qualitative exploration of acute care and psychological distress experiences of ECMO survivors. *Heart Lung* 2016;45(3):220–6. <https://doi.org/10.1016/j.hrtlng.2016.01.010>.
- [43] Savas H, Ozdemir Koken Z, Senol Celik S. Experiences of adult extracorporeal membrane oxygenation patients following discharge: a mixed methods study. *Heart Lung* 2020;49(5):592–8. <https://doi.org/10.1016/j.hrtlng.2020.03.009>.
- [44] Wang FZ, Zhang YH, Wu SJ, Xie HY, Lin DM, Wen XM, et al. Post-discharge experiences of patients with extracorporeal membrane oxygenation support: a qualitative study. *Perfusion* 2024;39(1):189–200. <https://doi.org/10.1177/02676591221135165>.
- [45] Highet BH, Cushenbery K, Sarangi S, Jena A, Banker H, Kilpatrick M, et al. Extracorporeal membrane oxygenation support: palliative care integration - patient experience and quality of life. *BMJ Support Palliat Care* 2025;15(6). <https://doi.org/10.1136/spcare-2025-005503>.
- [46] Villa M, Ausili D, Pegoraro F, Nava G, Bassi MG, Bramati S, et al. Family members' recollections of the care of ECMO patients transferred from a spoke hospital to a hub hospital: a qualitative study. *Nurs Crit Care* 2025;30(4). <https://doi.org/10.1111/nicc.70105>.
- [47] Van Sleuwen D, Zegers M, Ramjith J, Cruisberg JK, Simons KS, Van Bommel D, et al. Prediction of long-term physical, mental, and cognitive problems following critical illness: development and external validation of the PROSPECT prediction model. *Crit Care Med* 2024;52(2):200–9. <https://doi.org/10.1097/CCM.0000000000006073>.
- [48] Lorusso R, De Piero ME, Mariani S, Di Mauro M, Folliquet T, Taccone FS, et al. In-hospital and 6-month outcomes in patients with COVID-19 supported with extracorporeal membrane oxygenation (EuroECMO-COVID): a multicentre, prospective observational study. *Lancet Respir Med* 2023;11(2):151–62. [https://doi.org/10.1016/S2213-2600\(22\)00403-9](https://doi.org/10.1016/S2213-2600(22)00403-9).
- [49] Tiedebohl JM, DeFabio ME, Bell T, Buchko BL, Woods AB. ECMO survivors' quality of life and needs after discharge: a descriptive, comparative cross-sectional pilot study. *Intensive Crit Care Nurs* 2020;59:102829. <https://doi.org/10.1016/j.iccn.2020.102829>.
- [50] Cuzco C, Torres-Castro R, Torralba Y, Manzanares I, Muñoz-Rey P, Romero-García M, et al. Nursing interventions for patient empowerment during intensive care unit discharge: a systematic review. *Int J Environ Res Public Health* 2021;18(21):11049. <https://doi.org/10.3390/ijerph182111049>.