



## King's Research Portal

DOI:

[10.1016/j.jcrc.2023.154499](https://doi.org/10.1016/j.jcrc.2023.154499)

*Document Version*

Peer reviewed version

[Link to publication record in King's Research Portal](#)

*Citation for published version (APA):*

Rose, L., Saha, S., Flowers, E., & Allum, L. (in press). An Environmental Scan of Online Resources for Informal Family Caregivers of ICU Survivors. *Journal of Critical Care*, 80(154499).

<https://doi.org/10.1016/j.jcrc.2023.154499>

### **Citing this paper**

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

### **General rights**

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

### **Take down policy**

If you believe that this document breaches copyright please contact [librarypure@kcl.ac.uk](mailto:librarypure@kcl.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.

**Title:** An Environmental Scan of Online Resources for Informal Family Caregivers of ICU Survivors

**Authors:**

Emily Flowers, BSc <sup>a,b</sup>

Sian Saha, MA, RN <sup>a,c</sup>

Laura Allum MRes <sup>a,d</sup>

Louise Rose, MN, RN, PhD <sup>a,d</sup>

<sup>a</sup> Faculty of Nursing, Midwifery and Palliative Care, Kings College London, 57 Waterloo Road, London, SE1 8WA, United Kingdom.

<sup>b</sup> Physiotherapy Department, King's College Hospital. Denmark Hill, London, SE5 9RS United Kingdom.

<sup>c</sup> Department of Critical Care, King's College Hospital. Denmark Hill, London, SE5 9RS United Kingdom.

<sup>d</sup> Department of Critical Care, Guy's & St Thomas' NHS Foundation Trust

**Corresponding author:**

Louise Rose: Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, James Clerk Maxwell Building, 57 Waterloo Road, London, SE1 8WA [louise.rose@kcl.ac.uk](mailto:louise.rose@kcl.ac.uk)

**Conflict of interest:**

None

**Funding sources:**

This work was supported by the Burdett Trust [grant number SB\LG\101010662\736880]

Abstract (200 words)

*Purpose*

To collate a comprehensive repository of online resources for family caregivers of intensive care survivors to inform a recovery website and digital peer support programme.

*Materials and methods*

To identify resources, we conducted an environmental scan using processes recommended by the Canadian Agency for Drugs and Technologies in Health and guided by clinical experts, former patients, and family members. We searched internet sources, professional society websites, social media, and contacted our professional networks.

*Results*

Through expert consultation we identified 16 information categories and found 301 online resources. Five categories with the most resources were: how to look after yourself/recognise anxiety or post-traumatic stress/getting mental health support (n=63); information specific to conditions necessitating ICU admission (n=49); multiple category resources (n=46); symptoms of post-intensive care syndrome (n=44); stories of lived experience (n=23). Five categories with the least resources were physical, emotional and cognitive symptoms of post-intensive care syndrome-family (n=1); interacting with primary care (n=2); medical deterioration (how to recognise/what to do) (n=2); driving and accessing the community (n=3); end-of-life and bereavement (n=5). Of these resources, we included 45 on our recovery website.

*Conclusion*

This environmental scan identifies multiple resources addressing informational needs of family caregivers and highlights areas for resource development.

*Keywords*

Caregivers; family; critical care; recovery; resources; environmental scan

## Introduction

Approximately 80% of adults admitted to an intensive care unit (ICU) survive and are discharged home [1]. Many will experience new or worsening physical, mental, or cognitive problems known as post-intensive care syndrome (PICS) [2]. Up to a quarter of ICU survivors require assistance with activities of daily living (e.g., dressing, feeding and toileting) from family members in the home as well as help with rehabilitation activities up to one year after hospital discharge. The repercussions of surviving an ICU admission also extend socially and economically. A recent systematic review on return to work after critical illness found previously employed ICU survivors had a return-to-work prevalence of 64% at six months, 60% at one year, and 68% after five years. Despite returning to work, most survivors experienced decreased income and increased receipt of state financial support [3].

Family members of patients recently discharged from ICU also experience post-intensive care syndrome (termed post-intensive care syndrome-family (PICS-F)) [4-6]. Psychological morbidities associated with PICS-F include anxiety, depression, post-traumatic stress disorder (PTSD), and complicated grief [7, 8]. Moreover, most of the assistance or care needed in the home by ICU survivors is provided by informal family caregivers. Care needs can be substantial, with some individuals requiring over 50 hours each week, described as ‘never-ending care’ [4, 7]. This substantial burden on informal family caregivers can result in sleep disorders, nightmares, distress, and exhaustion [8]. Family members describe a cycle of worsening physical health, increasing mental distress, social withdrawal, and family crisis [4]. Family members may also have to undergo major adjustments to provide care in the home, including leaving employment and re-mortgaging or selling their homes [7].

Despite the documented repercussions of an ICU admission on both patients and family members, informal family caregivers continue to receive limited information about recovery from critical illness, both in ICU and following hospital discharge [9]. This is despite ICU survivors and family members expressing the need for this information. Provision of online resources has been highlighted as a successful support initiative by caregivers of ICU survivors [10]. Furthermore internet-based resources are now the predominant source of health-related information used by the public [11]. Therefore ensuring access to appropriate resources addressing identified needs on a range of topics relevant to supporting patient recovery and family member wellbeing is important.

Our overall aim was to collate a comprehensive repository of online resources on subjects important to the needs of informal family caregivers of ICU survivors once discharged from hospital as identified through consultation with clinical experts, former patients, and family members.

## Materials and methods

### *Study design*

We conducted an environmental scan using methods outlined by the Canadian Agency for Drugs and Technologies in Health (CADTH) environmental scan [12]. We selected this method as it is designed to provide an overview of current practices and the use of technologies to highlight existing or projected healthcare issues or issues associated with specific technology introduction, in our case, a website providing informational support for ICU survivors and family members. Following topic identification, this method consists of four phases: refinement, research, external review, and delivery.

### *Refinement phase: Consultation meetings*

To identify relevant information categories to guide our environmental scan, we conducted two consultation meetings, one with an Expert Advisory Group (EAG) and one with a project-specific Patient and Public Involvement (PPI) group.

We held consultation meetings in January 2022 via Microsoft Teams facilitated by two project team members and recorded with the participants' consent. The meetings were transcribed using the auto-transcription feature of Microsoft Teams and reviewed for accuracy. Using a pre-prepared question list (see Supplementary Material), we asked the EAG to identify information subjects important to informal family caregivers by considering questions they were frequently asked and what they felt family members needed to know. We also asked them to identify existing resources and those that needed development. We asked our PPI group what information and resources they thought should be available to family members when a patient is discharged from hospital following an ICU admission. We also explored what type of information they had received or accessed and found most useful.

### *Research phase: search for online resources*

#### *Online resource eligibility criteria*

The environmental scan inclusion criteria comprised: (1) a website, webpage, PDF document or similar (online resource) available via a hyperlink targeted to the needs of adult informal family caregivers to support adult ICU survivors during recovery; (2) an online resource relating to an information category identified through our expert consultation; (3) available in English; (4) suitable for a UK audience (either generic or UK-specific); and (5) free to access.

Exclusion criteria comprised: (1) resources targeted to paediatric patients, relatives, or paediatric-specific conditions; (2) inpatient ICU information; (3) resources specific to a regional (county) population within the UK (4) research publications; (5) information directed to healthcare professionals; (6) websites listed as advertising; and (7) Wikipedia.

### *Search resources and methods*

#### *Social media*

We used our Life Lines Twitter account ([https://twitter.com/LifeLines\\_ICU](https://twitter.com/LifeLines_ICU)) to seek information from followers on relevant online resources. Our Twitter account has 2,480 followers representing clinicians, researchers, and members of the public with an interest in intensive care.

#### *Professional networks*

We e-mailed health professionals and experts in our professional networks from the fields of ICU and ICU follow-up to request online resources provided to informal family caregivers. In addition, we contacted health professionals representing the clinical multidisciplinary team from six UK hospitals with dedicated ICU recovery services, (University Hospital of Wales, University Hospitals Plymouth, University Hospitals Coventry and Warwickshire, Guys and St Thomas' Hospital, King's College Hospital, and Barts Health NHS Trust). We also contacted experts from the Intensive Care Society and ICUSteps, the UK's leading charity for ICU survivors.

#### *Professional Society Websites*

We reviewed the following professional society websites for online resources; UK Intensive Care Society (<https://ics.ac.uk/>), Faculty of Intensive Care Medicine (<https://www.ficm.ac.uk/>), American Thoracic Society (<https://www.thoracic.org/>), Society of Critical Care Medicine (<https://www.sccm.org/>), and European Society of Intensive Care Medicine (<https://www.esicm.org/>).

### *Internet Searches*

We conducted internet searches using the Google search engine. We determined search terms by identifying keywords associated with the information categories identified during our consultation meetings. On entering a search term, we opened the first fifty results listed (five pages) and screened the content against our eligibility criteria. Only working links were opened, and duplicate online resources were disregarded. A complete list of the search terms and an example search using the search term “family support ICU” is provided in the Supplementary Material.

The search of professional society websites and internet searches was undertaken between December 2022 and January 2023. All identified online resources were collated on Microsoft Excel. One team member (EF) labelled each website an “ICU-specific online resource” or “an online resource with ICU applicable content”. Online resources were considered ‘ICU-specific’ if they contained information on ICU, critical illness, experiences of ICU patients or family caregivers, and critical illness recovery, for example, the ICU Steps website (<https://icusteps.org/>). Websites considered “ICU-specific” were searched for hyperlinks to further online resources. An online resource was considered to have “ICU applicable content” if the information contained was related to an informational category identified by our consultation meetings. An example of a website with ICU-applicable content was the British Red Cross website (<https://www.redcross.org.uk/get-help>) that provides information on mobility and cost of living support. Websites with “ICU applicable content” were not searched further for additional hyperlinks.

### *Online resource categorisation and review*

We used an iterative process to categorising online resources. One team member (EF) initially categorised each online resource as to the information category the content or purpose primarily fulfilled; for example, the homepage for the Carers Trust (<https://carers.org/>) fulfilled the category “physical strain and caregiver support”. A new information category was made if the content fulfilled our eligibility criteria but did not fit into an information category identified during our consultation meetings. The categorised list of online resources was then assessed by a second team member (SS) to confirm inclusion and fit with the information category. Conflicts regarding inclusion and/or categorisation

were resolved with discussion between the two reviewers (EF, SS) and confirmed by a third reviewer (LR).

### *External review phase*

To inform selection of resources for our local critical care recovery website hosted by Guy's & St Thomas' NHS Foundation Trust in London UK a third team member (LA) further reviewed the list for website inclusion, applying the following criteria:

1. Resources relevant to London boroughs.
2. Avoidance of PDF-only resources where possible to address accessibility issues.
3. Inclusion of only common ICU-related conditions to make the website more easily navigable. For example, online resources describing ICU-related anxiety were included, but not those relating to generalised anxiety disorder. It was assumed that people looking for condition-specific information (e.g., asthma, head injury, COVID-19) would find this elsewhere.

### *Delivery phase*

We planned to make the results of our environmental scan publicly available via a data repository and a critical care recovery website

## **Results**

### *Advisory group participants*

Our four EAG members were experts in ICU recovery and/or peer support and comprised two Nurse Consultants specialising in recovery following critical illness; one peer support expert; and one dietician specialising in critical illness and recovery. Our PPI group comprised one former ICU patient and three family members of ICU survivors. Membership of both was ethnically diverse, including Black Afro-Caribbean, White British, and Other ethnicities. All members of both groups were female.

### *Information category identification*

Our consultation meetings with our advisory groups identified 14 potential information categories: 10 from the EAG group and 4 from the PPI group (see Table 1). Following team discussion, we combined categories due to topic overlap/similarity. This included merging “social and welfare benefits” with “financial support”, as well as “how to look after yourself/recognise anxiety or post-traumatic stress, and getting support” with “mental health



support”. The category “what to expect from your relative including signs of deterioration” was changed into the two categories of “what to expect from your relative and practicalities of being at home” and “medical deterioration (how to recognise/what to do)”. This process resulted in 16 informational categories

### *Search results*

Our environmental scan identified 325 online resources: 23 from our consultation meetings; 19 from social media; 205 from our professional networks; 13 from professional society websites; and 81 from internet searches. On independent review, 14 online resources were excluded, predominantly due to the content being specific to COVID-19 lockdown or furlough. Disagreement between reviewers occurred for 48 online resources. After discussion of the 48 conflicts, 10 were excluded and the remainder included. The main reason for exclusion was that the content was more suitable for patients and their families at the time of ICU admission rather than in recovery at home

In total, 301 online resources were included and categorised. A flow diagram of our review processes is shown in **Error! Reference source not found.** The final information categories and the number of online resources identified per category is provided in Table 2. A full list of the 301 online resources according to information category, is provided in the Supplementary Material. This comprehensive online resource repository is now publicly available to family caregivers, patients, and clinicians via a data repository <https://data.mendeley.com/datasets/42mzcbtk3h/1>. Of the 301 online resources identified, 45 were selected for inclusion on our critical care recovery website <https://gstt.criticalcarerecovery.com>. This website has been adapted from a website originally developed for Scotland (<https://www.criticalcarerecovery.com>).

### **Discussion**

Through our expert consultation guided environmental scan, our work provides an understanding of the categories of informational needs of family caregivers of ICU survivors and has identified 301 online resources addressing these categories. This is now freely available as an online repository and via a critical care recovery website. Although we identified online resources within all information categories, we discovered a paucity in several categories, including: “physical, emotional and cognitive symptoms of PICS-F”,

“interacting with primary care”, and “medical deterioration (how to recognise/what to do)”. Importantly, multiple resources were identified that support mental health of both patients and family members. Interestingly, fewer resources were identified that focused on physical health and burden of family caregivers or practical guidance on how to manage the physical issues experienced by their relative recovering from critical illness.

We identified only one resource (YouTube video) specifically addressing PICS-F but 44 resources relating to PICS. This may reflect greater recognition of the physical, cognitive, and emotional consequences of critical illness for patients as opposed to their family caregivers. We also found few resources directly addressing family caregiver physical strain, the need for support and ways for caregivers to receive support. We did however identify multiple resources addressing emotional and psychological concerns. Psychological morbidity of family caregivers is prevalent and persistent. One longitudinal study found that 25% of family caregivers reported symptoms of PTSD at three months and 24% at one year [13]. Another study found 30% of family caregivers reported symptoms of PTSD 90 days after their relative developed chronic critical illness [14]. The reported prevalence of anxiety ranges from 42% to 80% and depression from 16% to 90% during the ICU or hospital stay. These symptoms persist with prevalence rates six months after ICU discharge of 15% to 24% for anxiety, 5% to 36% for depression, and 35% to 57% for PTSD [8]. It is, therefore, of utmost importance that family caregivers are made aware of the possible consequences of caregiving and provided with accessible informational resources and support.

We found only two online resources for the “interacting with primary care” information category. This is surprising given that primary care is the key care provider for ICU survivors and family members following hospital discharge. The lack of general practitioner knowledge about PICS and PICS-F enhances the need for informational resources on interacting with primary care so that the issues experienced by ICU survivors and family caregivers can be addressed appropriately [15]. One survey of general practitioners (GPs) based in the Netherlands found that 57% of responders were unfamiliar with the terminology and concepts relating to “PICS” and “PICS-F” [16]. In the UK, a survey of GPs found over 60% of responders were unaware of the ICU follow-up services provided by their local hospitals, with an expressed need for information about critical illness recovery [15]. Therefore, developing online resources to bridge this informational gap is imperative.

We identified only two online resources in the “medical deterioration (how to recognise/what to do)” category. This included the UK National Health Service (NHS) 111 online resource and a video called “3 soft signs of deterioration” on YouTube. A recent systematic review found that hospital readmission is common in this patient group with 17% readmitted at 30 days; 31% at 90 days; 30% at six months; and 53% at one year [17]. Therefore better information on the signs of deterioration and when to call for help in a timely manner may ensure timely access to appropriate support and health services, which in turn may reduce or avoid readmission to hospital. We therefore recommended this as a key and pressing area for resource development preferably using co-design methods to ensure resources are tailored to the needs of family caregivers.

Strengths of our work include expert and end-user consultation to establish key information categories and the use of rigorous environmental scan methodology. Our work has limitations. Though ethnically diverse, our EAG and PPI group members were all female. This may have shaped the views and opinions shared. We limited our Google search to the first 50 results relating to our search terms. This may have missed some relevant resources. For pragmatic reasons, we sought only resources in English as they needed to be evaluated by our team. Without translation, this limits accessibility to non-English speaking family members. However, our publicly accessible critical care recovery website has an inbuilt translation function enabling the translation of resources into over 50 languages. Given our objectives, we sought only online resources applicable to the UK population with those included on the website bespoke to the needs of our local population. To address this limitation, we also host the full environmental scan on our online repository. Lastly, information on topic categories may not have been found if embedded within resources not linked to our specific search terms.

## **Conclusion**

Our environmental scan has identified a substantial number of online resources relevant to the informational needs of family caregivers of ICU survivors, forming a comprehensive information repository. Many of these online resources focused on aspects of caregiver mental health or symptoms experienced by the ICU survivor. Fewer focused on the practical and physical issues family caregivers frequently face, specifically how to interact with primary care, recognise medical deterioration, and how to access help. Our work highlights a need for further resource development to address these gaps in informational resources.

**Acknowledgements:**

The authors wish to thank the members of the Expert Advisory Group; Dr Jo McPeake, Dr Pam Ramsay, Julie Repper, and Ella Terblanche MBE, and the members of our Patient and Public Involvement (PPI) group. As well as to thank the health professionals, experts, and individuals who provided online resources.

## References

- [1] Meyer J, Slack A, Waldmann C, Bastin A, Gager M, McPeake J, et al. Life after critical illness: a guide for developing and delivering aftercare services for critically ill patients, [https://www.ficm.ac.uk/sites/ficm/files/documents/2021-10/laci\\_life\\_after\\_critical\\_illness\\_2021.pdf](https://www.ficm.ac.uk/sites/ficm/files/documents/2021-10/laci_life_after_critical_illness_2021.pdf); 2021 [accessed 18 August.2023].
- [2] Geense W, Zegers M, Peters M, Ewalds E, Simons K, Vermeulen H, et al. New physical, mental, and cognitive problems 1 year after ICU admission: A prospective multicenter study. *Am J Respir Crit Care Med* 2021;203:1512–21.
- [3] Kamdar B, Suri R, Suchyta M, Digrande K, Sherwood K, Colantuoni E, et al. Return to work after critical illness: a systematic review and meta-analysis. *Thorax* 2020;75:17–27.
- [4] Kang J. Being devastated by critical illness journey in the family: a grounded theory approach of post-intensive care syndrome-family. *Intensive Crit Care Nurs* 2023;78:103448.
- [5] Serrano P, Kheir Y, Wang S, Khan S, Scheunemann L, Khan B. Ageing and postintensive care syndrome – family: a critical need for geriatric psychiatry. *Am J Ger Psych* 2019;27:446–54.
- [6] Needham D, Davidson J, Cohen H, Hopkins R, Weinert C, Wunsch H, et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders’ conference. *Crit Care Med* 2012;40:502–9.
- [7] Griffiths J, Hatch R, Bishop J, Morgan K, Jenkinson C, Cuthbertson B, et al. An exploration of social and economic outcome and associated health-related quality of life after critical illness in general intensive care unit survivors: a 12-month follow-up study. *Crit Care* 2013;17:R100.
- [8] van Beusekom I, Bakhshi-Raiez F, de Keizer N, Dongelmans D, van der Schaaf M. Reported burden on informal caregivers of ICU survivors: a literature review. *Crit Care* 2016;20:16.
- [9] Sevin C, Boehm L, Hibbert E, Bastin A, Jackson J, Meyer J, et al. Optimizing critical illness recovery: perspectives and solutions from the caregivers of ICU survivors. *Crit Care Explor* 2021;3:e0420.
- [10] King J, O’Neill B, Ramsay P, Linden M, Darweish Medniuk A, Outtrim J, et al. Identifying patients’ support needs following critical illness: a scoping review of the qualitative literature. *Crit Care* 2019;23:187.
- [11] Soroya S, Farooq A, Mahmood K, Isoaho J, Zara S. From information seeking to information avoidance: understanding the health information behavior during a global health crisis. *Inf Process Manag* 2021;58:102440.
- [12] Canada’s Drug and Health Technology Agency (CADTH). Environmental Scan Process V3.0, [https://www.cadth.ca/sites/default/files/pdf/FINAL\\_Env%20Scan%20External%20Process.pdf](https://www.cadth.ca/sites/default/files/pdf/FINAL_Env%20Scan%20External%20Process.pdf); 2015 [accessed 30th April.2023].

- [13] Alfheim H, Hofsø K, Småstuen M, Tøien K, Rosseland L, Rustøen T. Post-traumatic stress symptoms in family caregivers of intensive care unit patients: a longitudinal study. *Intensive Crit Care Nurs* 2019;50:5–10.
- [14] Wendlandt B, Ceppe A, Cox C, Hanson L, Nelson J, Carson S. The association between patient health status and surrogate decision maker post-traumatic stress disorder symptoms in chronic critical illness. *Ann Am Thorac Soc* 2021;18:1868–75.
- [15] Castro-Avila A, Jefferson L, Dale V, Bloor K. Support and follow-up needs of patients discharged from intensive care after severe COVID-19: a mixed-methods study of the views of UK general practitioners and intensive care staff during the pandemic's first wave. *BMJ Open* 2021;11:48392.
- [16] Vlase J, Wils E, van Bommel J, Gommers D, van Genderen M. Familiarity with the post-intensive care syndrome among general practitioners and opportunities to improve their involvement in ICU follow-up care on behalf of the HORIZON-ICU study group. *Intensive Care Med* 2022;48:1090–2.
- [17] McPeake J, Bateson M, Christie F, Robinson C, Cannon P, Mikkelsen M, et al. Hospital re-admission after critical care survival: a systematic review and meta-analysis. *Anaesthesia* 2022;77:475–85.

**Table 1 Information categories.**

	<b>Original information categories</b>	<b>Final information categories</b>
<b>Information categories from Patient and Public Involvement Group</b>	What to expect from your relative including signs of deterioration	What to expect from your relative and practicalities of being at home
	Practicalities of being at home	
	Nuggets of useful information	Resources spanning various categories
	How to look after yourself/recognise anxiety or posttraumatic stress, and getting support	How to look after yourself/recognise anxiety or post-traumatic stress, and getting mental health support
<b>Information categories from Expert Advisory Group</b>	Mental health support	
	Symptoms of PICS-F	Physical, emotional and cognitive symptoms of post-intensive care syndrome-family
	Social and welfare benefits	Social/welfare benefits and financial support (including care and return to work)
	Financial support	
	Access to equipment and home adaptations	Access to equipment and home adaptations
	Physical caregiver strain	Physical strain and caregiver support
	Interacting with primary care	Interacting with primary care
	Medical deterioration	Medical deterioration (how to recognise/what to do)
	Cognitive difficulties	Symptoms of post-intensive care syndrome
	Pain management	
<b>Additional information categories</b>	Post Intensive Care Syndrome (general)	
	Eating and nutrition	
	Sleep	
	Flashbacks/ hallucinations	
	Fatigue	
	Breathing related (shortness of breath, cough, and secretion clearance)	

	Smell change or loss	
	Hearing change or loss	
	Voice change or loss	
	Driving and accessing the community	Driving and accessing the community
	End-of-life and bereavement	End-of-life and bereavement
	Social networks	Social networks
	Physiotherapy, exercise, and activities for ICU survivors	Physiotherapy, exercise, and activities for ICU survivors
	Condition specific information	Information specific to conditions necessitating an ICU admission
	COVID-19 specific (including long-COVID)	
	Stories of lived experience	Stories of lived experience

The ‘Original information categories’ were identified by consultation meetings with our project-specific expert advisory and patient and public involvement groups. The project team developed these categories into the ‘Final information categories’ listed.



**Table 2 Final information categories resources**

<b>Category</b>	<b>Number of resources</b>
Physical, emotional and cognitive symptoms of PICS-F	1
Interacting with primary care	2
Medical deterioration (how to recognise/what to do)	2
Driving and accessing the community	3
End-of-life and bereavement	5
Physical strain and caregiver support	6
What to expect from your relative and practicalities of being at home	7
Access to equipment and home adaptations	7
Social networks	7
Physiotherapy, exercise, and activities for ICU survivors	15
Social/welfare benefits and financial support (including care and return to work)	21
Stories of lived experience	23
Symptoms of PICS	44
Information specific to conditions necessitating an ICU admission (i.e., sepsis)	49
How to look after yourself/recognise anxiety or post-traumatic stress, and getting mental health support	63
Multiple category resources	46

## Consultation meeting questions

These questions were prepared by one member of the project team (SS) ahead of the consultation meetings with the Expert Advisory Group (EAG) and the Patient and Public Involvement (PPI) group.

### Questions for the EAG:

- 1) What resources do you use to support families during/after their relatives ICU stay?
- 2) What resources are you aware of, to support families during/after a relatives ICU stay?
- 3) Where do you direct families to get support for their physical and emotional well-being?
- 4) Are these formal or informal resources (e.g. hospital information, social media (facebook/twitter/Instagram), GP surgeries, apps, charity websites, other websites, blogs)?
- 5) If you had a 'wish list' of resources you could offer families to support their physical and emotional wellbeing, during and after their relatives ICU stay, what would be on it?
- 6) What resources do you think family members need?

### Questions for PPI group:

- 1) What resources have you used to get support during/after you relatives ICU stay?
- 2) What resources are you aware of, to support families during/after a relatives ICU stay?
- 3) Where do you look to get support for your physical and emotional well-being?
- 4) Are these formal or informal resources (e.g. hospital information, social media (facebook/twitter/Instagram), GP surgeries, apps, charity websites, other websites, blogs)?
- 5) If you had a 'wish list' of resources you could find to support your physical and emotional wellbeing, during and after your relatives ICU stay, what would be on it?
- 6) What resources do you think you and other family members need?

**Professional society websites searched**

UK Intensive Care Society (<https://ics.ac.uk/>)

Faculty of Intensive Care Medicine (<https://www.ficm.ac.uk/>)

American Thoracic Society (<https://www.thoracic.org/>)

Society of Critical Care Medicine (<https://www.sccm.org/>)

European Society of Intensive Care Medicine (<https://www.esicm.org/>).

## **Search terms**

Search terms were determined by identifying keywords associated with the information categories identified during our consultation meetings.

- Family support ICU
- Family support intensive care
- Practical family support intensive care
- Carer support
- Anxiety family intensive care
- Depression family intensive care
- Posttraumatic stress disorder family intensive care
- Mental health support family intensive care
- Post intensive care syndrome family
- PICS-F
- Social welfare financial support
- Hospital discharge equipment
- Hospital discharge home adaptations
- Cognition after intensive care
- GP after intensive care
- Primary care after intensive care
- Pain after intensive care
- Deteriorating at home after intensive care
- Medical deterioration at home

## Example Search

An example search carried out on the Google search engine using the search term “family support ICU”. All results are listed excluding results listed as an “Ad”.

1. <https://healthtalk.org/intensive-care-experiences-family-friends/sources-of-support-in-icu>
2. <https://icusteps.org/information/guide-to-intensive-care/for-relatives>
3. <https://icusteps.org/>
4. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6452792/>
5. <https://www.apaservices.org/practice/ce/expert/supporting-families-icu>
6. <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-021-07095-8>
7. [https://www.stgeorges.nhs.uk/wp-content/uploads/2022/04/ICU\\_FLS.pdf](https://www.stgeorges.nhs.uk/wp-content/uploads/2022/04/ICU_FLS.pdf)
8. [https://journal.chestnet.org/article/S0012-3692\(20\)31852-3/fulltext](https://journal.chestnet.org/article/S0012-3692(20)31852-3/fulltext)
9. <http://www.readingicusupport.co.uk/for-relatives.html>
10. <https://www.nejm.org/doi/full/10.1056/NEJMc1809967>
11. <https://www.kingshealthpartners.org/our-work/lifelines/information-for-families/critical-care-recovery-covid-19>
12. <https://onlinelibrary.wiley.com/doi/full/10.1002/nop2.287>
13. [https://journals.lww.com/nursingcriticalcare/fulltext/2010/09000/developing\\_family\\_support\\_groups\\_in\\_the\\_icu.7.aspx](https://journals.lww.com/nursingcriticalcare/fulltext/2010/09000/developing_family_support_groups_in_the_icu.7.aspx)
14. <https://healthtimes.com.au/hub/critical-care/21/practice/hw/supporting-the-families-of-patients-in-the-icu/4315/>
15. <https://resident360.nejm.org/content-items/family-support-intervention-in-intensive-care-units>
16. <https://www.ficm.ac.uk/forpatientswhatisintensivecare/children-families-and-critical-care>
17. <https://www.icudelirium.org/medical-professionals/family-engagement-and-empowerment>
18. <https://evidence.nihr.ac.uk/alert/supporting-families-of-those-in-intensive-care-improved-family-satisfaction-but-didnt-reduce-family-distress/>
19. <https://www.atsjournals.org/doi/10.1164/rccm.201710-2032CI>
20. <https://www.frontiersin.org/articles/10.3389/fpsy.2022.837708/full>
21. <https://www.nytimes.com/2022/01/10/well/how-families-can-navigate-the-icu.html>
22. <https://www.friendsofpicu.org.uk/what-we-do/child-and-family-support/>
23. <https://healthbeat.spectrumhealth.org/families-of-critically-ill-patients-need-extra-support-too/>
24. <https://ebn.bmj.com/content/23/1/15>
25. <https://www.atlantichealth.org/conditions-treatments/intensive-care/icu-resources.html>
26. <https://cardiffcriticalcare.co.uk/leaflet-information/>
27. <https://www.chelwest.nhs.uk/your-visit/patient-leaflets/icu/intensive-care-unit-icu-information-for-family-and-friends>
28. <https://www.sciencedirect.com/science/article/abs/pii/S0883944120307176>
29. <https://www.wsh.nhs.uk/CMS-Documents/Patient-leaflets/CriticalCareServices/Web-resources-to-support-relatives-and-patients-in-Critical-Care-Unit-002.pdf>
30. <https://healthmanagement.org/c/icu/news/six-icu-patient-and-family-info-resources>
31. [http://ferronfred.eu/ferron\\_fred/classe\\_anesthesie\\_-\\_reanimation/Entrees/2010/3/30\\_articles\\_files/Supporting%20families%20in%20the%20ICU\\_-\\_%20A%20descriptive%20correlational%20study%20of%20informational%20support,%20anxiety,%20and%20satisfaction%20with%20care.pdf](http://ferronfred.eu/ferron_fred/classe_anesthesie_-_reanimation/Entrees/2010/3/30_articles_files/Supporting%20families%20in%20the%20ICU_-_%20A%20descriptive%20correlational%20study%20of%20informational%20support,%20anxiety,%20and%20satisfaction%20with%20care.pdf)
32. <https://nursinganswers.net/essays/family-support-programme-icu-patient-4590.php>
33. <https://caregiver.com/articles/surviving-ICU/>
34. <https://www.canadiancriticalcare.org/Patients-&-Families>
35. <https://www.nhs.uk/conditions/intensive-care/>

36. <https://www.rn.com/featured-stories/emotional-impact-on-icu-patients-and-families/>
37. <https://austinpublishinggroup.com/nursing-research-practice/fulltext/anrp-v6-id1044.pdf>
38. <https://www.uptodate.com/contents/communication-in-the-icu-holding-a-meeting-with-families-and-caregivers>
39. [https://media.gosh.nhs.uk/documents/When\\_your\\_child\\_is\\_in\\_the\\_Intensive\\_Care\\_Unit\\_ICU.pdf](https://media.gosh.nhs.uk/documents/When_your_child_is_in_the_Intensive_Care_Unit_ICU.pdf)
40. <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2781118>
41. [https://mydoctor.kaiserpermanente.org/ncal/Images/Family%20Guide%20to%20ICU\\_tcm75-854750.pdf](https://mydoctor.kaiserpermanente.org/ncal/Images/Family%20Guide%20to%20ICU_tcm75-854750.pdf)
42. <https://www.itmedicalteam.pl/articles/quality-of-life-and-family-support-in-critically-ill-patients-following-icu-discharge-106433.html>
43. <https://www.criticalcarerecovery.com/Search.aspx?tag=257>
44. <https://www.jwatch.org/na54562/2022/02/24/structured-family-support-helps-mitigate-grief-after-death>

### Online resources identified by the environmental scan.

Each online resource is listed and described. The information category each online resource fulfils is indicated by an 'X'.

Link to online resource	Description	Information category															
<a href="https://www.youtube.com/watch?v=8cbw14lWLkY">https://www.youtube.com/watch?v=8cbw14lWLkY</a>	Online video on intensive care unit acquired weakness	X															
		What to expect from your relative and the practicalities of being at home	Multiple category resources	How to look after yourself/recognise anxiety or posttraumatic stress disorder, and where to get mental health support	Physical, emotional and cognitive symptoms of post-intensive care syndrome-family	Social/welfare benefits and financial support (including care and return to work)	Access to equipment and home adaptations	Physical strain and carer support	How to interact with primary care	Medical deterioration (how to recognise/what to do)	Symptoms of post-intensive care syndrome	Driving and accessing the community	End-of-life and bereavement	Social networks	Physiotherapy, exercise, and activities for ICU survivors	Information specific to conditions necessitating an ICU admission	Stories of lived experience

[illegible]



[illegible]









[illegible]

[illegible]

[illegible]





[illegible]



[illegible]

[illegible]

[illegible]

[illegible]







[illegible]



[illegible]



[illegible]

[illegible]

[illegible]







<a href="https://www.criticalcarecovery.com/x24i57/your_gp.aspx">https://www.criticalcarecovery.com/x24i57/your_gp.aspx</a>	Advice from the critical care recovery website on visiting your GP								X								
<a href="https://www.criticalcarecovery.com/x31i125/when_should_i_go_to_my_gp.aspx">https://www.criticalcarecovery.com/x31i125/when_should_i_go_to_my_gp.aspx</a>	Further advice on speaking with your GP from the critical care recovery website								X								
<a href="https://www.youtube.com/watch?v=7gMo13z3BYI">https://www.youtube.com/watch?v=7gMo13z3BYI</a>	NHS video about spotting medical deterioration - "soft signs"									X							
<a href="https://111.nhs.uk">https://111.nhs.uk</a>	An NHS non-emergency medical advice service									X							
<a href="https://www.neuronation.com/">https://www.neuronation.com/</a>	An app with exercises to improve memory, strengthen attention, increase the speed of thought and train logical thinking. Both free and paid-for games are available.										X						
<a href="https://www.peak.net/">https://www.peak.net/</a>	An app with games that test your focus, memory, problem solving, mental agility and more. Free to use but can only play once a day										X						
<a href="https://invidious.fdn.fr/watch?v=EENsbqcbDc4">https://invidious.fdn.fr/watch?v=EENsbqcbDc4</a>	ICUSteps webinar on delirium										X						

<a href="https://www.icudelirium.org/patients-and-families/cognitive-impairment">https://www.icudelirium.org/patients-and-families/cognitive-impairment</a>	Information on cognitive impairment after ICU by ICUDelirium.org											X					
<a href="https://www.youtube.com/watch?v=g50VsYj90zM">https://www.youtube.com/watch?v=g50VsYj90zM</a>	YouTube video on cognitive and psychological problems after ICU admission											X					
<a href="https://constanttherapyhealth.com/constant-therapy/">https://constanttherapyhealth.com/constant-therapy/</a>	An app with speech, language, and thinking exercises. The app will customise a programme tailored to your recovery goals. A free trial is available but payment required after											X					
<a href="https://www.icudelirium.org/patients-and-families/overview">https://www.icudelirium.org/patients-and-families/overview</a>	Online information about ICU and delirium											X					
<a href="https://www.mycognition.com/">https://www.mycognition.com/</a>	A brain training app to help you think faster, focus better, and improve decision-making and memory.											X					
<a href="https://icusteps.org/assets/files/information-sheets/delirium.pdf?q=files/booklet/delirium.pdf">https://icusteps.org/assets/files/information-sheets/delirium.pdf?q=files/booklet/delirium.pdf</a>	ICUSteps delirium information											X					

<a href="https://www.criticalcarecovery.com/Search.aspx?tag=114">https://www.criticalcarecovery.com/Search.aspx?tag=114</a>	Pain information from the critical care recovery website											X					
<a href="https://www.criticalcarecovery.com/x11i84/numbness_and_pins_and_needles.aspx">https://www.criticalcarecovery.com/x11i84/numbness_and_pins_and_needles.aspx</a>	Pins and needles information from the critical care recovery website											X					
<a href="https://painconcern.org.uk/">https://painconcern.org.uk/</a>	Online information about managing pain via a link to painconcern.org.uk											X					
<a href="https://www.criticalcarecovery.com/x19l212/pacing_for_pain(1).aspx">https://www.criticalcarecovery.com/x19l212/pacing_for_pain(1).aspx</a>	Information video on the technique of pacing to help manage pain from the critical care recovery website											X					
<a href="https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/chronic-pain-self-help-guide">https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/chronic-pain-self-help-guide</a>	information and guidance on chronic pain from NHS Inform											X					
<a href="https://www.atlantichealth.org/conditions-treatments/intensive-care/post-icu-care-center/pic-syndrome.html">https://www.atlantichealth.org/conditions-treatments/intensive-care/post-icu-care-center/pic-syndrome.html</a>	Information on post-intensive care syndrome (PICS) and post-intensive care syndrome – family (PICS-f) from Atlantic Health System											X					

<a href="https://www.medicalnewstoday.com/articles/post-intensive-care-syndrome#summary">https://www.medicalnewstoday.com/articles/post-intensive-care-syndrome#summary</a>	Summary of PICS from Medical News Today										X						
<a href="https://my.clevelandclinic.org/health/diseases/21161-post-intensive-care-syndrome-pics">https://my.clevelandclinic.org/health/diseases/21161-post-intensive-care-syndrome-pics</a>	Information on PICS and PICS-F from the Cleveland Clinic										X						
<a href="https://www.youtube.com/watch?v=QyF8bknbAi0">https://www.youtube.com/watch?v=QyF8bknbAi0</a>	Information video describing PICS										X						
<a href="https://www.sccm.org/MyICUCare/THRIVE/Post-intensive-Care-Syndrome">https://www.sccm.org/MyICUCare/THRIVE/Post-intensive-Care-Syndrome</a>	Information on post intensive care syndrome from THRIVE										X						
<a href="https://icusteps.org/assets/files/information-sheets/nutrition-at-home.pdf">https://icusteps.org/assets/files/information-sheets/nutrition-at-home.pdf</a>	ICUSteps guide on nutrition after ICU										X						
<a href="https://icusteps.org/assets/files/information-sheets/tips-on-eating-problems.pdf">https://icusteps.org/assets/files/information-sheets/tips-on-eating-problems.pdf</a>	ICUSteps guide on eating problems after ICU										X						
<a href="https://www.bda.uk.com/resource/nutrition-at-home-after-critical-illness.html">https://www.bda.uk.com/resource/nutrition-at-home-after-critical-illness.html</a>	Online information about nutrition at home after critical illness produced by the Association of UK Dietitians										X						

<a href="https://www.ficm.ac.uk/index.php/forpatients/further-patient-resources">https://www.ficm.ac.uk/index.php/forpatients/further-patient-resources</a>	Video on nutritional advice after ICU from the Faculty of Intensive Care Medicine											X					
<a href="https://www.cc-sn.org/files/ugd/4a06ed_90a1cb7271154131ae92a717db3613e8.pdf">https://www.cc-sn.org/files/ugd/4a06ed_90a1cb7271154131ae92a717db3613e8.pdf</a>	Nutritional advice after ICU											X					
<a href="https://patient.info/mental-health/insomnia-poor-sleep">https://patient.info/mental-health/insomnia-poor-sleep</a>	Online information about how to improve your sleep											X					
<a href="https://pzizz.com/">https://pzizz.com/</a>	An app to help you fall asleep and stay asleep											X					
<a href="https://www.criticalcarecovery.com/x14i54/sleep_disturbances.aspx">https://www.criticalcarecovery.com/x14i54/sleep_disturbances.aspx</a>	Online information about sleep disturbances and strategies to help improve these from the critical care recovery website											X					
<a href="http://www.criticalcarerecovery.com/x30i108/problems_sleeping.aspx">www.criticalcarerecovery.com/x30i108/problems_sleeping.aspx</a>	Online information about problems sleeping from the critical care recovery website											X					

<a href="https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/sleep-problems-and-insomnia-self-help-guide/">https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/sleep-problems-and-insomnia-self-help-guide/</a>	Self-help information on sleeping problems from NHS Inform										X						
<a href="https://www.cc-sn.org/files/ugd/4a06ed_be6b4c1d739348a2a9dc00ee94514d2b.pdf">https://www.cc-sn.org/files/ugd/4a06ed_be6b4c1d739348a2a9dc00ee94514d2b.pdf</a>	Self-help guide on sleep										X						
<a href="https://www.criticalcarecovery.com/x14i53/flashbacks.aspx">https://www.criticalcarecovery.com/x14i53/flashbacks.aspx</a>	Online information about flashbacks following critical care from the critical care recovery website										X						
<a href="https://www.ficm.ac.uk/forpatientsrecoveryafterintensivecare/hallucinations-following-a-critical-care-admission">https://www.ficm.ac.uk/forpatientsrecoveryafterintensivecare/hallucinations-following-a-critical-care-admission</a>	Online information about hallucinations following critical care from the Faculty of Intensive Care Medicine										X						
<a href="https://www.youtube.com/watch?v=0XCmCG6sn3w">https://www.youtube.com/watch?v=0XCmCG6sn3w</a>	Video on managing flashbacks using the safe place technique										X						
<a href="https://www.criticalcarecovery.com/x19l211/pacing_for_fatigue(1).aspx">https://www.criticalcarecovery.com/x19l211/pacing_for_fatigue(1).aspx</a>	Information video on the technique of pacing for managing fatigue										X						



	from the critical care recovery website																
<a href="https://www.acprc.org.uk/Data/Publication_Downloads/GL-03EnergyConservation(1).pdf">https://www.acprc.org.uk/Data/Publication_Downloads/GL-03EnergyConservation(1).pdf</a>	Information sheet on energy conservation from the Association of Chartered Physiotherapists in Respiratory Care										X						
<a href="https://www.nhsggc.org.uk/media/261711/232434_2_0-energy-conservation.pdf">https://www.nhsggc.org.uk/media/261711/232434_2_0-energy-conservation.pdf</a>	Guidance on energy conservation from Greater Glasgow and Clyde NHS services										X						
<a href="https://icusteps.org/assets/files/information-sheets/breathing-problems.pdf">https://icusteps.org/assets/files/information-sheets/breathing-problems.pdf</a>	ICUSteps guide on breathing problems after ICU										X						
<a href="https://www.plymouthhospitals.nhs.uk/download.cfm?doc=docm93jijm4n8782.pdf&amp;ver=12279">https://www.plymouthhospitals.nhs.uk/download.cfm?doc=docm93jijm4n8782.pdf&amp;ver=12279</a>	Breathing 'exercises ' for shortness of breath from the Association of Chartered Physiotherapists in Respiratory Care										X						
<a href="https://www.plymouthhospitals.nhs.uk/download.cfm?doc=docm93jijm4n8783.pdf&amp;ver=12280">https://www.plymouthhospitals.nhs.uk/download.cfm?doc=docm93jijm4n8783.pdf&amp;ver=12280</a>	Positions of ease for shortness of breath from the Association of Chartered Physiotherapists in Respiratory Care										X						

<a href="https://www.plymouthhospitals.nhs.uk/download.cfm?doc=docm93jijm4n8784.pdf&amp;ver=12281">https://www.plymouthhospitals.nhs.uk/download.cfm?doc=docm93jijm4n8784.pdf&amp;ver=12281</a>	The active cycle of breathing techniques to aid secretion clearance from the Association of Chartered Physiotherapists in Respiratory Care											X						
<a href="https://abscent.org/noswell">https://abscent.org/noswell</a>	Help for those with their sense of smell affected											X						
<a href="https://www.fifthsense.org.uk/">https://www.fifthsense.org.uk/</a>	Help for those with their sense of smell affected											X						
<a href="https://www.hearinglink.org/">https://www.hearinglink.org/</a>	Information on hearing loss and services available											X						
<a href="https://www.britishvoiceassociation.org.uk/free-voice-clinics.htm">https://www.britishvoiceassociation.org.uk/free-voice-clinics.htm</a>	British Voice Association website's directory of NHS voice clinics											X						
<a href="https://www.accessable.co.uk/">https://www.accessable.co.uk/</a>	Website to search for places which are accessible for people with disabilities												X					
<a href="https://www.gov.uk/driving-medical-conditions">https://www.gov.uk/driving-medical-conditions</a>	Online government information about returning to driving after critical illness												X					
<a href="https://www.euansguide.com/">https://www.euansguide.com/</a>	Wheelchair accessible places with reviews												X					
<a href="https://www.cruse.org.uk/">https://www.cruse.org.uk/</a>	Website for Cruse, a bereavement support service													X				

<a href="https://www.goodlifedearthgrief.org.uk/content/support/">https://www.goodlifedearthgrief.org.uk/content/support/</a>	Good life, good death, good grief website. Advice for before and after death and dying. Targeted to a Scottish audience, however, has advice which is non-regional												X				
<a href="https://www.gov.uk/bereavement-support-payment">https://www.gov.uk/bereavement-support-payment</a>	UK government information available on financial support following bereavement												X				
<a href="https://www.gov.uk/funeral-payments">https://www.gov.uk/funeral-payments</a>	UK government information available on financial support for funeral costs												X				
<a href="https://www.ccsn.org/files/ugd/4a06ed12c08cd140b04e5c9bbf65f7b42a3bc9.pdf">https://www.ccsn.org/files/ugd/4a06ed12c08cd140b04e5c9bbf65f7b42a3bc9.pdf</a>	Self help guide on bereavement												X				
<a href="https://www.criticalcarecovery.com/Search.aspx?tag=257">https://www.criticalcarecovery.com/Search.aspx?tag=257</a>	Links to family support from the critical care recovery website													X			
<a href="https://icusteps.org/support">https://icusteps.org/support</a>	Support links via the ICU Steps website													X			
<a href="https://healthunlocked.com/search/posts?query=intensive%20care&amp;page=1&amp;community=all">https://healthunlocked.com/search/posts?query=intensive%20care&amp;page=1&amp;community=all</a>	Health unlocked - social network platform with a page dedicated to ICU													X			



[illegible]





[illegible]



[illegible]

[illegible]



[illegible]





[illegible]

[illegible]



[illegible]

[illegible]

[illegible]

## Figures

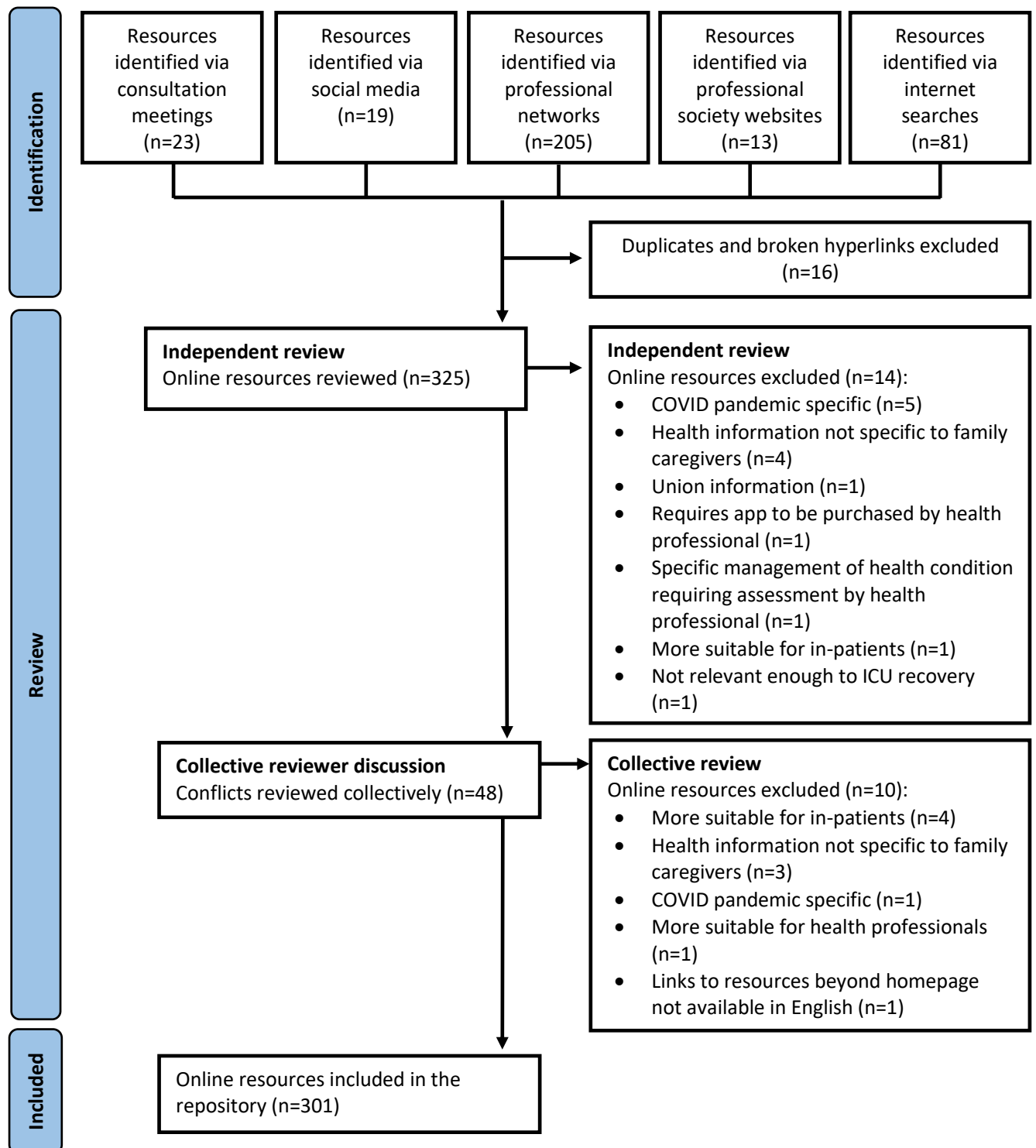


Figure 1 Flow diagram of the review process. This flow diagram demonstrates the number of online resources identified by each search method, the number excluded at each stage of the review, and the reasons for exclusion.