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An environmental scan of online resources for informal family caregivers of ICU survivors

Emily Flowers, BSc [a,b], Sian Saha, MA, RN [a,c], Laura Allum, MRes [a,d], Louise Rose, MN, RN, PhD [a,d,*]

[a] Faculty of Nursing, Midwifery and Palliative Care, Kings College London, 57 Waterloo Road, London SE1 8WA, United Kingdom
[b] Physiotherapy Department, King's College Hospital, Denmark Hill, London SE5 9RS, United Kingdom
[c] Department of Critical Care, King's College Hospital, Denmark Hill, London SE5 9RS, United Kingdom
[d] Department of Critical Care, Guy's & St Thomas' NHS Foundation Trust, United Kingdom

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ABSTRACT

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.

1. 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 h 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.

2. Materials and methods

2.1. 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.

2.2. 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.

2.3. Research phase: Search for online resources

2.3.1. 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.

2.4. Search resources and methods

2.4.1. Social media

We used our Life Lines Twitter account (https://twitter.com/LifeLines_ICU) to seek information from followers on relevant online resources. Our Twitter account has 2480 followers representing clinicians, researchers, and members of the public with an interest in intensive care.

2.4.2. 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.

2.4.3. 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/).

2.4.4. 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.

2.5. 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).

2.6. 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.

2.7. Delivery phase

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

3. Results

3.1. 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.

3.2. 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.

3.3. 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

Table 1
Information categories.

	Original information categories	Final information categories
Information categories from Patient and Public Involvement Group	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
Information categories from Expert Advisory Group	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
Additional information categories	Pain management	
	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.

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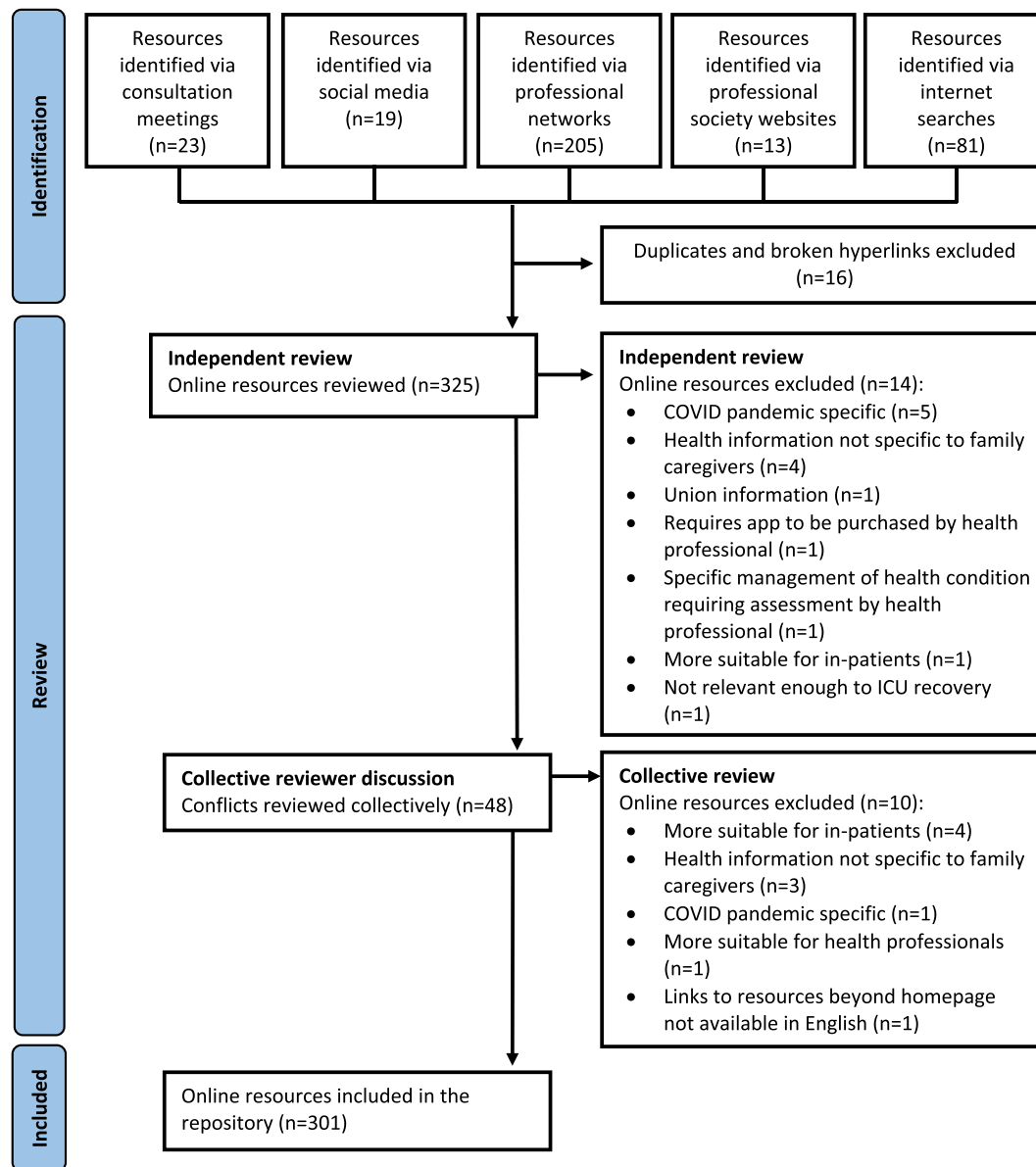
Fig. 1. Flow diagram of the review process. This flow diagram demonstrates the number of online resources identified by each search method, the number excluded at each stage of the review, and the reasons for exclusion.

301 online resources identified, 45 were selected for inclusion on our critical care recovery website http://gstt.criticalcarerecovery.com. This website has been adapted from a website originally developed for Scotland (https://www.criticalcarerecovery.com).

4. 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

Table 2
Final information categories resources.

Category	Number of resources
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

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.

5. 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.

CRediT authorship contribution statement

Emily Flowers: Conceptualization, Data curation, Formal analysis, Project administration, Writing – original draft. **Sian Saha:** Conceptualization, Data curation, Formal analysis, Funding aquisition, Project administration, Writing – review & editing. **Laura Allum:** Data curation, Writing – review & editing. **Louise Rose:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Project administration, Supervision, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

None.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jcrc.2023.154499.

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