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CLINICIAN AND PATIENT IDENTIFIED SOLUTIONS TO REDUCE THE FRAGMENTATION OF POST-ICU CARE IN AUSTRALIA

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TITLE: CLINICIAN AND PATIENT IDENTIFIED SOLUTIONS TO REDUCE THE FRAGMENTATION OF POST-

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KEY WORDS LIST

Aftercare, critical care, general practice**,** primary care, qualitative, recovery.

ABBREVIATIONS LIST

ICU: Intensive Care Unit

IRSAD: Index of Relative Socio-economic Advantage and Disadvantage

GPs: General Practitioners

PICS: post intensive care syndrome

ABSTRACT

Background: Critical care survivors experience multiple care transitions, with no formal follow-up care pathway.

Research Question: What are the potential solutions to improve the communication between treating teams and integration of care following an Intensive Care Unit (ICU) admission – from the perspective of patients, their caregivers, intensivists, and General Practitioners (GPs) from diverse socioeconomic areas?

Study Design & Methods: Qualitative design using semi-structured interviews with intensivists, GPs, and patients and caregivers. Framework Analysis was used to analyse data, and to identify solutions to improve the integration of care post-hospital discharge. Patients were previously mechanically ventilated for >24 hours in ICU and had access to a video-enabled device. Clinicians were recruited from hospital networks and a state-wide GP network.

Results: Forty-six interviews with clinicians, patients and caregivers were completed (15 Intensivists, 8 GPs, 15 patients and 8 caregivers). Three higher-level feedback loops were identified, that comprised of ten themes. **Feedback loop 1: ICU and primary care collaboration**: 1. Developing collaborative relationships between the ICU and primary care, 2. Providing interprofessional education and resources to support primary care, 3. Improving role clarity for patient follow-up care; **Feedback loop 2: Developing mechanisms for improved communication across the care continuum**: 4. Timely,

concise information sharing with primary care on post-ICU recovery, 5. Survivorship focused information sharing across the continuum of care, 6. Empowering patients and caregivers in self-management; 7. Creation of a care coordinator role for survivors; and **Feedback loop 3: Learning from post-ICU outcomes to improve future care**: 8. Developing comprehensive post-ICU care pathways, 9. Enhancing support for patients after hospital, 10. Integration of post-ICU outcomes within the ICU to improve clinician morale and understanding.

Interpretation: Practical solutions to enhance the quality of survivorship for critical care survivors and their caregivers were identified. These themes are mapped to a novel conceptual model that includes key feedback loops for health system improvements and foci for future interventional trials to improve ICU survivorship outcomes.

Survivors experience multiple care transitions in their recovery from the Intensive Care Unit (ICU) [1, 2]. Patients and their caregivers endure significant physical, psychological and cognitive disability after leaving the ICU, known as post intensive care syndrome (PICS) [3]. These outcomes are worsened by pre-existing health inequities, with lower socioeconomic position associated with increased mortality and worse mental health outcomes after ICU discharge [4, 5, 6].

Despite growing research interest, the provision of specialised ICU follow-up services for these patients remains limited in many regions [7, 8]. In Australia, primary care practitioners, known as general practitioners (GPs), provide healthcare outside of the hospital setting and operate across all socioeconomic groups. However, primary care practitioners have been somewhat neglected in understanding their role within ICU follow-up care [7]. In order to improve the integration of care from the ICU to primary care, a recent editorial called for the development of a standardised continuum of care for patients and families after critical illness [9].

Recent literature investigating the role of primary care in critical care recovery has highlighted significant communication gaps [10, 11, 12, 13, 14]. In a prior study, we described the interactions between ICU and primary care from the perspectives of healthcare users and healthcare providers. This prior study highlighted the *problems* - regarding gaps in communication, limited coordination of care between the ICU and primary care, that resulted in further care fragmentation [15]. Therefore, we conducted a further analysis of the same interview transcripts and data collected, with the aim of identifying potential *solutions* to improve the communication between treating teams and integration of care following an ICU admission – from the perspective of patients, their caregivers, intensivists, and GPs representing diverse socioeconomic areas, either by living (patient and caregivers) or working (intensivists and GPs) in diverse areas.

METHODS

This study is reported using the COnsolidated criteria for REporting Qualitative research checklist (e-Table 1) [16].

Setting and ethical approval

This multisite study was conducted across three metropolitan tertiary hospitals in Victoria, Australia, and a state-wide academic GP network within The University of Melbourne. Institutional ethical approval was gained from the Melbourne Health Human Research Ethics Committee (HREC/67240/MH-2020; Improving Integration Between Primary and Intensive Care After Critical Illness; Approval date 1 October 2020). All procedures were followed in accordance with the ethical standards of the Melbourne Health Human Research Ethics Committee and with the Helsinki Declaration of 1975. Verbal and written consent was gained for all participants prior to the interviews.

Study design

A qualitative study design was used, guided by the Framework Analysis method (e-Appendix 1), a preferred form of textual data analysis for consumer research, which aims to describe and interpret themes across cases in applied qualitative research [17], previously used in our healthcare research [2, 18]. Data collection and initial theme identification occurred using an inductive analysis approach, then a deductive analysis approach was utilised to map the themes to a previously published conceptual model.

Participants, sampling and recruitment

Purposive sampling was used to recruit participants representing socioeconomically diverse areas, as defined by the Australian Bureau of Statistics [19], using suburb of residence, for patients and caregivers, or suburb of work, for clinicians. Suburbs were used to calculate the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) score, ranging from 1 to 5, higher scores indicating relative advantage [19]. We aimed to recruit a target sample size of 15 participants per group, to achieve sufficient "information power" [20, 21]. Participants were screened and recruited as per Table 1. Interviews were arranged with the study coordinator for all participant groups. For patients, additional criterion sampling was used to seek out and select patients to promote variability and difference of survivorship experiences. Medical record data was used to identify risk factors for PICS including pre-ICU comorbidities, admission diagnosis, and requirement for outpatient rehabilitation [1].

Data collection and generation

A semi-structured interview schedule was used [15], that was informed by prior research [7, 22], and reviewed by an external qualitative expert. The interview schedule was designed to elicit ideas for improving the integration of care between the ICU and primary care. The lead author, with prior experience in qualitative interviews, conducted all interviews (NL, DPT, ICU physiotherapist/researcher, female). Some of the intensivist participants from one site had a clinical relationship with the interviewer, however all participants were aware of the interviewer's role, and

the interviewer was not directly involved in any of the patient participants' care. Interviews occurred from participants' homes and workplaces, conducted via Zoom (Zoom Video Communications, version 5.12.2) for 20-30 minutes. Only the participant and interviewer were present. If participants were recruited as dyads individual interviews occurred. No repeat interviews were conducted. Interviews were audio-recorded and transcribed verbatim using a transcription service. Member checking occurred with participants after transcription, and analysis, with no changes requested. Basic demographic information was collected from participants verbally at the interview, and further demographic details were collected from site ICU and hospital medical records for patient participants and stored in Excel (Microsoft, version 16.76).

Data analysis and rigor

Preliminary analysis of the data was completed by two experienced qualitative researchers (first and senior authors NL, KH) to develop a working analytical framework using the Phases of Trustworthiness [23], including use of recorded reflective discussions on interview content and each researcher's personal values and impressions, and field note recordings from both data collection and preliminary analysis stages. Four researchers (NL, KH, TR, KE) then used peer debriefing to code the data with regular reflection and cross-checking between researchers to ensure rigor and refinement of the analytical framework, to generate themes and reach agreement on the final analytical framework, see e-Table 2. Recruitment and data collection was ceased when data saturation, as determined using the concept of information power, occured when the analysis team determined no new themes were elicited from preliminary analysis of transcripts [20, 21]. Qualitative data was managed using Dedoose (SocioCultural Research Consultants, version 9.0.54).

RESULTS

Forty-six interviews with 15 intensivists, 8 GPs, 15 patients and 8 caregivers were conducted. There were no withdrawals. Most patients were originally admitted to ICU for cardiac or respiratory

failure, including COVID-19 diagnoses, and were recruited between 6 and 12 months after ICU discharge, see Table 2 for details.

A previously developed conceptual model (Figure 1) [15], was expanded upon to categorise potential solutions to improve the integration of care. The model included three key feedback loops: 1) ICU and primary care collaboration; 2) Developing mechanisms for improved communication across the care continuum; and 3) Learning from post-ICU outcomes to improve future care. Within these feedback loops, ten major themes were identified outlined below, and in Table 3. User-derived solutions are illustrated in Figure 2. Additional supporting quotes are provided in e-Table 3.

Feedback loop 1: ICU and primary care collaboration

1. Developing collaborative relationships between the ICU and primary care

Both clinician groups agreed improved collaboration was essential, although how to achieve this was unclear: "*I don't know what kind of model which we would work together in, but I think definitely some kind of link or service between the two*" (Intensivist, Male, 37 years, IRSAD 5). Information sharing was viewed as an important strategy to enhance patient care: "*if we strengthen our primary care and integrate GP care with hospital care, the patients will have better service, and a very rounded service provision*" (Intensivist, Female, 41 years, IRSAD 3).

2. Providing interprofessional education and resources to support primary care

Education on post-ICU impairments was viewed as important for both intensivists and GPs. Intensivists acknowledged not all clinicians working in ICU would be aware of the elements of PICS, risk factors and screening measures, and advocated for inclusion of this information in intensivist professional development: "*I remember giving the PICS presentation a few years ago at the Grand Round and a couple of my colleagues said "I had no idea that was as prevalent as it is"*" (Intensivist, Female, 39 years, IRSAD 3). Similarly, educational opportunities for GPs were suggested as a solution

to improve understanding of ICU care and post-ICU impairments, that should be co-designed with relevant stakeholders.

3. Improving role clarity for patient follow-up care

There was a lack of clarity regarding which clinical groups should be responsible for provision of follow-up care for ICU survivors. For some intensivists this was related to expertise, and also clinical interest in ICU follow-up clinics: "*I'm pretty confident it wouldn't be in the interest to many intensivists to attend that clinic or to be a part of that clinic… they wouldn't be good at it, they wouldn't get enjoyment or satisfaction out of it*" (Intensivist, Male, 46 years, IRSAD 3). GPs similarly felt whilst they may play some role in follow-up care for ICU survivors, they were not best placed to deliver comprehensive post-ICU care or rehabilitation, suggesting this role may be better suited to other members of the clinical team: "*I feel like my patients often have too many doctors in their life, but they don't have enough allied health in their life*" (GP, Female, 44 years, IRSAD 3).

Feedback loop 2: Developing mechanisms for improved communication across the care continuum

4. Timely, concise information sharing with primary care on post-ICU recovery

All participants described the importance of improved communication with primary care regarding post-ICU care needs, recommending a handover should occur - that is ICU specific, survivorship focused, concise, and timely. Caregivers identified the need for increased specificity of ICU issues in formal communication to community care providers, which would have a profound impact on timeliness of patient care, for a relatively small burden of time investment from ICU clinicians. Similarly, patient participants advocated for ICU specific information in the discharge summary provided to GPs: "*that would be helpful to provide the GP with a much more comprehensive picture of you know, all the relevant information. So that he's got that there at his fingertips*" (Patient, Female, 39 years, IRSAD 2).

5. **Survivorship focused information sharing across the continuum of care**

Intensivists advocated for more survivorship focused communication within hospital discharge summaries, emphasising the importance of a more functional-based, holistic approach to medical summaries for directed future care: "*putting more emphasis on some of the survivorship things in that discharge summary in addition to the acute medical problems*" (Intensivist, Female, 39 years, IRSAD 3). It was acknowledged that the synthesis and provision of this information may require additional resourcing: "*you can't expect a ward resident to be able to do that, maybe that's part of the liaison or the outreach service or the liaison service that could generate that information for the GP's or liaise with the GP's*" (Intensivist, Male, 45 years, IRSAD 5).

6. **Empowering patients and caregivers in self-management**

Empowering patients and caregivers through informational support may be a key solution to enhance patient recovery. Such information could include community service availability and patient and caregiver specific recovery information on nutritional, physical, psychosocial recovery. Patients highlighted how knowledge can be a powerful mediator of self-management, with one participant comparing hospital admissions: "*I cannot tell you the difference this time, it is like 80% difference in terms of knowledge, information, very particular support*" (Patient, Female, 61 years, IRSAD 5). One solution proposed was a patient and information portal, to contain recovery information to support improve self-management in the community.

7. **Creation of a care coordinator role for survivors**

Participants identified a new ICU specific care coordinator role to improve the coordination of care across the continuum, particularly useful at all key transition points: "*there's this person missing and that person missing should be the one that allows the patient connect to the workers you know in a better way*" (Patient, Female, 43 years, IRSAD 1). GPs felt this supportive role would advocate for patient and caregiver wishes, distil medical information and support patient and care expectations at

key transition points: "*there's somebody who bridges both worlds that isn't the patient, I think that's helpful across the board*" (Intensivist, Female, 39 years, IRSAD 3).

Feedback loop 3: Learning from post-ICU outcomes to improve future care

8. Developing comprehensive post-ICU care pathways

Participants described a post-ICU comprehensive care clinic solution would improve survivorship through comprehensive assessment and intervention for patients and caregivers. A multidisciplinary model was proposed, modelled off the success of the ICU team-based model of care, similar to long stay ICU patient meetings: "*to be able to talk through … what to expect are some of the long-term consequences of you know the medications and what happened*" (GP, Male, 38 years, IRSAD 5). However, which, if any, medical specialty would be required to run the clinic would need further consideration, as one Intensivist explained: *"you could absolutely run such a clinic without a single intensivist setting foot in it"* (Intensivist, Male, 44 years, IRSAD 5).

9. Enhancing support for patients after hospital

All participant groups suggested survivorship outcomes could be improved through greater awareness of, and access to community-based support, such as peer support: "*normalising the experience and sharing the experience and gaining strength through others having overcome difficulties and just a sounding board*" (Intensivist, Male, 44 years, IRSAD 5). Increasing awareness of post-ICU impairments with community-based clinicians could also support patient and caregiver expectations of recovery, and empower them to seek out recovery support services.

10. Integration of post-ICU outcomes within the ICU to support clinician morale and understanding

ICU follow-up programs can provide dual benefits for patients and clinicians, through creation of a feedback loop to potentially inform treatment decisions within the ICU. This awareness of outcomes

via patient visits to the ICU or follow-up clinics, could contribute to ICU care delivery: *"I don't think we have enough long-term feedback looped into the decision making in ICU about what people look like"* (Intensivist, Male, 43 years, IRSAD 5). Furthermore, some argued it was important to collect objective patient reported outcome measures, rather than just success stories.

DISCUSSION

This qualitative study investigated solutions to improve the integration between primary and intensive care, from patients, caregivers, intensivists and GP participants representing socioeconomically diverse areas. This study provided new insights into solutions, which may improve coordination of post-ICU care and linkages between primary and intensive care to improve post-ICU outcomes including: communication tools for primary and intensive care, solutions to improve education of clinicians and patients about PICS and care coordination on the journey from intensive to primary care. A conceptual model of care is provided, where the themes presented converge, and present opportunities to design and test new interventions to improve critical care outcomes.

Data presented in this study highlight the importance of improving relationships and availability of services across the continuum of care to reduce fragmentation between ICU and primary care. Issues can occur along this continuum, with feedback loops and potential solutions proposed that align with aspects of our previous research [2, 18]. Other studies from the UK and US have highlighted similar issues, such as information sharing between ICU and GP [10, 11, 13], limited patient knowledge of post-ICU issues [24], and the lack of awareness of PICS [7, 14]. Similarly, our data suggests virtual follow-up models of care and co-designed recovery models of care are likely to be helpful. These models are currently being developed in research [25], highlighting the time-lag phenomena between research and clinical practice. Our data also highlights the importance of expectation setting and empowerment through education, confirming previous research identifying the lack of survivorship focused communication and knowledge in ICU [26]. Improving communication from ICU to GPs was highlighted, confirming prior research [13]. Whilst a staggered, separate concise ICU summary may be of benefit for

some, and would provide greater emphasis on ICU specific issues, this may be not be time sensitive, and lack accuracy upon patient presentation to primary care. There is merit in a single, concise, comprehensive ICU and acute hospital synthesised discharge information package that includes information from pre-hospital, ICU and post-ICU hospitalisation to provide a holistic comprehensive summary and plan. Further research into the optimal design, mode of delivery, and clinical responsibility for this communication is required.

In contrast to prior research, our study provides more in-depth data through inclusion of patient and caregiver perspectives to identify solutions to address the current gaps in care. New concepts include non-medical led models of post-ICU care coordinator roles, similar to models previously studied involving nurse coordinators in sepsis survivors [27]. This solution potentially fills a gap that previously had funding and specialised provider resourcing limitation [28, 29].

In Australia, ICUs and hospitals are currently funded by the state government, whilst primary care is federally funded, which may pose further challenges when developing integrated care models, in contrast to healthcare funding models across Europe and the United States, where some regions may have more privately-funded healthcare. In Australia, approximately 85% of disease burden and overall healthcare costs are attributable to chronic conditions [30]. GPs are the most frequently accessed healthcare provider in Australia, accessed by 83.6% of Australians [31], and provide the majority of chronic disease management in Australia [32]. Whilst some concurrent care models with specialist consultants exist for antenatal, cancer and diabetes care [33], and novel shared care models are being investigated [34], there are no formal post-ICU care pathways in Australia, with a reliance on primary care to support chronic disease complications of surviving an ICU admission [2]. This increased burden, coupled with limited remuneration and burnout has led to a declining workforce, particularly in remote or rural areas, or a switch to private billing models, impacting accessibility [35]. Whilst there is increased availability of post-ICU services such as follow-up clinics in other regions including the United States and Europe, the challenges experienced by survivors are similar [2]. Acknowledging the heterogeneity of ICU survivorship issues, there are promising models of post-ICU care management

being explored globally, including care navigation [27], integrated health and social care [36], virtual peer

support (ACTRN12621000737831) and telehealth clinic models (NCT03926533). One of the few trials

of a primary-care intervention for ICU survivors, including nurse-led case management and clinical

decision support for GPs, did not demonstrate benefit in mental health outcomes [37]. This trial was

conducted in Germany and transferability to other regions with differing primary healthcare setups

remains uncertain. Our study highlights that, particularly in a system with publicly-funded hospitals

and GPs providing most primary care, improving the relationship between ICU and primary care,

better defining care pathways and clinician roles in those pathways, improving education and support

to GPs, and the development of improved, co-designed handover information by clinicians from both

primary and intensive care, would be important next steps in the field of ICU recovery. The Health

Pathways portal, an online clinician education platform, does not currently include PICS, and several

GPs proposed including information on PICS on the Health Pathways, or similar, portal. Whilst

resources similar to the patient and clinician education portal suggested in this study exist

(https://icusteps.org/; https://www.mylifeaftericu.com/), they may not necessarily be currently well

integrated within the healthcare system or be known by their target audience.

This study was rigorously conducted, and the first to include user-derived practical solutions,

and perspectives from a diversity of clinicians, including GPs, and participants representing diverse

socioeconomic areas, to inform data. This study had some limitations. Firstly, GP recruitment was

limited despite multiple recruitment methods, which may reflect workforce challenges resulting from

the COVID-19 pandemic and vaccine roll out. Secondly, the study sample reflects recruitment from

Melbourne, Australia, limiting transferability to international settings. Additional sampling bias may

exist related to the requirement of participants to have technology access to participate in the study,

potentially causing a digital inclusion bias, and the limitations of the location-based diversity measure

(IRSAD) without representative sampling to individual category characteristics, limiting the true

diversity representation in the sample. Further bias may be present related to the timing of

recruitment occurring during the COVID-19 pandemic, when a significant increase in respiratory

related and ICU admissions occurred in Australia, in conjunction with rapid implementation of reduced or telehealth models of outpatient care, which may have impacted the data captured from participants who had experienced the health system at this time. Thirdly, the clinicians involved in this research were not given a specific patient case to consider when participating in the interview, and therefore ideas generated will reflect the heterogeneity of the ICU patient population. Fourthly, the interviewer was an ICU allied health clinician which may have introduced bias into participants' responses, although all participants were encouraged at interview commencement to speak freely. Finally, whilst the integration between intensive and primary care was highlighted, an important intermediary in the transfer of information between these settings is the hospital and rehabilitation wards, however these views were not explicitly sought for this study. Future research including these groups is warranted to ensure survivorship improvement strategies are created for, and implemented across the spectrum of post-ICU care.

INTERPRETATION

Ten major themes to improve enhanced recovery support for critical care survivors within existing healthcare system structures by leveraging existing resources and expertise were identified, and practical solutions were suggested. Our data highlights the importance of comprehensive communication and active relationships between primary and intensive care clinicians. These themes are mapped to a novel conceptual model that includes key feedback loops for health system improvements and foci for future interventional trials to improve ICU survivorship outcomes.

Take Home Points:

Study Question: What are the potential solutions to improve the communication and integration of care between the intensive care unit and primary care?

Results: Practical solutions are identified to enhance recovery support for critical care survivors by leveraging existing resources and expertise within current healthcare system structures, including the primary care setting. These solutions include comprehensive communication, active relationships between primary and intensive care clinicians, and the role of allied health. A new conceptual model was developed that included description of three main feedback loops for health system improvements.

Interpretation: Solutions identified should be the foci for future interventional trials to improve ICU survivorship outcomes.

FIGURE LEGENDS

Figure 1: A conceptual model of user-derived solutions mapped to feedback pathways across transitions of care from ICU to primary care

Figure 2: User derived solutions to improve integrated care

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Table 1: Participant eligibility and screening

Participant Group	Inclusion criteria	Exclusion criteria	Recruitment process
1: Patients and caregivers	• ≥18 years of age • Mechanically ventilated for ≥24 hours • Access to a computer/tablet with a microphone, camera and internet, or smartphone (determined at screening)	• Non-English speaking • Any cognitive or neurological issue that limited complete participation in the interview	Identified through local discharge records and invited to participate in the study by the lead investigators at each participating ICU site. Carers were identified where present from hospital records, and recruited as patient-carer dyads.
2: Intensivists	Nil	Nil	Participants were identified and invited to participate via email within working networks at participating hospital sites. A follow-up phone call was completed by the study coordinator to obtain verbal consent
3: GPs	Nil	Nil	Participants were identified and invited to participate via the established University of Melbourne's Victorian Primary Care Practice-based Research and Education Network. A follow-up phone call was completed by the study coordinator to obtain verbal consent.

Table 2 – Participant demographics

	Participant Group 1		Participant Group 2	Participant Group 3
	Patients (n = 15)	Caregivers (n = 8)	Intensivists (n = 15)	General Practitioners (n = 8)
Age (years) Mean (SD)	59 (17)	59 (12)	43 (4)	46 (9)
Sex, n (%)				
Male	8 (53)	2 (25)	11 (73)	3 (38)
Female	7 (47)	6 (75)	4 (27)	5 (63)
IRSAD quintile, n (%)				
IRSAD 1 (most disadvantaged)	4 (27)	2 (25)	0 (0)	1 (13)
IRSAD 2	6 (40)	4 (50)	0 (0)	2 (25)
IRSAD 3	2 (13)	1 (13)	4 (27)	2 (25)
IRSAD 4	1 (7)	0 (0)	0 (0)	1 (13)
IRSAD 5 (most advantaged)	2 (13)	1 (13)	11 (73)	2 (25)
Cultural and language background, n (%)				
Aboriginal or Torres Strait Islander	1 (6.7)	-	-	-
English as primary language	15 (100)	-	-	-

ICU admission diagnostic category, n (%)				
Respiratory failure	3 (20)	-	-	-
Cardiovascular	3 (20)	-	-	-
Trauma	2 (13.3)	-	-	-
Neurological/neurosurgical	1 (6.7)	-	-	-
COVID-19	3 (20)	-	-	-
Other	3 (20)	-	-	-
Pre-ICU comorbidities, n (%)				
Mental Health problems (anxiety, depression, PTSD)	3 (20)	-	-	-
Self-identified physical problems (functional disability, frailty)	2 (13.3)	-	-	-
Other	2 (13.3)	-	-	-
None identified	8 (53.3)	-	-	-
ICU Length of Stay (days), median (IQR)	10 (7-38)	-	-	-
Mechanical Ventilation (hours), median (IQR)	143 (75-368)	-	-	-

Acute Hospital Length of Stay (days), median (IQR)	33 (13.5-66)	-	-	-
Illness Severity Score: APACHE III, mean (SD)	71.5 (24.0)	-	-	-
Length of time since acute hospital discharge, n (%)				
<6 months	5 (33.3)	-	-	-
7-11 months	6 (40)	-	-	-
1-2 years	4 (26.7)	-	-	-
Number of GP visits since acute hospital discharge, mean (SD)	7 (7.4)	-	-	-
Received outpatient rehabilitation, n (%)	10 (66.7)	-	-	-
Services received initially after acute hospital discharge, n (%)				
Physiotherapy	10 (66.7)	-	-	-
Personal Care assistance	1 (6.7)	-	-	-
Other allied health (SP, OT)	8 (53.3)	-	-	-
None	2 (13.3)	-	-	-
Services received at time of interview, n (%)				

Physiotherapy	8 (53.3)	-	-	-
Other allied health (SP, OT)	6 (40)	-	-	-
None	5 (33.3)	-	-	-
Relationship to patient, n (%)				
Spouse	-	5 (33.3)	-	-
Parent	-	1 (6.7)	-	-
Sibling	-	1 (6.7)	-	-
Other	-	1 (6.7)	-	-
Number of years' clinical experience (GP group only), mean (SD)	-	-	-	20.4 (11.3)
Number of years' specific clinical experience (critical care or GP as appropriate), mean (SD)	-	-	14.2 (4.2)	16.4 (10.6)
Average number of patients post-ICU cared for per year, mean (SD)	-	-	-	8.1 (11.5)

IRSAD = The Index of Relative Socio-economic Advantage and Disadvantage, a summary of information about the economic and social conditions of people and households within an area. A lower score indicates relatively greater disadvantage.

SP = Speech Pathology; OT = Occupational Therapy; APACHE = Acute physiology and chronic health evaluation; PTSD = Post traumatic stress disorder; GP = General practitioner; ICU = Intensive care unit

Adapted from: Leggett, N., Emery, K., Rollinson, T.C., Deane, A., French, C., Nankervis, J.A.M., Eastwood, G., Miles, B., Merolli, M., Abdelhamid, Y.A. and Haines, K.J., 2023. Fragmentation of care between intensive and primary care settings and opportunities for improvement. *Thorax*, *78*(12), pp.1181-1187.
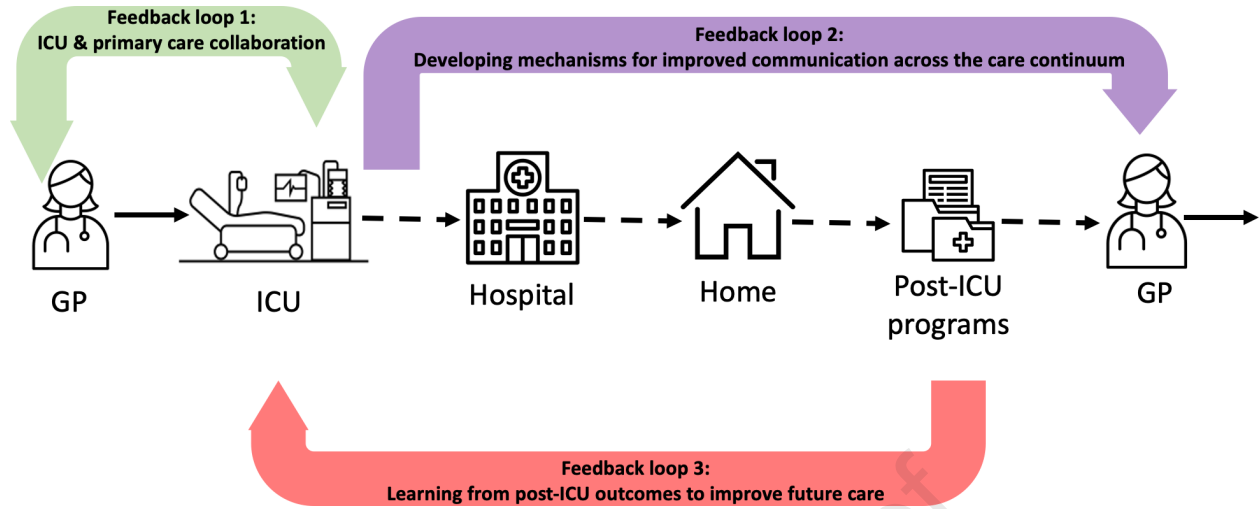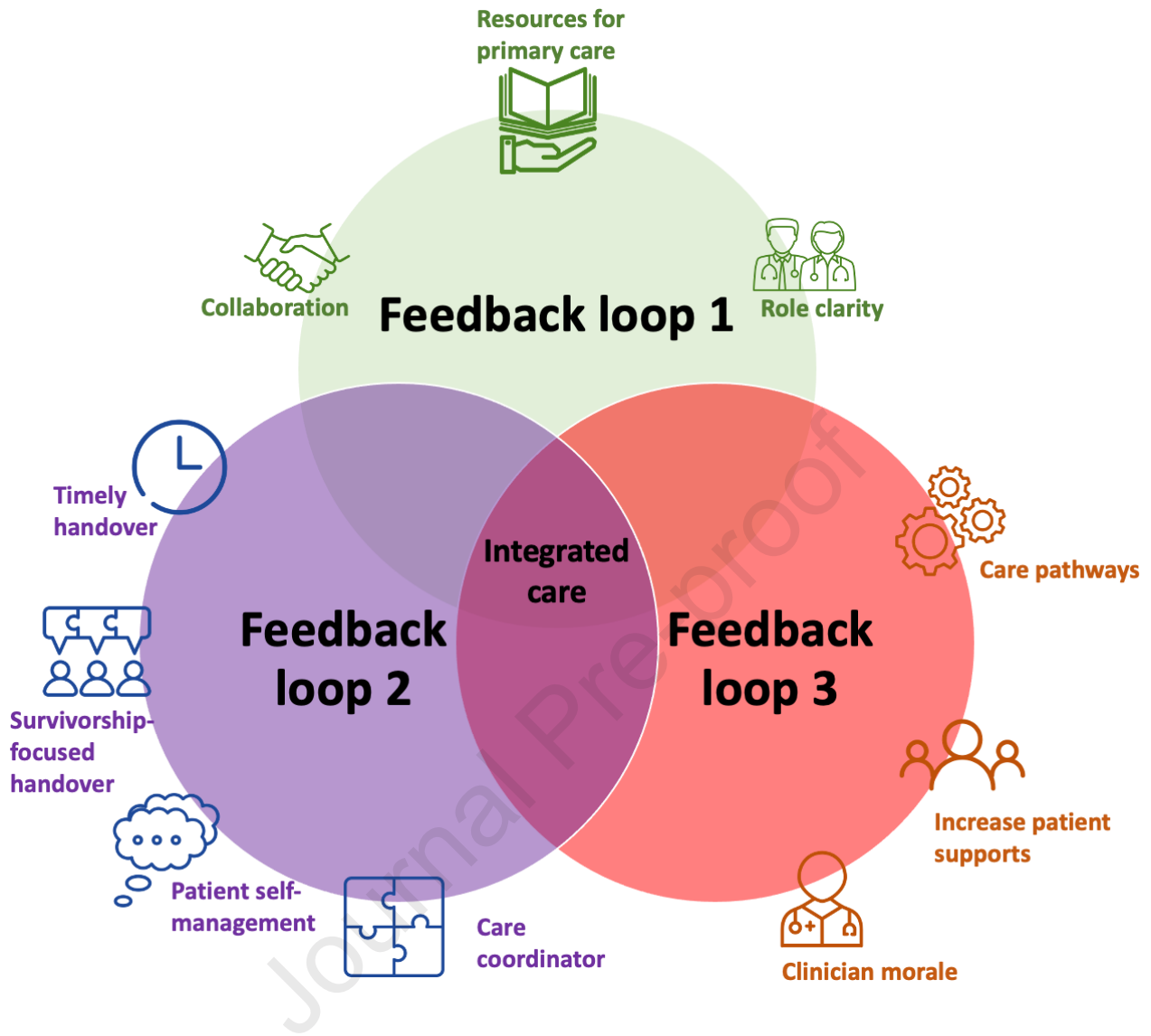
Table 3: User-derived solutions proposed

Feedback Loop	Theme	User-derived solution
ICU and primary care collaboration	1. Developing collaborative relationships between the ICU and primary care	Provision of direct ICU phone contact in discharge summary to GP
		Telephone update during ICU admission to GP
		Inclusion of patient GP via telehealth in ICU family meetings
		Invitation for hospital Grand Rounds to local GP networks
	2. Providing interprofessional education and resources to support primary care	Formal intensivist education on post-ICU sequalae
		GP education through attendance at ICU ward round
		Updating Health Pathways portal to include information on PICS assessment and management
		GP guideline development on specific post-ICU care
		ICU rotation during GP formal training
	3. Improving role clarity for patient follow-up care	Increased allied health role in post-ICU care
		Role clarity for GP and Intensivists in post-ICU care
Developing mechanisms for improved communication across the care continuum	4. Timely, concise information sharing with primary care on post-ICU recovery	Direct letter to GP from ICU with concise synthesis of the major issues and prognostic indicators
		Ensuring all patients have a GP and appointment prior to hospital discharge
		GP access to hospital electronic health record
	5. Survivorship focused information sharing across the continuum of care	Including functional-based, holistic information in medical discharge summary to GP
		Inclusion of ICU liaison and care coordinator recommendations and summary in medical discharge summary to GP
		Allied health input to ensure functional recovery plan in place before hospital discharge
	6. Empowering patients and caregivers in self-management	Develop patient information portal on recovery expectations, descriptions of PICS components and community supports available
		GP access to patient information portal
		Provision of PICS information to patients to take to their GP
Learning from post-ICU outcomes to improve future care	7. Creation of a care coordinator role for survivors	Non-physician led care coordinator role for ICU patients after ICU discharge to support at key transition points
	8. Developing comprehensive post-ICU care pathways	Post-ICU comprehensive care clinic co-designed with patients and carers

		Telehealth delivery model for post-ICU care clinic
		Targeting post-ICU clinic for long stay ICU patients
	9. Enhancing support for patients after hospital	Increased access to ICU diary programs
		Increased access to post-ICU peer support groups
		Expectation setting at pre-hospital discharge counselling
		Increased prevalence of post-hospital recovery/rehabilitation programs, including telehealth and home-based service options
	10. Integration of post-ICU outcomes within the ICU to support clinician morale and understanding	ICU survivor visits back to ICU
		Intensivist attendance at follow-up clinic

ICU = Intensive Care Unit; GP = General Practitioner; PICS = Post Intensive Care Syndrome

Feedback loop 1:
ICU & primary care collaboration

Feedback loop 2:
Developing mechanisms for improved communication across the care continuum

GP   ICU   Hospital   Home   Post-ICU programs   GP

Feedback loop 3:
Learning from post-ICU outcomes to improve future care

Resources for
primary care

Collaboration **Feedback loop 1** Role clarity

Timely
handover

Integrated
care

**Feedback
loop 2**

**Feedback
loop 3**

Care pathways

Survivorship-
focused
handover

Patient self-
management

Care
coordinator

Increase patient
supports

Clinician morale

SUPPLEMENTAL DIGITAL CONTENT

e-Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

e-Table 2 Working Analytical Framework: Group 1: patients and caregivers

e-Table 3 Additional Results Quotes

e-Appendix 1: Additional methodological information

e-Table 1: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	7
3. Occupation	What was their occupation at the time of the study?	7
4. Gender	Was the researcher male or female?	7
5. Experience and training	What experience or training did the researcher have?	7
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Table 1
12. Sample size	How many participants were in the study?	8
13. Non-participation	How many people refused to participate or dropped out? Reasons?	8
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	7
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Supplementary Table 3
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	7
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	7
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	7
20. Field notes	Were field notes made during and/or after the inter view or focus group?	7
21. Duration	What was the duration of the inter views or focus group?	7
22. Data saturation	Was data saturation discussed?	7
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	7
Domain 3: analysis and findings		
Data analysis		

24. Number of data coders	How many data coders coded the data?	7
25. Description of the coding tree	Did authors provide a description of the coding tree?	Supplementary Table 2
26. Derivation of themes	Were themes identified in advance or derived from the data?	8
27. Software	What software, if applicable, was used to manage the data?	8
28. Participant checking	Did participants provide feedback on the findings?	7
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	8-12
30. Data and findings consistent	Was there consistency between the data presented and the findings?	8-12
31. Clarity of major themes	Were major themes clearly presented in the findings?	8-12
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	8-12

e-Table 2: Working Analytical Framework: Group 1: patients and caregivers

Example of use of analytical framework to apply codes and themes to transcripts

THEME	PATIENT/CAREGIVER CODES	Example quote
Relationship and role of GP in patient recovery	Solution: improved discharge summary to GP, include ICU information	*"Just an update on my medication and you know if he gives me other medication to go on with I didn't know whether it was going to clash with what I was taking you know, so, I think that's important. I think it would have been important that they contacted him in that regard"* Patient, Male, 68 years, IRSAD 2
	Solution: priority scheduling for complex patients with GP	*"I'd love to see and maybe some GP clinics do this, a better way of, like the GP is great but just some way of flagging with reception, you know there are patients that maybe you know, might need to get in at last minute or just you know, to get a phone call back from the GP to talk about something. Or you know, might need a bit more urgent attention "* Patient, Female, 39 years, IRSAD 2
	Solution: nursing triage support at GP clinic	*"I think there's potentially more value that they could provide like at hospitals where they might take calls and help kind of triage a little bit. If someone really needs to you know, talk to a GP or just yeah, just strengthen that nursing support where that might be able to suffice in some cases you know, the GPs are busy or yeah"* Patient, Female, 39 years, IRSAD 2
Challenges of transitions of care	Solution: setting patient and family expectations	*"there should be some kind of family or support person conference that happens before people go in, or at the moment of admission or something, so that somebody can sit down and say these are all the things that are going to happen, this is what it's going to be like from the beginning"* Patient, Female, 61 years, IRSAD 5
	Solution: support person for patients at time of admission	*"I don't think it would take that long, and maybe that's what it is, it's part of the admission process, and you and a support person, if that's possible you know, that you have one"*

		Patient, Female, 61 years, IRSAD 5
	Solution: handover and prioritised waitlist for transition to community services	*"It would be a much smoother transition if you know I already knew in advance that once I'm not in hospital anymore that's what I'm doing and they should you know as someone being in hospital there shouldn't be a 14 week waiting list for me to see a psychologist like there should be you know a way that because I'm already in a system that I get accepted without there being some waiting list"* Patient, Female, 43 years, IRSAD 1
Awareness of and access to existing post discharge services	Solution: on call nursing support post discharge	*"There probably is some kind of nursing service that you can ring up for a fee"* Patient, Female, 61 years, IRSAD 5
	Solution: provide information on supports available post discharge and signposting level of care appropriate for each	*"Like a list just something really straightforward saying you know there's physio, there's this, there's that and just that being really black and white to know who to marry what to you know and to know to ask certain questions to certain people"* Patient, Female, 43 years, IRSAD 1

IRSAD = The Index of Relative Socio-economic Advantage and Disadvantage, a summary of information about the economic and social conditions of people and households within an area. A lower score indicates relatively greater disadvantage.

e-Table 3: Additional results quotes

Theme	Supporting quote
1. Developing collaborative relationships between the ICU and primary care	"*There is a complete lack of interaction between what goes on outside the hospital and what goes on inside it*" (Intensivist, Male, 50 years, IRSAD 3). "*Unless there's a much closer relationship between primary care services and hospital services, and more integration, things won't change*" (GP, Male, 55 years, IRSAD 5). "*I wouldn't call it relationship with the hospital*" (GP, Male, 59 years, IRSAD 4). "*I wonder if GPs could be involved more heavily right at the start. You know…Zoom the GP in with the family conversations*" (Intensivist, Female, 41 years, IRSAD 3) "*We've started getting invited to the Western Health grand rounds … somebody went oh we're doing it all online, why don't we invite all the GPs*" (GP, Female, 44 years, IRSAD 3). One solution was to provide the name and direct phone number of the treating intensivist in the discharge summary: "*direct communication is actually probably one of the best ways to actually allow these conversations to occur*" (Intensivist, Female, 45 years, IRSAD 5). Alternatively, others suggested a telephone update directly from ICU to the GP could occur for a select group of patients that may have higher care needs: "*I can't say for each and every patient they should call the GP… but sometimes I do get calls… you know the patients that really need care*" (GP, Female, 45 years, IRSAD 2).
2. Providing interprofessional education and resources to support primary care	"*Certainly, we need more education with the wider clinician group about the morbidities of critical care and how that impacts life*" (Intensivist, Female, 41 years, IRSAD 3). "*There would need to be a lot of education about the impacts of critical illness in the longer term that patients, that GP's may not be aware of*" (Intensivist, Male, 45 years, IRSAD 5) "*See what critical illness is and what being intubated and ventilated haemofiltered … looks and feels like, at a visceral sense*" (Intensivist, Male, 49 years, IRSAD 5) "*Rotate and spend a bit of time in ICU during their FRACGP [GP training]*" (Intensivist, Female, 45 years, IRSAD 5).

	GPs highlighted Health Pathways (developed by Canterbury District Health Board, New Zealand) as an online, evidence-based, medical information portal accessible in primary care that could be used to deliver such education: *"help guide any specific treatments or anything like that but also just to help guide patient expectations and for us to be able to provide that sort of information"* (GP, Male, 38 years, IRSAD 5). GPs suggested a clinical guideline to inform assessment and treatment of PICS, similar to other existing care coordination pathways, such as post-natal care: *"something similar like at one month post discharge… what's their exercise tolerance, and do this mental health screening… just to give you an idea of what you should be looking for"* (GP, Female, 31 years, IRSAD 1). *"I'd ask them what they thought would be helpful, ask them what they don't know and what would help… rather than just assuming we know what they don't know"* (Intensivist, Male, 44 years, IRSAD 5).
3. **Improving role clarity for patient follow-up care**	*"I would hesitate to endorse an ICU specialist led model because I think we will miss more than we find. I would never put us higher than co-managers of a model, and that I would argue that we're not experts in ambulatory care, and that it should be a multidisciplinary model, multi-professional model, and that we're going to need ambulatory outpatient experts, we're going to need absolutely physiotherapy as a more central if not the central determinant, and we're going to need a shared footprint with some psychological services, if not proper psychiatry"* (Intensivist, Male, 44 years, IRSAD 5) *"There's a sense of from a lot of people – this is not what I've signed up to do, so there is that phenomenon in ICU at the moment with outreach – oh we don't want to solve the ward's problems"* (Intensivist, Male, 44 years, IRSAD 5). *"There are consultants alive now who did not sign up for medical emergency teams at outreach and resent the very fact that that's thrust upon them. There are consultants who didn't sign up to outsource organ donation discussions with other people, and that change management is hard, and that changing how some of us dinosaurs think, and act is going to be challenging. But I think that the rising tide will lift all boats, if you put it out there as actually this is a positive and desirable thing to do, but we're not going press gang everybody into doing it, I think you'll find motivated individuals that will make it work and will demonstrate its workability"* (Intensivist, Male, 44 years, IRSAD 5). Clinician participants identified that allied health professionals could potentially have a greater role in ICU follow-up across the continuum of care: *"Allied Health are a great link between ICU and the wards because you follow their progress and often follow-up patients on the wards as well. And certainly, I think there might be a role [for allied*

		health] just like there's a patient liaison officer, this might be a role in itself is where you're helping the patients and their family's transition from ICU to the wards and then onto rehab" (Intensivist, Female, 41 years, IRSAD 3).
4.	**Timely, concise information sharing with primary care on post-ICU recovery**	*"It probably wouldn't be that hard for them to send a report and a brief summary of where NAME is at now and what she needs, so the doctor just knows straight away and it wouldn't take up too much of the GP's time to read a brief letter just to make everyone's life easier like you would in any other job in the world you'd do a quick handover"* (Caregiver (paid), Female, 38 years, IRSAD 1). *"I think the clinical handover should be you know this is the condition they were in hospital for – and this is being managed this way, they have a protracted stay in intensive care with these sort of complications and so these are the issues that we're looking out for and what needs to be managed"* (GP, Male, 59 years, IRSAD 4). *"I f it were easier for health care workers across professions and across GP and hospital land and across physio and doctor, and across outpatients and inpatients to actually access each other's information, I think that would be so much more straightforward"* (Intensivist, Female, 39 years, IRSAD 3) *"The holy grail would be that you don't get discharged from a hospital unless you've got an appointment with your local GP, and if you don't have a local GP, that the people can't discharge you from the hospital until you have an appointment with a GP who is considered to be of a reasonable standard to the hospital"* (GP, Male, 55 years, IRSAD 5). *"T hey tell me that we are sending this one but we want you to follow-up in a week or in 3 to 4 days and usually I put a reminder before the discharge summary that comes to me"* (GP, Female, 45 years, IRSAD 2). *"The new development or relatively new development of the staggered discharge summary has definitely been beneficial"* (GP, Female, 47 years, IRSAD 3) *"T here could've been a little bit more … this is your patient, he was admitted dadada this is what happened, we just wanted to inform you"* (Caregiver, Female, 47 years, Parent, IRSAD 1). Both intensivists and GPs emphasised the importance of a concise synthesis of information: *"it's a huge vast amount of information for a GP to go through and whatever's going to be a 15, 30-minute consultation"* (Intensivist, Male, 37 years, IRSAD 5).

		Information sharing should also inform onward care by GPs, particularly via inclusion of prognostic information, and screening for future impairments: *"if any of that happens obviously we want to know about it and what we can do about it or what the prognosis is"* (GP, Female, 44 years, IRSAD 3). Both clinician groups advocated for the timeliness of information following hospital discharge, and proposed digital health solutions such as telephone calls and electronic health records, to improve this, although participants expressed frustration within the current systems: "…[the electronic medical record is] *appalling and should be easier… like should be working for us instead of against us"* (Intensivist, Female, 39 years, IRSAD 3).
5.	**Survivorship focused information sharing across the continuum of care**	*"Unless we actually provide education to them in some forum, whether it be proper delineation of a post ICU syndrome and the options that are available, and things to look out for"* (Intensivist, Male, 43 years, IRSAD 5). At hospital discharge patients and caregivers acknowledged the allied health role was integral to their recovery trajectory: "*the dietitian was the one that set her* [the patient] *straight and what she was meant to be eating and drinking, and when and how… taught me how to manage things for her better"* (Caregiver, Female, 60 years, Spouse, IRSAD 5).
6.	**Empowering patients and caregivers in self-management**	*"When you leave there you don't really leave there with much, you know, it'd be nice to leave with a piece of paper that sort of says if you have any problem of this nature, contact your GP, if you have a problem of this nature contact you know – there's someone in between the GP and the emergency"* (Patient, Female, 61 years, IRSAD 5). *"I'm sure that a web-based repository of at least where to from here, either under a health service banner or an ICU survivors dot come or some other general domain could be a helpful thing, and that could be things that learned colleges support, whether it be physio or college of intensive care, they could certainly be endorsed and supported, those would be helpful ways of improving the flow of information"* (Intensivist, Male, 44 years, IRSAD 5). Patients felt they did not have sufficient knowledge to know where to direct specific concerns and caregivers reported such a portal would be a useful resource to be aware of supports available: "*telling people as much as you can and even if it's a generic list of potential services that you may or may not access but just knowing what you could access"* (Caregiver (paid), Female, 38 years, IRSAD 1). Clinicians suggested this would ensure more appropriate use of healthcare resources, where a patient self-managed portal could direct the patient to relevant clinical services to manage their specific issues: "*because the system is so siloed and doesn't link at all, I think patients feel like if they have a problem in the hospital, they should call someone in the hospital"* (Intensivist, Female, 39 years, IRSAD 3).

		It was suggested this information provision could provide patients and caregivers with the language to describe current issues or symptoms, and be a useful tool to communicate their post-ICU issues with their primary care providers: "*highlight things to patients that they may not often think of as something they could go to their own GP with*" (Intensivist, Male, 37 years, IRSAD 5). Health care providers may similarly benefit from such a resource: "*there would be some portal for the ongoing care providers too – for a specific question or a specific issue, they would have an avenue to actually seek clinician input from ICU*" (Intensivist, Male, 44 years, IRSAD 5). Furthermore, as PICS is a relatively unknown concept beyond the ICU setting, this was also suggested as a useful mechanism for providing specialist health information to GPs: "*if the patient was sent home with like generic information about okay this patient is at risk of all these conditions, that would be better*" (GP, Female, 31 years, IRSAD 1). Participants suggested a simple pamphlet may be useful, or improved accessibility via a web-based platform, and having it accessible at key transition points in the recovery trajectory: *"I don't necessarily know that patients will be receptive and retentive of information at ICU discharge… It'd be great to have some sort of ICU survivorship community that people were able to access, and that could be as simple as here's a web page that you can go to when you're ready to get all sorts of information about it"* (Intensivist, Male, 44 years, IRSAD 5).
7.	**Creation of a care coordinator role for survivors**	"M*y view would be probably the best staff in the hospital that are best placed to pick up this stuff is really Allied Health staff. So I mean the physios will see the weakness or the loss of power and the speech pathologists see the speech impairment. A psychologist might see the cognitive impairment, or an occupational therapist might see the functional impairment so look I think there'd have to be some sort of process where those Allied Health staff would identify the problems*" (Intensivist, Male, 45 years, IRSAD 5). "A*t these meetings, the consultant looking after the patient for the week, the bedside nurse, Allied Health all come together and then the primary consultant and nurse can come as well and then they discuss where the patients at, how to progress them and so on. And this group has knowledge about the patient, and they then move onto the wards as well*" (Intensivist, Female, 41 years, IRSAD 3). "T*he main thing is actually the sort of structured coordination of care that follows the patient along and having the mechanism to do that.*" (Intensivist, Male, 43 years, IRSAD 5). Both clinician groups agreed allied health could contribute to this role: "*the allied health input works well, so I think the physios communicate clearly between ICU and the ward*" (Intensivist, Male, 36 years, IRSAD 5).

8.	**Developing comprehensive post-ICU care pathways**	*"GPs won't pick up the phone traditionally because they've got nothing for doing it"* (GP, Male, 55 years, IRSAD 5). *"It's cheap…GPs get paid half of what all the other doctors on Medicare get paid, so we're a very cheap service. And we're everywhere, we're ubiquitous"* (GP, Male, 55 years, IRSAD 5). *"it would be hard to see everyone, that would be a very busy clinic and probably not practical"* (Intensivist, Male, 45 years, IRSAD 5). *"Self-selecting group of those that want to come"* (Intensivist, Male, 44 years, IRSAD 5). *"That have spent a significant period in the ICU, maybe longer than seven to ten days perhaps"* (Intensivist, Male, 45 years, IRSAD 5). Whilst there is no current specialised pathway for ICU survivors, participants identified that any future solutions proposed to improve outcomes need to consider the funding implications: *"part of the issue is the state/federal divide in funding … there might be more appetite and ability to integrate but you know as soon as they're out of the hospital system they're the Federal Government's problem"* (Intensivist, Male, 44 years, IRSAD 5). The economic cost to the healthcare system was acknowledged, and participants suggested leveraging existing models of outpatient care in favour of creating new models: *"whether the functions of the recovery clinic can be integrated with something that's already existing, like you know maybe the aged care clinics or the rehab clinics."* (Intensivist, Female, 41 years, IRSAD 3). While GPs reported the purpose of a post-ICU clinic would reduce the burden of multiple specialist appointments for patients after ICU: *"if it replaced the cardiology and the respiratory and the renal, and it was a one stop shop, that might be helpful"* (GP, Female, 44 years, IRSAD 3). Some participants suggested investigating telehealth models (phone and video based) of a comprehensive care clinic may be more accessible, particularly for regional and remote patients to attend, *"maybe it could be done over the telephone rather than having a formal clinic"* (Intensivist, Male, 49 years, IRSAD 5). Participants highlighted that such design decisions could be addressed by including patients and caregivers: *"it's about consumer engagement and consumer inclusion in decision making in how services are designed and I think that's a really under-utilised tool so even just the ideas of co-production, co-design"* (Intensivist, Male, 43 years, IRSAD 5).*

| 9. | Enhancing support for patients after hospital | "*I guess some patients find it quite hard to go into the hospital setting for follow up rehab or type of physio, OT type appointments, so whether there's any capacity for outreach services for those that are significantly mobility impaired and that type of thing*" (GP, Female, 47 years, IRSAD 3)

"*it would be a much smoother transition … there shouldn't be a 14-week waiting list for me to see a psychologist*". (Patient, Female, 43 years, IRSAD 1)

"*What we should be doing is assisting their families and friends on how to deal with the long recovery*" (Intensivist, Male, 49 years, IRSAD 5).

"*They don't need to come somewhere and be told the information, they need someone to come to their house and see how they're actually functioning*" (GP, Female, 44 years, IRSAD 3).

Use of diaries in the ICU, were also suggested as solution to enhance support: "*to try and make sense of things that they do remember, because people's perceptions of what happened in ICU are invariably weird, unpleasant, a bit scary often, and sometimes plain wrong*" (Intensivist, Male, 49 years, IRSAD 5).

Empowerment through expectation setting and pre-hospital discharge counselling may be beneficial: "*I think having an expectation of what the road is going to be like is not clear. We certainly don't really talk about what it's like in ICU, aside from saying it's going to be long*" (Intensivist, Male, 49 years, IRSAD 5). GPs suggested better access and increased availability of existing community support infrastructure, without the need for new service design and research: "*we need to have more pharmacists working with us, we need to have more physios working with us, we need to be more primary care focussed in terms of getting everybody working together. And then we can look after people, we don't need to have anything new*" (GP, Male, 55 years, IRSAD 5). |
|----|----|----|
| 10. | Integration of post-ICU outcomes within the ICU to support clinician morale and understanding. | "*As the intensive care consultant group we're getting the success stories, we're getting the positive feedback, but I don't think we're necessarily getting a structured assessment*" (Intensivist, Male, 44 years, IRSAD 5).

"*Otherwise you're left holding the baby, like okay you've pulled the cork out of the bottle now, what am I going to do with it. And in some ways it's – I think it's a really positive thing, but there could be perceptions of it as picking a scab, that you're picking away at the wound and you've uncorked all of these dramas, how do we help that patient move on for the rest of their journey*" (Intensivist, Male, 44 years, IRSAD 5). |

| | One intensivist described the value of seeing patients through an outpatient clinic: *"for the clinicians we would be able to get feedback about what is the outcome of our ICU survivors, we might also get a better understanding into the long-term issues that the ICU survivors face, so that might help us then adjust the treatments whilst the patients are in ICU"* (Intensivist, Female, 38 years, IRSAD 5).

Some argued this was part of the intensivists' responsibility *"to own those decision and help inform community-based decisions about ongoing care and I don't think we do it at all"* (Intensivist, Male, 43 years, IRSAD 5).

The ethical and moral implications of post-ICU care was raised by several intensivist participants, who reported worrying about the value of their care, and the impact this new knowledge and awareness may have on their practice: *"it really makes you question what you're doing when you have a patient wheeled in in a wheelchair after you thought he was going to make a good recovery post-ICU, and they can't look after themselves, they're essentially in a nursing home level care, and you wonder whether … what you made that patient experience was the right thing to do"* (Intensivist, Male, 43 years, IRSAD 5). Additionally, the potential burden of feedback from post-ICU clinics on intensivists was highlighted: *"I worry that potentially we would drown under the burden of the feedback if it came back, I worry that if we asked everyone how was the journey and how is your body going, our commitment to ongoing delivery of critical care might be somewhat dampened, oh my God what have we done to these poor people"* (Intensivist, Male, 44 years, IRSAD 5). |

IRSAD = The Index of Relative Socio-economic Advantage and Disadvantage, a summary of information about the economic and social conditions of people and households within an area. A lower score indicates relatively greater disadvantage; GP = General Practitioner; FRACGP = Fellowship of the Royal Australian College of General Practitioners.

e- Appendix 1: Additional methodological information

Framework analysis was used to analyse the data which has seven stages: (1) transcription; (2) familiarization with the interview; (3) coding; (4) developing a working analytical framework; (5) applying the analytical framework; (6) charting data into the framework matrix; (7) interpreting the data. This process was followed to complete analyses on the semi-structured interview transcripts. Two independent coders were assigned to each of the interview transcripts, which underwent iterative cross-checked coding with labels against text to identify meaningful passages. Coding was initially exploded, and grouped for main categories for each group. This coding process was completed for four transcripts (one per participant group), to generate a preliminary working analytical framework, completed by lead researchers (NL, KH). This working analytical framework was then refined and applied to the remaining transcripts, where any new codes were agreed upon by both researchers before being added to the framework. Each transcript was coded twice by an independent researcher (NL, KH, KE, TR), using the developed analytical framework. To ensure rigor, the research team performed regular crosschecking of analyses of transcripts, between the emergent themes and raw data (NL, KH, KE, TR). The research team then met to agree on the final analytical framework (NL, KH, TR, KE). The coding was completed in Dedoose, and codes were documented in Excel, with supporting quotes.

The primary analyses were undertaken by lead author (NL) and senior author (KH) who have received prior training in qualitative research methods through organisational-based training and research higher degree.