

# Opinions and priorities for an e-health platform

*A member consultation from an intensive care patient organisation*

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## Research paper

## Opinions and priorities for an e-health platform: A member consultation from an intensive care patient organisation



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## A B S T R A C T

**Background:** To prevent deterioration after admission to the intensive care unit (ICU), and to improve rehabilitation, the ICU team should use digital technologies to provide comprehensive and practical information alongside personalised support for survivors and their family members. However, a knowledge gap exists on the users' preferences for such an e-health platform in ICU follow-up services. **Objectives:** This study aims to explore the opinions and priorities for an e-health platform, including choices in digital elements, according to survivors of critical illness and their family members.

**Methods:** A cross-sectional survey was used among members and other interested individuals of the Dutch volunteer organisation 'Foundation Family- and Patient-Centred Intensive Care'. An investigator-developed questionnaire was disseminated through the newsletter and social media channels of the Foundation Family- and Patient-Centred Intensive Care. The results of this member consultation were analysed and reported as descriptive statistics on demographic variables and outcome measures in opinions and priorities of the participants.

**Results:** Most of the 227 participants were female (76%), aged 46–55 years (33%), and completed higher education (70%). The participants reported high confidence in advice delivered through an e-health platform (72%). They prioritised the provision of a guide including relevant professionals who may support them during their recovery when using an e-health platform.

**Conclusions:** ICU survivors prioritised the provision of relevant professionals who may support them during their recovery when using an e-health platform; however, selection bias means the population studied is likely to be more digitally connected than the general ICU population. Digital solutions could cater to their information and support needs. For family members, the highest priority reported was receiving help in managing their emotional distress. The development of an e-health platform considering the opinions and priorities of this target group could contribute to a personalised recovery trajectory promoting self-management while including digital elements addressing relevant ICU follow-up services.

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## 1. Introduction

Survival of critical illness might result in short- or long-lasting health-related challenges in the physical, psychological, and cognitive domain.<sup>1–4</sup> The lives of family members might be equally

impacted.<sup>5,6</sup> These health deteriorations, collectively referred to as post-intensive care syndrome (PICS)<sup>7,8</sup> and PICS-family (PICS-F),<sup>9,10</sup> affect survivors and family members respectively. Therefore, they should be provided with comprehensive and practical information alongside personalised support to prevent, reduce, or address symptoms of PICS and PICS-F.<sup>11,12</sup>

In worldwide trends, health care is transforming to a more personally adapted delivery of care in line with individuals' preferences and choices in life.<sup>13,14</sup> However, teams in the intensive care unit (ICU) might be understaffed to sufficiently address the goals

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for in-person follow-up service with tailored monitoring and supportive advice adjusted to and personalised for all ICU survivors and their family members. New digital techniques, easily accessible in the 24-h economy, might stimulate self-management in health processes at the times and places that best suit the users.<sup>15</sup> Self-management is defined as “those tasks that individuals undertake to deal with the medical, role, and emotional management of their health condition(s)” and includes a need for independence.<sup>16,17</sup> Current ICU follow-up services should therefore further improve their care provision by offering a personalised e-health platform that meets the users' self-management needs.<sup>18,19</sup> Previous research has reported that cancer survivors, postdischarge stroke patients, and patients with chronic pain are interested in self-managing their own care by means of e-health while having on-line contact with healthcare professionals.<sup>16,20,21</sup> Innovative health services, such as integrated health apps and home self-monitoring, are provided through digital devices that are always available and allow unceasing observation and measurement of patients' conditions. This means the opportunity to check the users' health by regularly completing short digital questionnaires and recording expected symptoms, thus raising awareness or reducing deterioration through timely professional support.<sup>22,23</sup> However, to achieve a sustainable model of ICU follow-up services using digital technologies, we need to know if and how an e-health program could meet the needs and priorities of ICU survivors and their family members.

The World Health Organization has defined e-health as “the use of information and communications technology in support of health and health-related fields”.<sup>24</sup> On the one hand, some factors hindering the use of e-health are known, such as trust-related barriers, design issues, and accessibility challenges.<sup>25</sup> On the other hand, there are facilitating factors, such as positive experiences in the ease of using e-health, improved communication, anonymity, and the capacity to overcome distance challenges.<sup>25–27</sup> These benefits could promote the integration and usage of e-health into ICU follow-up services. There is a gap in understanding of which elements of an ICU e-health platform would stimulate usage. Therefore, exploring this knowledge gap from the perspectives of the target group might provide valuable starting points or ideas for improvements to augment ICU follow-up services with digital technologies.

## 2. Objectives

This study aims to explore the opinions and priorities for an e-health platform, including choices in digital elements, according to survivors of critical illness and their family members.

## 3. Methods

### 3.1. Design

A cross-sectional survey study has been conducted as part of a broader research program aiming to develop and test a new e-health intervention as part of ICU follow-up service, for which the study protocol has been published previously.<sup>28</sup> The Strengthening the Reporting of Observational Studies in Epidemiology Statement and the Checklist for Reporting Results of Internet E-Surveys have been used as a reporting guideline for the current study.<sup>29,30</sup>

### 3.2. Setting and participants

The Dutch volunteer organisation ‘Foundation Family- and Patient-Centered Intensive Care’ (FCIC) endeavours to reduce the emotional impact of an ICU admission. Foundation FCIC is a

collaborative force of ICU patients' and family members' representatives (addressed as experts-by-experience), professionals, and researchers.<sup>31</sup> The patient organisation ‘IC Connect’, as part of Foundation FCIC, provides peer support and voices the opinions and experiences of ICU survivors and their family members.<sup>32</sup> Only ICU survivors and their family members can be part of IC Connect, and join as volunteer in projects or communication activities that contribute to the organisation goal. The current study used a convenience sample of interested individuals connected to this public organisation.

The REhabilitation After Critical illness and Hospital discharge (REACH) expertise network collaborated in the study because of their knowledge and expertise in the domain of post-ICU rehabilitation. This network comprises physiotherapists, occupational therapists, dieticians, and medical professionals from different hospitals and primary care, and its mission is to improve knowledge and expertise around rehabilitation after critical illness in the Netherlands.<sup>33</sup> To help ICU survivors and their families finding the right professional during their recovery trajectory, REACH network and the Foundation FCIC have published an online infographic, with information on the role of various professionals in the recovery after critical illness ([Supplementary Fig. 1](#)).

A member consultancy procedure provides an expert-based contribution to research as the opinions and values of members/supporters could be explored, in this case, the experts of IC Connect.<sup>34</sup> Therefore, all volunteers and other interested individuals of IC Connect were eligible participants in this study. The inclusion criteria were as follows: (i) being an ICU survivor or family member; (ii) being aged 18 or above; (iii) being a legally responsible and cognitive capable person; and (iv) having sufficient Dutch-language proficiency. Geographically, eligible participants could live throughout the Netherlands. ICU patients admitted to a hospital or rehabilitation centre and their family members were excluded because of an expected emotional burden at study onset. No other exclusion criteria were used.

### 3.3. Ethical approval

The Medical Ethics Committee of Erasmus MC, Rotterdam, the Netherlands, has reviewed the research proposal (MEC-2022-0153) and judged that the rules laid down in the Medical Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO) do not apply to this research proposal. The study was conducted according to the principles of the Declaration of Helsinki, 64th World Medical Association General Assembly, Fortaleza, Brazil, October 2013 and in accordance the Netherlands Code of Conduct for Scientific Practice from the Association of Universities in the Netherlands. Participation in this study was on voluntary basis without incentives, retracting was possible at any time without specifying why. In the participant information brochure, we advised to contact the principal investigator, ICU nurse, and psychologist for emotional support if participants felt needed. Participants provided informed consent with the use of their data; no retraceable personal data were gathered.

### 3.4. Measurement instrument

The research team developed an ad-hoc questionnaire with mostly closed-type statements derived from the literature and their expertise regarding ICU follow-up services and e-health. Two members of the research team (AZ and PvdM) simultaneously established the items of this new measuring instrument with the help of their supervisors and principal investigator (MvM) in English ([Supplemental File 1](#)) and Dutch ([Supplemental File 2](#)). Two other members of the research team (MM and MvdS) reviewed

item-by-item to ensure that they were accurate and grammatically correct, with forwards–backwards adaptations, and all items were finally proofread by a native English speaker. The development process took several rounds, including a pilot test with five patient experts by experience as volunteers from IC Connect. This test phase was used to evaluate the logical structure of the questionnaire, the clarity of the terms, whether the items were understandable and not offensive, to determine missing topics, the technical functionality of the digital questionnaire, and to receive suggestions for possible improvements. The final version was built using a template in the SurveyMonkey® platform.

The measurement instrument consisted of three parts with 39 items in total. Part 1 consisted of five items on demographic characteristics: age, gender, educational level, country of birth, and cultural background. Part 2 consisted of nine items regarding ICU admission and the period thereafter, including having experienced ICU admission as patient or as a family member. Three items had a dichotomous answer category ('Yes/No'), whereas another item had four answer categories ('Yes/No, but I would have liked/No, no need for/Not applicable, I was a relative'). Part 3 consisted of 24 items regarding opinions on digital ICU follow-up services and preferences for elements of an e-health platform. All answer categories were on a Likert-type scale, varying from 1 = Strongly agree to 5 = Strongly disagree. One open-ended item was added: 'When developing a digital health program in ICU aftercare, we will consider cultural diversity. Do you think there is a difference in needs for a digital health program among people from different cultural backgrounds?' The total questionnaire was open in one-view page and was expected to be completed in 15 min.

### 3.5. Procedures

All volunteers and other interested individuals of the patient organisation IC Connect received an invitation to participate in the study via the general newsletter of Foundation FCIC, which was sent out to 1658 subscribers. In addition, the invitation was spread through social media channels of IC Connect such as Facebook, Instagram, and LinkedIn, varying between approximately 330 and 950 followers. The invitation (Supplemental File 2) included background information on the aim and research questions, expectations on the time needed to complete the questionnaire, considerations of privacy and anonymity, what would be done with the results, and a link to the digital questionnaire. It was emphasised as a questionnaire for ICU survivors and family members. The researchers had no interference with recruitment of the participants in this member consultancy, other than reposting a message on social media in their network once without addressing their involvement in the study. Participants provided informed consent with the first and obligatory item before starting to answer all other items. Logfiles, IP address, cookies, view rates, and time of completing the questionnaire were not archived. Possibility to review and change the answers was enabled through a 'back button'.

### 3.6. Statistical analysis

Data from participants who did not grant permission to use their data or those who completed less than 90% of the questionnaire were deleted from the data analysis. Missing data were not imputed; we considered an expected loss of 30% due to non-relevance of some items for participating family members of ICU survivors. Statistical Package for the Social Sciences (SPSS) version 28.0 (Chicago, Ill, USA) was used. Data were checked for normality with kurtosis and skewness between  $-2$  and  $2$  considered as near normal.<sup>35</sup> The five-point-Likert answer categories were recoded if appropriate to rank the lowest score as 1 and the highest score as 5.

All statistical tests were bilateral with a significance level set to  $p < 0.05$ .

We used a principal component analysis to explore underlying factors and consistency of the items in the newly developed questionnaire. Direct oblique rotations were applied because we expected potentially relatedness of the items. To identify a relevant factor loading, with high-enough correlations between the items and a sufficient number of participants, the preliminary requirements were set for a Kaiser–Meyer–Olkin measure of sampling adequacy of  $\geq 0.60$ , and Bartlett's test of Sphericity was required to be significant. Items with multicollinearity ( $r > 0.80$ ) were removed from further analysis. We inspected the scree-plot visually and considered factors important if eigenvalue measured  $\geq 1.0$  with factor loadings of  $\geq 0.40$ . We analysed the internal consistency of the found factors as subscales in the measuring instrument using Cronbach's  $\alpha$ , with  $\alpha \geq 0.70$  indicating that a subscale was sufficiently reliable.<sup>35</sup>

Descriptive statistics (e.g., means, proportions, or range, as appropriate) were used for demographic variables (i.e., age, gender, educational level, and cultural background) and outcomes (i.e., opinions on ICU follow-up service and prioritising elements of an e-health platform). We used a Student's T-test to analyse differences between groups based on gender and cultural background. We ranked the preferences in using elements of an e-health platform based on the item means according to ICU survivors and family members separately.

Answers on the open-ended item on an expected need for cultural specificity for an e-health platform were categorised and counted as 'No', 'No idea', 'Language barriers', 'Personalised needs', 'Spiritual/cultural needs', and 'Age'.

## 4. Results

### 4.1. Characteristics of participants

Due to the study procedure and character of social media, the total reach of the invitation for study participation, and therefore the response rate, remains unknown. Most of the 227 participants were female ( $n = 172$ , 76%), aged 46–55 years ( $n = 75$ , 33%), and completed higher education ( $n = 159$ , 70%). More than half were ICU patients ( $n = 129$ , 57%), and almost one-third were family members ( $n = 68$ , 30%). Table 1 provides an overview of all demographic characteristics of the participants.

### 4.2. Factor and reliability analysis

A summary of factor analysis for the questionnaire is provided in Table 2. The item 'I possess adequate skills and knowledge to use a digital device that has access to the internet' showed a non-normal distribution with skewedness above  $-2$  and kurtosis above  $2$  and was removed from further factor analysis due to nonapplicability. To determine the underlying structure of the new measuring instrument, factor analyses were conducted on the 22 remaining items (all using a 5 point Likert scale). The factor analysis met all the requirements, with excellent Kaiser–Meyer–Olkin measure of sampling adequacy (0.80), and Bartlett's test of Sphericity was significant ( $p < 0.000$ ). No multicollinearity was found. The scree-plot showed a first drop after two factors, labelled 'Elements of an e-health platform' and 'Access', and was stabilising after in total six factors with an eigenvalue of  $>1.0$  contributing to 63.12% explained variance. The internal consistency ranged between 0.89 and 0.35 for the separate subscales, with a Cronbach's  $\alpha$  of 0.74 for the overall measuring instrument (Table 3).

**Table 1**  
Demographic characteristics of participants N = 227.<sup>a</sup>

Variable	Number (%)
Age category	Median 46–55
1	18–25 14 (6.2)
2	26–35 16 (7.0)
3	36–45 40 (17.6)
4	46–55 75 (33.0)
5	56–65 56 (24.7)
6	66–75 26 (11.5)
	76–85 0 (0)
Gender	
	Female 172 (75.8)
	Male 54 (23.8)
	Other/prefer not to say 1 (0.4)
Education	
	Primary school 4 (1.8)
	Secondary/high school 71 (31.3)
	First degree (BSc, BA) 106 (46.6)
	Second degree (MSc, MA, MPhil) 34 (15.0)
	Doctoral (PhD) 12 (5.3)
Country of birth	
	The Netherlands 213 (93.3)
	Belgium 1 (0.4)
	Germany 1 (0.4)
	Iran 1 (0.4)
	Marocco 6 (2.4)
	Suriname 1 (0.4)
	Syrië 2 (0.8)
	Tanzania 1 (0.4)
	Prefer not to say 1 (0.4)
Non-Western background	
	No 182 (80.2)
	Yes 22 (9.7)
	Missing 23 (10.1)
ICU experience	
	ICU patient 129 (56.8)
	Relative of ICU patient 69 (30.4)
	Missing 29 (12.8)
Year of ICU admission	Range 1993–2023
Number of days admitted in the ICU	Range 1–99

ICU, intensive care unit; IQR, interquartile range = Q3 (75%) category 5 (age: 56–65)–Q1 (25%) category 4 (age: 46–55).

<sup>a</sup> Total responses n = 242. No permission to use data n = 3. Missing all data n = 12 (5.0 %).

#### 4.3. Experiences with ICU follow-up service

In general, participants were satisfied with ICU treatment (n = 58, 84%). After ICU discharge, 78% of the participants experienced the need to contact a healthcare professional for support or treatment of their perceived health impairments. Of these, 87 participants faced difficulties trying to approach one (i.e., 17% totally disagreed and 41% disagreed on the statement for easiness of finding a healthcare professional). Only 21 participants (29%) were provided with a rehabilitation plan, whereas most felt the need for such a plan but never received one (n = 46, 66%). Familiarity with the symptoms or concepts of PICS and PICS-F was reported in 52% and 43% of participants, respectively.

#### 4.4. Opinions on ICU follow-up service via an e-health platform

The majority of the participants in the member consultation reported easy access to digital resources for information (n = 88, 56%) and support (n = 94, 60%) regarding their own health situation. They considered themselves sufficiently competent to use the internet to acquire health information (n = 150, 96%). Although most participants were interested in personalised digital ICU follow-up services, they did not prefer this to be the only form of communication (n = 94, 60%). Confidence in receiving advice

**Table 2**  
Summary of factor and reliability analysis for the newly composed questionnaire N = 157.

Variable	Mean (±St. Dev.)	Skewness	Kurtosis	Factor loading <sup>a</sup>
Interested in digital ICU aftercare	4.21 (±0.85)	−0.99	0.82	1
Available every moment of the day	3.89 (±0.94)	−0.74	0.37	1
Videos with information on symptoms	4.22 (±0.76)	−1.11	1.99	1
Videos with physical exercises	4.10 (±0.86)	−0.99	1.21	1
Helping with lifestyle interventions	4.00 (±0.82)	−0.58	0.29	1
Managing emotional distress and stress	4.09 (±0.92)	−1.02	1.08	1
Possibility to contact with peers	3.93 (±0.94)	−0.63	0.19	1
Overview of relevant professionals	4.24 (±0.74)	−0.90	1.50	1
Keeping a diary	3.84 (±0.98)	−0.83	0.60	1
Communication in real time	4.00 (±0.96)	−1.02	0.98	1
Communication in non-real time	3.98 (±0.96)	−1.05	1.05	1
Timeline of events	4.01 (±0.97)	−0.87	0.41	1
Unfamiliarity with digital means	3.97 (±1.08)	−0.84	−0.11	2
Easy access to online support	3.47 (±1.30)	−0.55	−0.83	2
Easy access to online health information	3.41 (±1.18)	−0.51	−0.65	2
Distrusting advice of a digital health tool	3.96 (±0.87)	−0.52	−0.08	3
Sceptical on sharing personal information	3.62 (±0.97)	−0.49	−0.24	3
Wishing training to use a digital health tool	3.08 (±1.09)	−0.12	−0.32	4
Searching for online health information	4.00 (±1.10)	−1.12	−0.60	5
Entertaining component	2.85 (±0.97)	−0.03	−0.32	5
Challenge to search online health info	2.88 (±1.00)	0.01	−0.49	6
No other means necessary to contact with health care professionals	3.49 (±0.96)	−0.69	0.01	6
Sufficiently online competency	4.70 (±0.66)	−3.17	12.79	–

ICU, intensive care unit; St. Dev, standard deviation of mean.

<sup>a</sup> Factor loading 1 = 'Elements of digital health tool' (12 items); 2 = 'Access' (3 items) 3 = 'Distrust' (2 items); 4 = 'Training' (1 item); 5 = 'Gaming' (2 items); 6 = 'Challenge' (2 items).

through a digital health program was found to be high among participants (n = 113, 72%). No significant differences in the stated opinions on ICU follow-up service via an e-health platform were found between ICU survivors and family members or between participants with different cultural backgrounds (dichotomised into western and a nonwestern background). Most participants reported to have 'No idea' about potential cultural differences regarding an e-health platform, followed by expected 'Language barriers'. Some emphasised prioritising personalised support without accountability for cultural diversity. "I think each person has their own needs. That is independent of a western background or not. It needs to be a personalised tool, not a computer or technical issue". [Supplemental File S3](#) provides an overview of participants' opinions on support in ICU follow-up service via an e-health platform.

#### 4.5. Prioritising elements of an e-health platform

In the assessment of various elements from which an e-health platform can be built, a prioritisation has been drawn up for both ICU survivors and their family members ([Table 4](#)). The top three priorities in using an e-health platform for ICU survivors are as follows: (i) providing an overview of relevant professionals who can be consulted for support in their personal health situation; (ii) providing videos with information on the symptoms (of PICS) experienced; and (iii) providing videos with exercises from a physiotherapist or rehabilitation therapist. The top three priorities



**Table 3**  
Scale reliability N = 157.

Factor	Total explained variance	Cumulative %	Cronbach's $\alpha$
Elements of an e-health platform	5.82	26.43	0.89
Access	2.23	36.55	0.64
Distrust	1.68	44.19	0.68
Training	1.47	50.85	Not applicable
Gaming	1.39	57.19	Not applicable
Challenge	1.31	63.12	0.35
Overall measuring instrument			0.74

**Table 4**  
Preferences in using elements in an e-health platform for ICU survivors and their family members.

Variable	I would use a digital health program because...			
	ICU survivors		Family members	
	Priority	Mean (St. Dev.)	Priority	Mean (St. Dev.)
... it provides an overview of relevant professionals for support in my health situation.	1	4.28 ( $\pm 0.75$ )	3	4.14 ( $\pm 0.68$ )
... of videos with information on the symptoms that I experience.	2	4.23 ( $\pm 0.77$ )	2	4.21 ( $\pm 0.75$ )
... of videos with exercises from a physiotherapist or rehabilitation therapist.	3	4.21 ( $\pm 0.79$ )	6	3.90 ( $\pm 1.00$ )
... it helps me with lifestyle interventions, (e.g., being active, a healthy diet, quitting smoking).	5	4.05 ( $\pm 0.82$ )	7	3.88 ( $\pm 0.80$ )
... it could help me manage emotional distress and stress (e.g., exercises for relaxation, meditation, yoga).	6	4.03 ( $\pm 0.99$ )	1	4.24 ( $\pm 0.79$ )
... of the possibility to contact with peers.	9	3.95 ( $\pm 0.99$ )	10	3.09 ( $\pm 0.80$ )
... of keeping a diary on the ICU admission and thereafter.	10	3.87 ( $\pm 1.00$ )	9	3.76 ( $\pm 0.91$ )
... to include communication with a clinician in real time (e.g., video meetings).	7	4.00 ( $\pm 1.00$ )	4	4.00 ( $\pm 0.86$ )
... to include communication with a clinician in non-real time (e.g., chat room, emails, text messages).	8	3.99 ( $\pm 0.99$ )	5	3.95 ( $\pm 0.88$ )
... of a timeline with the professionals where I have been and the phases in my recovery.	4	4.07 ( $\pm 0.95$ )	8	3.86 ( $\pm 1.02$ )
... it is entertaining (seems like a game).	11	2.79 ( $\pm 0.99$ )	11	3.00 ( $\pm 0.91$ )

ICU = intensive care unit; St. Dev = standard deviation of mean.

in using an e-health platform for family members are as follows: (i) helping to manage their emotional distress and stress; (ii) providing videos with information on the symptoms (of PICS-F) experienced; and (iii) providing an overview of relevant professionals for support in personal health situations.

## 5. Discussion

In this study, we explored the opinions and priorities, including choices in several digital elements, for an e-health platform offering ICU follow-up services among Dutch ICU survivors and their family members. Our study outcomes provided a detailed report highlighting areas of interest from the perspectives of the target group. This can serve international initiatives in the development of digital support in addition to regular ICU follow-up care. Participants

expected to use a specified e-health platform with clear information on signs and symptoms of health impairments and a personalised health programme if it suited their goals for a recovery trajectory. Similarly, this goalsetting was found to be important in the UK and Canadian e-platform TouchAway™.<sup>19,36</sup> It might enable users to achieve personal and realistic progress in their recovery. Participants in our study reported that an approach via the internet and their individual digital skills for using an e-health platform in ICU follow-up services were not a perceived barrier. A large (n = 6766) quantitative study identified commonly reported benefits and concerns regarding digital health services during COVID-19.<sup>37</sup> Here, low digital literacy was found to be hindering access and use of e-health, suggesting that more attention was needed for older patients. In comparison, the cohort in our study was mostly female, middle aged, and digitally linked to the patient organisation of IC Connect. Therefore, the reported digital skills might be overestimated and should be interpreted with caution. Videos with information on the symptoms of PICS and PICS-F were reported as high priorities among ICU survivors and family members. Similarly, health-information seeking and attending health tutorials (i.e., information-based activities such as watching videos), sharing experiences, tracking, and self-monitoring (e.g., utility-based activities) have been priorly identified as the most engaged and desired activities by e-health users.<sup>16,38</sup>

### 5.1. Acknowledgements of PICS and PICS-F

Public acknowledgement of the symptoms and recovery trajectory of PICS and PICS-F was recognised in only half of the Dutch participants (52% and 43%, respectively). This was particularly surprising because of the participants' expected familiarity through their own experiences and linkage with the patient organisation IC Connect. The large spread of years of ICU admission, from 1993 to 2023, could have affected our results, given that ICU care and post-ICU care have changed significantly over time. However, symptoms of PICS are still not sufficiently recognised by many healthcare providers as well.<sup>39,40</sup> ICU aftercare clinics, and support in rehabilitation, can be taken into practice by ICU professionals. However, it is essential that other professionals, such as general practitioners, psychotherapists, and primary care physiotherapists, acknowledge the health-related problems following an ICU admission. Integrated service can be provided by clinicians specialised in these areas in collaboration with the ICU; however, the availability will be dependent on the healthcare system and the single-country nature.

### 5.2. Self-management in an ICU e-health platform

An essential part of an e-health platform is to stimulate self-management.<sup>36</sup> This might differ depending on the recovery phase; in the first weeks or months after critical illness, it might be difficult to become motivated to use an e-health platform due to cognitively insufficient capabilities.<sup>41</sup> Self-determination theory (SDT) is a useful model that provides valuable insights into patients' perspectives and preferences regarding e-health platform.<sup>42</sup> SDT is a theoretical framework to explain how behaviour unfolds: the more a behaviour is self-determined, the more individuals are motivated to take responsibility and self-manage aspects in life, including their health care.<sup>43</sup> A desire for communication with peers and healthcare staff, informational needs, control over their health situation, and keeping track of their progress are participants' expectations. Through SDT, they correspond to feelings of connection and communication with peers (relatedness), perceived capacity to do something about their health situation (competence), and the need for control over it (autonomy).<sup>44</sup> ICU survivors seek connection and support, prefer well-informed post-ICU resources, and ask

for a Frequently Asked Questions section for their informational and control needs over their health issues. This promotes motivation, active recovery, and satisfaction of autonomy needs. Relatedness supports emotional well-being, competence is fostered by autonomy, and self-management tools enhance autonomy. This could keep them motivated and active in their recovery, reinforcing their need for competence. Being active, self-managing their health care, and using an e-health platform, through which they can monitor their symptoms and progress, could satisfy their need for autonomy.<sup>43</sup> Relatedness is a sense of support associated with emotional well-being, gaining a sense of competence is facilitated by autonomy, and autonomy is supported by self-management tools.<sup>42,44</sup> Furthermore, as participants in our study reported, finding the most relevant and suitable healthcare professional to support the survivors' recovery path was difficult. This might limit their self-management. We acknowledge that a gap exists in received care related to information needs and the organisation of care: which professional can help best at what time of the recovery trajectory. Similarly, a continuum of care, as the standard to strive for, was reported important in an overview article on outcomes of critical illness.<sup>45</sup> In the context of societal changes related to a growing population with complex healthcare needs and a decrease in health care providers, digitalisation could support bridging the gap in ICU survivors' and family members' experiences.

### 5.3. Future directions

In a next step from the findings of our study, further research and development of digital interventions are needed to support ICU survivors and their family members in the recovery trajectory, which should include their voice on the needs and priorities. First, more knowledge should be available to recognise the symptoms of PICS and PICS-F, including preventive strategies. A bibliometric network analysis of Web of Science showed that most of the 373 published articles addressing PICS and PICS-F, in the decade from 2012 to 2021, originated from the US, England, and the Netherlands.<sup>46</sup> It was shown that only a few keywords and articles were found on effective ways to prevent PICS.<sup>46</sup> Therefore, primary healthcare professionals worldwide should pay attention to this specific domain. Second, individuals with limited (health-)literacy, a lower socioeconomic background, and those belonging to ethnic minority groups should be addressed to explore their specific needs and preferences in using an e-health platform. Third, for assessment of opinions and priorities for an e-health platform, the developed questionnaire could use further refinement based on the preliminary results of this study. Some other digital elements, such as the introduction of large language models could be added to shed light on the usefulness as perceived by the target group. Using large language model could bring new opportunities to personalised health care and ICU follow-up service, enabling a new era in digital solutions.

### 5.4. Strengths and limitations

The results of our study used quantitative member consultancy to report opinions and priorities of an e-health platform for ICU follow-up service. A limitation of this study is that the questionnaire used was not validated, limiting comparison of results to previous literature. Although the factor analysis met all the requirements, the sample size of our cohort was at a minimum for proper assessment of model fit.<sup>47</sup> Secondly, the recruitment and participation methods used were likely to result in a selection bias to those with both an interest and skill in digital resources. Thirdly, despite efforts to achieve diversity in gender, age, education, and cultural background, the convenience sample was limited to

typically highly educated middle-aged individuals, without a migration background, who survived an ICU admission. This non-generalisability could have biased the study results and should be considered in further innovation of an e-health platform. Additional challenges in providing digital health information and support are likely to exist and greater exploration of vulnerable sections of the community who may lack connectivity and digital health literacy is required in order to support their needs and priorities in ICU follow-up services.

## 6. Conclusions

A digitally connected cohort of ICU survivors prioritised the provision of relevant professionals who may support them during their recovery when using an e-health platform. Digital solutions could cater to their information and support needs. For family members, the highest priority seemed receiving help in managing their emotional distress. The development of an e-health platform with the opinions and priorities of this target group could contribute to a personalised recovery trajectory with self-management and digital elements addressing relevant ICU follow-up services.

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### CRediT authorship contribution statement

Anna Zacharelou: Project administration; Investigation; Data curation; Formal analysis; Writing original draft of the study.

Mel Major: Methodology; Writing—review and editing.

Puck van der Meer: Project administration; Investigation; Writing—review and editing.

Lilian Vloet: Conceptualisation; Writing—review and editing.

Marieke van der Schaaf: Methodology; Writing—review and editing.

Margo M.C. van Mol: Conceptualisation; Funding acquisition; Methodology; Data curation; Formal analysis; Supervision; Writing original draft, review & editing.

All authors agreed the final version of the manuscript.

### Conflict of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this manuscript.

### Data availability

Data gathered and analysed during the study will not be available publicly due to legal and ethical restriction. Anonymised data will be freely available at a reasonable request to any scientist wishing to use them for noncommercial purposes. The results of this study will be disseminated to the funding agency, the healthcare professionals, the health services authorities, and the public via presentations at national and international meetings. A lay

summary of the results will be written and shared with the Dutch ICU patient organisation IC Connect.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.aucc.2024.03.009>.

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