



# criticalcarerecovery.com: an e-health resource to support patients & families



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# The scale

- **120,000** ICU survivors/year
- **£5.88 billion** healthcare costs in the year post-hospital discharge (£49K/patient)<sup>1</sup>
- **15,600** hospital readmissions within 1 month<sup>2</sup>
- **27,600** hospital readmissions within 3 months<sup>2</sup>
- **48,000** hospital readmissions within 6 months<sup>2</sup>

# Post Intensive Care Syndrome

Physical

Muscle wasting  
Fatigue  
Weight loss  
Joint pain/stiffness  
Impaired mobility  
Impaired ADLs

Psychological

Anxiety  
Depression  
PTSD

Cognitive

Amnesia  
Delirium  
Cognitive impairment

Social

Delayed RTW  
Reduced social participation  
Health and wellbeing of carers

# Complex needs

- Pre-existing multi-morbidity<sup>2-4</sup>
- Socioeconomic deprivation<sup>2-3</sup>
  - Drug & alcohol dependence
- Variable health & social care support<sup>2-3</sup>
  - Reliance on carers
  - Mobility aids & home adaptations
  - Money worries

# Information failure

## Acute care

- Limited ward knowledge of PICS<sup>4-8</sup>
- Limited ward-based rehab.<sup>4-8</sup>
- Short post-ICU stays<sup>1</sup>
- Fragmented discharge planning<sup>3-5,7</sup>

## Primary care

- Communication failure<sup>4,9</sup>
- Limited GP knowledge of PICS<sup>10,11</sup>
- Limited referral pathways<sup>11</sup>
- Limited follow-up<sup>12</sup>

# The aspiration

## Those at risk of co-morbidity....

2. have a **handover** of care, including their individualised rehabilitation programme, on ward transfer.
3. are given **information** based on their rehab goals before hospital discharge
4. and spend >4 days in ICU **have a review 2 to 3 months after ICU discharge**

To support patients and families “as they start living at home again”  
(ICS-JLA research priority)<sup>14</sup>

**NICE Quality Standards (2017)<sup>13</sup>**

*“Survivorship will be the defining challenge of critical care in the 21st century” (Iwashyna, 2010)<sup>15</sup>*

How can we deliver this

- At scale?
- At a distance?
- Within existing resources?
  - Expertise
  - Cost

# Can e-health help?

## **Myth 1:** *“Older patients don’t use the internet”*

- Increasing IT use among elderly & socioeconomically deprived<sup>16</sup>
- Strong correlation between poor health and ehealth use<sup>17</sup>

## **Myth 2:** *“It’s just information...”*

- Improves (equity of) access to health and social care
- Provides support, helps share experiences, informs healthcare decision-making<sup>18</sup>
- Strong evidence of benefit in other patient groups<sup>19</sup>
  - HRQoL
  - Mortality
  - Healthcare resource use & readmission rates



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## Popular Topics

amnesia, anxiety, benefits, bereavement, breathless, **carer**, carers assessment, community care, death, depression, diaries, dreams, driving, drugs, employment, exercise, family, family & friends, fatigue, flashbacks, health, housing, information, joint, legal, legal rights, mobility, money, muscle wasting, nightmares, Occupational Therapist, Pacing, pain, pharmacist, physiotherapist, **Physiotherapy**, Post traumatic stress, power of attorney, psychological, social work, spiritual, strange memories, support, support groups, tiredness, visiting, ward, weakness, wheelchair, work



**Welcome to the Intensive Care Recovery Service**

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## Suggestion Box

We'd welcome your feedback on the content and how the website works, please complete the form below...



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# QUAL evidence base

	ICU experience	Ward care	Home 3 months	Home 6 months	Home 12 months
PhD: QoL following prolonged critical illness <sup>4</sup>	✓	✓	✓	✓	
RECOVER: trial of in hospital rehabilitation <sup>1,7</sup>	✓	✓	✓		
RELINQUISH: longitudinal QUAL study of healthcare & support needs <sup>8</sup>	✓	✓	✓	✓	✓
PROFILE: drivers for early unplanned hospital readmission <sup>3</sup>	✓	✓	✓		

# Development at a glance...

2015	<b>Development</b>	Qualitative data (>120 interviews) Co-produced with patients, clinicians, web developers: focus groups & feedback loops
2016	<b>Implementation</b>	Royal Infirmary of Edinburgh
2016	<b>Evaluation</b>	Royal Infirmary of Edinburgh (mixed methods)
2017	<b>Scale-up</b>	Western General Hospital (NHS Lothian) St Johns Hospital (NHS Lothian) Borders General (NHS Borders) Queen Elizabeth Hospital (NHS Greater Glasgow & Clyde) Aberdeen Royal Infirmary (NHS Grampian)
	Guys & St Thomas	

# Media & functionality

## Media

- Patient stories
- Patient & clinician webcasts
- Links to credible information (e.g. NHS website)
- Links to health & social care & 3<sup>rd</sup> sector agencies
- Forum (healthtalkonline)

## Functionality

- Easy search options
- Read aloud
- Translates into >100 languages (Google translate)
- Registered users can:
  - develop a secure, online personal library
  - allow clinician input e.g. information & rehab plans

# Evaluation (QUAL)

“It was great to read about...and watch the videos about other people’s stories. It really helps to know you’re not the only one and that things do get better” (patient)

“It’s important to get information around the psychological issues that you would never have thought of...that’s where the website comes in” (patient)

“It was just as helpful for me...because it helped me understand what he was going through” (wife)

“I used the website to direct a family member to...counselling. She told me it really helped her cope” (ICU nurse)

Video: <https://vimeo.com/180062863/3d110cb6bf>

# Traffic at a glance (2018)

<b>All users</b>	9905
<b>Sessions</b>	12,666
<b>Pages</b>	75,996
<b>Origin</b>	UK: 51% USA: 15% India: 6% Oz: 4% France: 4%

<b>UK users</b>	5082
<b>Sessions</b>	7381
<b>Pages</b>	55,874
<b>Origin</b>	England: 73% Scotland: 21% Wales: 3% Ireland: 3%
<b>Access</b>	PC: 49% Mobile: 43% Tablet: 8%

# Awards

**2019:** Winner Digital Health & Care Award (Scotland)

**2019:** Winner, Digital Impact Award (Scotland)

**2018:** Top 5 Scottish Social Enterprise (Scotland)

**2017:** Scottish NMAHP Research Awards (Impact)

**2017:** Research Excellence, Edinburgh Napier  
University

# An invitation to...scale-up!

## Geographical

- Local images
- Webcasts from local patients & clinicians
- Transport links, hospital services, Unit policies, etc
- Local health & social care resources (taxonomy of needs)
- Twitter feeds, etc

## Specialty-specific

- Bolt-ons (would need funding for QUAL aspect)
- Functionality to share & edit content with other specialty sites

*Can be done remotely. Cost @£5K/year*



# Contact



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<http://www.criticalcarerecovery.com>



@critcarerecover

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