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)$^1$
- **15,600** hospital readmissions within 1 month$^2$
- **27,600** hospital readmissions within 3 months$^2$
- **48,000** hospital readmissions within 6 months$^2$
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\textsuperscript{2-4}
• Socioeconomic deprivation\textsuperscript{2-3}
  – Drug & alcohol dependence
• Variable health & social care support\textsuperscript{2-3}
  – Reliance on carers
  – Mobility aids & home adaptations
  – Money worries
Information failure

Acute care
- Limited ward knowledge of PICS\textsuperscript{4-8}
- Limited ward-based rehab.\textsuperscript{4-8}
- Short post-ICU stays\textsuperscript{1}
- Fragmented discharge planning\textsuperscript{3-5,7}

Primary care
- Communication failure\textsuperscript{4,9}
- Limited GP knowledge of PICS\textsuperscript{10,11}
- Limited referral pathways\textsuperscript{11}
- Limited follow-up\textsuperscript{12}
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)

NICE Quality Standards (2017)
“Survivorship will be the defining challenge of critical care in the 21st century” (Iwashyna, 2010)\textsuperscript{15}

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\(^\text{16}\)
- Strong correlation between poor health and e-health use\(^\text{17}\)

**Myth 2:** *“It’s just information…”*
- Improves (equity of) access to health and social care
- Provides support, helps share experiences, informs healthcare decision-making\(^\text{18}\)
- Strong evidence of benefit in other patient groups\(^\text{19}\)
  - HRQoL
  - Mortality
  - Healthcare resource use & readmission rates
## QUAL evidence base

<table>
<thead>
<tr>
<th>Study</th>
<th>ICU experience</th>
<th>Ward care</th>
<th>Home 3 months</th>
<th>Home 6 months</th>
<th>Home 12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>PhD: QoL following prolonged critical illness(^4)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
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<tr>
<td>RECOVER: trial of in hospital rehabilitation(^1, 7)</td>
<td>✔️</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
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<tr>
<td>RELINQUISH: longitudinal QUAL study of healthcare &amp; support needs(^8)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>PROFILE: drivers for early unplanned hospital readmission(^3)</td>
<td>✔️</td>
<td>✔</td>
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## Development at a glance...

<table>
<thead>
<tr>
<th>Year</th>
<th>Stage</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>Development</td>
<td>Qualitative data (&gt;120 interviews)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Co-produced with patients, clinicians, web developers: focus groups &amp; feedback loops</td>
</tr>
<tr>
<td>2016</td>
<td>Implementation</td>
<td>Royal Infirmary of Edinburgh</td>
</tr>
<tr>
<td>2016</td>
<td>Evaluation</td>
<td>Royal Infirmary of Edinburgh (mixed methods)</td>
</tr>
<tr>
<td>2017</td>
<td>Scale-up</td>
<td>Western General Hospital (NHS Lothian)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>St Johns Hospital (NHS Lothian)</td>
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<tr>
<td></td>
<td></td>
<td>Borders General (NHS Borders)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Guys &amp; St Thomas</td>
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<tr>
<td></td>
<td></td>
<td>Queen Elizabeth Hospital (NHS Greater Glasgow &amp; Clyde)</td>
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<tr>
<td></td>
<td></td>
<td>Aberdeen Royal Infirmary (NHS Grampian)</td>
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</tbody>
</table>
# Media & functionality

**Media**
- Patient stories
- Patient & clinician webcasts
- Links to credible information (e.g. NHS website)
- Links to health & social care & 3rd 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)

<table>
<thead>
<tr>
<th>All users</th>
<th>9905</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sessions</td>
<td>12,666</td>
</tr>
<tr>
<td>Pages</td>
<td>75,996</td>
</tr>
</tbody>
</table>
| Origin    | UK: 51%  
            | USA: 15%  
            | India: 6%  
            | Oz: 4%  
            | France: 4% |

<table>
<thead>
<tr>
<th>UK users</th>
<th>5082</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sessions</td>
<td>7381</td>
</tr>
<tr>
<td>Pages</td>
<td>55,874</td>
</tr>
</tbody>
</table>
| Origin   | England: 73%  
            | Scotland: 21%  
            | Wales: 3%  
            | Ireland: 3% |
| Access   | 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
References


References


