criticalcarerecovery.com
-spread throughout Scotland

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Background

- 140,000 patients admitted to ICU in the UK each year
- >70% of patients survive
- Short post-ICU stays (median 10 days at RIE)$^1$
- >70% of patients go directly home
- High mean secondary care costs (£49K/patient annually)$^1$
- High unplanned hospital readmission rates$^1$
  - 23% within 3 months
  - 40% within 6 months
• No dedicated rehab pathway
• Limited ward-based rehab
• Poor knowledge of PICS

• Information failure
• Limited follow-up
• Poor self-management
• Limited GP knowledge of PICS
• Limited referral pathways
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
Policy drivers

- NICE guidelines (2009, 2012)
- ICS & James Lind Research Priority Setting Partnership

“How can patients and their families be best supported as they start living at home again?”
Why might ehealth help?

• Evidence of benefit among other patient groups\textsuperscript{12}
• Strong correlation between poor health and internet/ehealth use\textsuperscript{13,14}
• Increasing internet use among retired & socially deprived\textsuperscript{13,14}
Evidence base

QoL following prolonged critical illness: a mixed methods study\textsuperscript{15}

RCT of enhanced ward-based rehabilitation\textsuperscript{4}

A longitudinal qualitative study of support needs at >1 year after hospital discharge\textsuperscript{16}

A mixed methods study of reasons for unplanned acute hospital readmission\textsuperscript{17}
Benefits of other people’s experience

- Finding information
- Feeling supported
- Sharing experiences
- Maintaining relationships with others
- Healthcare decision-making
Development

Researchers

Patients & families

Website developers

Healthcare professionals
Implementation

Finalised website for tablet and phone

Wrote to a 2 year retrospective patient cohort

ICU Follow Up Team

Approached family members on wards
Implementation
Evaluation

Online survey

Postal questionnaire

Interviews with patients & families (n=35)

Focus group with ICU staff
Findings (QUANT)

• 778 site visitors with 12,046 page views
• 97% online respondents: “extremely”/”very” useful
• 97% “ “ : “easy”/”ok” to use
• 69% postal respondents: “most useful” after discharge home
• Most useful content
  – Other peoples’ experiences
  – Finding out more about ICU
  – Info & advice on common problems after ICU
  – Info & advice on getting help
Findings 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 and social 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 support. She told me it really helped her cope” (ICU nurse)
Findings: QUAL

‘One of the things I found really helpful...was the support links for dealing with the psychological and social issues...after getting home. There’s...the emotional trauma of being in intensive care and...there are financial and employment issues...because you’ve been off work and will be for months. The website is very helpful in directing you to where to get support for these things’. (former patient)

Current work

Spread & localisation

• 8 Scottish ICUs
  – 2 starting very soon!
• Non INSPIRE sites
• Carbon copy of site (12 months)
• Easily customised
• Training & support to customise
• Materials (tablet, posters, etc)
• On costs (social enterprise)
Interested in localising the website for your patients?

Email us:

p.ramsay@napier.ac.uk
dave.hope@ed.ac.uk
Planned work

Further spread & localisation

- 12 Critical Care Networks in England & Wales
- £500K
- Health Foundation
- Outcome October/November

Monitoring & individualised support

- Online measures of PICS
- SMS text messaging/prompts
- Real time patient feedback
- Individualised support & referral ("virtual clinics")
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References


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