

# Innovating for Improvement

Supporting patients and families after critical illness: implementation and evaluation of a novel e-health resource.

NHS Lothian



## About the project

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### **Project title:**

Supporting patients and families after critical illness: implementation and evaluation of a novel e-health resource

### **Lead organisation:**

NHS Lothian

### **Project lead/s:**

Professor Tim Walsh & Dr Pam Ramsay

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## Part 1: Abstract



[www.criticalcarerecovery.com](http://www.criticalcarerecovery.com)

***“There’s a lot of humanity about the way the site has been developed that’ll make patients and families feel confident and reassured at a time when they’re very vulnerable”*** (John, former ICU patient)

### Introduction

Over 140,000 patients are admitted annually to Intensive Care Units (ICUs) in the UK. Over 70% survive, but many suffer from Post Intensive Care Syndrome (PICS):

- Physical – muscle wasting, fatigue, weight loss, joint pain, impaired mobility
- Psychological – anxiety, depression, post-traumatic stress disorder
- Cognitive – amnesia, delirium, cognitive impairment
- Social - delayed return to work, reduced social participation, carers’ health

Unplanned hospital readmission rates are high. 23% of patients are readmitted within 3 months of discharge, rising to 40% within 6 months of hospital discharge (Lone et al, 2013). Although developing interventions to support recovery are now a national priority, patients face a difficult situation:

- No dedicated post-ICU rehab pathway (NICE, 2009)
- Limited ward knowledge of PICS (Ramsay et al, 2014)
- Limited follow-up in the community (Connolly et al, 2014)
- Limited GP knowledge of PICS (Cuthbertson et al, 2009)
- Limited referral pathways (Cuthbertson et al, 2009)

### Background

To better support patients and families within hospital and following discharge, we had previously developed a novel website: [www.criticalcarerecovery.com](http://www.criticalcarerecovery.com). We developed content based on over 120 interviews with patients, and designed the website in partnership with patients and families using focus groups. Acknowledging their specific needs, the website provides the following for both patients *and* family members:

- relevant, meaningful information e.g. on common PICS symptoms

- advice and support e.g. on where to get help in the community
- a chat room for peer and professional support

## **Project aims**

To integrate the website into our existing post-ICU, ward-based rehabilitation and follow-up service at the Royal Infirmary of Edinburgh.

## **How our project developed:**

We held several “launch” meetings, introducing the project to staff and managers across the allied health professions. After adding and improving content, the website went live in August 2015. We developed posters and leaflets for patients, family members and staff. We introduced the website at our site, using various strategies and refined and tested it in real time by interviewing patients, families and healthcare professionals.

### *Introducing the website to patients and families on the wards*

We started introducing the website to recovering patients and families, using a tablet. We quickly realised that many patients were too physically and psychologically frail to engage fully with the website. Also, many told us they were not frequent or confident internet users. However, family members seemed more able and motivated to use the website. Our access to them, however, was limited to visiting time within normal working hours.

### *Follow-up after hospital discharge*

We felt that we were perhaps trying to engage with patients too early, so we followed them up after hospital discharge, by telephone and letter. ICU patients often come from difficult to reach groups (with high rates of alcohol/drug abuse and social deprivation) and initial attempts at telephone follow-up were difficult. However, we found postal follow-up more efficient and sent personal letters with details of the website to a total of 207 patients and 79 family members. We included a short questionnaire about their thoughts on the website. Overall response rates, however, were low.

### *Introducing the website to family members via ICU staff*

Recognising family members’ willingness to engage with the website, we decided to introduce the website to them earlier in the patient’s journey. This not only supported the family earlier and more directly, it also meant that they could help their relative to access the website later in their recovery, when they were ready. ICU nurses spend a lot of time with family members, and we realised that they would be best placed to introduce families to the site. We worked hard at trying to embed early use of the website with them and demonstrated it to nurses individually, using a tablet.

We had some very positive feedback about the website from patients and family, so we fed this back via a staff newsletter. Staff were motivated by this positive feedback, eliciting in turn, positive engagement and feedback from them too.

## **Evaluation**

### *Questionnaires*

Overall response rates were low: we received only 63 responses to the mailed questionnaires. We also received feedback from 29 “pop-up” questionnaires completed online. Responses to both questionnaires were nonetheless very positive overall, with most rating the site very or extremely useful.

### *Interviews with patients, family members and staff*

Because the questionnaire response rate was low, we focused our efforts on evaluating the website by interviewing patients (n=16) and family members (n=19). This gave us detailed insight into their experience of using the website. Again, their evaluation was very positive, but it included some constructive criticism, which we used to actively improve the overall design and layout of the website. We also included ICU staff in a focus group, who recognised clear benefits for patient care and supporting relatives. They also made useful suggestions for more actively incorporating the website into routine practice.

## **Outcomes**

By concentrating on this qualitative approach, we have evaluated the site (just as we developed it), by listening to patients and their families. What they had to say has demonstrated just how valuable the website can be to them. It also helped identify potential improvements, which we have started implementing, for the benefit of other users. Implementing and evaluating the website has been challenging, but by refocussing our efforts towards families and bedside staff in ICU, we have been able to embed it as part of routine ICU care.

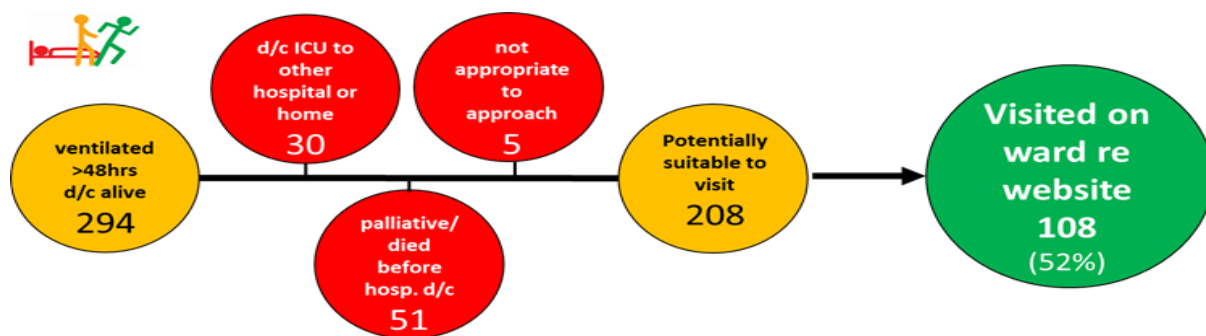
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## Part 2: Progress and outcomes

### 1. Overcoming the challenges of implementation

#### *Introducing the website to patients and families during ward-based care*

When the website went live, we started introducing it to recovering ICU patients seen by an existing ward-based rehabilitation service. Patients were typically those with the most complex rehabilitation needs, having required mechanical ventilation (or “life support”) for ≥48 hours in the ICU. We were only able to approach patients and families during normal working hours, but we visited 52% of patients (n=108) in person.



**Ward visits to offer website for patients d/c from ICU 14/08/2015-13/08/2016**

We found that patients were often too physically and psychologically frail to engage with the website. One patient, for example, with whom we spent 45 minutes demonstrating the site only “vaguely remembered” the discussion when reminded during telephone follow-up. Also, we learnt that many patients were not frequent or confident internet users.

We also approached family members. We found that some were abler and more motivated to use the website. Indeed, patients often identified a (younger) family member who already helped them to use the internet. We realised that family members might be key to implementation, but our access to them was limited to visiting hours. Some, understandably, were pre-occupied with spending time with their relative.

#### *Follow-up after hospital discharge*

By telephone: We learned that we were engaging with patients too early, but found it difficult to predict when patients might be ready. Approximately six weeks after discharge home, we telephoned patients and their family members to remind them about the website, and to ask about their use of it. Unfortunately, we found telephone follow-up difficult (often requiring out-of-hours contact) and inefficient. 40-50 calls yielded only 12 contacts.

By mail: We sent patients and their next-of-kin a personalised letter to remind them of the website, and included a short questionnaire (see appendix 1) with a stamped addressed envelope (SAE). To improve response rate, we also wrote to all patients previously seen as part of our post-ICU rehabilitation service over the previous 18 months. In total, we contacted 207 former patients and 79 family members.

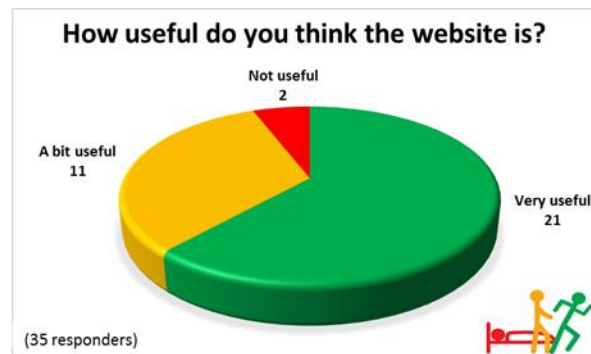
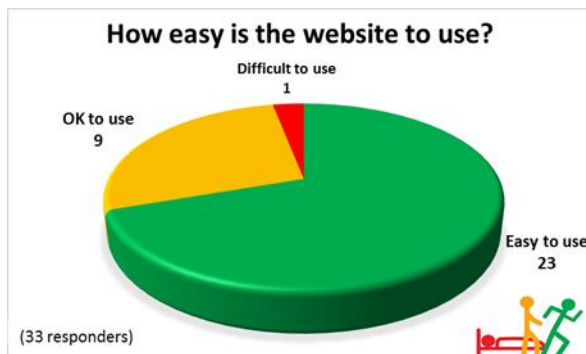
### *Introducing the website to family members via ICU staff*

Our most successful implementation strategy was engaging family members via ICU staff, who spend a lot of time with families due to open visiting hours. We refocussed our efforts on embedding early use of the website with families on the ICU, and spent time introducing the site to individual nursing staff, and providing positive patient and family feedback via a staff newsletter.

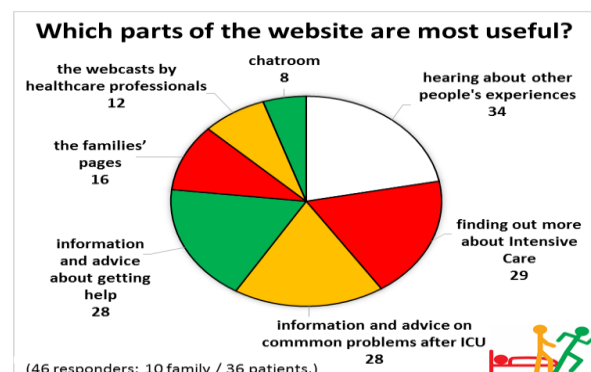
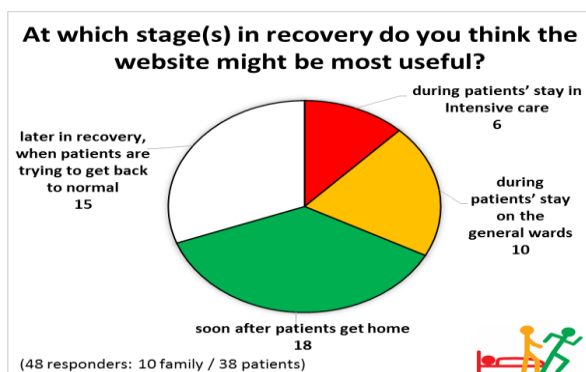
## **Chasing outcomes**

### *Postal questionnaire responses*

We received 50 replies from patients (24% response rate) and 13 from carers/family members (16% response rate). Many patients (20/63) did not have internet access, but of those who did, 94% found the website “useful” or “very useful”, and 97% found it “ok” or “easy to use”



When asked about preferences for content, the most preferred content was “hearing about other peoples’ experiences”. Our users indicated that the best time to engage was “after patients get home” and “later in recovery”.



### Online pop-up questionnaire responses

Anyone accessing the website received a short “pop-up” questionnaire, asking for feedback. We received 29 responses (15 patients, 3 family members, 8 healthcare professionals and 3 others), all but one of whom rated the site “useful” or “extremely useful”.

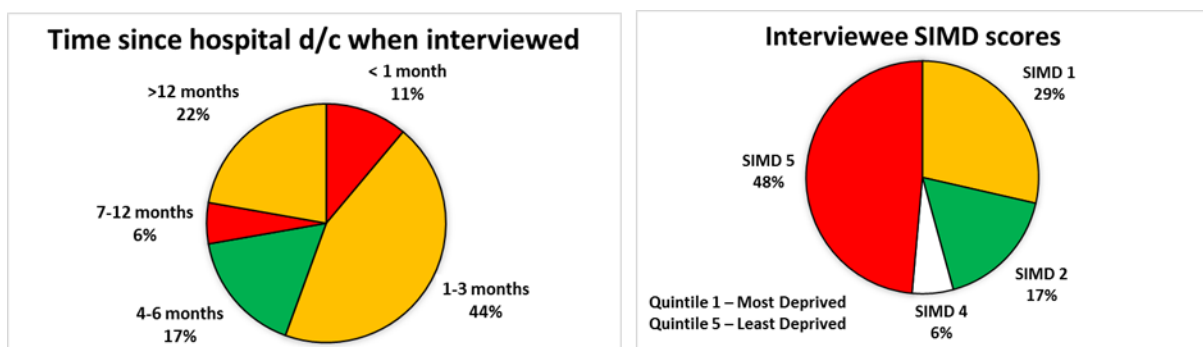
### Website usage

We collected data via Google Analytics. Over the 12 months since going live, 778 people have visited the website, viewing a total of 12,046 pages. See appendix 1 for more detail.

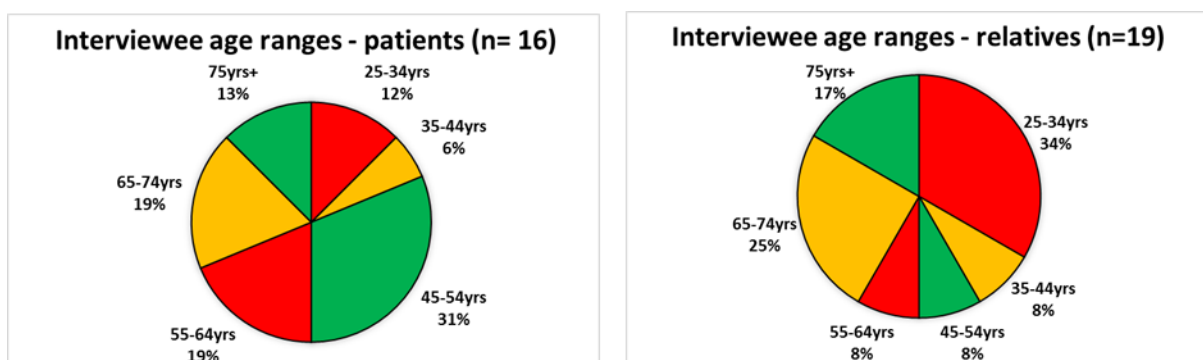
## Our qualitative findings

### Interviews with patients and families

As previously described, our evaluation focused mainly on interviews with patients (n=16) and family members (n=19). We identified potential participants from telephone follow-up and postal questionnaires. We included a broad range of participants by age, gender, sociodemographic status and length of time since hospital discharge.



\*SIMD= Scottish Index of Multiple Deprivation





*Key findings:*

We found that patients' and family members' need for information and support varied according to their personal circumstances, and over time.

*'The problem is that nobody is prepared for going into ICU. They don't expect it and don't know anything about it and what people, patients and families badly need at that stage is information. And it's different types of information at different stages'. (former patient)*

*"The great thing about the website is that it's available 24/7 so you can access information at any time." (former patient)*

Most felt unprepared for the psychological and social impact of critical illness. Information, advice (e.g. on anxiety, depression and flashbacks) and where to get help was particularly valued:

*'One of the things I found really helpful...was the support links for dealing with the psychological and social issues that we had to face after getting home. There's...the emotional trauma of being in intensive care and the consequences of that...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)*

Participants particularly valued "Other people's stories", finding them informative, reassuring and inspiring:

*'Going through the trauma of intensive care can be quite an isolating experience. Going onto the website and reading and watching the videos of 'Other Peoples' Stories' was really helpful to me, because it made you realise that you're not alone. That other people have gone through this and come out the other end, and been able to get on with their lives again.... That gives you hope, which is important'. (former patient)*

The families' page was valued by both patients and family members:

*As a patient you're not really aware of what's going on...but for your family members, it can be really traumatic for them to see you like that. So having the website...explain what all the equipment was and what it was there for and what it did, I know my wife found really helpful'.*

Participants welcomed the active involvement of other patients, families and healthcare staff in developing the website, identifying its "humanity" as a major strength

*'...when I was originally invited to take part in building the website... I wondered if I was just being asked...so you could rubber stamp this and say 'well look we've involved patients and it gives us a bit more authority'. But I found right from the outset that our opinions as patients and carers/family*

*members were genuinely valued and indeed needed to create a website that reflected intensive care patients' real needs'. Because of that there's a lot of humanity in this website"* (former patient)

### **A focus group interview with ICU staff**

Our focus group comprised a consultant, 2 nurses, 2 physiotherapists and a dietitian. We asked for their views on the website and how it could be embedded into routine practice. ICU staff were generally enthusiastic about the website, seeing clear benefits for patient care and supporting families.

*"I would often like to spend more time with the relatives...but I don't have a lot of time as I'm looking after patients...this website goes part of the way to giving information, not a substitute from talking to staff, about what is going on and why". And it's about supporting patients and their families when they get home which is just as important as when they're in hospital'. (ICU nurse)*

*"I used the website to direct a family member of a critical care patient where to get counselling support. She told me later that it really helped her cope." (ICU nurse)*

There were also benefits for non-ICU staff

*"It brings the language of critical care more into lay terms for patients and families, but also for staff that don't work in critical care who will come into contact with these patients". (ICU nurse)*

Staff also identified strategies for continued embedding into routine care, which we will actively use.

*"Have it in all staff offices, have three or four in the patient waiting rooms on the wall so that relatives can view it while they're waiting". (ICU Consultant)*

*"The staff have got huddles where they get together and discuss a case and then liaise with family members. It would just take two seconds to mention the role the website could play in helping family members". (ICU nurse)*

**WORD COUNT 1352 (including quotes – 553 words)**

## Part 3: Cost impact

### *Known healthcare costs among ICU survivors*

Unfortunately, cumulative costs for health and social care for recovering ICU patients are not routinely collected. We know from previous work, however, (RECOVER trial: see Appendix 1) that patients who are eligible for our rehabilitation service spend a median of 11 days in hospital after ICU discharge. We also know that approximately 23% of patients require an unplanned emergency hospital readmission within 3 months of hospital discharge, and that this figure rises to 40% within 6 months (Lone et al, 2013). We found that secondary care costs in the RECOVER trial were a mean £49K (range £7K-£249K) per patient, over the 12 months following ICU discharge. The majority of these costs were accrued during the remainder of their post-ICU hospital stay, and due to early unplanned readmission following discharge. In all, we estimated that the total cost for around 300 patients per year is approx. £15 million.

In *this* project, we have been offering the website to patients identified as having the most complex rehabilitation needs. These patients are much more likely than many RECOVER participants to have longer acute hospital lengths of stay and higher unplanned hospital readmission rates, making meaningful comparison almost impossible. We also recognized that the use of our website might incur additional health and social care costs, by identifying and addressing unmet need.

In short, we realised that meaningful economic evaluation was beyond the scope of the current project. Indeed, the project was not intended to achieve measurable cost savings e.g. reducing acute hospital length of stay, rates of GP or outpatient attendance, known high acute hospital readmission rates or Quality Adjusted Life Years (QALYs). We therefore did not aim to carry out any formal or detailed analyses of cost, but would aim to do so in subsequent research.

### *Impact on processes of care*

In our mixed-methods process of the RECOVER trial (Walsh et al, 2015), we found that intervention patients (those being seen by our Rehabilitation Assistant) reported better experiences of care, greater person-centredness and overall coordination of care. We anticipate that the introduction of multidisciplinary ward-based “huddles” in *this* project improved communication and discharge planning, possibly expediting hospital discharge, but we were unable to collect reliable evidence during the project’s timeframe.

### *Impact on patient outcomes*

We also recognize the potential impact that our intervention might have on “softer” patient outcomes such as improved self-management, self-confidence, health literacy (knowledge, ability and confidence to deal with health issues) or perceived self-efficacy (the ability to cope with difficult situations). Exploring potential benefits

and identifying suitable outcome measures would also require additional, detailed research over a lengthier period than was available to us in this project.

#### *Identified maintenance costs for sustainability*

Our intervention is low cost and could continue to operate as one. Introducing family members to the website via ICU staff will be cost-neutral as it is now embedded as part of routine practice. Familiarizing new staff with the website will be done as part of the induction process, accruing no additional costs. Our Rehabilitation Assistant is funded as part of the existing in-hospital rehabilitation staff (approx. £25K per year), and she is now actively involved in promoting the use of the website with patients and their family members. Fixed costs for internet services such as website hosting and maintenance, video hosting and accessibility software incur only a relatively small annual charge (less than £3000). A salaried administrator with a modest budget could continue to inform patients and families of the website by mail and manage website content at relatively low cost (£3-4000/year). We propose to approach NHS Lothian to sustain the website after study end.

#### *Project costs*

The cost of this project was £67,580, and was delivered in line with original projected costs. We were able to fund website development, based on patients' and families' feedback through a moderate redistribution of monies, with The Health Foundation's kind permission.

**WORD COUNT 649**

## **Part 4: Learning from your project**

We learned a great deal throughout the course of this highly challenging, but very enjoyable and rewarding project. Through engaging with staff, we have now established an innovative system that gives patients and families access to the types of information, advice and support they need throughout the long recovery process.

### ***Challenges***

*Getting started:* In the initial stages of the project, we were overly concerned with getting the website ready to go “live”, as it was not quite complete. In hindsight, this made the process feel somewhat “rushed”, but we were able to continue to improve and develop the website throughout the course of the project.

*Engaging with patients and family members on the wards:* We found it much harder than anticipated to engage with patients. Visiting patients was often time-consuming, given that they were being cared for in many different wards across the hospital. Visits were frequently unsuccessful as patients were often off the wards e.g. having tests or examinations, “boarding” elsewhere, or had been discharged home without warning. Many were unable to engage with the website due to ongoing illness, fatigue, poor concentration and a lack of confidence with internet technology (particularly among some of our older patients).

Attempts to engage with family members were also often challenging, as we were only able to approach them during visiting hours. Many, having travelled long distances, were rather more concerned with spending time with their recovering family member.

*Technical issues:* While we have enjoyed support from NHS Lothian management, we faced some technical problems. Also, Wi-Fi was not available in the general wards, which meant that we had to use 3G enabled tablets to demonstrate the site. We were required to re-post all video content to meet Trust IT security requirements, but most staff were unable to hear video content at work, because Trust computers do not have speakers.

We were not permitted to install internet-enabled devices in unstaffed ICU relative’s waiting areas, although we have provided a tablet for relatives’ use under staff supervision. We have been unsuccessful thus far in amending our electronic patient records to include reference to the website when sending discharge letters to GPs, as we had hoped.

*Follow-up after hospital discharge:* Telephone follow-up was difficult as it was restricted to normal working hours, or when other clinical activities took precedence. Patients often reported during telephone follow-up that they were still too tired or lacked concentration to engage with the website, but many responded well to our prompts. Family members had often had to return to work, making access difficult,

and many reported having “too much to deal with” in terms of the added caring for recovering family members.

*Collecting outcomes:* Questionnaire response rates were disappointingly low, and we were unable to collect many of the measures we originally planned (e.g. HRQoL, patient satisfaction). We also realised at an early stage that our plans to evaluate healthcare costs were over-ambitious and unlikely to produce meaningful results.

*Research team appointments:* In hindsight, we would have benefitted from a full-time, rather than part-time project manager. This did not detrimentally affect the project or prevent us from meeting our project aims, but juggling or sharing roles was often cumbersome and created uncertainty. We were unable to appoint our qualitative researcher until much later in the project than anticipated, due to contractual issues. However, we used this cost reduction to make additional changes to the website, based on patient and family feedback, and to include a Knowledge Exchange event.

## **Successes**

*Engaging with staff:* We invested a great deal of effort into engaging with a range of staff, initially on the general wards. This was not as successful as we had hoped, due largely to time and staffing constraints. We did find, however, that the introduction of multidisciplinary “huddles” worked well on the general wards, with anecdotal reports of improved communication of patients’ complex care needs and discharge plans.

Engaging with the ICU staff was highly successful, particularly once we introduced them to the website on an individual basis, and once we shared positive patient feedback with them. We were actively able to capture their interest and enthusiasm through highlighting their pivotal role as trusted providers of information to patients and family members. We were delighted to hear of positive instances of the website’s use and by staff’s agreement to contribute short videos; reflecting, we believe, a renewed sense of ownership.

*Team working and creativity:* We worked very collaboratively together as a team, sharing ideas and options and agreeing revisions to our original plans in the light of our experience. We thoroughly enjoyed working alongside our web developers (Shaw Design). With their expertise, creativity and commitment, we were able to ensure that the website was relevant, sensitive, safe and tailored to meet patients’ and family members’ needs. We are enormously grateful to Mr Bob Glen, a former patient whose insightful contribution to website development was invaluable, and to several of the original focus group participants for their continued enthusiasm and involvement.

### ***Advice for others doing similar work***

As a team, we worked very well together. We would suggest careful consideration of team members' individual skills and contributions, project infrastructure (e.g. communication, meetings and reporting) and the general working style of the team. What our setbacks taught us most was to be adaptable. We revised our plans to be realistic and achievable and focussed our efforts where we could achieve most. For example, with less quantitative data than originally intended, we played to our strengths and increased the scale of our qualitative evaluation. Finally, we would encourage others to make full and abundant use of their dedicated facilitator. Mr Richard Edgeworth has been stalwart in his encouragement and expert support throughout this project.

**WORD COUNT 949**

## **Part 5: Sustainability and spread**

We fully expect to be able to sustain the use of the website in its current form within our existing rehabilitation service at very little cost. We will seek formal endorsement of the website by NHS Lothian and support for maintenance costs.

We also recognise how quickly things are evolving in the field, and recognise the enormous potential that e-health innovations can have in improving equity of access to healthcare expertise that is otherwise unavailable, in promoting self-management among patients and families, improving health outcomes and reducing healthcare costs. We are therefore actively committed to securing additional funding for sustainability and ongoing development.

### ***Sustainability***

*Local dissemination:* We have engaged with NHS Lothian clinicians and managers across multiple disciplines and have successfully embedded our intervention into routine practice at our site. By releasing the website to open access, we have raised awareness in the two additional ICUs in NHS Lothian, the larger of which will be centralised to our local site later in 2016. We have also met with colleagues in NHS Greater Glasgow and NHS Tayside, to broaden interest to other areas of NHS Scotland.

We have ongoing support from NHS Lothian's Tele-healthcare and Innovations Programme Boards and hope to be able to further develop the service in line with NHS Lothian's Strategic Plan - "Our Health, Our Care, Our Future". This includes a clear commitment to "providing and ensuring that information and knowledge, along with specialist advice and equipment is made accessible to support people effectively in their own self-care". We approached the Scottish Government's e-health Department, who recently posted an online article on NHS Scotland's eHealth website: <http://www.ehealth.nhs.scot/news/>.

We will be hosting a Knowledge Exchange Event at the Wellcome Trust, Western General Hospital Edinburgh on 16th September to showcase the website and discuss next steps in the website's development. We have invited NHS managers and clinicians and representatives from government and third sector community organisations. The event will be available to view via live streaming, and we have advertised the event widely to national and international colleagues via social media (Twitter: @critcarerecover). For details go to: <https://www.eventbrite.co.uk/e/a-website-to-support-recovery-after-intensive-care-tickets-26638105290>). We have also made very preliminary enquiries to a TV production company (maverick tv) about the possibility of making a documentary which follows recovering critical care patients.



*Wider professional dissemination:* We have presented our work at multiple professional conferences including: What's New in ICU (a locally hosted conference for UK critical care staff); the Scottish Intensive Care Society's Annual Research Conference; the British Association of Critical Care Nurses; the United Kingdom Critical Care Research Forum, amongst others. We will present at a prestigious international conference, the 5<sup>th</sup> International Conference on Rehabilitation following Critical Illness in Baltimore in November.

#### *External interest and recognition*

We have engaged widely with charitable and third sector organisations. Our website has been included on the Scottish Centre for Telehealth and Telecare site, ALLISS (A Local Information System for Scotland) and Living it Up. The latter recently published an online article highlighting the "patient-centredness" of our website (<https://www.livingitup.scot/your-area/local-news/new-website-launched-for-people-recovering-from-intensive-care/>). We have approached media teams from the University of Edinburgh, Edinburgh Critical Care Research Group, and Edinburgh Napier University; all of whom have actively contributed to advertising our website, using internal and external communication. We were recently interviewed by The Sunday Times about our research on rehabilitation following critical illness (for publication 28<sup>th</sup> August 2016).

#### **Spread**

*Generalisability:* Our resource is readily generalizable to other hospitals and Health Boards across Scotland and the UK. Although we designed the website specifically to provide local information, the simple content management system provides the potential for spread. From a national perspective, we will collaborate with ALLISS (A Local Information System for Scotland) to facilitate access to local community-based support throughout Scotland, using a bespoke, largely cost-neutral "portal" to their information systems. Additional funding would be required, but costs would be relatively small (e.g. some additional programming costs). From a wider UK perspective, colleagues at Guys and St Thomas Hospital (London) have already committed to developing and localising our website for their patients and families, and to share their learning on this process. Our aim is to incorporate this learning into training materials for future collaborators.

#### *Future funding*

We had hoped to be able to further develop the website, by a recent application to the Chief Scientist's Office. Our aim was to develop and test patients' online self-assessment of Post Intensive Care Syndrome, with triggers for professional support including teleconsultation. Total funding requested was £300,000. Our application was one of only 11 short-listed via a new, rigorous screening process, of which 5 were ultimately funded. Sadly, we were unsuccessful, but formal feedback included

suggested improvements and a recommendation that our application had potential for success with other large scale funders e.g. NIHR/HTA.

We are applying for CSO funding of £35,000 (Catalytic Grants Scheme) in order to conduct a proportion of the developmental work required for submission elsewhere. We will also apply to the Health Foundation's Spreading Improvement Programme, in order to help disseminate our intervention throughout Scotland and the UK (£30,000 available).

**WORD COUNT 837**

## Appendix 1: Resources and appendices

### Google Analytics



Analytics All Web  
Site Data Audience (



Analytics All Web  
Site Data Pages 201!

### Patient stories video

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

### Knowledge Exchange



invite &  
programme.pdf

### Mailing contents



discharged patients  
letter.docx



NOK letter.docx



previous patients  
letter repeat.doc



website intro.docx



website  
instructions.docx



Website  
questionnaire v2.do



BUSINESS CARD  
ICU Website.pptx



discharged patients  
letter without Q.doc

### Presentations



Presentation to  
surgeons.pptx

### Living it Up website entry

<https://www.livingitup.scot/your-area/local-news/new-website-launched-for-people-recovering-from-intensive-care/>

### eHealth website article (case study)

<http://www.ehealth.nhs.scot/>