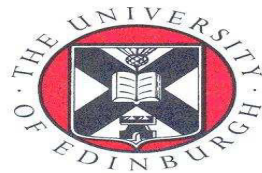




# A patient and family-focused website to support recovery after Intensive Care

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

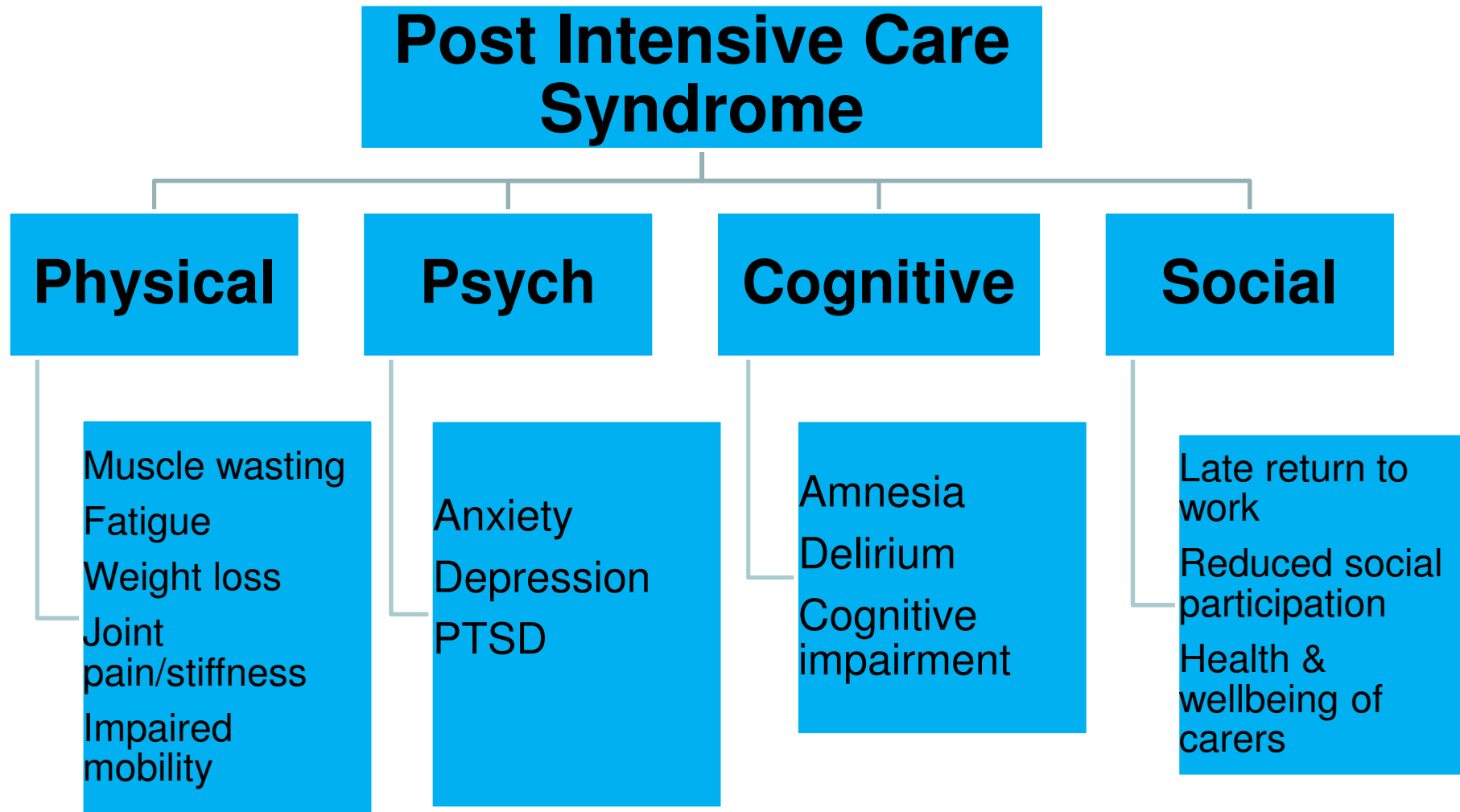
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Edinburgh Napier University



## 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)\*
- >70% of patients go directly home
- High unplanned hospital readmission rates\*
  - 23% within 3 months
  - 40% within 6 months

\* Lone et al, 2013



# The patient journey





# The evidence base: patient experience

## **QoL following prolonged critical illness: a mixed methods study** (Ramsay, 2010)

- 20 interviews with patients at  $\leq 6$  months post-ICU discharge

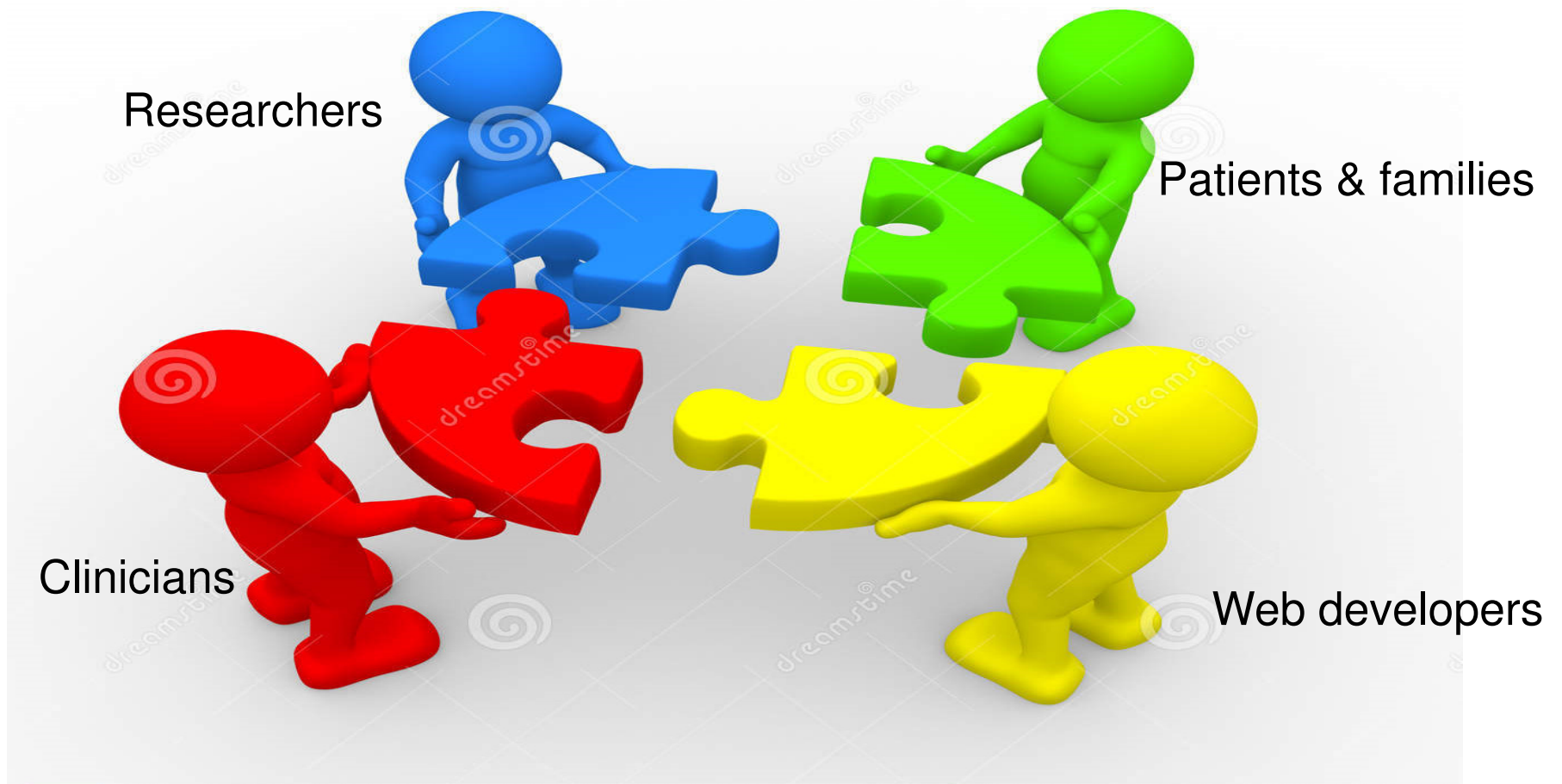
## **RECOVER:** RCT of post-ICU rehabilitation

- 4 FGs with patients & families at  $\geq 3$  months post-ICU discharge

## **RELINQUISH:** longitudinal qualitative study of recovery

- 78 interviews with patients over 12 months post-ICU discharge

# The process



## 5 key questions

1. How can I find out more about...
  - what happened to me?
  - what to expect?
2. What professional help will I get?
3. What can I do to help myself?
4. What can my family do to help?
5. What help is available after I've gone home?

# Implementation



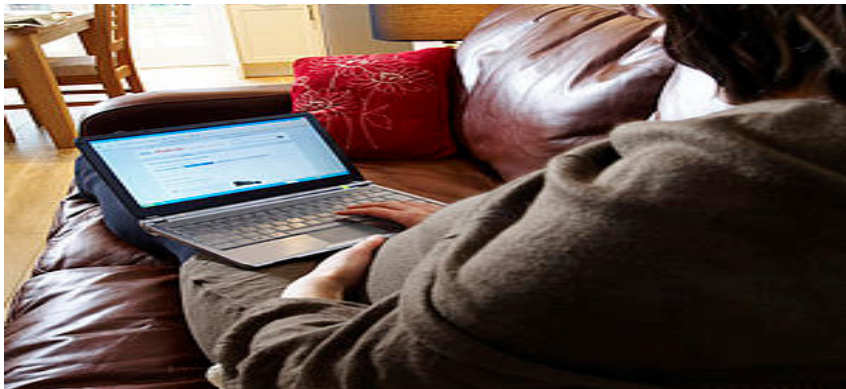
## Strategies

1. Patients & families on general wards at RIE
2. **Family members in ICU...via ICU nurses**





# Evaluation



- Online questionnaires
- Postal questionnaires (n=60)
- Face-to-face interviews with patients & family members (n=35)
- Focus group with ICU staff (n=8)

# Findings

- 784 visitors/year (August 2015-2016)
- >12,000 page views
- 94% found it “useful” or “very useful”
- 97% found it “ok” or “easy to use”
- Most preferred content?
  - Hearing about other people’s stories
  - Common problems after ICU
- Most useful?
  - Shortly after discharge home
  - Later in the recovery process

## Findings: patients

“The great thing about the website is that it’s available 24/7 so you can access information at any time.”

“Other Peoples’ Stories’ was really helpful...because it made you realise that...other people have gone through this and...have been able to get on with their lives again...That gives you hope, which is important”

## Findings: patients

“...when I got home, I was very low and I was struggling with not working. So the information on depression...was very helpful...the links to different support organisations was also helpful. Especially the one to Citizens Advice who actually helped me to complete the forms about my work situation and then getting support.” (patient)

Quick Search




### Helping you along your Intensive Care journey

Click on one of the buttons below for more information and advice...



**Your time in Intensive Care**



**Your time on the general wards**




**Getting home**



**Moving on**

**How to use this website**



**About us**



**Forum and chat room**



### Create your own library...

Use our scrapbook to create a library of content featured on this site.

Start here



### 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 rights, medication, mobility, money, muscle wasting, nightmares, Occupational Therapist, Pacing, pain, pharmacist, physiotherapist, **Physiotherapy**, Post traumatic stress, prescription, psychological, social work, spiritual, strange memories, support, support groups, tiredness, visiting, weakness, wheelchair, work



**Welcome to the Intensive Care Recovery Service**

About us

### Suggestion Box

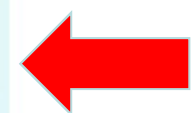
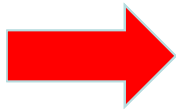
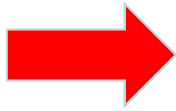
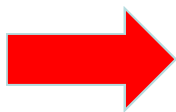
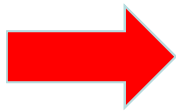
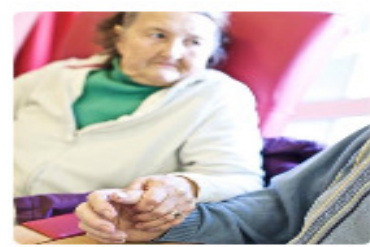
We'd welcome your feedback on the content and how the website works, please complete the form below...

Your name...

Your email...

Your suggestion...

Send your suggestion



# Where next?



## Spread

- NHS Scotland
- UK-wide
- International?

## New functionality

- Online patient self-monitoring of PICS (HTA?)
- Real time patient feedback (HTA)
- Access to healthcare experts (HTA)
- Teleconsultation (“virtual clinics”) (HTA)
- Telerehabilitation?



## Contact **p.ramsay@napier.ac.uk**

- For more information
- If you'd consider “localising” the website for your area
- Free promotional materials
  - Posters
  - Leaflets
  - Business cards
  - Video