



EPIC: A patient and family focused website to support recovery following critical illness

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What's New in ICU? 26th of June 2013

Funders

- Edinburgh and Lothian Health Foundation
 - Scottish Intensive Care Society
 - Edinburgh Critical Care Research Group
 - Health Services Research Unit
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Collaborators

- Prof Tim Walsh (intensivist/researcher)
 - Dr Janice Rattray (nurse researcher)
 - Prof Pam Smith (nurse researcher)
 - Dr Susanne Kean (nurse researcher)
 - Dr Tara Quasim (intensivist/researcher)
 - Shaun Maher (charge nurse, ICU)
 - Mr Bob Glen (former ICU patient)
 - Mr Neil Francis (web developer)
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Overview

- Background
 - A qualitative meta-synthesis
 - Doctoral thesis (QoL following prolonged critical illness)
 - RCT of enhanced rehabilitation (RECOVER study)
 - Longitudinal qualitative study (RELINQUISH study)
 - The website so far...
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Background

- ~100,000 admissions annually to ICUs in the UK
- ~330,000 ICU bed days (~£500million)
- High in-hospital mortality (~33%)

N.b. Demographic trends

Absence of central Scottish funding for follow up

Policy emphasis on primary healthcare

Physical morbidity

- Muscle wasting
- Profound weakness
- Fatigue
- Joint stiffness
- Peripheral neuropathy
- Severe weight loss
- Voice changes
- Hair loss

Psychosocial morbidity

Psychological

- Anxiety (12-43%)
- Depression (10-30%)
- Post traumatic stress disorder (10-39%)
- Post traumatic stress symptoms (9-51%)

Cognitive

- Impaired short term memory
 - Impaired executive function (decision making)
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A qualitative meta-synthesis*

Interview based research as part of:

- **PhD:** Quality of life following **prolonged** critical illness (2005)
- **The RECOVER study:** Trial of enhanced in-hospital rehabilitation (2010)
- **The RELINQUISH study:** Longitudinal qualitative study of healthcare and support needs at up to 1 year after hospital discharge (2010)

***Over 100 in depth interviews with patients (and some family members) at <1 year after hospital discharge**

PhD: key findings

ICU experience

- Amnesia*
- Delirium*
- Hallucinations*



Limited

understanding of the critical illness event and morbidity

(*linked to psychosocial morbidity)

Ward care

- Amnesia & delirium
- Debilitation
- Dependence
- Specialty specific care
- Staff attitudes



Desperation for hospital discharge

PhD: key findings

Ward rehab

- Importance
- Limitations
- Discharge criteria



Deilitation at hospital discharge

Getting home

- Abandonment
- **Family**
- Self management



Protracted, incomplete recovery

RECOVER: RCT of enhanced hospital rehabilitation (n=240)

Key elements

- Case management (dedicated rehab. assistant)
 - Physiotherapy
 - Dietetic
 - Occupational Therapy
 - Speech & Language Therapy
 - Follow up phone call
 - Information
 - Common morbidity
 - Consultant visit
 - Lay summary
 - Visit to ICU
 - Intensive Care Recovery Manual (Jones et al)
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RECOVER focus groups (n=4)

With patients and families (at >3 months after hospital discharge)

- Importance of information and involvement in care
 - Desire for ongoing rehabilitation
 - Desire for psychological support
 - Importance of family involvement
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RELINQUISH: healthcare and support needs

Aim: to identify common issues at key stages in the recovery process

Interviews with patients (n=24)

- Prior to hospital discharge
 - 4-6 weeks
 - 6 months
 - 12 months
- } after hospital discharge
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RELINQUISH: key findings

- Poor communication between hospital and community (eg home aids and adaptations)
 - Ongoing physical and psychological issues
 - Limited understanding among GPs
 - Financial issues
 - Impact on/of family on recovery
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Key findings: summary

Improved understanding of the *experiences, needs and preferences* of patients in terms of addressing the physical, psychological, emotional, economic and social issues they face in their everyday lives.


Website aims

To provide:

- **Information** (e.g. on common problems)
 - **Advice** (e.g. on self-management, accessing benefits)
 - **Support** (from other patients, healthcare staff)
 - **Access to healthcare professionals**
(online and real time, face to face)
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Development: patient involvement

- Evidence base!
- Study design (co-applicant)
- Concept
- Content (utility, breadth, sensitivity)
- Media
- Personalisation features
- Ease of use
- Online evaluation



focus group
methodology

Schedule of meetings

Jun 2013	Aug 2013	Oct 2013	Dec 2013	Feb 2014	April 2014
Patient and family Focus Group 1	FG2 Your time in ICU	FG3 Your time on the wards	FG4 Getting back to normal	FG5 Longer term recovery	Knowledge Exchange Event
Expert Advisory Group		Expert Advisory Group		Expert Advisory Group	
Steering Committee		Steering Committee		Steering Committee	

Expert advisory group

Representation from:

- Intensivists
 - ICU nurses
 - ICU Follow Up and Outreach services
 - Physiotherapy (ICU and ward)
 - Dietetics (ICU and ward)
 - Occupational Therapy
 - Speech and Language Therapy
 - Pharmacy
 - Chaplaincy
 - *Social Work (TBA)
 - *Community-based clinicians (TBA)
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Expert Advisory Group: purpose

Expert content on:

- Professional role/activities
 - Commonly reported issues
 - New/bespoke issues raised by patients and families (via contact facility)
 - Webcasts
 - Consultation?(online or face to face)
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The website so far.....

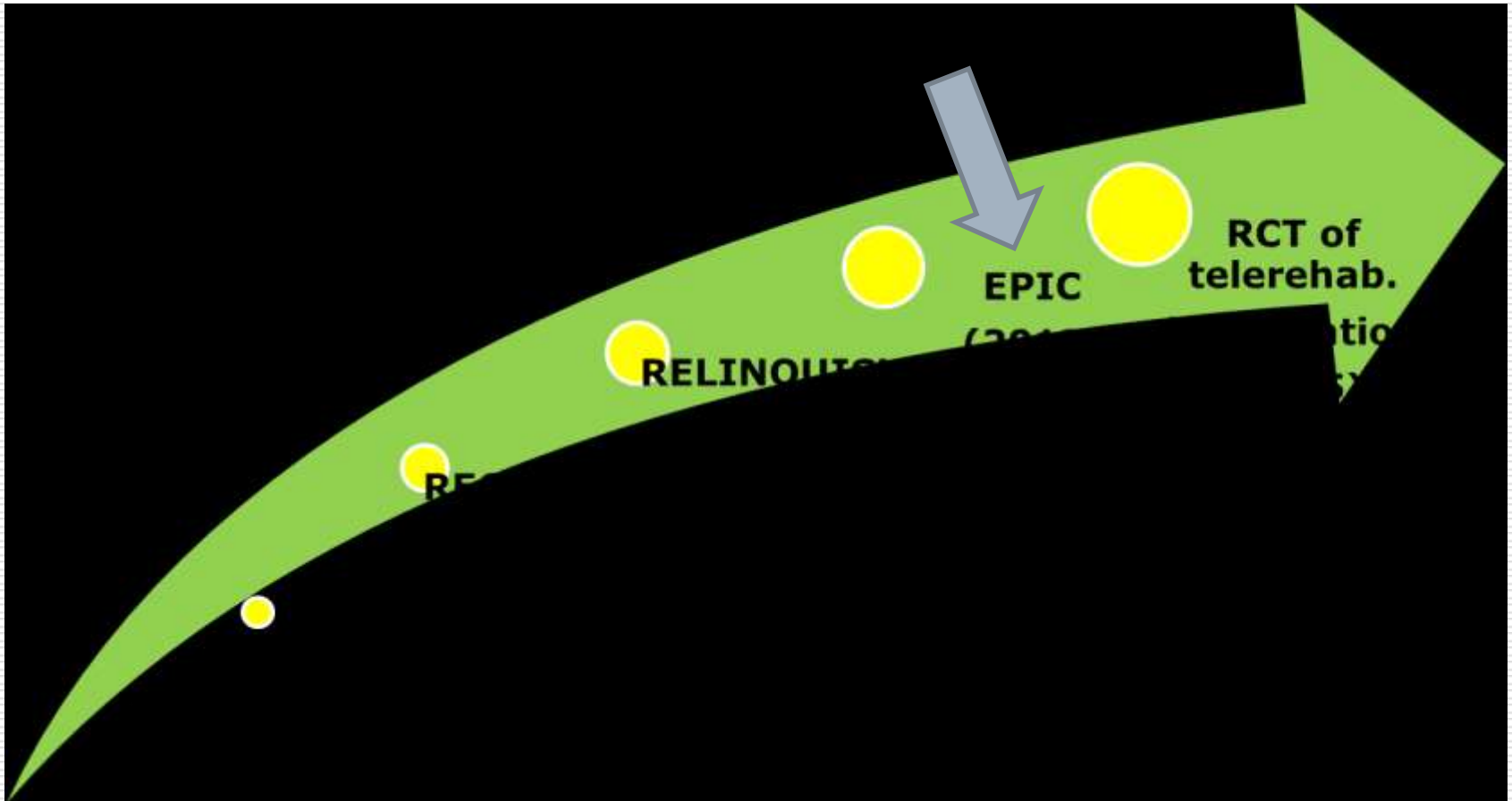
Feedback (focus group work)

“It’s great to hear about other people’s experiences. *You do tend to have a sense of isolation...like you’re the only one..*”

“ I wish there’d been something like that when I came out of hospital. It might’ve saved me a couple of *pointless* trips to the GP”

“I really like the families' page. You often feel like you’re on the outside of everything....until they come home”

Future work



References

- Ramsay, P (2011). Quality of life following prolonged critical illness: a mixed methods study (Unpublished thesis, University of Edinburgh)
 - Ramsay, Huby, Rattray et al (2012). A longitudinal qualitative exploration of healthcare and informal support needs among survivors of critical illness: the RELINQUISH protocol. *BMJ Open* 2012 doi:10.1136/bmjopen-2012-00150
 - Walsh, Salisbury, Boyd, Ramsay et al (2012). A Randomised Controlled Trial Evaluating a Rehabilitation Complex Intervention for patients following Intensive Care Discharge. The RECOVER study. *BMJ Open* 2012:2:e001475.
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QUESTIONS?
