

ICU DIARIES: WHAT WORKS, FOR WHOM AND IN WHAT CIRCUMSTANCES?

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OVERVIEW

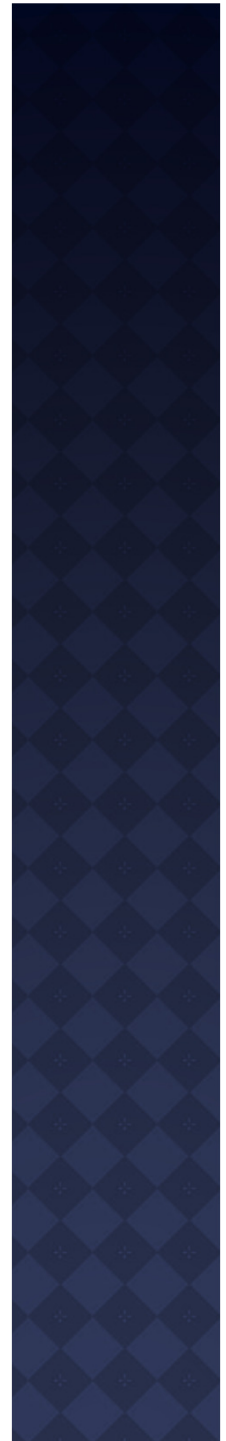
- ⦿ Professional and Personal Drivers
- ⦿ Background
- ⦿ Aim and objectives
- ⦿ Methodology
- ⦿ Findings
- ⦿ Conclusions

DRIVERS FOR THE STUDY: PROFESSIONAL PERSPECTIVES

- ◉ Focus has shifted from survival to complexity of life following critical illness
- ◉ James Lind Alliance ⁽¹⁾
‘How can patients and their families be best supported as they start living at home?’
- ◉ NICE guidelines ⁽²⁾
Rehabilitation after critical illness

DRIVERS FOR THIS STUDY: PERSONAL PERSPECTIVES

- ◉ Dissertation for MSc Advanced Professional Practice
- ◉ ICU staff nurse
- ◉ Personal experience of being ICU patient



BACKGROUND

- ④ Acute hospital mortality following ICU admission is 25.8% but the remaining **74.2%** of patients will **recover** and be discharged from hospital ⁽³⁾
- ④ ICU survivors frequently face a difficult and protracted recovery ⁽⁴⁻⁵⁾
- ④ Growing body of literature on short and long-term consequences of post-intensive care syndrome ⁽⁶⁾
- ④ Provision of follow-up care remains inadequate ⁽⁷⁾

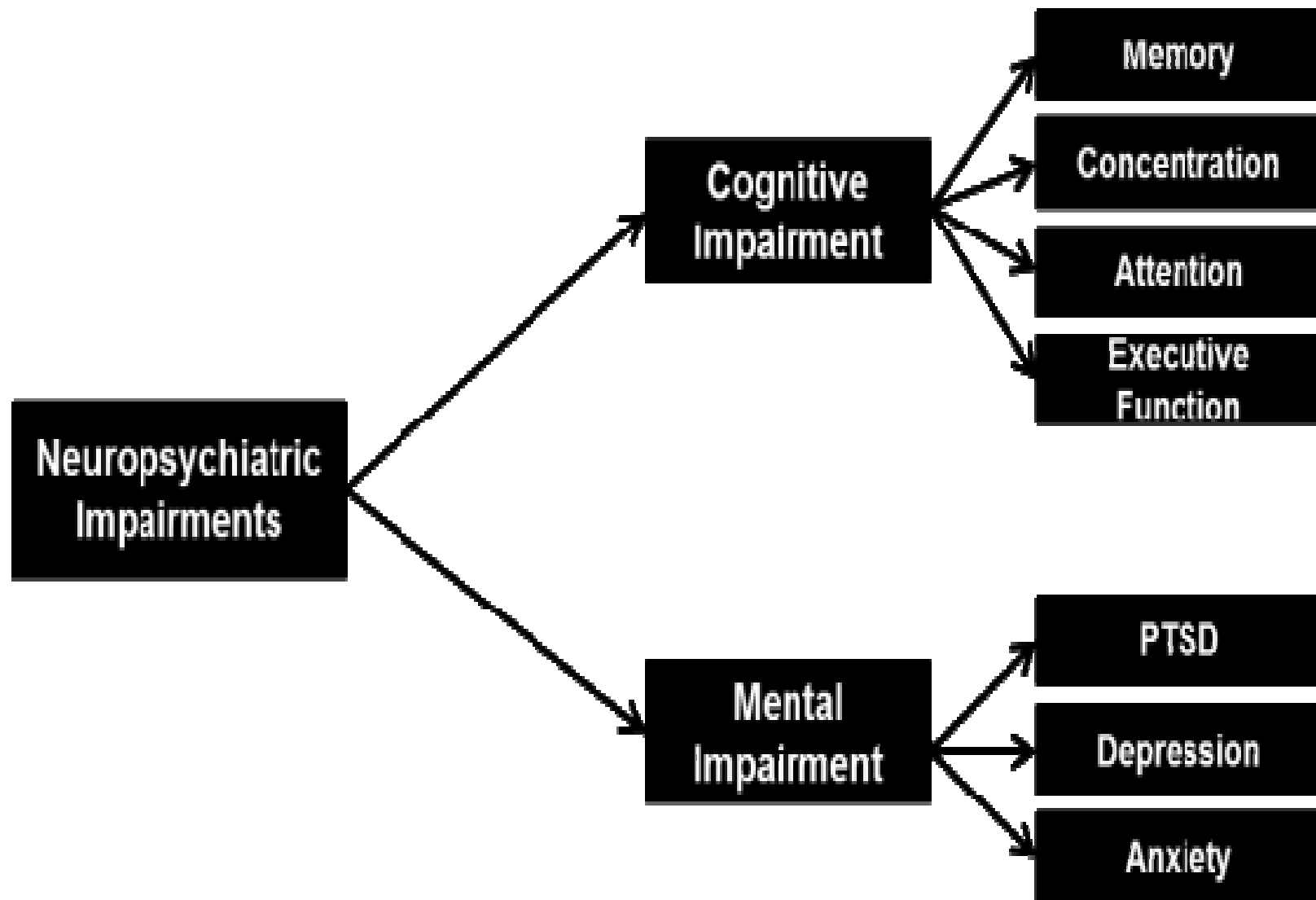


Figure 1. Post-intensive care unit neuropsychiatric impairments PTSD post-traumatic stress disorder

ICU DIARIES

- ◉ Rarely standard practice in ICU
- ◉ By proxy, nurses, healthcare staff and relatives write for patient
- ◉ Daily account of ICU stay:
 - Provision of a factual narrative of a patient's ICU stay
 - Enables amnesic memory gaps to be clarified
 - Provides context for delusional memories
- ◉ Given to patients following ICU stay

ICU DIARIES: DO THEY HELP?

- ◉ Mixed evidence supporting diary use
- ◉ Generally favourable feedback from patients and relatives (9-11)
- ◉ Aitken et al (12) literature review:
 - Lack of clear underpinning theory to support diary use
- ◉ Ewens et al (13) literature review:
 - Implementation and ongoing use of diaries is disparate
- ◉ One existing systematic review on patient diaries: (14)
 - Minimal evidence of benefits or harms of diaries
 - Focus on minimisation of bias to provide quantifiable summary of effectiveness

SO WHY ANOTHER REVIEW?

- ◉ Diaries as a complex intervention
- ◉ Differing content, processes, timelines and multiple human components
- ◉ Heterogeneity of ICU patients
- ◉ Question changes from:
'What works?' to 'what is it about this intervention that works, for whom and in what circumstances?'

AIM AND OBJECTIVES

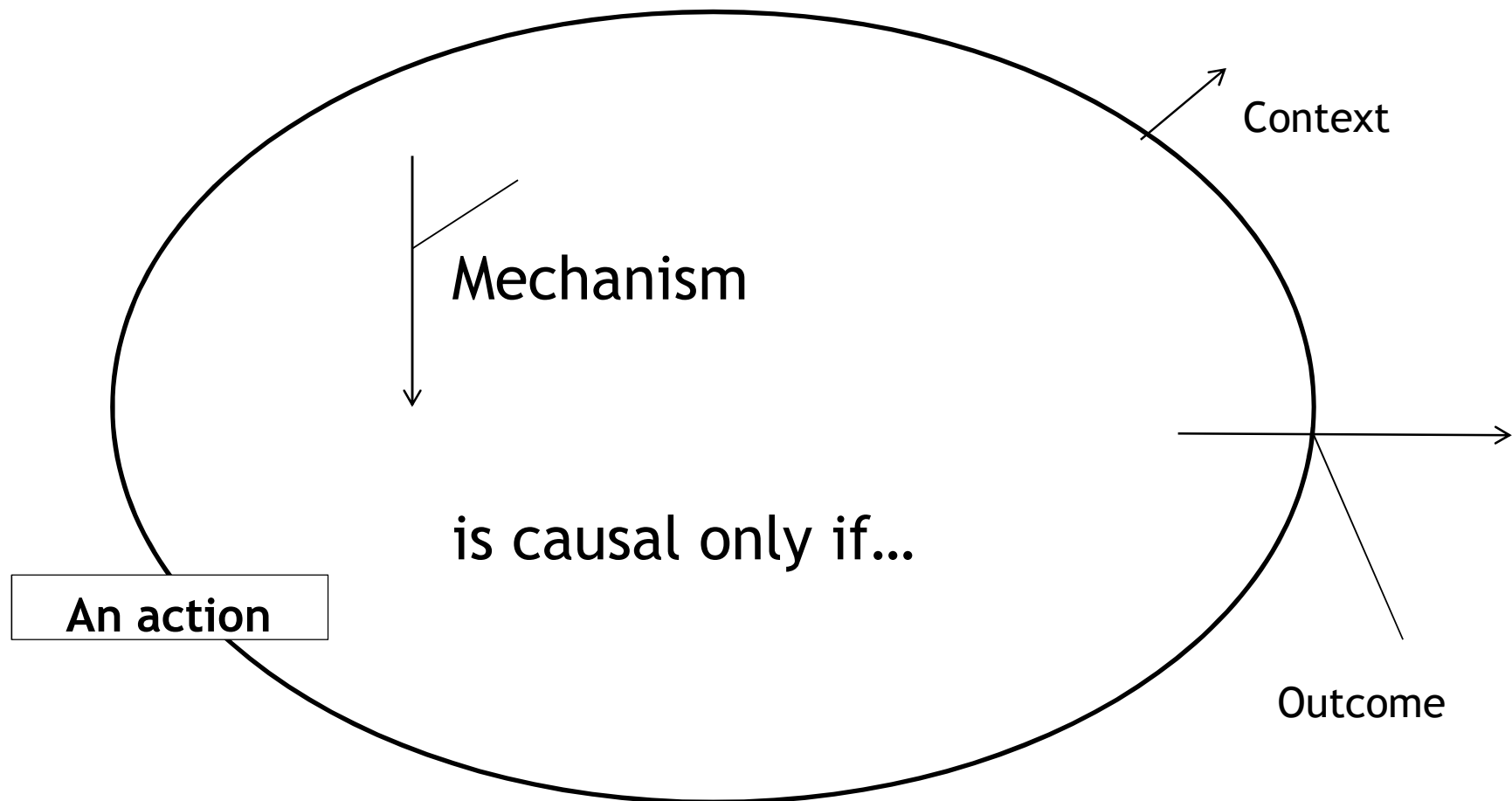
- ◉ What are the mechanisms by which patient diaries are expected to affect psychological wellbeing?
- ◉ What are the key contextual factors which determine whether the different mechanisms produce intended outcomes?
- ◉ For whom do patient diaries work and for whom do they not work?

METHODS

- ◉ Realist review
- ◉ Alternative to traditional outcome evaluation
 - Seeks to identify underlying components that are needed for an intervention to work
 - Importance of context
- ◉ Material from across disciplines and not restricted by literature type

	REALIST REVIEW	SYSTEMATIC REVIEW
Type of Intervention	Complex	Simple; discrete
Aim / Focus	EXPLANATORY - how 'x' works, in what contexts, for whom	JUDGEMENTAL – how much does x,y, z improve health
Rigor	Very Rigorous	Very Rigorous
Relevant Types of Evidence	Includes a wide range of research and non research (i.e., both quantitative and qualitative)	RCTs ideal. Mostly quantitative research on effectiveness (e.g., controlled & uncontrolled before & after studies, interrupted time series..)
Evidence Source	Peer reviewed journal literature, policy reviews, stakeholder analysis, focus groups, gray literature (reports, conference proceedings).	Peer reviewed literature (finite set of data)
Method	Theory-driven synthesis: deconstructs intervention into component theories. Context data retained, basic theory is refined concerning applicability in context.	Statistical synthesis/Meta-analysis: data from individual studies are combined statistically and then summarized
Usefulness	How to make an intervention most useful	Demonstrates which intervention has largest or smallest effect

CONTEXT + MECHANISM = OUTCOME



...its outcome is triggered by mechanism acting in context

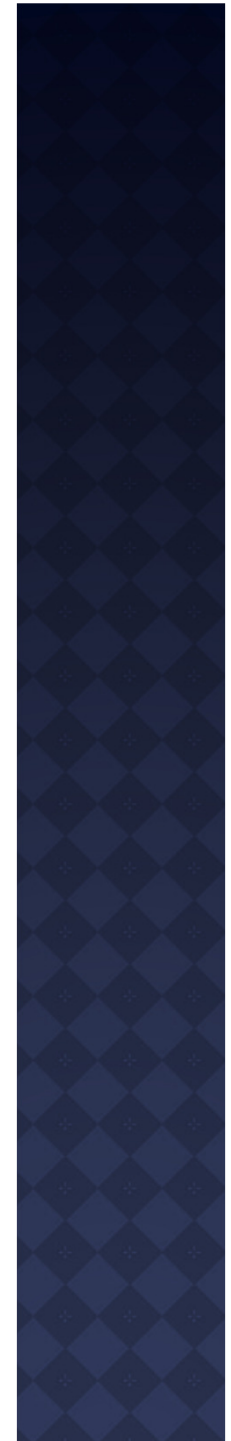
SCOPING THE LITERATURE



SEARCH STRATEGY

- ◉ Seven databases searched:
 - Cochrane Library
 - EMBASE
 - CINAHL
 - PsycINFO
 - Medline
 - Web of Science
 - PILOTS
- ◉ Grey literature search
- ◉ Bibliographies
- ◉ Study selection was informed by a review of abstracts and the application of pre-determined inclusion criteria

Inclusion criteria	Exclusion criteria
Provided data on information evaluating the use of a diary	Focused on the populations of children and young people
Compiled for adult (i.e. over 18 years) ICU patients	Focused on other areas of speciality care, e.g. cancer care, military personnel
In English language	
Published between 1995-2015	



SEARCH OUTCOMES

- ⦿ A total of 37 papers formed the review
- ⦿ Research mainly qualitative design ($n=13$)
- ⦿ Predominately European countries

- ⦿ **Population:**
 - Patients
 - Relatives
 - Healthcare professionals

- ⦿ **Participant characteristics:**
 - Mechanical ventilation
 - Minimum length of stay from 24 hrs to 1 week

SEARCH OUTCOMES

◉ Study Objectives:

- Evaluation of use of diaries to aid psychological recovery in patients and/or relatives ($n=11$)
- Patients' and/or relatives' experiences of receiving diaries ($n=9$)
- Quantification of extent of diary use ($n=6$)
- Investigation of diary structure and/or content ($n=5$)
- Healthcare professionals' perceptions of diaries ($n=3$)

SEARCH OUTCOMES

- ◉ **Diary structure and content**
 - Guidelines or standardised format ($n=18$)
 - Widespread use of photographs ($n=28$)
- ◉ **Diary authorship**
 - No consensus in literature
 - MDT staff with or without family involvement
 - Primarily nursing staff
- ◉ **Diary delivery**
 - No consensus on time and manner
 - Part of follow-up programme
 - Upon ward transfer with no explanation

FINDINGS: 4 KEY THEORIES

1. Diaries lessen the impact of distressing memories and delusions from a patient's ICU stay
2. Diaries facilitate communication between patients, relatives and staff during the ICU stay
3. Diaries illustrate caring acts and attitudes between patients, relatives and healthcare staff
4. Diaries help the patient to comprehend the gravity of their illness and formulate appropriate recovery goals following ICU

1. Diaries lessen the impact of distressing memories and delusions from a patient's ICU stay

Context	Mechanisms	Outcomes
<ul style="list-style-type: none">• Prolonged ICU stay• Mechanical ventilation• Positive patient attitudes• Positive relative attitudes• Staff engagement	<ul style="list-style-type: none">• Fills amnesic memory gap• Differentiates hallucinations from real events• Exposure to negative memories/feelings and desensitises them over time	<ul style="list-style-type: none">• Lessens frequency and impact of delusional memories• Lessens anxiety, depression and distress associated with those memories

2. Diaries facilitate communication between patients, relatives and staff during the ICU stay

Context	Mechanisms	Outcomes
<ul style="list-style-type: none">• Prolonged ICU stay• Mechanical ventilation• Positive patient attitudes• Positive relative attitudes• Staff engagement	<ul style="list-style-type: none">• Helps relatives comprehend information• Allows relatives to reflect on patient's progress• Includes and connects family to patient	<ul style="list-style-type: none">• Helps relatives cope with anxiety generated by ICU

3. Diaries illustrate caring acts and attitudes between patients, relatives and healthcare staff

Context	Mechanisms	Outcomes
<ul style="list-style-type: none">• Prolonged ICU stay• Mechanical ventilation• Positive patient attitudes• Positive relative attitudes• Staff engagement	<ul style="list-style-type: none">• Provide evidence of holistic care• Testament to presence of family	<ul style="list-style-type: none">• Provides comfort and assurance to patient of caring attitudes of relatives and staff

4. Diaries help the patient to comprehend the gravity of their illness and formulate appropriate recovery goals following ICU

Context	Mechanisms	Outcomes
<ul style="list-style-type: none">• Prolonged ICU stay• Mechanical ventilation• Positive patient attitudes• Positive relative attitudes• Staff engagement	<ul style="list-style-type: none">• Accurate information about illness and ICU treatment helps patient to realise and reflect on gravity of their illness	<ul style="list-style-type: none">• Helps patient to form appropriate expectation about rehabilitation

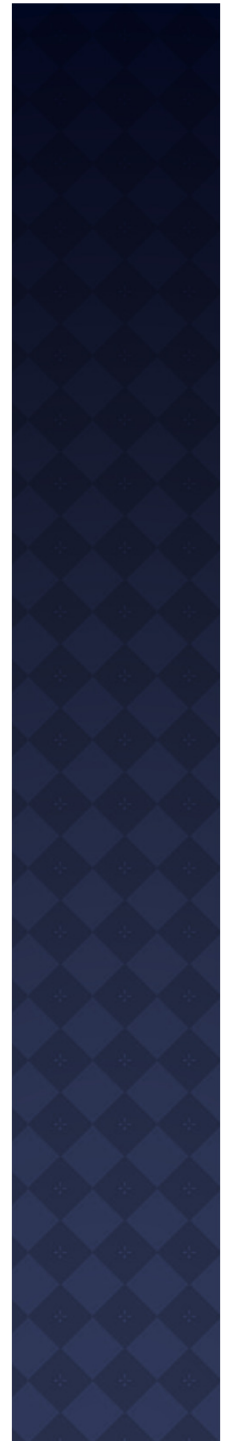
IMPORTANCE OF CONTEXT

- Few studies provided explicit discussion of contextual factors
- Organisational culture:
 - Sufficient resources, including time
 - Family-centred care
 - Diary team
- Healthcare professionals' characteristics:
 - Experience
 - Attitudes and beliefs
 - Commitment
- Patient characteristics
 - Longer term, 'sicker' patients
- Positive relatives' attitudes

CONCLUSIONS

- ◉ All 4 theories mutually interactive
- ◉ Predominant feature- contribution to filling memory gap
- ◉ Diary as a therapeutic treatment akin to trauma-focused CBT and imaginal exposure
- ◉ Caution must be warranted:
 - Need for suitably qualified professional to answer questions
 - Need for regular and continuous sessions
 - Can diaries really be delivered in single session?
- ◉ Some patients refused to access their diary

- ⦿ Inconsistencies prevail in use, timing, delivery and personnel involved
- ⦿ Variability raises challenges with identifying optimal diary model
- ⦿ Diaries should be written in chronological order, include photographs and provide information covering a patient's entire ICU stay.
- ⦿ Information on both positive and negative events should be documented.



- ◉ Staff require support from management to ensure protected time for diary writing
- ◉ Education and training for entire MDT may increase staff engagement with diary concept.
- ◉ Provision of a nurse in a link role or a 'diary team' would provide other staff with information and reassurance on diaries.
- ◉ Family members should be viewed as an integral component of the diary intervention.

RECOMMENDATIONS FOR RESEARCH

- ◉ Greater investigation into the most appropriate method and timing of diary delivery
- ◉ Effects of diaries over longer periods of time, with greater focus on those patients who decline their diaries
- ◉ Subgroups of ICU patients, e.g. individuals with pre-existing psychological problems
- ◉ Greater inclusion of former ICU patients and relatives in studies investigating design and delivery of diaries.

REFERENCES

1. James Lind Alliance. *Intensive Care Top 10 Priority Setting Partnerships 2016*. <http://www.jla.nihr.ac.uk/priority-setting-partnerships/intensive-care/top-10-priorities/> (accessed 1 August 2016).
2. National Institute for Health and Care Excellence. *Clinical Guidelines 83: Rehabilitation after critical illness*. National Institute for Health and Care Excellence, 2009.
3. Intensive Care National Audit and Research Centre. *CMP case mix and outcome summary statistics*. Intensive Care National Audit Research Centre, 2010. <https://www.icnarc.org/documents/summary%20statistics%202008-9.pdf> (accessed 09 September 2016).
4. Van der Schaaf M, Beelen A, Dongelmans DA, Margreeth B, Nollet F and Nollet FB. 'Poor functional recovery after a critical illness: a longitudinal study', *Journal of Rehabilitation Medicine*, 41 (13) (2009), 1041-1048.
5. Cuthbertson BH, Scott J, Strachan M, Kilonzo M and Vale L. 'Quality of life before and after intensive care', *Anaesthesia*, 60 (4) (2005) 332-339.
6. Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H *et al*. 'Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference', *Critical Care Medicine*, 40 (2) (2012), 502-509.
7. Melhorn J, Freytag A, Schmidt K, Brunkhorst FM, Graf J, Troitzsch, U *et al*. 'Rehabilitation interventions for postintensive care syndrome: a systematic review', *Critical Care Medicine*, 42 (5) (2014), 1263-1271.
8. Damm T and Patel J. 'Long term outcomes after critical illness: a concise clinical review', *PulmCCM Journal* <http://pulmccm.org/journal/article/long-term-outcomes-after-critical-illness/> (accessed 01 September 2016).
9. Akerman E, Ersson A, Fridlund B and Samuelson K. 'Preferred content and usefulness of a photo diary as described by ICU patients- a mixed method analysis', *Australian Critical Care*, 26 (1) (2013), 29-35.

REFERENCES

10. Egerod I, Christensen D, Schwartz-Nielsen K and Agard AS. 'Constructing the illness narrative: a grounded theory exploring patients' and relatives' use of intensive care diaries', *Critical Care Medicine*, 39 (8) (2011), 1922-1928.
11. Engstrom A, Grip K and Hamren M. 'Experiences of intensive care unit diaries: 'touching a tender wound'', *Nursing in Critical Care*, 14 (2) (2008), 61-67.
12. Aitken LM, Rattray J, Hull A, Kenardy JA, Le Broque R and Ullman AJ. 'The use of diaries in psychological recovery from intensive care', *Critical Care*, 17 (6) (2013), 253.
13. Ewens B, Chapman R, Tulloch A. and Hendricks JM. 'ICU survivors' utilisation of diaries post discharge: a qualitative descriptive study', *Australian Critical Care*, 27 (1) (2014), 28-35.
14. Ullman AJ, Aitken LM, Rattray J, Kenardy J, Le Brocque R, MacGillivray S. *et al.* 'Diaries for recovery from critical illness', *Cochrane Database of Systematic Reviews*, 12 (2014), Article No.: CD010468.
15. Pawson R and Tilley N. *Realistic Evaluation*, (London: Sage, 1997).
16. Pawson R, Greenhalgh T, Harvey G and Walshe K. *Realist synthesis: an introduction. RMP Methods*. ESRC Research Methods Programme. Paper 2/2004, 2005.