Rationale for developing devastating brain injury pathways

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A case for stopping the early withdrawal of life sustaining therapies in patients with devastating brain injuries

Alex R Manara, Ian Thomas and Richard Harding

Abstract

Early progression in patients with a devastating brain injury is not always accurate and can lead to inappropriate decisions. We present case histories to support the recent recommendations of the Neurocritical Care Society that treatment withdrawal decisions should be delayed by up to 72 hours. Patients. Development of pathways incorporating these recommendations can improve progression, enhance end of life care given to these patients and their families, and increase the opportunities to explore the donation wishes of more patients. They may also standardise the approach to decision making in the same way that the recommendations for management of patients after out of hospital cardiac arrest have done.

Keywords: Devastating brain injury, critical care management, neurocritical care, and end of life care, organ donation.

Introduction

A devastating brain injury (DBI) has recently been defined by the Neurocritical Care Society as either a neurological injury posing an immediate threat to life or a severe neurological insult where early limitation of therapy is being considered. Patients with a DBI will frequently die while others may survive with severe neurological impairment, the precise numbers of patients facing no hope dependent on many factors such as the cause of DBI (trauma, subarachnoid haemorrhage, strokes, hypoxic injury, etc), the severity of the neurological insult, the presence of co-morbidities and the educational and beliefs by clinicians to recommend the withdrawal of life sustaining treatments (WLS). Some patients, however, may have better functional outcomes than originally expected. Inaccuracies in prognostication may result in early and inappropriate withdrawal of life sustaining treatments so creating a self-fulfilling prophecy of death or survival with severe disability. The Neurocritical Care Society recommends that patients with a DBI undergo repeated neurological examination to increase confidence in initial prognostications. They also recommend that physiological stability is maintained and repeated neurological examination undertaken for a period of up to 72 hours after the neurological examination to allow sufficient opportunity for prognostic evaluation, end of life care planning, and consideration of organ donation, even when early limitation of aggressive treatment is being considered. We were aware of five patients admitted with DBI to Emergency Departments (ED) in the past 2 years, where the WLS was delayed because the family had agreed need to organ donation. Three patients were admitted to our neurocritical care unit and two to neighbouring neurocritical care units. All the patients survived. Two returned to independence and employment, and three survived with moderate disability. As a result of these cases and following discussions with ED and neurosurgical colleagues we have developed a pathway for patients with DBI incorporating the recommendations of the Neurocritical Care Society, as well as NICU guidance and NHSBT’s strategy on best practice in the identification and referral of potential organ donors. 2) We set out specific parameters that determine the decision to withdraw life-sustaining treatments. These include: no evidence of neurological improvement after a period of 7 days; no return of ability to sustain life; significant disability; and evidence of irreversible neurological disease. The number of patients admitted (21) to our neuro-intensive care unit in the past 2 years that had irreversible neurological disease and were judged to have consent for organ donation.

Since the original online publication of the article “A Case for Stopping the Early Withdrawal of Life Sustaining Therapies in Patients with Devastating Brain Injury?” in JICS, we are able to provide an update on the first year of implementation of the devasting brain injury (DBI) pathway at Southmead Hospital, Bristol. Between July 2015 and June 2016:

- 21 patients were admitted to intensive care unit (ICU) instead of undergoing withdrawal of life sustaining treatment (WLS). In one department;
- Five patients had treatment limitation decision reversed and treated actively;
- Three patients survived – two cognitively intact and one still in rehabilitation;
- One patient died, all within 48 hours of admission;
- End-of-life care enhanced in all patients;
- Nine surrogates approached for organ donation; organ consent (90%);
- Five become actual donations after brain death diagnosis and two actual donors after cardiac death diagnosis.

The number of patients admitted (21) to our neuro-intensive care unit in one year suggests that such a pathway should not be without ICU bed capacity for many general ICUs. The pathway has met all the stated aims of its introduction in that postponing the decision to withdraw life-sustaining treatments has resulted in unexpected survivors, has enhanced end-of-life care, and has given families the option of organ donation when there was this possibility in meeting their dying relatives’ wishes.

The number of patients admitted is small and it is difficult to reach firm conclusions based on the experience of one neurosurgery ICU. However, they may give some insight into what might be achieved if such pathways were more widespread. A simple calculation of the number needed to treat (NNT) and number needed to harm can provide such insight. The NNT (for the number of ICU admissions in the DBI pathway) to achieve one survivor is 7. The NNT to reverse a decision to WLS and treat actively is 4. The NNT to successfully facilitate one actual organ donation is 3. The NTT to result in one potential survivor with a good outcome not being treated to avoid one survivor with a poor outcome is 2.

Finally, the 90% consent rate to organ donation from the families of these patients compares favourably to the national consent rate of 61%. This in itself suggests that families of these patients are appreciative of the end-of-life care provided.

We understand that these numbers are too small to address the legitimate concerns of clinicians, but perhaps the time has come for guidance from our professional bodies on this issue. There is also a need for development of appropriate audit tools to accurately identify patients admitted to ICU as part of a DBI pathway, both to improve clinical care and also to remove distractive to ICUs and neurosurgeons from adopting such pathways for fear of the impact on an individual clinician’s or institutions’ standardised mortality ratios.

References


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Management of perceived devastating brain injury after hospital admission: a consensus statement from stakeholder professional organizations

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Abstract

Patients with severe grades of life-threatening brain injury are commonly characterized as having devastating brain injury (DBI), which we have defined as: 'any neurological condition that is assessed at the time of hospital admission as an immediate threat to life or incompatible with good functional recovery and where early limitation or withdrawal of therapy is being considered'. The outcome in patients with DBI is often death or severe disability, and as a consequence rapid withdrawal of life sustaining therapies is commonly contemplated or undertaken. However, accurate prognostication in life-threatening brain injury is difficult, particularly at an early stage. Evidence from controlled studies to guide decision-making is limited, and there is a risk of a 'self-fulfilling prophecy', with early prognostication leading to early withdrawal of life sustaining therapies and death. The Joint Professional Standards committee of the Faculty of Intensive Care Medicine and the Intensive Care Society convened a consensus group with representation from stakeholder professional organizations to develop clear professional guidance in this area. It recognized that the weak evidence base makes GRADE guidelines difficult to justify. We have made 12 practical, pragmatic recommendations to help clinicians deliver safe, effective, equitable, and justifiable care within resource constrained healthcare systems. In the situation where patient-centred outcomes are recognized to be unacceptable, regardless of the extent of neurological improvement, then early transition to palliative care is appropriate. These recommendations are intended to apply where the primary pathology is DBI, rather than where DBI has compounded a progressive and irreversible deterioration in other life-threatening comorbidities.

Keywords: brain injury, clinical decision making, practice guideline

12 recommendations
"Any neurological condition that is perceived at the time of hospital admission as an immediate threat to life or incompatible with good functional recovery"

AND

"where early limitation or withdrawal of therapy is being considered."

Proposed definition of Perceived Devastating Brain Injury

RCEM 2018
DBI Current UK Practice

Patient admitted to ED – ABCD approach
Investigations and Imaging – CT Scan
Refer to neurosciences
Advised not for intervention – varied language
Consideration of donation / referral to SN-OD
Approach to family in ED
If consented admit to ICU
If refusal then WLST and EOL care in ED

Is this best practice?
Or is it unacceptable practice?
OHCA Pathway well defined
Percutaneous Coronary Interventions
Routinely admitted to ICU
Managed with Temp Control
No prognostication for 72 hours
IMPROVED OUTCOMES (Neuro)
Early WLST inconsistent with current guidance
Patient Admitted with a Devastating Brain Injury

- Investigations and Imaging
  - Prognosis uncertain or considered very poor
  - Neurosurgical intervention considered inappropriate

Delay WLST for up to 72 hours
Continue supportive interventions
Reassess patient every 24 hours

- Progressing towards brain death
  - Discuss with Donor Coordinator
  - Decision to test for Brain Death
    - Brain Death confirmed
      - Consider / Offer DBD
    - No improvement
      - WLST being considered
        - Discuss with Donor Coordinator
          - Decision to WLST
            - Consider / Offer DCD

- No improvement
  - Review management plan

- Improved
  - Increased prognostic certainty
  - Improved EOL care for patient & family
  - Increased consideration of donation potential
Delaying decision to WLST

- Improved prognostic accuracy
- Better EOL care for patients and relatives
- Reduced pressure on ED
- Maximize organ donation potential and best practice
We recommend using a 72-h observation period to determine clinical response and delaying decisions regarding withdrawal of life-sustaining treatment in the interim (strong recommendation).
What we are **not suggesting**

- Elective Intubation
- Admitting patients not intubated
- Patients who are actively dying
- Not considered for ICU normally
- Always waiting 72 hours
- Providing CPR, dialysis
Legitimate Concerns

- Is our prognostication really inaccurate?
- Do we have the resources in our ICUs?
- Will we increase poor neurological outcomes?
- Will it improve EOL care?
- Will it make a difference to organ donation?
How accurate are we at prognostication?

“Prediction is very difficult, especially about the future”
Niels Bohr
Danish Nobel prize winning physicist
How good is our prognostication in ICU?

Meadow et al Crit Care Med 2011

Individual or collective predictions can be inaccurate

If a single member of ICU team predicts death 50% survive to hospital discharge

If all team members unanimously predict death 15% survive

If all team members unanimously predict death on 3 or more days 12% survive

Consensus on outcome decreased over time in ICU
What happens after the WLST in ICU?

3904 admissions from 1994 – 2000
WLST in 318 (8.1%)
41% of all ICU deaths follow WLST
60% die in ICU
33% die later on an general ward
7% discharged alive from hospital
Median survival 1.4 months
4 patients (1.26%) alive 5 years later

Most patients, but not all, die after the WLST
What happens after the WLST in UK ICUs

ICNARC Database 2011

122,891 Admissions in 2011
Treatment withdrawn in 9%
45% of ICU deaths after WLST
8% alive for > 24 hours
0.7% discharged alive from hospital
ICU Variation 0 -10%

Most patients, but not all, die after the WLST

These data derive from the Case Mix Programme Database. The CMPD is the national, comparative audit of patient outcomes from adult critical care coordinated by ICNARC. These analyses are based on data for 128,480 admissions to 204 adult, general critical care units based in NHS hospitals geographically spread across England, Wales and Northern Ireland. For more information on the representativeness and quality of these data, please contact ICNARC.
Time to death in 150 non-proceeding DCD donors April – Dec 2013

2% of non-proceeding DCD donors survive are discharged home alive
Legitimate Concerns

- Is our prognostication really inaccurate?
- **Do we have the resources in our ICUs?**
- Will we increase poor neurological outcomes?
- Will it improve EOL care?
- Will it make a difference to organ donation?
Admission to ICU for Palliative Care /Organ Donation

- Database study 2007-2016
- 177 Adult ICUs in Aus / NZ
- Facilitating family discussion most common reason for admission
- Increased proportionate to increased no of admissions
- Mean LOS 33.8 vs 44.7 hrs (74.2 hrs for active Rx)
- Hospital mortality 86.6% vs 95.9%
- Concluded resource use not disproportionate

Melville et al Care Med 2017
# SW PDA Data April 2014 – March 2015

<table>
<thead>
<tr>
<th>Financial year</th>
<th>Audited patient deaths</th>
<th>Patients undergoing WLST</th>
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<td>2014/15</td>
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# SW Referral Records Apr 2014 – Mar 2015

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<td>29</td>
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<tr>
<td>2014/15</td>
<td>244</td>
<td>46</td>
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Admission of a dying patient to the ICU for EOL care and possibly organ donation yields on average seven times more QALYs in transplant recipients per ICU bed-day compared with the average benefit for the admission of an ICU patient expected to survive.
Legitimate Concerns Raised

- Is our prognostication really inaccurate?
- Do we have the resources in our ICUs?
- Will we increase poor neurological outcomes?
- Will it improve EOL care?
- Will it make a difference to organ donation?
Outcomes OHCA non Cardiac Causes

Japan study >14,000 patients admitted after OOHCA
All non-cardiac 1114 diagnosed as stroke 4.9% alive at 1 month 1.5% survived with a good outcome
Better outcome if no arrest?
Legitimate Concerns

- Is our prognostication really inaccurate?
- Do we have the resources in our ICUs?
- Will we increase poor neurological outcomes?
- **Will it improve EOL care?**
- Will it make a difference to our donor numbers?
Will DBI pathways enhance EOL care?

Fit 82 year old with AF on dagibatran
Admitted GCS 5
CT large ICH
Deemed unsurveiveable - advice WLST
Accompanied by frail wife
Likelihood of progression to BSD explained to wife
Transferred to ICU
Next day tested
All family present and witnessed tests
Donated kidneys and liver
Family Communication

“If we do it badly, our patients and families will never forgive us

“If we do it well they will never forget us”

Robert Buckman 1992
Physical and cognitive outcomes discussed < 12%
Patient preferences or values not discussed in 30%
EOL recommendations based on the patient’s preferences or values in 22%
CT Head:
Within the posterior fossa, there is a large amount of high density material consistent with acute parenchymal haemorrhage. There is adjacent surrounding oedema and compression of the fourth ventricle. There is dilatation of the temporal horns consistent with hydrocephalus. No midline shift. There is descent of the cerebellar tonsils and crowding at the level of the foramen magnum. No skull fracture.

78 year old female
Fit & walks 5km a day
Admitted after collapse
GCS 4
CT Scan – Not for surgical intervention
Legitimate Concerns

- Is our prognostication really inaccurate?
- Do we have the resources in our ICUs?
- Will we increase poor neurological outcomes?
- Will it improve EOL care?
- Will it make a difference to organ donation?
Some of these non-survivors can proceed to organ donation (OD), and transplantation could be considered a secondary outcome for OHCA. The donation of these organs is beneficial to the recipient and society, cost-effective and can offer grieving families some comfort.”

Cheetham et al Resuscitation 2016
A Donation After Circulatory Death Program Has the Potential to Increase the Number of Donors After Brain Death

Andrew R. Broderick, MS; Alex Manara, FFCCM, FRCA, FRCPh; Simon Bramhall, MD, FRCP; Maria Carmill, MB, ChB, FFCCM(SN); Dale Gaultier, MBBS, FFCCM; James Neuberger, DM, FRCP

Objectives: Donation after circulatory death has been responsible for most of the increase in the number of deceased organ donors in the United Kingdom. There has been concern that the success of the program has not matched the potential number of donors who could be identified. The objective of this study was to determine the impact of the donation after circulatory death program on donation after brain death in the United Kingdom.

Methods: A retrospective cohort study.

Setting: A national organ procurement organization.

Patients: Patients referred and assessed as donation after circulatory death donors in the United Kingdom between October and December 2013.

Interventions: None.

Main Outcomes and Results: A total of 257 potential donors were referred for donation after circulatory death. Of these, 193 were eligible donors. Three patients were deemed medically not suitable following surgical inspection, and 94 patients did not proceed due to extensive or prohibitive factors. Of those patients who proceeded, 38% had sufficient data available for analysis. Therefore, 66 cases were analyzed in total. Organ donation would not have been possible in 18% of the 150 actual donors if donation after circulatory death was not available. Thirty-seven donation after circulatory death donors (20%) were judged to have the potential to progress to brain death if withdrawal of life-sustaining treatment had been delayed by up to 24 h. A further 12 donation after circulatory death donors had brain death confirmed or had clinical indications of brain death with clear mitigating circumstances in all but three cases. We determined that the maximum number of potential donors who could be safely transferred to donation after circulatory death was limited to 28%.

Conclusions: The development of a national donation after circulatory death program has had minimal impact on the number of donation after brain death donors. The number of donation after brain death donors could increase with changes in end-of-life care practices to allow the evolution of brain death and increasing the availability of available testing.

Key words: donation after brain death; donation after circulatory death; withdrawal of life-sustaining treatment.

In the United Kingdom, as elsewhere, the potential solid organ donor pool has been shrinking, in part as a result of better public health measures (L1) and improvements in medical management (L2).

Broderick et al
Crit Care Med 2016
All UK DCDs
Oct – Dec 2013
- 257 consented Potential DCDs
- 193 Eligible DCD
- 134 Actual DCD
- 28% had potential for DBD if WLST delayed by 36h
- Median time admission - WLST 31 vs 84 hrs
### DONOR AND TRANSPLANT ACTIVITY

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<th>% Change&lt;sup&gt;2&lt;/sup&gt;</th>
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<tr>
<td><strong>ORGAN DONORS</strong></td>
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<tr>
<td>Donors after brain death (DBD)</td>
<td>956</td>
<td>829</td>
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<tr>
<td>Donors after circulatory death (DCD)</td>
<td>619</td>
<td>584</td>
<td>6.0</td>
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<tr>
<td>Total deceased donors (DD)</td>
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<td>1413</td>
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<td><strong>ORGAN TRANSPLANTS</strong></td>
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<td>Total DD transplants</td>
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<td>Transplant Waiting List</td>
<td>6044</td>
<td>6388</td>
<td>-5.4</td>
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</tbody>
</table>
Factors influencing the family consent rate for organ donation in the UK

W. Hulme, J. Allan, A. R. Masara, P. G. Murphy, D. Gardiner and G. Popple

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3 Consultant, Anaesthetics and Intensive Care Medicine, North Bristol NHS Trust Southmead Hospital, Bristol, UK
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6 Head of Service Design, Directorate of Organ Donation and Transplantation, NHS Blood and Transplant, Bristol, UK

Summary
The referral rate for organ donation in the UK is 44%, among the highest in Europe. We extracted data on every family approach for donation in ICU/EDs or Emergency Departments between 1st April 2012 and 30th September 2013, and performed multiple logistic regression to identify modifiable factors associated with consent. Complete data were available for 1359 of 1899 approaches during the study period. Consent for donation after brain death was 66.0%, and for donation after circulatory death 44.3% (p < 0.0001). Patient ethnicity, knowledge of a patient’s wishes and involvement of a specialist nurse in organ donation in the approach were strongly associated with consent (p < 0.0001). The impact of the specialist nurse was stronger for donation after circulatory death than for donation after brain death, even after accounting for the impact of prior knowledge of patients’ wishes. Involvement of the specialist nurse in the approach, encouraging family discussions about donation wishes and promotion of the organ donor registry are key strategies to increase UK consent rates, and are supported by this study.

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Accepted: 25 April 2016
Endocarditis brain death causes organ donation transplantation

Introduction
There was a 48% increase in the number of deceased organ donors in the UK in the first 6 years following the publication and implementation of the recommendations of the Organ Donation Taskforce 2010 [1]. This increase was the result of improved identification and referral of potential organ donors based on best practice guidelines [2], rather than any increase in family consent rates (authorisation rates in Scotland). Indeed, the current UK consent rate for deceased donation has been static at around 50% over this period, and compares poorly with consent rates exceeding 60% achieved in many other European countries [3]. It is well recognised that the UK will never have a world class donation and transplantation service unless consent rates increase, and this is reflected in the current UK strategy for organ transplantation, which aims to achieve a consent rate of 80% in the UK by 2020 [4]. To achieve this ambitious change in public attitude to donation is essential, but adopting best practice in how the family is approached when explaining donation is also necessary [5]. This

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4703 Family approaches in UK
1741 for DBD, 2962 for DCD
Consent DBD 69%, DCD 57%
Significant effect on consent rates
DCD > DBD

Hulme et al
Anaesthesia 2016
• 21 admissions with DBI who would have been extubated in ED
• 5 had treatment limitation / withdrawal decision reversed
• 3 survivors – 2 cognitively intact
• All enhanced EOL Care
• All died within 48 hours except 5 who were treated
• 13 approaches for OD, 12 consented (92%)
• 5 went on to DBD and 2 DCD

Outcomes of the first full year of implementing a devastating brain injury pathway
Alex R Manara and Ian Thomas

Since the original online publication of the our article “A Case for Stopping the Early Withdrawal of Life-Sustaining Therapies in Patients with Devastating Brain Injuries” in JICS, we are able to provide an update on the first full year of implementation of the devastating brain injury (DBI) pathway at Southmead Hospital, Bristol. Between July 2015 and June 2016:

• 21 patients were admitted to intensive care unit (ICU) instead of undergoing withdrawal of life-sustaining treatment (WLST) in emergency department;
• Five patients had treatment limitation decision reviewed and treated actively;
• Three patients survived – two cognitively intact and one still in rehabilitation;
• Other 18 patients died, all within 6 h of admission;
• End-of-life care enhanced in all patients;
• Nine relatives approached for organ donation; eight consented (89%);
• Five became actual donors after brain death donors and two actual donor after cardiac death donors.

The number of patients admitted (21) to our neuroscience ICU in one year suggests that such a pathway should not overwhelm ICU-biased capacity for many general ICUs. The pathway has met all the stated aims of its introduction in that postponing the decision to withdraw life-sustaining treatments has resulted in unexpected survivors, enhanced quality of care, and has given families the option of organ donation when there was this possibility in meeting their dying relative’s wishes.

The number of patients admitted is small and it is difficult to reach firm conclusions based on the experience of one neuroscience ICU. However, they may give some insight into what might be achieved if such pathways were more widespread. A simple calculation of the number needed to treat (NNNT) and number needed to harm can provide such insight. The NNNT (or the number of ICU admissions in the DBI pathway to achieve one survivor) is 7. The NNNT to reverse a decision to WLST and treat actively is 4. The NNNT to successfully facilitate one actual organ donation is 3. The NNNT to result in one survivor with a potentially poor neurological outcome is 21. The NNTH to result in one potential survivor with a good outcome not being treated to avoid one survivor with a poor outcome is 2. Finally, the 89% consent rate to organ donation from the families of these patients compares favourably to the national consent rate of 61%.

This in itself suggests that families of these patients are appreciative of the end-of-life care package.

We understand that these numbers are too small to address the legitimate concerns of intensivists, but perhaps the time has come for guidance from our professional bodies on this issue. There is also a need for development of appropriate audit tools to accurately identify patients admitted to ICU as part of a DBI pathway, both to improve outcome data and also to remove disincentives to ICUs and neurosurgons from adopting such pathways for fear of its impact on an individual clinical’s or institutions’ standardised mortality ratios.

References

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Corresponding author: Alex R Manara, Aesthetics and Innovations in Care Medicine, North Bristol NHS Trust, Bristol BS10 5NB, UK. Email: Alex.Manara@nhs.uk
**RISKS**

- NNT to reverse decision to WLST = 4
- NNT to produce 1 survivor = 7
- NNT to facilitate 1 donor = 3

**BENEFITS**

- NNH: admissions to result in 1 poor survival = 21
- NNH: number of good survivors lost to avoid 1 poor survivor = 2
Early prognostication in perceived devastating brain injury should be avoided.

Delaying the withdrawal of life sustaining treatments improves prognostication and end of life care, and allows adoption of best practice in organ donation.

Implementation of DBI pathways are dependent on close cooperation between the ED and ICU communities.
Acknowledgements

Dr Ian Thomas CLOD Southmead ICU & ED Colleagues