



Minutes

Meeting:	All Party Parliamentary Group on Intensive Care		
Location:	Virtual meeting by Zoom		
Date:	25 January 2022	Time:	5pm-6.30pm
Chair:	Sir Gary Streeter MP		

No	Item
1.	<p>Welcome</p> <p>All were welcomed to the All-Party Parliamentary Group meeting on Intensive Care. It was noted that a parliamentary vote was taking place at 6pm and to make best use of the available time the key matters for the APPG’s attention; namely the presentations and panel discussions would be brought forward. Given the parliamentary vote and other activities at Westminster, it was agreed that Dr Sandy Mather, Chief Executive of the Intensive Care Society would Chair the remainder of the meeting to allow discussions to continue.</p>
2.	<p>To agree minutes of the last meeting and to receive an update on the actions</p> <p>The minutes were agreed, and it was noted that work was ongoing to consider the minimum staffing configuration for modern ICU, stepdown to the ward and in the community. It was hoped that an update may be shared at the next meeting of the APPG.</p>
3.	<p>Presentation with short question and answer session National data – The Intensive Care National Audit and Research Centre (ICNARC)</p> <p>Professor Kathy Rowan, founder and director of ICNARC introduced herself and the role ICNARC plays to facilitate the best possible critical care through the structure, process and outcomes and experiences for patients and those who care for them. She noted good quality critical care is that which is effective, humane and equitably delivered in a resource efficient way. Through a cyclical process of research, clinical audit and information sharing ICNARC delivers upon its charitable objects. Professor Rowan highlighted that ICNARC collates national ICU data which is collected locally. This data includes sociodemographic, organ support, physiological, transition</p>



	<p>data and finally outcome data at unit level and hospital discharge. Importantly ICNARC supports data linkage to reduce data collection burden. A snapshot of available outcome data including patient mortality and hospital readmission post ICU stay was also provided.</p> <p>Three key areas for future work were noted, firstly a greater understanding was required of the need for rehabilitation post ICU to inform priorities, secondly more work was required to measure rehabilitation need and when this was most effective. This was something that could be developed from the good work developed during the Intensive Care Society's pilot to document a patient's rehabilitation needs when stepping down from ICU to acute care (PICUPS tool). Finally further work was required to map rehabilitation services and also to link the different data repositories (such as ICNARC and PICUPs pilot data hosted by UKROC) to enable data analysis of patient outcomes after they leave ICU and transfer through to the acute ward and then the community.</p> <p>The APPG was advised that while similar organisations to ICNARC exist internationally that host and benchmark outcomes against their own critical care data; ICNARC was an early adopter. It's combination of audit and research and the volume of work ICNARC conducts is unique to ICNARC and the UK.</p> <p>Its funding model was noted, it provides a service to the NHS where each intensive care unit, pays a sum to participate in the national clinical audit and it also competes for funds like a research department.</p>
4.	<p>Panel discussion with short question and answer: Surviving the intensive care experience, hearing from former ICU patients and family representatives</p> <p>The APPG heard from patient and family representatives who shared their personal experiences of ICU, the transition on discharge to the ward and the impact these experiences have had on family life.</p> <p>Despite the differences in time, geographic location and cause of the ICU admission; a number of cross cutting themes emerged.</p> <p>Professor Michael Rosen began by highlighting his intensive care experience of ICU during the pandemic and the trouble he faced in making sense of his ill health during step down to the ward. Despite asking questions he did not have clear answers from ward staff about the reasons for his hospital stay. This experience was disorienting. The panel also heard from Richard Huff and his daughter Bethany about his own ICU admission in 2017. Richard echoed Professor Rosen's sentiments about the confusion when admitted onto a general ward. While a patient may be well enough to be on a</p>



'general' ward, this marks the very beginning of someone's rehabilitation and recovery journey. Some patients falsely believe they have recovered because their surroundings seem to indicate they are 'better'. The real journey ahead was unclear or unknown to patients. A focus on open, balanced communication and humanising intensive care and the ward was important to help overcome these barriers.

Bethany Rose Huff Guelbert shared that as a relative there was a disparity between the level of information and support available to families about the health and wellbeing of their loved one, in the ICU as compared to the ward. Intensive care feels like a better signposted, informed, forthcoming environment and the ward can feel as though the patient and the family have been abandoned.

This feeling of abandonment, the advocate role that relatives take on for their loved ones and importance of communication and compassion for both the patient and their families were key issues raised by the panel.

Dr Colette Grundy shared her experience of supporting her brother during his ICU stay and recovery in 2017/18. Like Bethany she felt fortunate to have resources and capacity to stay informed of the rapidly changing events in her brothers' health and to advocate for her brother's care. She appreciated working for a good employer who accommodated her need to support her family during this difficult time. She also felt fortunate that her brother was recommended by his medical team for ECMO treatment to save his life. Dr Grundy asked if the APPG could be sent the following link <https://ecmofamilysupport.com/ecmo-stories/>

A challenge she found was the lack of information for relatives about ICU induced delirium. It can leave families feeling very distressed and confused. Other experiences of ICU can feel very dehumanising for example witnessing some families face bereavement, in bereavement spaces attached to general waiting rooms. This can cause great anxiety and trauma. She noted that compassionate care and communication makes a great difference.

Finally, Catherine White, an ex-ICU patient and CEO of ICU Steps a charity for ICU patients and families, highlighted the progressively tough transition beginning in Intensive care, onto the ward and then finally back home. The return home can feel extremely lonely and isolating. Patients who are discharged from ICU can have longer term challenges and can find it difficult to access the appropriate multi-professional support via their GPs.

Baroness Finlay highlighted the importance of family space detached from bereavement areas. A question was asked regarding data on suicide among ex ICU



	<p>patients. While such research did not appear available, there was data available on the difficulties families faced on navigating post ICU life. Families needed to ‘learn a new life’ and there was often grief and guilt associated with new set of circumstances. Concerns about staff wellbeing and mental health were also raised. Staff in ICU work closely with patients and families and so can be impacted by a patient’s decline in health or their death. Greater support for staff was proposed.</p> <p>It was asked whether there could be a position for patient advocates made available in units. It was noted that this exists already in hospital through the patient advice and liaison services (PALS) however this does not exist for post ICU patients. Patient diaries were raised as a good resource which many units provide to allow the patient a greater understanding about their stay in ICU.</p> <p>While making the difficult transition from ICU to step down to the ward requires further work, the panel acknowledged the creation of the High Dependency Unit (HDU) and the work of Critical Care Outreach services who escalate and de-escalate patients within the hospital in recognition of a change in need.</p> <p><u>Patient wellbeing and the human touch</u></p> <p>The panel discussed the things that brought meaning to their recovery, the kindness of a staff member who presented their patient with an ice lolly which brought untold joy, the work of nurses to note key developments at the end of each day in the patient’s diary. This diary is invaluable, it helps the patient to piece together their recovery particularly when memories may be patchy or inconsistent. The diary also helps families to reflect on the strides they’ve made.</p> <p>The panel spoke about the voluntary work they had committed to as a result of their own ICU experience. They did this to support other patients and families as they navigate ICU and prepare for their post ICU life. They spoke of registering as organ donors and regularly giving blood knowing how important this was.</p> <p>The APPG thanked all panel members for their courage in speaking so openly and for giving their time to share their experiences.</p>
5.	<p>Summary of actions and next steps</p> <p>Dr Sandy Mather thanked all for their important contributions to today’s APPG meeting. She highlighted the areas of focus in its first two meetings moving from the clinical overview of intensive care and one patient’s experience to today’s meeting providing a much greater breadth of patient and relative experience as well as the available data that is collated and analysed by ICNARC about patient care on ICU. She advised that the chair would debrief with the Intensive Care Society team and indicate how work would progress.</p>



The All-Party Parliamentary Group
Intensive Care



6.	AOB and date of next meeting The tentative date of the next meeting of the APPG: 26 April 2022. This will be confirmed and details circulated in due course.
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In attendance

Name

Kathy Rowan, John Jones, Alex Day, Asha Abdillahi, Baroness Masham of Ilton, Bethany Rose Huff Guelbert, Catherine White, Colette Grundy, Stephen Webb, Baroness Findlay of Llandaff, Kate Tantam, Michael Rosen, Richard Huff, Sandy Mather, Rebecca Smith, Zudin Puthucheary, Rachael Maskell MP.

Apologies

Name

Jeremy Hunt MP, Laura Farris MP, Lord Bethell, Matt Western MP, David Duguid MP, Alec Shelbrooke, PC, MP, Sir Roger Gale MP.