Meeting:	Inaugural meeting for the new APPG on intensive care		
Location:	Virtual meeting by Zoom		
Date:	16 November, 2021	Time:	5.20pm – 6.30pm
Chair:	Sir Gary Streeter MP		

Disclosure of interest

Members are reminded that they should disclose to the Chairman any relevant conflicting interest of any kind (financial or otherwise) arising in relation to any item on the agenda. Where a relevant interest has been disclosed, the member may, subject to the Chairman's agreement, remain during, and participate in, any debate on the item concerned, but must not vote.

No	Item
1.	**Introduction** The start of the meeting was deferred due to a parliamentary vote. Baroness Finlay welcomed all and opened the meeting.
2.	**Presentation: "What intensive care is: Healthcare professional and patient perspectives"** Prof Montgomery began by explaining what intensive care is and does as an ICU Consultant and Prof Rosen shared his experience of being treated in intensive care in 2020 and his journey to recovery. Admission into intensive care takes place after a serious decline in health, this may take place via accident and emergency, post operatively or after review on a ward. An expert intensive care team treats these patients and their complex needs. The team is made up of nurses and medics, expert therapy teams – including speech and language, physiotherapy, dietetics as well as expert pharmacy input. A truly team-based approach drives the service. Staff are dedicated, motivated and capable but can face challenges in delivering the service. Intensive care is invasive and lifesaving interventions can create issues for patients both in ICU and post-discharge. These challenges can be physical and psychological. For example, muscle loss from a critical care stay is approx. 2.4% a day, so a 3-7 day admission can have a significant impact on patients. The patient's family will often have to help the patient face the consequences of their critical illness. When things go well, the patient is discharged but there is little to no information about what has happened post-ICU. Follow up clinics are not always funded. Prof Rosen described having no recollection of the 40 days and nights he spent in ICU caused by the heavy sedation. He recalled having strange dreams and has since learnt that

	other post ICU patients can have very distressing nightmares. He recalled the changes to his physical appearance being very stark and that he was unable to walk at all. His breathing was very laboured and noisy. In addition to the memory loss he suffered, he also contended with brain fog. He was fortunate that he spent time in a dedicated rehabilitation centre post hospital discharge where the team worked intensively with him to relearn how to walk. The time on the ward was particularly challenging, it generated feelings of abandonment and separation. These experiences brought back other difficult memories. He also described the difficulties experienced by next of kin and once discharged the struggle to know who to speak to regarding ongoing concerns related to his recovery. While sympathetic, the GP was not equipped to address the level of complexity post ICU. The discussion highlighted that the feeling of being bereft and abandoned are common for post-ICU patients and that most patients do not return to the life they had before they were critically ill.
3.	**Election of Officers** Sir Gary Streeter proposed that the following MPs and Peers to be elected as Chair and Vice-Chairs of the APPG, • Sir Gary Streeter MP - Chair • Baroness Finlay - Vice Chair • Baroness Watkins - Vice Chair • Lord Wigley - Vice Chair • Ms Rachael Maskell MP - Vice Chair Baroness Masham seconded the election of officers and agreed to be a member of the APPG. The chair confirmed that the balance of officers met the requirements of the House rules for APPGs.
4.	**Panel Discussions** A panel discussion took place between invited guests of the APPG, Professor Hugh Montgomery, Dr Stephen Webb, Dr Sandy Mather, Dr Zudin Puthucheary, Ms Sarah Wallace, Ms Kate Tantam, Prof Michael Rosen and the MPs and Peers present. During critical illness, patients with complex needs have frequent input from a host of intensive care health professionals. Intensive care service provision offers a level of predictability and support that is not available at ward level. Patients can then feel abandoned when discharged onto the ward. Additional challenges faced by patients include the distress and anxiety about their own recovery that they do not disclose to loved ones. Routes for them to ask questions about their recovery and rehabilitation upon discharge would be helpful to allay concerns. This could take the form of a telephone service, but greater signposting is needed. Patients' can be worried about protecting their family and loved ones from the full extent of their concerns. They are often mindful that the ICU experience is distressing for family members as they liaised directly with the hospital when the patient had no capacity. They have far better recall of the seriousness of events. Two areas of consideration were raised by the group:

- How do we make the transition and step down from an ICU stay to the ward less stark for patients and their relatives?
- How do we address the next transition of hospital discharge and return home?

A review of the facilities available and capacity for multi-professional support to post ICU patients is needed at all levels was recommended.

The panel agreed that in order to define a rehabilitation pathway from critical care admission to return home, the extent of the patient's needs must be determined. Currently mortality rates are measured, not quality of life outcomes post ICU.
Furthermore, once quality of life outcomes are measured and analysed, the appropriate infrastructure is needed to address the gaps and streamline delivery. Funding and an integrated package are needed. Additionally, the group agreed that where multiple data repositories exist, they need to be able to link in/speak to each other.
Gathering longitudinal data was also identified as a priority.
It was noted that with the Healthcare Bill there was an opportunity to integrate systems.

Reflecting on access, the group noted that not all ICUs have access to the expert services to help patient's fully recover, this may be dedicated rehabilitation therapy services or clinical psychology.
Additionally, the lifesaving interventions delivered in ICU can seriously impair the patient's basic speech, walking and swallowing function which creates significant distress. Delirium and post-traumatic stress are also acutely distressing for patients and without psychological support to address these issues they are unable to return to work or resume other parts of their normal life.
As clarity is gained about how best to address needs, a team approach to delivering a team service must be retained. Furthermore, if the multi-professional team is readily accessible and early rehabilitation implemented, the ICU stay can be reduced, and patient outcomes improved. The experience of the National Tracheostomy Safety (NTSP) demonstrates that it is very cost effective to get rehabilitation right from the beginning. The quality improvement project demonstrated that it can save £29K a year per patient, which over two years amounted to £220 million.

The group highlighted that patients have different priorities as they navigate their rehabilitation journey. Plans need to be individualised so they are meaningful and can be driven by the patients with input and support from experts. For some its return to work, others major personal milestones etc.
The first goal of discharge from hospital often unearths a raft of other concerns that need support. Rehabilitation priorities need to be defined by the patient and the system needs to be able to deliver individualised care. The importance of coordinating the care of patients on their rehabilitation journey and the input of the right experts at the right time was stressed as was the need to build a package of care before patient discharge.

Patients also need to feel that someone owns their care clinically and understand the resources that are available so they can own and better support their own recovery. Awareness and access to support groups that have some clinical input can be empowering.

Another challenge for patients is the language and literacy to describe their ICU/Hospital stay. They may have no memory, distorted memory, nightmares on top of their physical health issues; not being able to articulate their experience is another challenge.
The process of writing or speaking about the past or current experience can be cathartic in the moment and to reflect on. Patient diaries recorded by nursing teams are invaluable. Not all ICU patients get it but it is a fantastic resource to help patients understand what happened.

	The group agreed that routinely measuring impact on family and facilitating ways to record their experiences particularly for children of ICU patients is important. The ultimate goal is for patients to recover and thrive returning as close to their normal lives with their family and friends. It cannot be limited to surviving an ICU stay**.**
5.	**Summary of Actions and next steps** It was agreed the following actions would be considered ahead of a follow up meeting earmarked for January 2022: • Conduct an analysis to identify the minimum staffing configuration needed to deliver modern services at ICU, step down to a ward and in the community. The next meeting would focus on the importance of collecting data and how sharing this data with relevant bodies informs decision making. As such representative(s) from the national body, Intensive Care National Audit & Research Centre (ICNARC), would be invited to speak. Similarly former ICU patients and the relatives of former patients would be invited to present. Potential guests that could be invited are the Post ICU support group led by Peter Julian, the ICS Patients Relative and Public Advisory Group and ICU Steps. The group also agreed that future workforce planning is an important area of consideration for the group. The group recognised the emotional, psychological and physical strain that intensive care staff are under and have faced during the last 18 months. The Chair thanked the Intensive Care Society and its representatives and Professor Rosen who attended today's meeting.
6.	**AOB** The Society and Sir Gary Streeter to debrief (17/11/21) and agree details of the next meeting, content and background work. Prof Rosen is to be invited to join January meeting.
7.	**Reflections, close and date of next meeting** The panel, MPs and Peers were thanked for their contributions to the inaugural meeting. The session has helped to inform the APPG and will support the development of plans for 2022. Proposed date of next meeting: January 2022 (exact date to be confirmed)