



# Designing a follow-up service after Intensive Care: valuing the involvement of carers and patients

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## Session objectives

- First a little debate...
- Why do we need follow up services?
- Background of follow up provision in ICU
- Why service user involvement is so important – value of PPI
- What I did to get service users involved
- What they taught me
- What I did with the results

# Are we superheroes ....



Versus

# Or supervillians

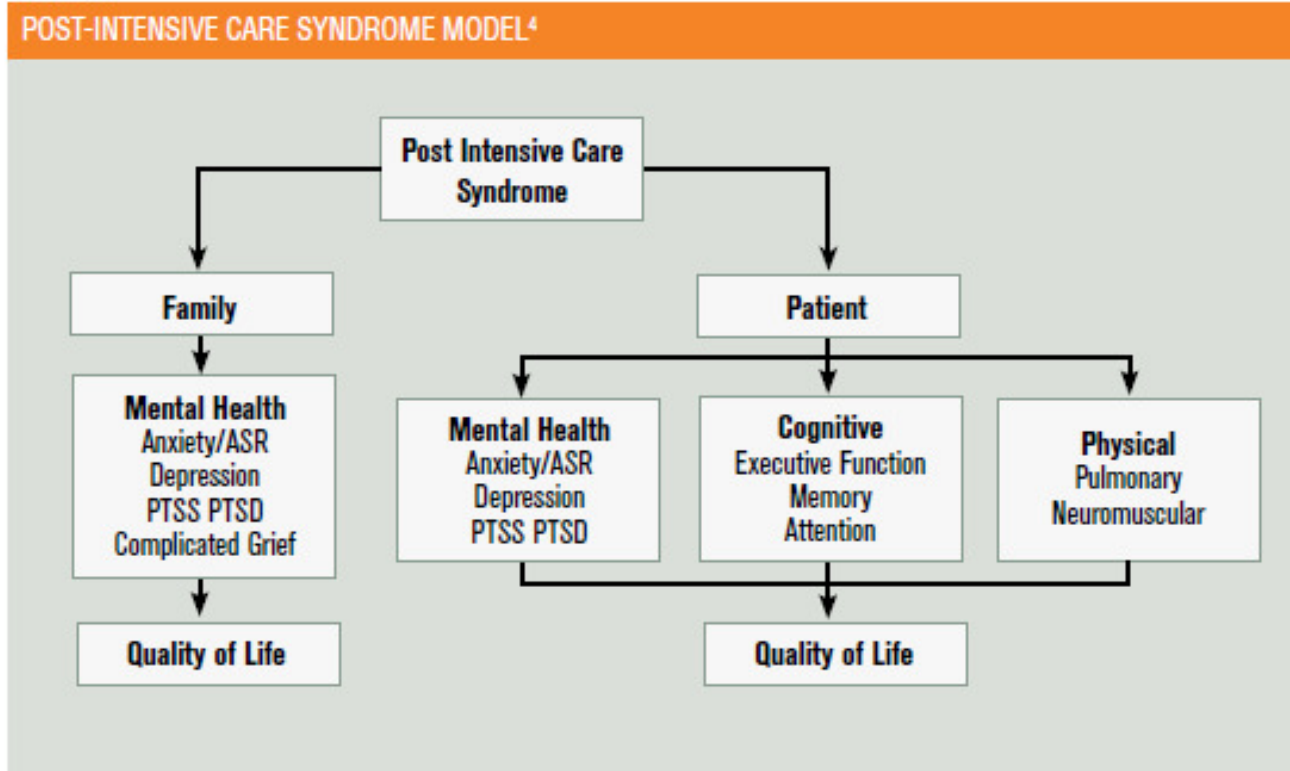


## One womans journey...

“I came home from an unexpected critical illness in my early 30s. I was barely able to walk, had been discharged very quickly and was still very ill. I was given no information or follow-up. Physically I had a long rehabilitation period ahead of me (with no support given) but I was also deeply traumatised by what had happened to me in ICU. I had flashbacks and couldn't make sense of what happened (I had very confused memories from ICU, some of which were from delirium and were unreal, but I didn't know which were true and which were false). Though my family were very supportive, no one could understand quite what I had experienced, or how to help me and there was no internet info about rehabilitation, for either physical or psychological advice. Because of my age, none of my friends had experienced anything similar, so they couldn't empathise. I was also 12 weeks pregnant before my critical illness, so I was profoundly sad at the loss of that pregnancy. It felt like my life had been torn apart. Three months after my illness, my husband had a break down over what he had gone through while I was ill”.

# Post Intensive Care syndrome

Figure 1.



ASR = acute stress reaction; PTSS = posttraumatic stress symptoms; PTSD = posttraumatic stress disorder

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## The scale of PICS

- Internationally each year millions of people require treatment in ICU for organ failure (Needham *et al.*, 2012).
- ICU treatments are improving = higher survival rates but bringing new challenges for ICU survivors and their family members.
- Treatment in ICU can be extremely stressful both physically and psychologically (Adamson *et al.*, 2004) and this is an issue for both the patient being treated and the carers observing and supporting the patient (Jensen *et al.*, 2015).

- The side effects of PICS are well documented and manifest with short and long term health problems, and a reduction in QOL in both carers (Fumis et al., 2015) and patients (Paparrigopoulos et al., 2014)
- Post-traumatic stress disorder (PTSD) being identified in 20% of the post ICU patient population (Parker et al., 2015).
- The literature is clear that patients and their carers need therapy and support after treatment, and as such standards for ICU services have been established by professional societies (Faculty of Intensive Care Medicine 2013).

- Follow-up provision has been identified as a priority since the National Institute for Clinical Excellence (NICE) introduced new guidance regarding ICU discharge requirements (NICE 2009).
- The policy has been patchily introduced and there remains much work to be done to improve patient's experiences of follow-up provision (Connolly et al., 2014).
- Patients and carers have recently been invited to support the setting of research priorities in ICU in partnership with the James Lind Alliance (Reay and Arulkumaran 2014).
- Post-ICU care was identified as an emerging research priority and this provides the rationale for the patient and carer involvement in further studies.



## But what is PPI?

- This patient and public involvement (PPI) is fundamental to good research practice, it not only supports the research process (recruitment, retention, protocol design) but it allows the researchers in the field to be fully engaged and aware of the priorities and experiences individuals at the foundation of the research (Staniszewska et al., 2011).
- Public involvement in research has been identified as a key priority since 2008 (DOH, 2008) with the National Institute for Health Research (NIHR) initiating the INVOLVE group (INVOLVE 2012) to identify the values, principles and standards for public involvement in research (NIHR 2014).

# I had an idea...



**And I needed a  
plan to create and  
fund a follow up  
service**



- The aim of this PPI consultation was to explore the experiences of patients' and carers' after exposure to ICU and to inform a follow-up ICU study design.
- ICU steps was asked to support the project – they forwarded an online questionnaire to their PPI group.
- 21 responses
- Varying in age, gender and relationship to ICU (patient and carer)

## What did I want to know?

- What were the most challenging things that you faced when you returned home after intensive care?
- What support would you have liked to receive after intensive care?
- What are the things that were offered to you from your local health services that you think helped you after intensive care?
- Can you describe how you would have liked staff from intensive care to contact you and support you after you left?

# Results

The responses were collated and sub themes from which three themes emerged:

1. Physical impact of critical illness.
2. Lack of support and understanding.
3. Psychological aftershock of ICU.

<b>Physical Impact of Critical illness</b>	<b>Psychological aftershock of ICU</b>	<b>Lack of support and understanding</b>
<ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Loss of mobility</li> <li>• Loneliness</li> <li>• Role</li> </ul>	<ul style="list-style-type: none"> <li>• Post Traumatic Stress Disorder</li> <li>• Desire to visit ICU</li> <li>• Reassurance</li> </ul>	<ul style="list-style-type: none"> <li>• Need for Education and information</li> <li>• Reassurance</li> <li>• Guilt</li> <li>• Lack of support to organise community care packages</li> <li>• Need for Follow-up Service</li> </ul>

## What I did with the results

- I wanted to create an assessment tool that measured the impact on the quality of life of the ICU survivors.
- An assessment tool was developed that used the Nottingham Health Profile and the Post traumatic score with 14 questions.
- These assessment tools have never been used in partnership in this population before – so I wanted to check their validity.

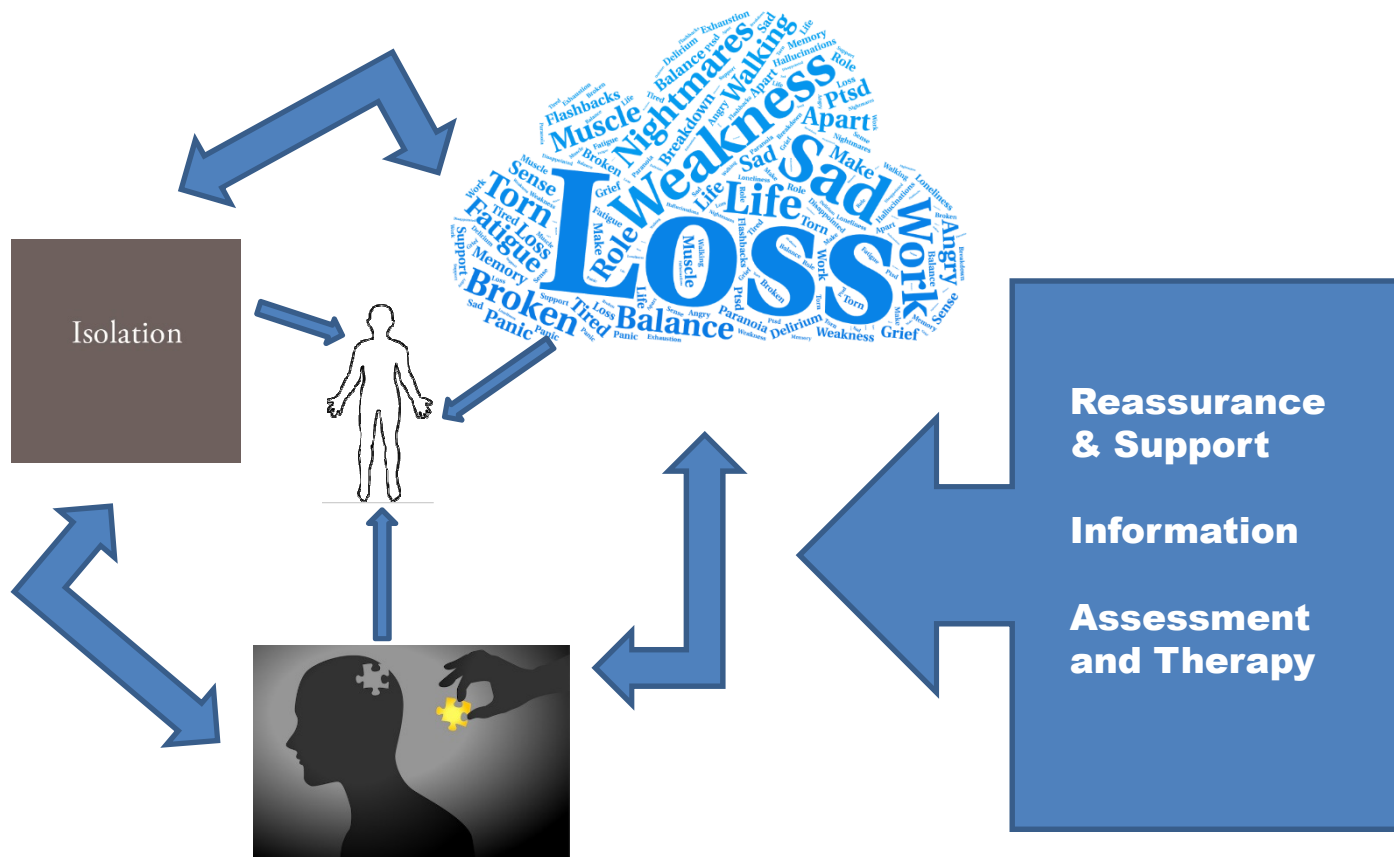
**Nottingham Health  
Profile measuring  
Quality of Life**

6 domains =

- Physical mobility
- Energy
- Pain
- Sleep
- Social isolation
- Emotional reactivity

**PTSS – 14  
Post Traumatic  
Stress Score**

14 questions  
assessing for  
symptoms of  
PTSD



## What I am doing now

- Collecting data from our patients on the impact of their ICU experience at 6 months post discharge
- Using NHP and PTSS-14
- Data collection started and analysis soon
- Part of a long term programme of research using our new rehabilitation team
- However Interim data analysis allowed me to write a business case for a ICU bespoke Rehabilitation service
- Funding agreed for band 7 physio, band 4 Physio assistants and an clinical psychologist.



## What kept me going

“A follow-up service would have been an absolute life line. Somebody who could call to see how I was, invite me back to meet with them, and who I could call on with any concerns”.



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