# A Qualitative Evaluation of the Impact of InS:PIRE on ICU Survivors & their Caregivers

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## **Funding**

• SHINE award given by The Health Foundation in 2014.

## Background

• In the UK over 100,000 patients are admitted to ICU every year costing over £2,000 per patient per day

Quality of life remains poor for many (1-3)

 Two thirds of survivors experience significant physical and psychological problems impacting quality of life (4-6)



 Family members are also at risk of psychological problems: caregivers being thought to provide a buffer for the physical and social limitations faced by ICU survivors

 NICE Guidelines no.83 Rehabilitation After Critical Illness in Adults (7)



#### What is InS:PIRE?

 Intensive Care Syndrome: Promoting Independence & Return to Employment



#### What is InS:PIRE?

- Five week rehabilitation and support programme for ICU survivors and their families
- Inclusion criteria and recruitment
- Patients attended a five week peer supported rehabilitation programme
- Multidisciplinary programme: pharmacy, physiotherapy, nursing, medical and psychological input
- Support for the social aspects of living also available for patients, including advice on housing, finance, benefits and employability
   InS:PIRE

## **Evaluation Strategies**

- EQ5D questionnaire: used to measure health related quality of life
- Generalised Self-Efficacy tool
- Brief Chronic Pain Inventory
- Semi Structured Interviews: to understand the impact of InS:PIRE on participants



#### Research Aim

• To evaluate the impact of a quality improvement project upon intensive care survivors and their caregivers



#### Methods

- Purposive sampling of people attending follow up sessions 6 months post intervention
- Aimed to recruit 10-12 participants
- Data saturation reached after 11<sup>th</sup> interview
- In depth semi-structured interviews audio recorded and transcribed verbatim



- Written consent obtained
- Ethical approval was sought from the local ethics committee however this was deemed as service evaluation



# Findings

| Future                                      | Physical                             | Psychological                                  | Support   |  |
|---|--------------------------------------|--|---|--|
| Longer time/<br>balance with<br>dependency. | Increased confidence & independence. | Understanding of symptoms – coping mechanisms. | Patient volunteers  – hope, optimism, peer support, resource. |  |
| Importance of follow-up.                    | Use of goals / personal goals.       | Family benefit – reassurance.                  | Staff (MDT) – cohesive approach.                              |  |
|   | Importance of involving caregivers.  | Feeling normal / acknowledgment of illness.    | Community   |  |
|   |                                      |  | InS:P   |  |

#### **Future**

- A longer course than 5 weeks
- Important to maintain independence and <u>not</u> dependence on InS:PIRE
- Follow up after critical care: people felt isolated on hospital wards and fear of leaving the critical care environment



 "It is terrifying to come out of ICU and it really is because you feel isolated...nobody has a clue how you feel."



## Physical Impact

- Increased confidence levels
- Re-gaining independence in daily life
- Personal goal setting: Allowed people to think about what is possible to achieve
- Involving caregivers helped them to understand what each persons limitations may be



 "I was able to see just what he was able to do an where his limitations were as well...that was beneficial for me at home, cause I was maybe expecting him to do a bit more than he was actually able."



## InS:PIRE



## Psychological Impact

- Gained understanding of symptoms
- Developed coping mechanisms
- Acknowledgement of illness
- Feeling normal
- Caregivers gained reassurance about the experiences they had with regard to recovery



• "..it was so good to know that you were normal. I didn't feel like an abnormal person anymore, I felt like everything I was feeling was a normal reaction."



## Support

- MDT had cohesive approach providing clarification & reassurance
- Patient Volunteers: huge source of peer support for everyone
- Common bond with everyone enabling the feeling of a community



• "I think that's what gave me encouragement. When I found out how unwell he had been and yet he was out running and going to the gym and all that..I thought there is a way back from this.."



# Peer Support



#### **Future Research**

- Increasing ICU survival rate Needs to be a meaningful survival
- Further research of peer support not only in ICU survivors but also caregivers
- Further research into effectiveness of initiatives like InS:PIRE in different hospital locations



## Acknowledgments

- All the ICU survivors & caregivers who took part in this research.
- The Health Foundation.
- The InS:PIRE team: Helen Devine, Joanne McPeake, Pamela MacTavish & Tara Quasim.



#### References

- 1. Broomhead LR, Brett SJ (2002): Clinical Review: Intensive care follow-up-what has it told us? Critical Care, 6(5): 411-417
- 2. Griffith J et al (2006): A self report-based study of the incidence and associations of sexual dysfunction in survivors of intensive care treatment. Intensive Care Medicine, 32(3): 445-451
- 3. Griffith J, Fortune G, Barber V, Young JD (2007): The prevalence of post traumatic stress disorder in survivors of ICU treatment: a systematic review. Intensive Care Medicine, 33(9): 1509-1518

- 4. Lee CM et al (2009) Education and support needs during recovery in acute respiratory distress syndrome survivors. Critical Care 13: R153.
- 5. Mehlhorn J et al (2014) Rehabilitation Interventions for Postintensive Care Syndrome: A systematic review. Critical Care Medicine 42 (5): 1263-1271.
- 6. Griffith J et al (2013) An exploration of social and economic outcomes and associated health related quality of life after critical illness in general intensive care survivors: a 12 month follow up study. Critical Care; 17: R100.
- 7. National Institute for Health and Clinical Excellence (2009) Rehabilitation after Critical Illness. NICE Clinical Guideline 83 <a href="https://www.nice.org.uk">www.nice.org.uk</a> (accessed 15th Jan 2015).

# Questions?

