Shine 2014 final report

Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE)

NHS Greater Glasgow and Clyde

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Part 1: Abstract

Project title: Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE)

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Partner organisation: University of Glasgow

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Abstract:

Original Aim: The main aim of this project was to improve the health and wellbeing of patients at 12 months post Intensive Care Unit (ICU) discharge. Specifically, we aimed to increase in the number of ICU survivors who returned to work by 20% and decrease the number of GP visits in ICU survivors by 20%.

Intervention: The project team have successfully tested a prototype rehabilitation intervention for ICU survivors. InS:PIRE (Intensive Care Syndrome: Promoting Independence and Return to Employment), is a five week rehabilitation programme which focuses on patient education, peer support and the facilitation of self management.

Each week patients receive one hour of physiotherapy as a group, as well as individualised sessions with health professionals, to help facilitate an accelerated recovery and return to employment. Patients and their caregivers receive appointments with the doctor and nurse from the ICU, the ICU pharmacist, as well as an individual appointment with the physiotherapist. Personal goals are created with patients across these group and individual appointments. Patients and caregivers also receive psychological support, specifically aimed at coping skills. Finally, we provide a social prescription week where patients can meet with third sector organisations from the community. This is the first programme which has also placed specific emphasis on recovery for family members.

Key Results and Impact: This project is still in follow up. We will have our primary outcomes measures in June 2016. However, as we set out to do within the terms of Shine 2014, we have gathered evidence from all the programme participants, their carers and the staff involved which has confirmed the tremendous success of the project in bringing tangible benefits to ICU survivors and their carers.

We have demonstrated impact primarily through qualitative evaluation, including using video clips, where patients and carers discuss the benefits derived from speaking to patient volunteers, the peer support, access to services such as Citizens Advice and the use of personal goals to facilitate self management. The following link provides an insight into patients' and family members' experience of InS:PIRE: https://vimeo.com/110552052 (password: InS:PIRE).

To capture changes in self efficacy for patients, we used self efficacy scores (Schwarzer and Jerusalem 1995) at the start and the end of the InS:PIRE programme to understand how 'in control' patients feel about their future. The scale ranges from 10-40 (10 lowest possible self efficacy and 40 being top score). At the start of the clinic, the average self efficacy score was 26 but within five weeks it increased to 28 ($p=0.04$) demonstrating that patients feel more able to cope with the future after attending the clinic. We have also seen this improvement sustained at six months.

Finally, we also have qualitative data which demonstrates the positive impact of the InS:PIRE programme. We interviewed 10 participants (both caregivers and patients). The data demonstrated the positive benefits of the health and social support given, as well as positive changes to both psychological and physical health.

Key Challenges and Learning: The value of peer support in this patient group cannot be underestimated. Further, the use of patient volunteers alongside staff in the clinic has been very successful. Health and social integration will always be challenging with programmes such as this, however, with the health and social integration agenda being fully implemented within the NHS, this should become easier over the coming years.

Part 2: Quality impact: outcomes

Tests of change and adjustments made throughout the project

We made a number of tests of change over the course of the project. These include:

- Following ICU discharge, many patients have cognitive problems such as poor memory and concentration. As a result, many patients struggled to remember to attend the clinic. We created a generic mobile phone number for the InS:PIRE programme. On the morning of the clinic, we sent a text message to patients to remind them of the location and time of their appointment. We seen our patient numbers double within one week and had very positive feedback from patients and their caregivers in response to this change.
- Initially, we had patient volunteers only at the clinic. However, a family member approached us and asked why we did not also have family/caregiver volunteers. During the next cohort we asked a caregiver to also act as a volunteer at the clinic. Again, we received very positive feedback about this during the qualitative interviews and throughout the programme.
- One of the main aims of the InS:PIRE programme is to empower patients to take control of their health and wellbeing. However, due to the cognitive problems mentioned previously, this is a challenge for many ICU survivors. To overcome this problem, the pharmacist piloted the use of the National Patient Safety Foundation's *Ask Me Three* education tool to help patients become active members of the healthcare team (we utilise this tool when patients require to ask their GP about ongoing care and medicine use). We have received extremely positive feedback from both patients and local GPs about this approach.

Primary and Secondary data used to demonstrate impact on quality

The primary data being collected to demonstrate impact on quality is: quality of life (utilising the EQ-5D quality of life tool); return to employment; and GP visitations at one year post intensive care discharge. We will have a complete data set for this information in June 2016. Some data is available from the 6 month return appointments.

Since the start of the programme, we have also included two other secondary outcome measures. One of the main aims of the programme was to empower patients to have more control over their health and wellbeing. We decided therefore, to include a validated self efficacy questionnaire to understand if we were achieving this aim. We measure self efficacy at the start and end of the InS:PIRE programme and also at six and 12 months. Further,

with the caregivers, we did not have a questionnaire which measured overall strain (i.e. emotional, financial and physical). As a result, we included the Carer Strain Index. This was measured at the start of the clinic, at six months and at 12 months. The use of this tool also allowed us to compare carer strain between healthcare populations (i.e. dementia and stroke caregivers) as this tool has been widely used in these populations.

We also completed a qualitative evaluation of the programme with ten patients and caregivers. In depth, semi structured interviews were completed at the six month follow up appointments.

We did not find this data difficult to access. We did ask patients and caregivers for feedback about how easy/difficult questionnaires were to complete. Only one questionnaire was seen as difficult and lengthy to complete (the Impact of Events Scale, utilised to collect data on Post Traumatic Stress). As a result, we are now piloting another questionnaire with patients and caregivers to collect information on Post Traumatic Stress.

Findings

Quality of Life Measures

The EQ 5D is a widely used, validated, self reported questionnaire which rates quality of life. A five digit number is given to each scoring matrix, with 1.0000 being perfect health. A score of less than 0 is also possible and represents a fate worse than death.

At the start (baseline) of the InS:PIRE clinic, the average (mean) EQ 5D value for working age patients attending was 0.2977. We have data on approximately 50% of patients at 6 months. The mean EQ 5D at six months for this group (working age) has increased to 0.3962. At 12 months (June 2016), we will directly compare the EQ 5D values for those who did and did not receive the intervention (we have previously collected data). However, these initial interim results are extremely promising.

Qualitative findings

The themes and subthemes generated from the qualitative interviews are summarised in Table One. These are presented alongside quotes from patients and caregivers. Figure One shows some patients taking part in an InS:PIRE exercise class.

Baseline Family data

We have fully analysed the baseline family data collected. We did this as this data is completely novel (we cannot find any published data which has analysed caregiver strain,

Table One: Themes and Subthemes generated from qualitative interviews.

Theme	Subthemes	Patient Quotes
Overarching support from programme	• Patient volunteers giving hope, optimism and peer support; • Cohesive MDT approach; • Access to community resources.	"It is good to see how far somebody who has been so ill, like yourself, can improve and recover over a period of time."
Psychological impact of the programme	• Understanding symptoms; • Reassurance for family members; • Normalisation.	"'every feeling you have got from being scared to being excited there is someone to talk to, there is someone who knows exactly how that feels, every base is covered"
Physical impact of the programme	• Increased confidence and independence; • Positive impact of personal goal-setting; • Importance of caregiver involvement.	"it gave me confidence to sort of sit up, take recognition of where I had been, where I was then and where I wanted to be in the future"
Future of InS:PIRE	• Longer programme/ balance with dependency; • Importance of ongoing follow up.	"By the time week 5 came they were really looking forward to it, it was giving them an incentive, it was giving something to aim for, looking forward to a Thursday afternoon, it was like the first social thing some had done"

levels of anxiety or rates of insomnia anywhere in the literature). Further, this is the first time caregivers for this group have received any type of intervention. We therefore had to justify why we felt caregiver support was so important.

36 caregivers attended InS:PIRE and completed the questionnaire set. 64% were female and 67% were either the spouse or partner of the patient. Carer strain was present in 53% of carers. This is significantly higher than other carer populations (for example, 38% in dementia and 39% in stroke). Severe anxiety was present in 25% of caregivers and symptoms of depression (mild, moderate or severe) were present in 56% caregivers. Further, 53% of caregivers had symptoms of post traumatic stress and one third of them had moderate or severe clinical insomnia. This data has recently been submitted for publication, highlighting the support of the Health Foundation.

Figure One: InS:PIRE exercise class

Below are links to three short presentations which have been created about the InS:PIRE programme. They demonstrate the positive impact of the programme for patients and caregivers. These have been shared with a number of audiences, including senior staff from the Scottish Government and NHS England:

http://vimeo.com/116684784
password is InS:PIRE

https://vimeo.com/110953521
password is InS:PIRE

https://vimeo.com/110953522
password is InS:PIRE

InS:PIRE has also been mentioned in two National newspaper/magazine articles:

http://m.scotsman.com/news/citizens-need-to-know-where-to-find-support

https://www.holyrood.com/articles/feature/jane-ankori-aliss-programme-director

Self Efficacy

We used self efficacy scores at the start and the end of the InS:PIRE programme to understand how 'in control' patients feel about their future. The scale ranges from 10-40 (10 lowest possible self efficacy and 40 being top score). At the start of the clinic, the average self efficacy score was 26 but within five weeks it increased to 28 ($p=0.04$) demonstrating that patients feel more able to cope with the future after attending the clinic. We have also seen this improvement sustained at six months.

Pharmacy Data

We have collected data on pharmacy safety issues in the months following ICU discharge as part of the InS:PIRE intervention. Of the 48 patients who attended InS:PIRE 47 of those received the pharmacy intervention. A total of 284 drugs were prescribed regularly before ICU admission, 287 on ICU discharge, 348 at hospital discharge and 370 when seen at the InS:PIRE clinic. The pharmacist made 68 recommendations which were communicated to the patient's GP by letter or a telephone call. These included 20 interventions for drug omissions mainly involving drugs for chronic disease states which had been omitted during the hospital stay but should now have been restarted. Dosage adjustments were suggested on 13 occasions and new drug recommendations were made for 10 patients mainly for symptoms of pain. Duration of treatment for new medications started during the hospital

admission was clarified on 11 occasions. Lastly adverse drug effects were reported on 4 occasions and the incorrect drug was prescribed on two occasions.

The impact of the interventions made by the pharmacist was classified, 34% were judged to improve the standard of care to the patient, 57% increased the therapeutic benefit or avoided significant side effects and lastly 6% were judged to have prevented serious therapeutic failure of drug treatment.

Follow Up Rate

One of the most encouraging and positive aspects of the InS:PIRE programme is the low dropout rate during the course of the intervention. We have only had one patient attend, who did not complete the programme (2%). Further, we have seen high numbers of patient return to follow up appointments. Our 6 month follow up rate is currently >90%, which is one of the highest documented for any ICU intervention.

Personal Goals

The InS:PIRE team set a number of goals with each patient and caregiver. These are measurable targets designed to improve health and wellbeing. Table Two demonstrates some of the personal goals set and achieved with patients.

Table Two: Examples of personal goals met through InS:PIRE

Individual personal goals met throughout the InS:PIRE programme:

- One individual, who had a newly formed stoma struggled to cope. His main aim was to go swimming with his grandson. Through the use of peer support within InS:PIRE and input from the stoma service in our Health Board, within six months he has been on holiday to Spain and has been swimming with his grandson.
- One patient had been involved in a significant trauma and was unable to return to work due to ongoing mental health problems resulting from the accident. He is now involved in a local gardening project and has become a volunteer trainer. This link was made through InS:PIRE.
- We had a young man who underwent a significant trauma leaving him with bilateral amputations. He previously worked as a waiter. It was no possible and he did not wish to return to this role. Since InS:PIRE he is in the process of returning to education (college) to re train and hopefully gain a University place.

Part 3: Cost impact

It was not intended that we would carry out an economic analysis of InS:PIRE. However, in response to the evident early successes that we were achieving for patients and carers, we met our Chief Executive to discuss whether the organisation might provide ongoing support to sustain the programme post-Shine. The outcome was that we were set the challenge to establish an economic case for continuing investment. The initial economic work has concentrated on the question: **'what are the cost implications of recovery from an ICU stay, with no support or rehabilitation?'** This in itself is innovative work which has never been fully explored within the critical care literature.

Using data collected previously from the Glasgow Royal Infirmary, we are utilising health utility scores to determine quality adjusted life years (QALYs). QALYs are commonly used in healthcare literature to assess cost effectiveness. In England and Wales the National Institute for Clinical Excellence (NICE) uses a cost effectiveness threshold of £20,000-£30,000 per QALY when deciding and recommending new treatments and drugs.

The main findings from our initial financial costings has shown that:

- If a patient returns to employment after ICU their cost per QALY (CPQ) is £9,448, which is within the NICE threshold;
- For the retired ICU population, the CPQ is £11,718, again falling well within the cost effectiveness threshold for NICE;
- If a patient is unemployed after ICU, the CPQ increases to £88,602 based on the health utility score for these patients;
- Lastly, if a patient is chronically sick after their ICU stay, their CPQ is £137,082.

This data does not take into account any increases in healthcare utilisation after ICU for patients. We are also exploring healthcare utilisation in this group from a local database in NHS Greater Glasgow and Clyde. This will help us to further understand the cost implications of **not** supporting this vulnerable group. We will also be able to analyse the impact of the InS:PIRE project longer term from this database (i.e. impact on readmissions, clinic appointments and pharmacy costs). However, if we are to assume higher healthcare utilisation for this group, with the lower health utility score which we have collected from our local population, the CPQ would be between £168,290 and £261,913. This clearly gives justification for efficient and effective interventions for this cohort of patients which targets return to employment as the InS:PIRE clinic does.

This work has recently been submitted for publication. This work recognises the invaluable support of the Health Foundation's Shine programme.

The InS:PIRE intervention and implementation costs

A full economic evaluation of the InS:PIRE programme is currently in progress, however, initial work is encouraging. InS:PIRE has produced improved Quality of Life (at six months post ICU discharge). Assuming no increase in healthcare utilisation, the cost per Quality adjusted Life Year (QALY) for the working age population has fallen from £119,867 at the start of InS:PIRE clinic to £17,235 at 6 months post clinic. We have historical data that highlights those receiving the InS:PIRE intervention have improved quality of life, compared to those who have not.

It has been calculated that one cohort of InS:PIRE costs £7,821 to run (up to 12 participants in each cohort). This equates to approximately £650 per participant.

Our baseline data demonstrated that the caregivers of ICU survivors suffered significant upheaval also. All caregivers receive the same interventions as their relatives within the InS:PIRE programme. If we include the cost of eight family members within each cohort (not all participants bring a caregiver), this brings the cost of the InS:PIRE intervention to approximately £390 per participant.

A full cost-benefit evaluation will take place at the end of the 12 month follow up period by a health economist.

Part 4: Learning from your project

Did we achieve what we set out to achieve?

From the data which we have collected thus far and from listening to those who have attended InS:PIRE, we have achieved what we set out to achieve. This is, so far, evidenced through the qualitative evaluation of the programme and the significantly higher self efficacy scores which were achieved over the course of the programme. Further, the initial data on quality of life is also encouraging. We will have all of the quality of life data in June 2106.

Initially, we did not intend to undertake a full economic evaluation of InS:PIRE. However, to ensure sustainability, it has been necessary to show the benefit of InS:PIRE from a financial perspective as well as a patient perspective. This has been a key learning point for the team.

Contributions from other groups

The support we have received from third sector organisations has been invaluable; this is especially true for the input from the Citizens Advice Centre (CAB). CAB has provided information and advice on housing; benefits and employment. Moving forward, we are in the process of creating a formal agreement between the CAB in Glasgow and NHS Greater Glasgow and Clyde, to ensure their continued input into the project.

The Carers Centre have also been key in the success of the InS:PIRE programme. They attend each cohort and offer carers advice and opportunities for further support. We have now sustainable/permanent input from a Senior Carers adviser for the coming InS:PIRE cohorts. The introduction of the Carers Strategy from the Scottish Government will also ensure that when spreading InS:PIRE to other sites, we will be able to facilitate this input elsewhere.

How has InS:PIRE influenced organisational culture?

The learning which we have gained from InS:PIRE has fed directly in care and practice in our ICU. For example, the learning which we gained from pharmacy has led us to create new medicine reconciliations processes in our ICU. We also now aim to give family members (who have been in the unit for greater than three days) carers packs. These packs give information on financial and emotional support, as well as information on the local carers centre. These are changes which we are aiming to spread to other ICUs.

What didn't work quite as well as we had hoped?

We had planned to have a significant focus on employability within our programme. However, over the course of the year, it was clear that many participants needed support before thinking about re entering the employment market and this step would have been too much for many. Further, for many participants, their lives had changed completely and a focus on education was more appropriate. Therefore, in line with the Scottish Government's policy on employment, we have worked closely with the Glasgow Volunteering Sector. Many participants are now fully engaged with volunteering (we have individuals volunteering at local gardening initiatives for example) and we have other participants starting college courses.

Organisational Factors

We have been incredibly lucky with staffing throughout the programme, in that none of the core staff have left and the team remained very cohesive and dedicated to delivering InS:PIRE through the duration of the project. However, we have been careful to avoid any 'person dependence' and have actively sought to get other members of the team from our ICU involved in the programme to ensure that that this would not become a risk to sustainability. The success of the project has been a great incentive for other ICU team members, from both our own ICU and others to become involved.

Organising six cohorts over the course of the year has also been challenging for the team. Preparing and recruiting has been logistically difficult due to a lack of time between cohorts. As a result, one of the biggest pieces of learning is that we will reduce InS:PIRE in the Glasgow Royal Infirmary to four cohorts over the course a year. We will still be able to accommodate similar numbers of patients and caregivers within the four cohorts. Further, this will result in a significant cost saving moving forward.

Advice for others undertaking a similar project

The main learning from InS:PIRE has come directly from participants. This programme was co produced with patients and caregivers. Any site/team who wishes to undertake this type of programme must firstly engage with their local population to ensure that the programme they are planning to implement will be safe, person centred and effective.

At the end of each cohort the team have a 10 minute session with participants on what went well and areas for improvement. The main learning for the project team has been the importance of encouraging peer support and using the experience and knowledge of

previous patients and caregivers. This has been key to the successful delivery of the InS:PIRE programme.

Part 5: Plans for sustainability and spread

Sustainability

Our organisation (NHS Greater Glasgow and Clyde) and the Scottish Government have agreed to fully support the sustainability of InS:PIRE in Glasgow Royal Infirmary for the next three years (we have received almost £120,000 to do so).

Spread

We have had senior management figures from other Health Boards and senior figures from the Scottish Government attend InS:PIRE. There has been much enthusiasm for the role out of InS:PIRE to other areas and we are working with other ICUs to help create an infrastructure to do so. We have also had visitors and interest from other specialities who wish to create a similar programme.

To ensure spread we have also been nominated for a number of awards. Several of the patients who attended the programme nominated the team for a NHS Greater Glasgow and Clyde Chairman's Award. The Senior Management team within the Health Board have also nominated the InS:PIRE MDT for a Scottish Government Healthcare Award. Finally, one of the patient volunteers for InS:PIRE has been shortlisted for the Scottish Government's Self Management Inspirational Person of the year award. Alex, along with the InS:PIRE team have been invited to attend the Scottish Parliament on the 30th of September for an award ceremony.

The InS:PIRE team have also spoken at a number of national conferences across many disciplines. These include:

- National Learning Session for the Person Centred Health and Care Collaborative National Learning and Development Day (Beardmore Hotel, November 3rd). Title: The use of Personal Outcomes
- Scottish Intensive Care Society Audit Group Meeting (Beardmore Hotel, September 2015). Title: InS:PIRE

Further, members of the team will also attend the biggest Critical Care Conference in the world in February to present the preliminary findings from InS:PIRE. All presentations highlight the invaluable support of the Health Foundation.

Finally, we are in the process of applying for a Spreading Improvement Award from the Health Foundation. We aim to create video resources for Healthcare Practitioners who wish

to utilise the approaches we have adopted within the InS:PIRE clinic. We also plan to fund a showcase event where we will invite ICU staff from across the UK to an event which disseminates the findings from InS:PIRE. We will also have a variety of patient groups at this showcase event.