



***Intensive Care Syndrome:  
Promoting Independence and Return to Employment***

***Evaluation of the scaling up of  
a quality improvement initiative  
abridged report***

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# Contents

Contents.....	ii
LIST OF FIGURES.....	iv
LIST OF TABLES.....	v
ACKNOWLEDGEMENTS.....	vi
ABBREVIATIONS.....	vii
EXECUTIVE SUMMARY.....	viii
Background.....	viii
Methods.....	viii
Principal findings.....	ix
Conclusions.....	x
CHAPTER 1: Background.....	1
1.1 The Health Foundation’s Scaling Up Innovation programme.....	1
1.2 The InS:PIRE programme: Intensive Care Syndrome: Promoting Independence and Return to Employment.....	1
1.3 Evaluation.....	3
1.3.1 Evaluation Plan (EP) details.....	3
1.3.2 Ethical considerations.....	3
1.4 The evaluation report.....	4
CHAPTER 2: Review of the InS:PIRE project team’s driver diagram (and underpinning logic models) and external recognition.....	5
2.1 Specific aim.....	5
2.2 Findings.....	5
2.3 External Recognition.....	8
2.4 Key insights.....	11
CHAPTER 3: Formative Evaluation of the Implementation of the Improvement Programme:.....	12
3.1 Background.....	12
3.1.1 General aim.....	12
3.1.2 Evaluation strategy.....	12
3.3 Findings.....	14
3.3.1 Set-up and operational aspects of the InS:PIRE intervention: staff reflections.....	14
3.3.2 Delivery and experience of the InS:PIRE intervention.....	18
QUALITY IMPROVEMENT (QI) REFLECTIONS.....	25
3.3.3 Ongoing sustainability and evolution of InS:PIRE over time.....	26

3.4 Key findings .....	28
CHAPTER 4: Formative Evaluation of the Implementation of the Improvement Programme: Behavioural diagnosis of delivery and scaling up of InS:PIRE .....	30
4.1 Specific aim .....	30
4.2 Evaluation strategy .....	30
4.3. Methods.....	31
4.3.1 Analytical approach.....	31
4.3.2 Data collection .....	31
4.3.3 Data analysis .....	32
4.4 Findings .....	32
4.4.1 Common Facilitators .....	32
4.4.2 Common Barriers .....	36
4.5 Key insights .....	39
CHAPTER 5: Summative Evaluation .....	40
5.1 Specific aim .....	40
5.2 Evaluation strategy .....	40
5.3 Methods.....	40
5.4 Findings .....	41
5.4.1 Throughput .....	41
5.4.2 Data on patient and carer reported outcomes.....	42
5.4.3 Patient reported outcomes.....	42
5.4.4 Carer outcomes.....	43
5.5 Key insights from summative evaluation.....	44
CHAPTER 6: Summary, discussion and conclusions.....	46
6.1 Summary of main findings .....	46
6.2 Discussion of findings.....	47
6.2.1 What are the active components of the intervention? .....	47
6.2.2 Underlying theory of change .....	47
6.2.3 Discussion of InS:PIRE in the light of previous literature?.....	48
6.2.4 InS:PIRE – the “brand” .....	50
6.3 Strengths of evaluation.....	50
6.4 Limitations of evaluation .....	51
6.5 Conclusion.....	52

## LIST OF FIGURES

<b>Figure</b>	<b>Description</b>	<b>Page</b>
Figure 2.1	ORIGINAL INS:PIRE LOGIC MODEL	5
Figure 2.2	REVISED LOGIC MODEL	6
Figure 2.3	REVISED DRIVER DIAGRAM (VERSION 1.1, 2016- 2018)	7
Figure 2.4	REVISED DRIVER DIAGRAM (VERSION 1.2, JUNE 2018)	8
Figure 2.5	THE PROJECT TEAM AT THE BRITISH MEDICAL JOURNAL AWARD CEREMONY (MAY 2016)	9
Figure 2.6	THE CROSSHOUSE TEAM AT THE AYRSHIRE ACHIEVES 2017 CEREMONY (JUNE 2017)	9
Figure 3.1	TIMELINE OF QUALITATIVE ANALYSIS (I.E. FORMATIVE EVALUATION)	13
Figure 4.1	TDF V2 (MICHIE ET AL. IMPLEMENTATION SCIENCE 2011, 6:42)	31

## LIST OF TABLES

<b>Table</b>	<b>Description</b>	<b>Page</b>
Table 4.1	COMMON FACILITATORS TO INS:PIRE DELIVERY AT SCALE	35
Table 4.2	COMMON BARRIERS TO INS:PIRE DELIVERY AT SCALE.	38
Table 5.1	THROUGHPUT OF PATIENTS AT EACH SITE (NUMBERS OF PATIENTS REPORTED)	41
Table 5.2	PATIENT OUTCOME MEASURES AT BASELINE	42
Table 5.3	CHANGES IN PATIENT OUTCOME MEASURES FROM BASELINE TO 3 MONTHS	42
Table 5.4	CARER OUTCOME MEASURES AT BASELINE	43
Table 5.5	CHANGE IN CARER OUTCOME MEASURES FROM BASELINE TO 3 MONTHS	43
Table 6.1	DELIVERY AND INTERPRETATION OF INS:PIRE SCALE-UP	48

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## ABBREVIATIONS

Acronym	Description
ALISS	A Local Information System for Scotland
CAB	Citizen's Advice Bureau
CI	Confidence interval
EA	Evaluability Assessment
EAG	Evaluation Advisory Group
EP	Evaluation Plan
ERF	Evaluation Research Fellow
ET	Evaluation Team
GCP	Good Clinical Practice
GJNH	Golden Jubilee National Hospital
GRI	Glasgow Royal Infirmary
HADS	Hospital Anxiety and Depression Scale
HIS	Healthcare Improvement Scotland
HM	Heather Morgan
HSRU	Health Services Research Unit, University of Aberdeen
ICU	Intensive Care Unit
InS:PIRE	Intensive Care Syndrome: Promoting Independence and Return to Employment
JN	John Norrie
MC	Marion Campbell
MDT	Multi-disciplinary team
MR	Magdalena Rzewuska
NHS	National Health Service
QI	Quality Improvement
SD	Standard deviation
SICS	Scottish Intensive Care Society
THF	The Health Foundation
ZS	Zoë Skea

NB. 'project team' refers to the team at Glasgow Royal Infirmary (GRI) and 'implementation team(s)' to teams at any site (cf. 'evaluation team' at University of Aberdeen)

# EXECUTIVE SUMMARY

## Background

The evaluation of the Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE) project was designed to help understand whether and how the scaling up of the programme achieved its stated aims and objectives. Of particular interest was identifying how the scaling up process was enacted – what the scaling up achieved (or did not achieve) – as well as ‘did it scale up in the way that was expected?’ and what facilitated the scale up and what did not.

## Methods

The evaluation consisted of three phases – an evaluability assessment, a formative assessment and a summative assessment.

In Phase One of the evaluation, we conducted an Evaluability Assessment (EA). The purpose of it was to carefully scrutinise all aspects of the proposal and how it would translate into a workable project, with achievable goals, set to realistic timelines. We undertook in-depth discussions with the lead project team at Glasgow, undertook a full document review and assessed the proposed plan for scale up and evaluation. We produced a document detailing this process, and our findings, and developed an Evaluation Charter. We also formulated an Evaluation Plan (EP) for Phases Two (the formative evaluation) and Three (the summative evaluation).

In Phase Two, we conducted a formative evaluation. This was the most substantial part of the evaluation, adopting a mix of formative and rapid cycle evaluation, which was characterised by detailed and purposive interaction between the evaluation and project teams. It comprised ethnographic work, involving document analysis and observational activities at all sites across the InS:PIRE programme scale-up. It also comprised: a series of qualitative interviews with staff and patients/carers at each scaling up site at different time phases of scale up; follow up telephone interviews with Quality Improvement (QI) leads at each site at the end of a number of cohorts; a QI focus groups at a national learning event and behavioural change theory-based interviews with QI/clinical leads around the barriers and facilitators to scaling up towards the end of the evaluation. In addition, we engaged with teams on an ongoing basis via social media and with the wider national and international Intensive Care Unit (ICU) follow-up community.

Phase Three was a summative evaluation drawing on quantitative data from a full cohort of patients from each site. This included demographic data, throughput data and analysis of patient measures for a subset of patients and carers, collected as part of the scale up process. This sought to identify whether the programme was acting in the hypothesised manner at each site and whether contextual factors influenced the scale up of the programme.

Key learning points focussed on: both successes and failures (what worked/did not work in the scale up process for whom and why) of the scale up; the evaluation of the intervention implementation over time; how well the implementation used the method to adopt the intervention (fidelity); did the intervention reach its target population (reach), did the participant receive the right amount of intervention (dose) and the mechanism(s) through which the intervention was perceived to work; barriers and facilitators to implementation and to ongoing sustainability; and generalisable lessons for the wider scale-up of quality improvement interventions.



## Principal findings

Our Evaluability Assessment found that evaluation of the scaling up of InS:PIRE was feasible and that the original plan – a mixed methods, formative and summative evaluation – was appropriate. The Assessment highlighted the need for the project team to revise their driver diagram (as it did not represent the InS:PIRE programme as it was being delivered) and the requirement for the Evaluation Team (ET) to seek ethics and National Health Service (NHS) Research & Development approvals to conduct the proposed evaluation research. All appropriate ethics and NHS Research & Development approvals for the formative and summative evaluations were subsequent sought and approved.

Insights from the interviews and the ethnographic work during the active scale-up phase identified a number of issues. It was clear that the InS:PIRE programme could, in principle, be scaled up in a feasible manner at different sites. Scale-up occurred in a variable manner, however, with extensive tailoring to the local context.

The InS:PIRE programme was popular amongst patients and carers who participated in it. Patients and carers reported gaining in confidence as a result of participating in the programme and that their coping appeared to improve. Patients particularly valued certain elements of the programme particularly receiving a letter from their consultant explaining everything that had happened to them. Having dedicated time to go through the letter and to ask questions, as well as having them answered, was deemed to be important. Visits to the ICU offered closure to many participants and their relatives. Peer support was also highly valued in the ‘making sense’ of what happened process and appeared to be key to recovery. The additional components that contributed to the programme (physiotherapy, pharmacy, sleep training, etc.) were seen as less central to the patients; they were variably received and variably reviewed – not all patients/carers make use of all components - but having access to all services within one clinic setting was valued.

InS:PIRE was transformative for the staff who delivered the programme within and across sites. Staff perceived that they were making a real difference to patients, and their carers, and could quickly see visible results. Staff appeared to gain a great deal of professional and personal satisfaction from being able to see patients as people, working with them in unconventional ways (for post-ICU care) to see improvement in their general health, and physical, mental and social functioning. Staff noted positively how they worked differently in the InS:PIRE programme, working across traditional professional boundaries, around patient need. InS:PIRE clinics were also held in neutral settings, staff would not be in uniform and would interact on first name terms with patients. Staff also valued being part of the InS:PIRE network benefitting from the cross-site learning and collectively contributing to the high national profile and recognition of the InS:PIRE programme.

InS:PIRE also developed a significant external profile over the course of the scale-up – winning multiple awards and being quoted in a number of government policy documents, including the Chief Medical Officer’s report. It was also showcased on television and was the subject of numerous national and international conference presentations. These external markers of esteem significantly helped to develop the InS:PIRE “brand” and added useful prestige and legitimacy to the product and further enable participating staff to develop a strong sense of identity with their role in InS:PIRE.

As the scale up of programme matured there was increasing awareness that the InS:PIRE programme in its full form was likely not a sustainable model for longer term provision as an NHS service given the current context of severe fiscal constraint within the NHS. Teams constantly reviewed their service provision and homed in on the central elements that were important to patients – especially the one-to-one with the medical staff and the peer support – supplementing them with a range of other

services as seen to be beneficial/available (although retaining the concept of having access to all services if needed).

The theory-based interviews suggested that there were a number of elements that contributed to facilitating scale-up at sites. At an individual health professional level, this included a sense that they were doing something valuable for individual patients, commitment to working across professional and disciplinary boundaries and a personal sense of satisfaction in seeing improvement in patients and witnessing the growth of the programme and its staff. System enablers also included the recognition by employers that staff roles within InS:PIRE were additional to their routine NHS roles and which were remunerated accordingly. This was greatly facilitated by the external funding the Health Foundation grant provided.

Conversely, trying to scale-up InS:PIRE required relentless effort from the teams to mitigate numerous practical obstacles, within scopes of their personal capacity, opportunities and motivation. Notably, scaling up against a background of fiscal constraint within the NHS was a main barrier, as was the large extra administrative burden of organising venues, attendance of patients etc., and managing the sometimes chaotic circumstances of patients (e.g. managing transport, parking, non-attendance, etc.).

Data from the cohort showed that approximately 50% of those invited chose to attend InS:PIRE clinics. Changes in patient reported outcomes – including anxiety, depression and quality of life were in the hypothesised direction (*i.e.* towards reductions in anxiety and depression and towards an increase in quality of life). For self-efficacy, however, there was no apparent change from baseline. Carer outcomes also demonstrated changes in the hypothesised directions – towards a reduction in carer strain, anxiety, depression and insomnia severity. Together, this suggests that the intervention reached part of its target population and change was likely delivered through mechanisms other than self-efficacy.

## Conclusions

Our evaluation suggests that the InS:PIRE programme could be successfully scaled up to other clinical sites; however, the implementation of InS:PIRE was highly variable and changed repeatedly over time. InS:PIRE had a transformative effect on the staff engaged with it and patients perceived the programme very positively and early indications suggested improvement in outcomes. Our findings suggest that InS:PIRE is perceived to be driven by three core “active ingredients” – provision of one-to-one time with the ICU clinical staff to discuss their ICU journey; provision of peer support; and the provision of multi-faceted patient-centred care facilitated by blurring of professional boundaries to solve patient problems. Implementation was greatly facilitated through commitment of intrinsically motivated staff to working across traditional professional and disciplinary boundaries and their beliefs that they were engaging in something of great value to patients (reinforced through satisfaction perceived improvement in patients).

The organisation and delivery of the intervention was resource-intensive, however, requiring high level of staff buy-in and administrative input. In addition, only a small proportion of potentially eligible patients receive the intervention. The actual mechanism of change is unclear, which likely decreased the chances of the intervention changing the behaviour in the desired direction. Implementation was significantly facilitated by the external resource provided through the scale-up grant – which was viewed as typically unavailable through standard NHS channels - and the fact that the InS:PIRE clinics sat somewhat out with routine NHS services. Against a background of fiscal constraint within the NHS, future embedding and even more so scale up of an InS:PIRE service must address these issues.

# CHAPTER 1: Background

## 1.1 The Health Foundation's Scaling Up Innovation programme

In April 2015, The Health Foundation issued a call for proposals to its Scaling Up Innovation (Round Two) programme. It had £3.5 million on offer to support up to seven project teams. Each project team could receive up to £500,000 in funding to design, implement and evaluate their proposed intervention.

A project team at Glasgow Royal Infirmary (GRI), led by Dr Joanne McPeake and Dr Tara Quasim, were successful in their application to the programme. They were awarded a grant to scale up 'Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE)', a post-intensive care rehabilitation programme, across Scotland.

## 1.2 The InS:PIRE programme: Intensive Care Syndrome: Promoting Independence and Return to Employment

Research has demonstrated that many patients have a poor quality of life following an intensive care admission.<sup>1</sup> Furthermore, it had been well recognised that families and caregivers of those patients who have been critically unwell, also suffer psychosocial morbidity in the years and months following intensive care discharge.<sup>2</sup> There are almost 180,000 admissions to ICU in the UK each year.<sup>34</sup> More patients are now surviving ICU and being discharged from hospital, which will have a significant impact on healthcare utilisation as well as an increasing societal burden.<sup>56</sup>

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<sup>1</sup> Needham, DM. Davidson, J. Cohen, H. Hopkins, RO. Weinert, C. Wunsch, H. Zawistowski, C. Bemis- Dougherty, A. Berney, SC. Bienvenu, OJ. Brady, SL. Brodsky, MB. Denehy, L. Elliott, D. Flatley, C. Harabin, AL. Jones, C. Louis, D. Meltzer, W. Muldoon, SR. Palmer, JB. Perme, C. Robinson, M. Schmidt, DM. Scruth, E. Spill, GR. Storey, CP. Render, M. Votto, J. Harvey, MA. (2012) Improving Long term outcomes after discharge from intensive care: a report from a stakeholders conference. *Critical Care Medicine*; 40(2):502-9.

<sup>2</sup> Haines, K. Denehy, L. Skinner, EH. Warrillow, S. Berney, SB. (2015) Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. *Critical Care Medicine*; 43(5):1112-1120.

<sup>3</sup> Intensive Care National Audit and Research Centre (2014) Key Statistics from the Case Mix Programme 2012/2013. Accessed 10th of May 2015. <https://www.icnarc.org/Our-Audit/Audits/Cmp/Reports/Summary-Statistics>.

<sup>4</sup> Scottish Intensive Care Society Audit Group (2014) Audit of Critical Care in Scotland 2014 (Reporting on 2013). Accessed 10th of May 2015. <http://www.sicsag.scot.nhs.uk/docs/2014-08-12-SICSAG-Summary.pdf?1>

<sup>5</sup> Lone, NI. Marta, S. Wild, S. Rowan, K. Murray, G. Walsh, TS. (2013) Surviving intensive care: a systematic review of healthcare resource use after hospital discharge. *Critical Care Medicine*; 41(8):1832-1843.

<sup>6</sup> Griffiths, J. Hatch, RA. Bishop, J. Morgan, K. Jenkinson, C. Cuthbertson, BH. Brett SJ. (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.

There had been two randomised trials in this area (RECOVER and PRACTICAL); neither of which had shown any quantitative improvement in outcome.<sup>7,8</sup> Work had focussed on patient education, the use of rehabilitation assistants within the ward environment and one-off follow-up appointments.

Reasons for the apparent lack of success of these trials may have included lack of engagement with service users, poor integration between health and social care or a lack of focus on the promotion of self-efficacy for patients and their family members. Evidence also demonstrates that providing patient education in isolation is unlikely to improve outcomes or motivate lasting changes.<sup>9</sup>

There is an emerging body of evidence, however, which demonstrates that patients and family members who have been through ICU appreciate meeting others with similar experiences.<sup>10</sup> None of the aforementioned interventions had utilised peer support within their approaches to rehabilitation and none of the approaches had included support for family members. In an attempt to address these known limitations, the team at Glasgow Royal Infirmary proposed a scaling up improvement project using their local InS:PIRE model as a starting point<sup>11</sup>.

InS:PIRE was originally constituted as a six week rehabilitation programme at Glasgow Royal Infirmary, which focused on patient education, peer support and the facilitation of self-management. Each week, for five weeks, patients were to 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. In week six, a staff learning session was scheduled, supported by a Quality Improvement lead. Staff were to reflect on participants' feedback in order to progressively improve the service. This unique programme also placed specific emphasis on recovery for caregivers (as well as the patients) and sought to integrate health and social care.

The team aimed to scale up InS:PIRE into a programme across five further centres in four Health Boards in Scotland, which should each run a series of 'cohorts' of the InS:PIRE programme for the project duration. Whilst the project team continue to focus on rehabilitation in the general ICU population, they also set out to include the Golden Jubilee National Hospital's (GJNH's) cardiac ICU. This centre deals with adults who have congenital heart disease, who have their own specific needs following complex heart surgery.

Outcome measures for both patients and family members were to be collected. Patients and healthcare professionals were also to set personal goals at the start of the programme, to be used to assess improvements. In addition, teams were asked to explore return to employment following ICU discharge as an outcome measure. The project team had significant experience in utilising these

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<sup>7</sup> Cuthbertson, BH. Rattray, J. Campbell, MK. Gager, M. Roughton, S. Smith, A. Hull, A. Breeman, S. Norrie, J. Jenkinson, D. Johnston, M. (2009) The PRACTICAL study of nurse led, intensive care follow up programmes for improving long term outcomes for critical illness: a pragmatic randomised controlled trial. British Medical Journal; 339:b3723.

<sup>8</sup> Walsh, TS. Salisbury, LG. Merriweather, J. Boyd, JA. Griffith, DM. Huby, G. Kean, S. MacKenzie, SJ. Krishan, A. Lewis, SC. Murray, G. Forbes, JF. Smith, J. Rattray, JE. Hull, AM. Ramsay, P. (2015) Increased hospital based physical rehabilitation and information provision after intensive care unit discharge. The RECOVER Randomized clinical trial. JAMA; 175(6):901-910.

<sup>9</sup> Health Foundation (2011). Evidence: Helping people help themselves. health.org.uk. Accessed 10th May 2015.

<sup>10</sup> Walker, W. Wright, J. Danjoux, G. Howell, SJ. Martin, D. Bonner, S. (2015) Project Post Intensive Care exercise (PIX): A qualitative exploration of intensive care unit survivors perceptions of quality of life post discharge and experience of exercise rehabilitation. Journal of the Intensive Care Society; 16(1):37-44.

<sup>11</sup> McPeake J, Shaw M, Iwashyna TJ, et al. Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE). Early evaluation of a complex intervention. PLoS One. 2017 Nov 29;12(11): e0188028

measurements. The project further aimed to improve health and wellbeing in ICU survivor/caregiver participants in a sustainable way across six hospital sites in Scotland.

## 1.3 Evaluation

It was a necessary component of the funding programme to include an independent evaluation of the scale up process. The evaluation was led from the Health Services Research Unit (HSRU), University of Aberdeen. The scaling up of InS:PIRE launched in May 2016. The evaluation began in August 2016 and ran until the end of 2018. The evaluation was designed to address the possibility that the original quality improvement project's implementation (at Glasgow Royal Infirmary), and its reported successes in terms of outcomes, may have been dependent on context (site, personnel and organisational structures) and not a consequence of the intervention (content and delivery) – the InS:PIRE programme.

### 1.3.1 Evaluation Plan (EP) details

Following an Evaluability Assessment (EA), which scrutinised all aspects of the proposed scale up proposal and how it would translate into a workable evaluation project with achievable goals, set to realistic timelines, the following purposes for the evaluation were set:

1. evaluate all aspects of the improvement implementation using a formative approach to share insights and suggest modifications to the improvement project (revising the driver diagram to reflect the development of theories of change) during implementation; and
2. deliver a final evaluation (summative approach), with appropriate focus on the process of the scaling up project – whether and how it successfully reached its aims as stated in grant proposal or protocol – what did and/or did not go according to plan and what the remaining challenges are for nationwide adoption of this intervention and/or other complex health interventions.

The evaluation team (ET) explored this through a mixed methods approach, involving observations and collection, analysis and synthesis of complementary qualitative and quantitative data.

### 1.3.2 Ethical considerations

The evaluation was conducted in accordance with the principles of good clinical practice (GCP). The evaluation assessment highlighted the requirement for the Evaluation Team to seek ethics and NHS Research & Development approvals to conduct the proposed evaluation research. As such, in addition to Sponsorship approval (University of Aberdeen), a favorable ethics opinion was obtained from an NHS Research Ethics Committee (17/WM/0108, 29 March 2017), and NHS Research & Development approvals were obtained from the NHS boards for each site for the qualitative research (Phase Two). We also obtained a favorable ethics opinion for the quantitative summative evaluation (Amendment: IRAS 219910. SA03, 8.11.17 17/LO/0185, 10 Jan 2018) and similarly obtained approval from each NHS Board site.

## 1.4 The evaluation report

Given the intensive nature of the research methodology, our evaluation generated extensive qualitative and quantitative data. To ensure that our findings were both accessible to a wide range of readership yet comprehensive, we wrote the data up in two complementary formats:

1. a fully comprehensive report summarising all the methods and data in full (copies of the comprehensive report are available from both the project and the evaluation team); and
2. an abridged report (this version) that summarised all the main data and findings but which omits much of the finer detail of the evaluation methods and the presentation of the full granular data

The subsequent sections of this abridged version of the evaluation report is laid out in the following manner: Chapter 2 provides full details of the underpinning driver diagrams and about the InS:PIRE brand and external exposure; Chapters 3-4 summarise different elements of the formative evaluation; Chapter 5 summarises the summative evaluation using quantitative data from the patient cohorts at each site and finally Chapter 6 integrates the findings across all the evaluation components and provides summary conclusions.

# CHAPTER 2: Review of the InS:PIRE project team’s driver diagram (and underpinning logic models) and external recognition

## 2.1 Specific aim

A key function of the evaluation was to help identify the underlying mechanisms of change that were perceived to underpin the InS:PIRE intervention. To address this we undertook regular reviews of the underpinning InS:PIRE driver diagram and documented any changes. In this section we outline these changes charting how the perceived mechanisms of change underpinning the intervention were refined over the scale up period.

## 2.2 Findings

Figure 2.1 shows the original intervention driver diagram, which was used in the funding application to the Health Foundation. It represents the intervention as it had been implemented at its home site, Glasgow Royal Infirmary. It had been refined through the SHINE project<sup>12</sup>, and this diagram was prepared by the team to summarise their intentions for the follow on scaling up project InS:PIRE, as their successful intervention was established at five other sites across Scotland.

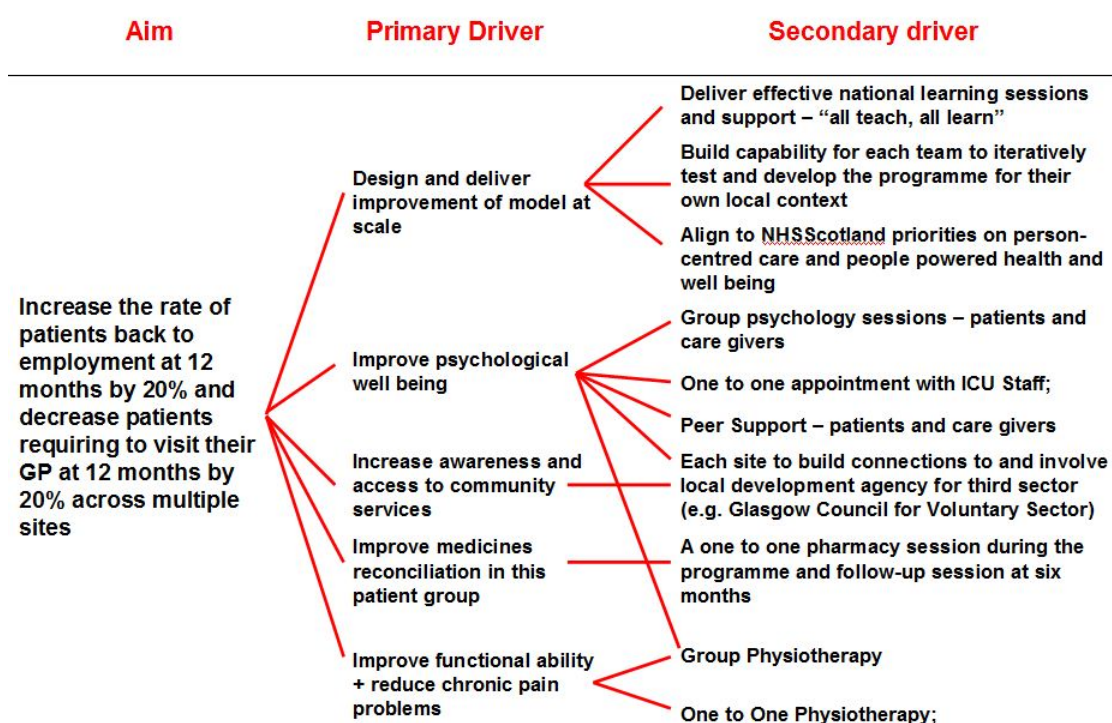


FIGURE 2.1: ORIGINAL INS:PIRE LOGIC MODEL

<sup>12</sup> McPeake J, Shaw M, Iwashyna TJ, et al. Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE). Early evaluation of a complex intervention. *PLoS One*. 2017 Nov 29;12(11): e0188028

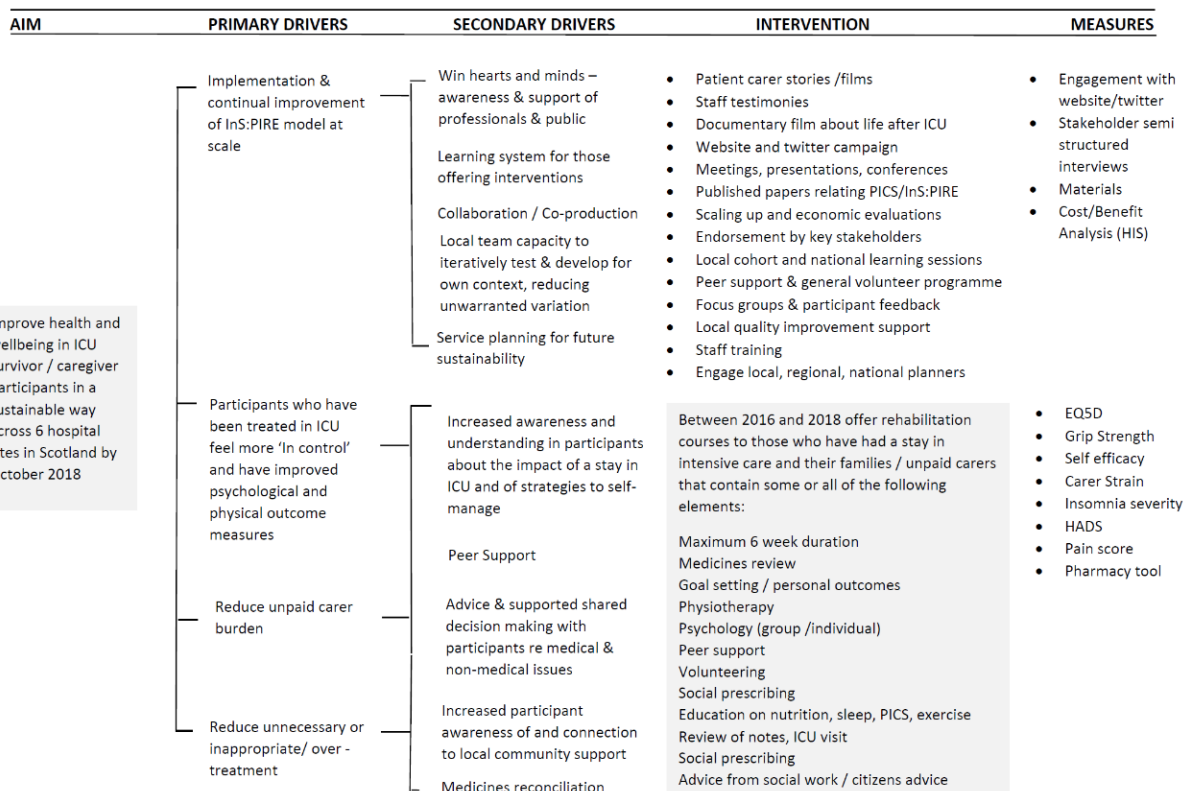
During our Evaluability Assessment, we discovered (through documentary review and participant observer ethnographic work) that the intervention had already begun to develop and was taking a moderately different form from the original, with evolving functions, within just a few months. The key changes were to the original aim, which took a significant shift from a focus on increasing % employment of and reducing follow up GP visits by ICU survivors to more of a focus on soft intelligence about participants’ needs and an informed review of what could be achieved through the intervention and a truer reflection of its ethos – i.e. a focus on improving health and wellbeing of ICU survivors and their caregivers and how this could become sustainable across the scaling up sites by 2018. The emerging logic model helped the project team to, by December 2016, identify core components in more detail than their original driver diagram had contained, as well as indicating stakeholders, workflows and resources and more detail based on the team’s specific knowledge of implementation components and processes, actual activity and reflections developed through sharing and articulating the intervention beyond the local (GRI) team in its initial scaling up. The resulting logic model #2 (Figure 2.2) goes into more detail and offers two levels: scaling up programme and ‘coal face’ delivery for sites, which can broadly be seen across two rows. Within each, the facets of interest to both the evaluators and scaling up sites can be seen, with indicators and tools being outlined. These comprehensive outlines provided a renewed sense of purpose aligned with the ‘feel’ of the developing intervention and its scaling up, as well as offering a road map and toolkit for those involved. Employment, goal setting and the walk test, as specifics, were not considered universal and so were not included in driver diagram.

The revised driver diagram and logic model can be found in Figures 2.2 and 2.3 below.

Situation	Inputs	Outputs		Outcomes	Aim
		Activities	Audience		
After ICU patients and caregivers experience persistent physical, psychological and social symptoms (Post Intensive Care Syndrome) that cause significant burden to individuals, caregivers and society. A post-discharge intervention (InS:PIRE) has been successfully trialled for patients and caregivers in one hospital site but it is not yet known if this intervention can be successfully delivered at other hospital sites in Scotland	Staff	Rehabilitation courses	Patient and caregivers	Increased patient self efficacy, reduced carer strain, improved physical and psychological wellbeing	Improve health and wellbeing in ICU survivor / caregiver participants in a sustainable way across 6 hospital sites in Scotland by October 2018
	Volunteers	Learning Sessions	InS:PIRE teams	Improved local team capacity to develop and iteratively test in own context	
	Funding	Website	InS:PIRE teams, patients, general stakeholders	Improved team capacity, stakeholder engagement and collaboration, improved patient and caregiver wellbeing	
	Equipment / Materials	Films	InS:PIRE teams, patients & caregivers, planners, policymakers, funders	Stakeholder engagement and collaboration	
	Venues	InS:PIRE Pack	InS:PIRE teams, commissioners, planners	Materials to offer the intervention to commissioners throughout NHS in UK	
			Evaluation	Planners, policymakers, funders, academics, clinicians	

FIGURE 2.2: REVISED LOGIC MODEL





**FIGURE 2.3: REVISED DRIVER DIAGRAM (VERSION 1.1, 2016- 2018)**

As the formative evaluation evolved and modifications were continually suggested to the improvement project, the project team were regularly prompted to revisit the driver diagram to reflect on the perceived theory of change during implementation. By March 2018, discussion around the driver diagram considered the following:

- Learning network of staff – and a question around whether this is more about professional development than patient intervention – multidisciplinary team working
- Acceleration of recovery
- Social inclusion

Also discussed was the issue of sustainability (which became the main aim at logic model #2) and funding non-clinical time (as cheaper than clinical hours) and because nursing staff pay/hours is hard to organise. In addition, the difficulty of trying to adhere to a common ordering and schedule of activities across all the sites was noted as an operational challenge. No components were thought to warrant dropping altogether, but physiotherapy was continually questioned and had been set aside at some sites. Consistency in eligibility criteria was lacking, the definitions of InS:PIRE were various across sites and the issue of sustainability was seen as more dependent on how InS:PIRE was being framed (with a staff rather than patient emphasis).

This led to the development of the final version of the driver diagram, which shows a more detailed version of the measures for the top level, although other changes were subtler including:

- In Primary Drivers - 'Reduce unpaid Carer Burden' has been changed to 'Acknowledge unpaid carer burden'
- In Secondary Drivers – 'reducing unwarranted variation' has been removed
- In Measures – 'stakeholder semi structured interviews' has changed to 'staff questionnaire'

InS:PIRE Programme 2016-2018 version 1.2 June 2018

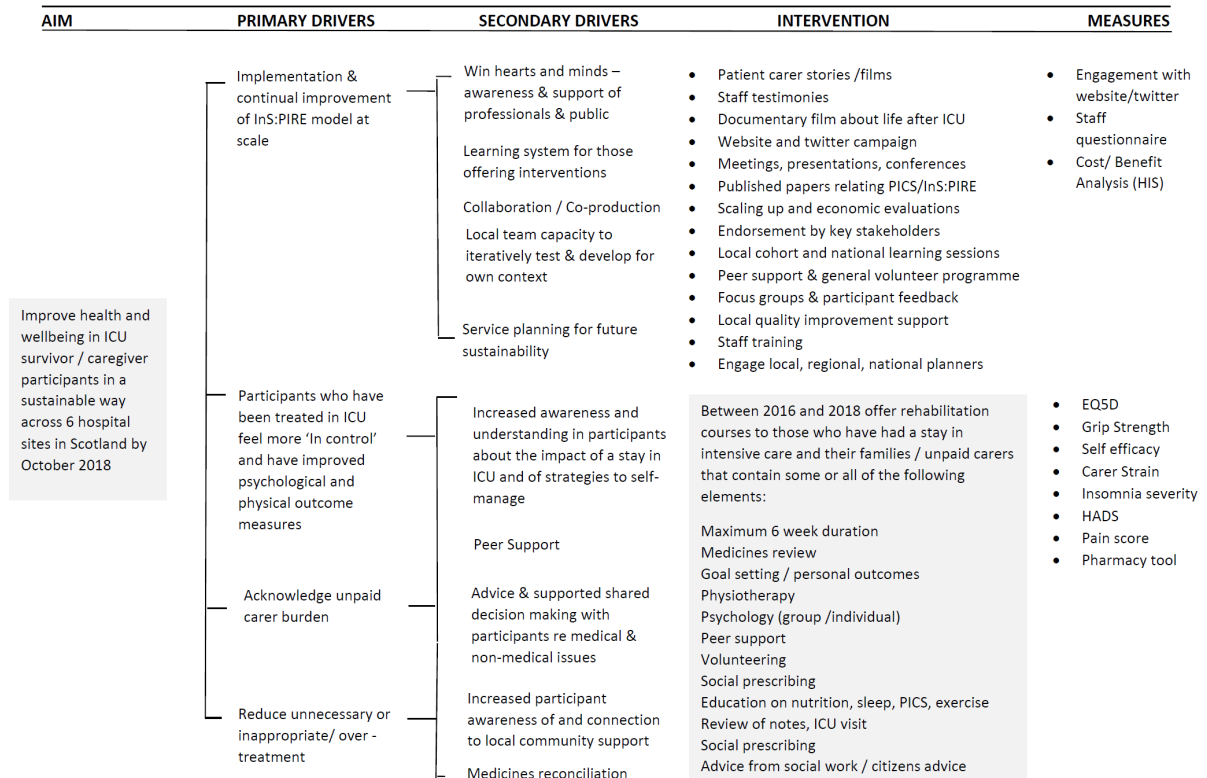


FIGURE 2.4: REVISED DRIVER DIAGRAM (VERSION 1.2, June 2018)

## 2.3 External Recognition

InS:PIRE developed a significant external profile over the course of the scale-up – winning multiple awards and being quoted in a number of government policy documents, including the Chief Medical Officer's report. It was also showcased on television and was the subject of numerous national and international conference presentations.

Specific high-profile recognition and awards include:

- **The British Medical Journal award (2016)** – this pre-dated the scaling up improvement project (<https://www.nhsggc.org.uk/about-us/media-centre/news/2016/005/inspire-team-win-prestigious-bmj-accolade/>), but provided a strong and proud backdrop to the challenges

ahead of the scaling up project. It demonstrated value-recognition for the intervention and was motivational for both the project team and implementation teams as they embarked upon InS:PIRE. InS:PIRE leads also won the NHS Greater Glasgow and Clyde award in 2016: <https://www.nhsggc.org.uk/about-us/professional-support-sites/inspire/further-information/news-chairmans-award/> and the St. Mungo’s Medal in 2017: <https://www.nhsggc.org.uk/about-us/media-centre/news/2017/02/st-mungos-medal/>.



**FIGURE 2.5: THE PROJECT TEAM AT THE BRITISH MEDICAL JOURNAL AWARD CEREMONY (MAY 2016)**

- **Individual sites going for team awards locally** – it was not only the project team which was recognised for InS:PIRE. Local teams went on to win awards too, most notably Crosshouse from NHS Ayrshire and Arran. Crosshouse also welcomed MSP Aileen Campbell, Minister for Public Health and Sport, to their hospital in May 2017, when the team showcased InS:PIRE.



**FIGURE 2.6: THE CROSSHOUSE TEAM AT THE AYSRSHIRE ACHIEVES 2017 CEREMONY (JUNE 2017)**

- **Reporting Scotland filming** – InS:PIRE was featured as part of a nightly BBC news programme.
- **Mention in Realistic Medicine** – InS:PIRE was cited as a case study in innovative multi-professional working to improve care quality and outcomes in the Chief Medical Officer’s annual report in 2017: <https://news.gov.scot/news/realising-realistic-medicine> (see p.23 in the full report: <https://www.gov.scot/binaries/content/documents/govscot/publications/report/2017/02/chief-medical-officer-scotland-annual-report-2015-16-realising-realistic-9781786526731/documents/00514513-pdf/00514513-pdf/govscot%3Adocument>).
- **Mention in the NHS Scotland Report** – InS:PIRE was identified as an exemplar of quality and person-centred care in the Chief Executive’s 2017/18 report (<https://www.gov.scot/binaries/content/documents/govscot/publications/report/2018/12/nhs-scotland-chief-executives-annual-report-2017-18/documents/00543741-pdf/00543741-pdf/govscot%3Adocument> – p.15).

This range of external recognition of InS:PIRE validated the programme at national as well as local levels, giving it prominence as a quality improvement project and highlighting the need for management to consider sustainability at scaling up sites. The celebrations also consolidated local teams’ feeling part of something bigger and bolstered a sense of pride and feeling valued, as well as ensuring continued investment in delivering the quality improvement project.

## 2.4 Key insights

### Key insights panel 1

- ✚ **InS:PIRE has both theoretical and scientific bases (the driver diagrams and their underpinning theories of change).** The development of an underpinning theory of change (in this case via a driver diagram) allowed transparent and critical assessment of the intended content of the InS:PIRE intervention and the perceived mechanisms of action.
- ✚ **Early review of the driver diagram ensured that underpinning logic model aligned with the goals of the programme.** At the start of the programme, there appeared to be a disconnect between the actual implementation of the programme and the postulated underlying driver diagram. Early reflection facilitates consistency of understanding for all parties.
- ✚ **Regular reflection on the driver diagram allowed changes to, and refinement of, the intervention over time to be captured.** As the InS:PIRE intervention matured and understanding deepened, the driver diagrams underwent review and revision. These can provide pictorial representations of the evolution of a programme learning over time and will provide useful learning for any future scale-up programme.
- ✚ **The highly variable implementation of the intervention at different sites made it difficult to capture a driver diagram that was universally applicable across all sites.** Whilst a number of the InS:PIRE activities were common across sites, a number of the components (e.g. physiotherapy, third sector engagement) were variably delivered. As such, for scale-up programmes which are implemented in a variable manner, trying to produce a universally applicable driver diagram can be problematic.
- ✚ **InS:PIRE was perceived to be a hugely successful entity (with a high "brand" value) externally.** From the outset InS:PIRE was viewed externally as highly successful and this encouraged the take up at sites. Engagement of key stakeholders, including representatives from Scottish Government, facilitated the development of this external esteem.

## CHAPTER 3: Formative Evaluation of the Implementation of the Improvement Programme:

### 3.1 Background

#### 3.1.1 General aim

The aim of the formative evaluation was to understand the process of InS:PIRE scale up and seek to identify why InS:PIRE produced specific results across settings for future iterations<sup>1</sup>. This also involved giving the implementation teams feedback and opportunities to refine their local interventions in the context of the scaling up project, via sharing our findings around stakeholder experiences, but also through their reflections, which were encouraged during data collection.

#### 3.1.2 Evaluation strategy

This substantial part of the formative evaluation adopted a mix of formative and rapid cycle evaluation<sup>13</sup>, which is characterised by detailed and purposive interaction between the evaluation and project teams. This was to promote refinement of the intervention and strengthen its potential for successful implementation. The main focus of the formative evaluation was to produce coherent feedback on problems or barriers to the scaling up of the programme. This included feedback both at the level of individual learning at each site and collective learning across sites. Our full protocol for this work can be found in the full report.

In summary, a mixture of the following evaluation techniques was used:

1. The main method included in-depth semi-structured interviews with key stakeholders at each site (interviews conducted with at least one member of all key stakeholder groups at each site including lead ICU clinician, patients, caregivers and rehabilitation clinic personnel). Core to these interviews was identifying what worked/did not work, for whom and why with the ultimate aim of refining the underpinning mechanisms of action/theory of change model for the improvement intervention whilst being alert to the impact of the different contexts and external environments. Interviews were carried out at three different times in the implementation of the scale-up reflecting different stages of early set up, mature implementation and plans for sustainability (wave 1, 3 and 3);
2. Insights from the end of cohort (week six) intentional learning and reflecting sessions (which are built into the intervention package), including feedback from Quality Improvement leads, supplied by implementation teams;
3. Documentary review, staff and participant observation at sites and the programme's national learning sessions, advisory group meetings, events, as well as engagement with teams via Twitter; and
4. Regular revisiting of the programme driver diagram to allow reflection and integration of the perceived mechanisms of action.

Our qualitative research involved an iterative process, which drew on ethnographic and grounded theory approaches for both the collection and analysis of the qualitative data. These approaches

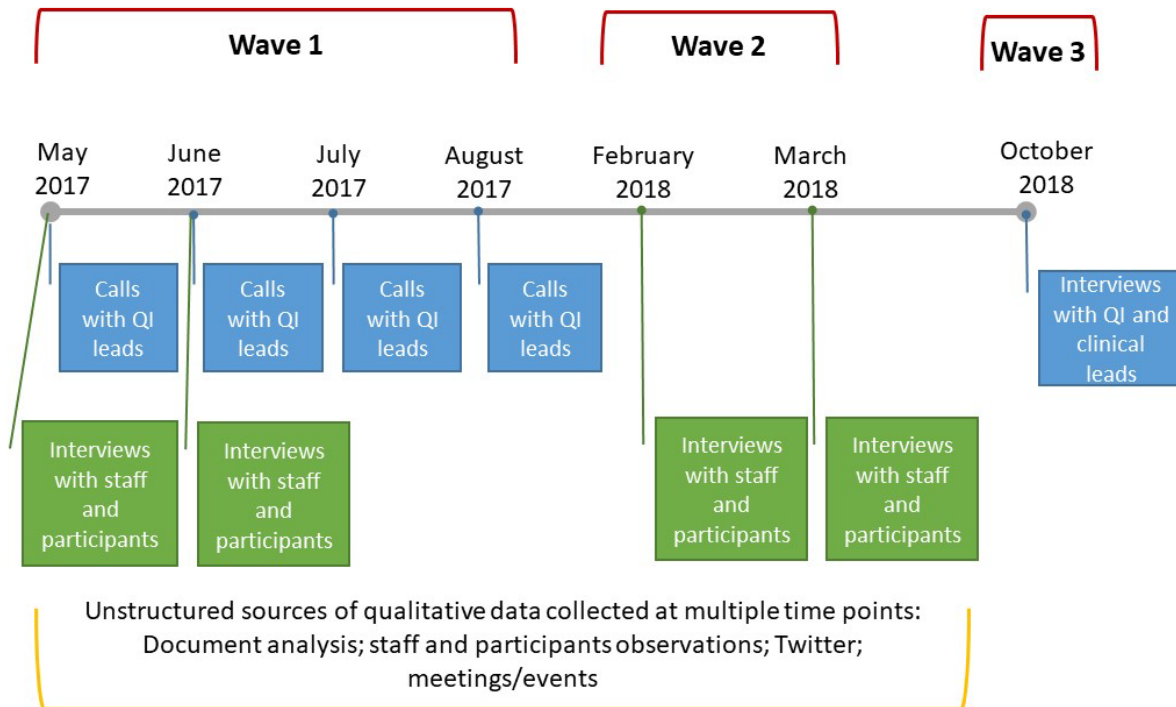
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<sup>13</sup> Evaluation: what to consider. Commonly asked questions about how to approach evaluation of quality improvement in health care. The Health Foundation: London.

allowed for systematic and rigorous data collection while using an inductive analysis to systematically and rigorously generate theory.

## EVALUATION TIMELINE

The formative evaluation was conducted mostly at three different points over the duration of the scale up period in order to capture different phases of the intervention maturity and experience: including early experiences; experiences as the intervention matured and barriers and facilitator to scaling up over three periods. (Figure 3.1).



**FIGURE 3.1: TIMELINE OF QUALITATIVE ANALYSIS (I.E. FORMATIVE EVALUATION)**

Specific aims of three waves of qualitative data collection:

1. Wave 1: To capture early experiences of scale up of the intervention at each site. Specifically, initial issues and solutions employed for the introduction of the intervention at the scale up sites, together with reflections on how the intervention was being implemented at each site. Data and ongoing analysis were used to inform the next stages of qualitative data collection and analysis.
2. Wave 2: To capture experiences of the scale up of the intervention as it matured in each site, identifying how the delivery of the intervention had evolved over time at each site, which elements were viewed as core to the intervention and which had been dropped/made optional. Views on longer term sustainability of the intervention and how it might be integrated into normal NHS practice were also explored.
3. Wave 3: To understand the nature of InS:PIRE-related behaviour and the context in which it occurs, specifically identify contextual influences on InS:PIRE scale up (the findings from this component are summarised in Chapter 4).

Interviews were audio recorded with consent. Audio files were transcribed verbatim by an independent transcription service and checked by the interviewer. Themes from within and across transcripts were identified - this time by an interviewer and another team member – and then discussed with the wider team.

Details on the characteristics of those who participated in the wave 1 and wave 2 interviews are provided in the full report.

## 3.3 Findings

We present our findings under four main sections, each detailing different aspects of the Ins:PIRE scale up. The separate section summarise experiences and reflections on:

- the set-up and operational aspects for Ins:PIRE
- the delivery and experience of the Ins:PIRE intervention
- potential areas for improvement the Ins:PIRE intervention
- ongoing sustainability and evolution of the Ins:PIRE intervention

### 3.3.1 Set-up and operational aspects of the InS:PIRE intervention: staff reflections

**InS:PIRE seemed timely.** There was a real sense among staff that there was a need to do something. Some teams had been doing other things previously for ICU survivors (e.g. nurse led phone follow ups), but staff articulated that this was not consistently delivered or resourced and there was a will to do more. InS:PIRE plugged the niche.

*“I wish we could do it for more people, basically. I feel there is such -- I mean we’re reaching out to a few people, which is great, but I just wish we could reach so many more people that go through ICU” (Site B)*

**There was a clear recognition that ICU survivors are a special group and that nothing really existed for them** (cf. rehabilitation for other populations/condition-specific). While there may not be huge numbers in InS:PIRE, there are no other rehabilitation services for ICU patients and many various concerns about how to address this. There was broad recognition that patients, and their carers, experience a ‘journey’ and that there is a need to sensitively offer multidisciplinary/holistic ‘follow up’ (vs. ‘rehab’).

*“You could quite easily say any patient’s had a life changing experience whether it’s cardiac rehabilitation or stroke rehabilitation. These all these services in place, but ICU has probably been on the back burner a lot of times. We’ve kind of thought that we’ve done our best at the time, but in actual fact we’ve kind of passed patients on to another service but not really supported it sort of thing” (Site A)*

*“I think ICU is a bit special... especially to do with being unconscious, and being on breathing machines, and I think it is quite specialised.” (Site D)*

**Staff seemed conscious of the need to firstly establish the InS:PIRE programme locally, and to know what it is and does.** The interviews with individual staff at scaling up sites revealed that sites had started out by offering a version of InS:PIRE that closely mirrored what GRI offered, as communicated



to them in the 'InS:PIRE pack' and articulated at national meetings. There was reticence early on about how to develop a tailored local service, or how to experiment, and so teams seemed keen to follow what had worked at GRI before trying anything different. As time progressed experimentation and more variation increased.

*"I think the biggest change that we're all quite nervous about is dropping the physio session... We've changed lots of things because every week we change something for next week. So I think the evolution of change is there all the time". (Site A)*

*Yeah, so there was some feedback, and changes we made from the first cohort, just wee things as we've gone along. Trying to think of an example of what we've done. So, for example, in the first cohort our psychologists split up patients and carers into different groups. ... they were quite upset about that, so we changed what we did this time. (Site C)*

**Staff highlighted the informal atmosphere provided by InS:PIRE as crucial.** Observations across sites highlighted informal atmospheres, staff coming in on days off to ensure they could participate in the programme and staff enjoying a sense of freedom in not wearing uniforms and interacting with patients and carers as people.

**Staff participation remained voluntary and often strongly interest-based, suggesting that staff present with immediate or acquired high levels of intrinsic motivation.** Participating staff included: original programme creators; those who had joined on the basis of being a member of a participating ICU team; those who were directly approached by InS:PIRE on the basis of being known to have a special interest in critical care; those who were invited by the leaders of organisations approached by InS:PIRE; and those who became aware of the programme through special interest groups or meetings.

**Members of ICU teams participating in InS:PIRE described enjoying a good rapport with each other since the commencement of the programme,** most likely due to pre existing bonds/familiarity between team members.

**Some multi-disciplinary team (MDT) staff had initial doubts about their role in the programme.** However, this was described as having been temporary and interviews suggested that in the end staff members very much appreciated input from and collaboration with health professionals from a range of specialties.

*"So initially I felt a little bit unsure about how they felt about having a psychologist involved and wasn't sure how I was going to be met, whether I was going to be met with enthusiasm or whether I was going to be met with scepticism. But over the time I think the relationship's grown and I've been very much accepted as part of the team now, which is lovely." MDT staff Site D*

*"I thought there was a lot of medical staff, and I thought where do I ... then I thought, I am a carer support worker, so it's the carers I am supporting within it, and I think that was just me ... the first hour of week one, and after that I've been fine." MDT staff Site B*

**As InS:PIRE developed, it continued to be a source of positive staff experience and a contributor to high staff morale, attributable to being able to offer continuity of care and work in a MDT that served as a platform for capacity building towards improved overall quality of ICU care.** Perceived specific benefits of InS:PIRE included improved team work and awareness of the ICU patient journey, and subsequently enhanced quality of ICU care practice in general (e.g. more compassionate and holistic care) and positive publicity for an ICU department. Staff discussions during the Learning Sessions suggested that InS:PIRE presents with three factors that are known to lead to better performance and personal satisfaction, that is autonomy (a desire to be self-directed), mastery (the

urge to get better at the thing we do) and common purpose (a shared reason to participate in the programme)<sup>14</sup>.

*"I think, job satisfaction. Knowing if what you are doing is the right thing. I think that helps us to work out, knowing what has happened and the outcomes for patients helps me understand whether my patient selection criteria for intensive care is appropriate."* ICU staff Site C

*"And coming to InS:PIRE it's just completely different to what our normal day job is and getting the chance to speak to the patients and speak to the carers about their drugs in a completely different environment, it's just a really refreshing change. And also you get to have quite a detailed discussion with them about their drugs and you get to spend time with them finding out what the issues are, and obviously you get to communicate that with their GP, speak to the team as a whole to see what other changes [...]"* ICU staff Site B

**The InS:PIRE scaling up programme changed staff and their practices around ICU in a number of positive ways.** These ways relate to how staff are working locally and nationally to scale up InS:PIRE, but also extend beyond the content and delivery of the programme itself. The impact on staff delivering the programme is nuanced, but apparent. It is morale boosting, as staff are more conscious of the good work they are doing, and they are enjoying it. Staff roles are developing and staff are reflecting more on their purpose and practices (e.g. diaries being used among one of the scale up teams).

*"And for us it's a good morale boost as well because we feel like we're able to help people more because we know that they're going to be struggling and you feel that they'll need that help. So, it's good to know that this is happening... I've never done anything like this. It's weird even coming in in your own clothes to work quite sounds a bit silly".* (Site B)

*"[S]uppose quite different, if you are used to nursing unconscious people... I think it's fabulous. It's the best bit of my week! I think that I enjoy InS:PIRE".* (Site D)

There are also more tangible changes. There is greater emphasis on delivering patient-centred care and in findings ways to do things that do not necessarily cost money, but which make a difference.

*"What matters to you?" and again, that's the kind of buzz words just now and saying, "Right, what matters to the relatives and what matters to the patients?"* (Site A)

InS:PIRE staff are really enjoying the different kinds of contact they are now having with patients.

*"There's a balance ... it is not a "them and us", and we are all used to being in uniform and here we are in normal clothes".* (Site D)

**A strong local team, gradually complemented by the addition of 'InS:PIRE graduate' volunteers, was felt to be needed to set up and deliver InS:PIRE.** Across scale up sites, it was noted that expansion of the core InS:PIRE team was required to help run the service locally. Secretarial support was deemed to be invaluable. Staff also noted that they had to learn new skills in project management (e.g. organising internal payments). Staff were also networking with each other using social media (WhatsApp locally and Twitter across Scotland) and learning sessions for sharing ideas, with the most recent learning session seeing staff group by discipline rather than site during the lunch break. There is also a sense of the wider community and spreading the word for international reach.

**Recruitment strategies were reported to vary across sites, some mostly reliant on an invitation letter to identify eligible patients, but also direct verbal invitation or posters outside InS:PIRE clinics or ICU waiting area.** The content of invite letters varied across sites, again perhaps reflecting the fact the InS:PIRE is not necessarily perceived to be one discrete thing

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<sup>14</sup> Pink, DH (2009). Drive: The surprising truth about what motivates us. New York, NY: Riverhead Books.

**Response rates were unequivocally reported as problematic across all sites.** Staff noted that response to invitations to attend were low - estimated to be at the level of around 40%. While numbers of participants recruited were variable, they were observed to stabilise or increase with time. Poor recruitment rates were occasionally attributed to time of the year (i.e. summer time having a lower attendance rate).

**Improving response rates was clearly regarded as a high priority for teams,** reflected in the level of recognition of influences on participation rate and efforts to improve recruitment. The subject of recruitment was a key subject of group discussion during the Learning Sessions, proposed solutions included lifting call barring mobile phone number, leaving messages, calling around tea times, leaving two messages, increasing the amount of calls; adding to the invite letter a 0800 phone number; text reminders and making better use of admin support, broadening out inclusion criteria (but this would require assessing mental health issues that some staff felt they were lacking competency in).

**Reported eligibility criteria were inconsistent across sites and had changed over time.** Staff seemed to struggle with describing eligibility criteria, except for individuals involved in the programme development or actual patient selection. The underlying rationale across sites was to initially target complex cases (i.e. patients at an increased risk of post-intensive care syndrome), but gradually criteria became more inclusive, seemingly to improve recruitment figures.

*“So my understanding is that the patients who are selected for the programme need to have been in ICU for at least within the last three months, and that they need to have had a certain length of time on a ventilator when they were in ICU as well. Though I think that... and we started off with very strictly adhering to the criteria that we have. I can’t remember any of the other criteria, there probably are... Yes, so this cohort is different, absolutely. So we’ve started inviting patients who were in ICU a lot longer ago, so up to over a year ago. So we’ve got a couple of patients in this group who have been in ICU a lot longer ago than three months, and we’re just testing out whether they can benefit as much as the patients who have more recently been in ICU.” MDT staff Site D*

**Staff recognised the challenge of inviting patients at the right time, and most expressed preference for keeping the current strategy, that is inviting patients 3-6 months post discharge.** They argued that some patients recruited 6 weeks after discharge found it to be too early.

*“So it was tested back in May of 2016, we invited patients earlier, so some patients were invited I think within 6 weeks post-discharge and we asked patients was it the right time for them. Some said it was perfectly timed, others said it was too early, and the people who were on the phone that we were following up on invitations they said, “It’s too early for me”. So it just goes to show it just is dependent on the patient. Some patients are ready to engage in a programme such as InS:PIRE very early on, and others need a bit of time, whether it’s for physical or psychological reasons [..]” MDT staff Site E*

**Staff reported that attendance varied across weeks but was maintained on a high level.** One site defined ‘attendance’ as each patient receiving nursing, medical, pharmacy and physiotherapy - something that hasn’t been mentioned at other sites. Hypothesised reasons for dropping out included patients realising the programme was not for them. Attrition was also attributed to not needing the program any longer, hence attendance was taken as a sign of the programme being viewed as beneficial.

*“We would define an attendance by each patient having each of three core discipline assessments, which would be medical and nursing, pharmacy and physio. So say for instance today there may only be 10, but on other weeks all 12 patients have received all 3 interventions. And the reason being, these patients are still going to hospital appointments, so it might not be actually physically possible for them to be here on all five weeks together, so that’s how we define that complete attendance.” MDT staff Site E*

*“Some of our patients just come along and just don’t feel it’s for them, and don’t turn up after the second or third week. Some of our patients have gone back to work. We’ve got one patient who came along for the first week, but he’s gone back to work and can’t come along, which is great.” ICU staff site C*

**Perceived common reasons for non-attendance were rehospitalisation or hospital appointments and holidays.** One staff member observed that the timing of joining InS:PIRE indirectly impacted attendance rates, through the link with likelihood of rehospitalisation. Memory problems were another perceived reason for non-attendance, hence patients being typically followed up with reminders. For some patients a lack of private transport or commuting a long distance was perceived to be a barrier, hence sites offered taxis and patients offered assistance to each other. Patients who missed an opportunity to attend are usually offered an opportunity to return to the next cohort for the session that was missed.

**The set-up of InS:PIRE at sites led to a number of operational issues:** Sites reported that there are a number of logistic/bureaucratic challenges faced when setting up InS:PIRE at sites and also acknowledged potential negative staff burdens/unintended consequences (e.g. staff ‘taking it home’, worries about what happens after the two year scaling up programme, onerous workload, that study paperwork is sometimes unclear, that the work is time consuming, the need for a programme manager), which might threaten the sustainability of InS:PIRE beyond this project and in terms of establishing it as a service. Whilst it is seen as transformational for staff (see below), it was felt that it does not readily fit in the existing organisational ethos/workload/structures at sites. Staff were also conscious that pressures of time limits exist and, if InS:PIRE is to become sustainable, it is essential to invite management to get buy in/plan ahead. The need to build the team was identified as crucial for this process.

**InS:PIRE staff displayed an emerging sense of pride in recognition of the programme’s success and identification with the programme.** Many of the scaling up sites’ members signed up to ‘Twitter’ accounts to connect with @InS:PIREICU and each other. The evaluation team often followed and joined in these conversations, particularly around the learning and coming together at national learning sessions, but also in between. Interactions were particularly evident online around professional prestige, staff development and external recognition. These were associated with the awards InS:PIRE had received and through publishing patient videos. These patient videos were perceived to be particularly powerful to staff, the ICU community, hospital managers, etc. One site’s success is enjoyed by the wider ‘InS:PIRE family’ and the morale boost is experienced together through inter-site encouragement and congratulations at multiple sites, a ministerial visit, presentations at national and international conferences.

### 3.3.2 Delivery and experience of the InS:PIRE intervention

#### STAFF EXPERIENCES AND REFLECTIONS

**Staff noted that it is was important for patients to have one to one opportunities and going through what happened.** Staff reflected that patients want to share experiences, goal setting is important and ICU visits help patients to make sense of what happened, especially if they have struggled with delirium.

**Scaling up sites were initially reluctant to experiment too much with the InS:PIRE content/model they understood had been successful at GRI but slowly started to adapt the intervention for their**

**local setting.** For example, a group exercise class was used at all sites as an icebreaker in the early weeks, however, sites started to remove this.

*"I think it was good we took the exercise class because I did that in the first cohort and I think it was good to get everybody -- it was a good way of getting people to know each other and have a wee laugh and their dance moves and whatever. I think it was good to have them do something like that together but it wasn't really benefitting anybody. It was quite difficult in that room as well because there is not a lot of room, there are no windows. So we took that away which I think was a good thing". (Site B)*

**Sites recognised the importance of the patient letter, but felt that their preparation is time-consuming.** Staff recognised that the letter is positively received by patients and their carers. However, it was raised that going through various NHS systems to prepare a letter for patients is difficult and time consuming.

**Staff noted that the essential components and target of InS:PIRE refined and changed over time.** The focus of InS:PIRE initially was on return to employment. It was acknowledged, however, that employment might not be the most appropriate focus, and measuring improved health and wellbeing may be more appropriate. They acknowledged that what rather seems to be happening within InS:PIRE is that they focus on seeing that patients and carers are 'getting back to normal', and seeing patients looking "great" has a huge impact on patients, carers and staff.

**Initial recruitment to the InS:PIRE intervention was viewed to be a struggle and some sites developed intensive approaches to ensuring that patients register and attend.** Those included having to institute a system of multiple phone calls, text messages, etc. In addition, the consent process was perceived to be time consuming.

**Staff reported a number of changes in the structure of the InS:PIRE interventions as it was implemented across sites.** This was mostly driven by attempts to cut costs and also a desire to improve participation rates. Staff continued to develop their customised model using a 'trial and error' method. Interviewed staff reported experimenting with the InS:PIRE content and adapting the intervention for their local setting and cohort's need.

*"I suppose that's how the programme has matured over time, and we've needed that time for all of us to be informed with what's available locally. So we really encourage people no matter whether you were working before or not, retired or not into volunteering roles to try and help you get back to some form of I suppose having a purpose in your life as well, and getting back out and having a routine. So yeah, we've just I suppose through investigating and tapping into other services within our area we've been educated on what's available. " ICU staff site C*

**When asked to reflect on the nature or essence of InS:PIRE, staff gave varied definitions, reflecting the fact that InS:PIRE was not regarded as one discrete thing, but rather a multi-faceted intervention for multifaceted problems (i.e. a multi-morbidity clinic).** The nature of what tended to happen during the programme depended on the patients to some extent. Collectively the quotes provided illustrate that it is a form of continuity of critical care and specifically a support programme for ICU survivors addressing biopsychosocial aspects of recovery.

*"Because all I say to people is that when you come into intensive care the first domino falls over, and unfortunately a lot of other dominos fall in other directions, and I said, "What InS:PIRE tries to do is to help you pick up as many of those dominos that have fallen over", and that's all I say to them. So I don't define it because I leave that up to them to define what they need. But I just say, "Look, a lot of what has gone wrong, InS:PIRE will hopefully help you to pick some of it back up". And I do explain that there are components, but I try and not limit it to that so, and just make it*

*more about, "Whatever your problems are we will listen and try and help you maximise your recovery".*" ICU staff Site A

**InS:PIRE programmes consist of four main elements: a multi-disciplinary team, peer support, social prescription and volunteer support.** Signposting is a crosscutting strategy used in MDT and social prescription elements. At all sites patients were offered access to the following MDT core components: nurses, physicians, pharmacist, physiotherapists, and psychologists. Specific content and level of involvement of MDT members varied across the sites and ranged from talks to one to one sessions with referrals or signposting. There was a general consensus amongst staff that all current elements of the programme were required. The extent of the value of each element was perceived as dependent on specific patient need.

- **Group physiotherapy was not delivered as a core component** at most sites as the programme progressed – and so contact with the different physiotherapy professions might have been by referral. This was done due to operational difficulties and perceived isolation of patients who opted out from group therapy. Group physiotherapy was kept at one site, reportedly due to perceived benefit for promoting interactions between patients and patient-staff.

*"We also had... some cohorts were quite big, so from a safety point of view we had concerns about continuing the programme. But probably the biggest reason why we stopped it was because we felt some patients who did not want to do exercise felt probably isolated"* MDT staff site E

- **Peer support involved facilitated interactions** with other current or previous cohort members.
- **Social prescription and patient volunteers are apparently the least established elements** of the programmes as the relationship building with social care organisations takes time, as does building a network from previous cohorts.
- **Two sites currently have healthcare professionals trained and experienced in emotional support (a carer support worker) and psychological care (a clinical psychologist) continuously supporting staff and participants** through all programme sessions.

**Some staff members felt that the scale of psychiatric needs (i.e. a psychological element) of programme participants was somewhat underestimated and at most sites remain only partially provided for,** as reflected in only partial participation of psychology personnel and a perceived lack of training or limited support for InS:PIRE teams in terms of managing cognitive and mental health aspects of InS:PIRE participants' care.

*"I think if you spoke to any other member of the ICU team here I think they would say to you that they had completely underestimated the level of psychological difficulty that patients present with, and probably I did as well actually. Coming in I didn't anticipate pretty much every patient that we've had come through these groups have had some kind of psychological problem, whether that be a cognitive difficulty or flashbacks and nightmares or low mood and depression or anxiety."* MDT staff Site D

**At several sites the intervention duration has changed over time, mostly shortened, for operational reasons and to improve cost-effectiveness.** By the end of the scale-up phase, InS:PIRE tended to be delivered over the course of 4 or 5 half days or 2 full days and sites with 5 week long programmes are considering reducing the duration to 4 weeks. While some staff expressed the view that shortening the length of the programme could be particularly useful for sites with an issue of long-distance commuting, the idea was approached with caution. It was felt that when considering the duration of the programme it was crucial to ensure that patients had sufficient opportunities and time for interaction with each other and that staff have sufficient time for observing implemented changes.

*“Yeah, I know other health boards have done that haven’t they, so for example, the [name] does two full days doesn’t it rather than the five weeks approach that we’ve taken. So I can see why in a service like the [site name] why they would do that because patients are probably coming from much further afield, and the idea of coming for a two hour session once a week for five weeks is a much greater commitment than coming for two days, so. I don’t think that would work as well here in that certainly in the beginning stages of the programmes we’ve been running” MDT staff Site D*

**Good group dynamics were often achieved, given enough time to interact and subsequently bond.**

A more relaxed environment – in turn- was observed to further induce between-patient interactions and consequently more peer support.

*“We found that probably it was maybe a more relaxed environment; we found patients were more involved together and had more time together and being peer supported”. MDT staff Site D*

**Negative influences on group dynamics were described in several interviews with staff.**

One staff member described the importance of the presence of a psychologist in terms of managing possible challenges around group dynamics, including dominant versus less assertive group members and managing patients who were apparently reluctant talking in a group setting. Several staff members perceived that small cohorts had poorer group dynamics, attributable to a diminished chance for patients to find somebody relatable. Some interviewees described how patients who opted out from group exercises appeared to feel isolated.

*“If you’ve got just a few more patients you seem to get people who you can normally relate to, whereas with the four patients none of them really connected with each other, so just the smaller number there just wasn’t the same connection, whereas a bigger number there’s a greater chance of finding somebody you’ve got something in common with sort of thing. And I think it was just the personalities as well.” ICU staff Site B*

**Staff reported having perceived a generalised positive impact of InS:PIRE on patients’ health status.**

Commonly reported specific examples of benefits were social inclusion, improved physical functioning and psychological well-being. Staff found it hard to explicitly attribute a specific health benefit to an exact element of the programme, perhaps reflecting its multifaceted character. It was felt that the perceived value of specific elements would likely vary from case to case, reflecting the fact that InS:PIRE attempts to address the needs of a population with heterogeneous biopsychosocial problems and hence highlighting the importance of maintaining a person-centred character to the intervention.

## PATIENTS’ AND CARERS’ EXPERIENCES AND REFLECTIONS

**In terms of timing, patients and their carers felt that InS:PIRE was offered at a good time. The length of the programme was felt to be appropriate.**

The days/times that InS:PIRE was offered varied across scaling up sites, but there was little feedback from patients on preferences/convenience although local timings did not seem to pose any significant problems. Location was also non-controversial - some patients travelled far to attend (e.g. one patient makes a weekly 200-mile round trip). Splitting patients and carers for relevant parts of the programme was perceived positively as the two roles come with different issues and InS:PIRE helps to address those. The informal nature of the space was also valued.

*“It’s good the fact you get a wee coffee as well, I mean that was quite good, you didn’t quite go... it’s not like being in a classroom sort of a thing, it was kind of you went in and it was like a bit of banter and you have a coffee and a biscuit and you know, or you did your gym at the beginning you know, your gym, your warm up and you’ve got your circuits, asked to speak,*

*and then you get a wee speech and you have a coffee and a wee speech and it was good, it was good". (Site A)*

**The dedicated one to one opportunity to discuss their own case notes and experiences with a doctor was viewed as most important.** In terms of the interventions that comprise the InS:PIRE programme of particular importance was receiving a summary/letter detailing what happened and having it explained by a consultant. Being able to ask questions and getting those questions answered was crucial for most participants. This component was not however explicitly referred to in the initial driver diagrams/theory of change, but seems to be a core element.

*"I only know of those complications [had in ICU] in detail through here, through the InS:PIRE programmes, when the nice lady or the nurse and a surgeon gave me the layman's written document telling me what happened. I have similar comments from my family who were in the ICU for weeks. But hearing it in a very structured clinical manner is beneficial. It was to me"* (Site B)

*"The consultants go over with you everything that had happened when you were in intensive care and again, that was something I was really keen for... I had quite a lot of questions about various things so I was really keen to do that as well". (Site C)*

While speaking with the doctor was perceived to be very important, participants were aware of the resource implications, and one participant wondered whether the session could be delivered by someone trained, but at a lesser grade, although it was noted that speaking to someone with specialist knowledge was important.

**Peer support was also highly valued by patients and carers across the scaling up programmes.** Connecting with others who have had a similar experience was deemed important. This had been identified as an important part of the programme, and was highlighted by the GRI team in their proposal as a component of rehabilitation programmes for ICU survivors that is often overlooked.

*"There was other people, not necessarily going through the same thing, the illness, but through ICU, which is... but all their experiences were relatively the same; they didn't remember very much about it. That's what I found was very useful, being able to communicate with other people that have been through the same". (Site D)*

**The opportunity to visit ICU was deemed to be very important by those who took up the offer.** Visiting ICU was offered at all sites and was taken up by some, but not all, participants. This was deemed to help with understanding delirium and experiences of audio and visual memories.

*"The best bit for me I found a lot of folk didn't do it, I think it was the first person to do it in this class was I wanted to visit ICU, and I did that the following week". (Site A)*

**Benefits commonly attributed by patients included: reduced anxiety, closure, social inclusion and accelerated recovery time.** In addition to health benefits patients reported a positive impact of InS:PIRE on their overall quality of life, for example through gained self-awareness and coping skills.

*"I think it has helped me a great deal to assess my capabilities and such like after intensive care, it has helped me. Now, I'm going on to a programme that I'm going to be walking and such like and I wouldn't have had that if it wasn't for InS:PIRE". Patient Site E*

**Perceived usefulness of physiotherapy, psychology and pharmacy varied across patients' specific needs (e.g. age and comorbidities) and modes of delivery (e.g. group vs individual).**



*“For me personally the pharmacist wasn’t so useful because I’m seen by a lot of doctors you know, over the year I have maybe got 10 or 15 consultant appointments so my medication is pretty well managed through all of the consultants that are seeing me, so it wasn’t so useful to me.” Patient volunteer Site A*

*“A medication passport, which I thought was very good. The drugs that are in there that I actually take, my name, my hospital number, date of birth, all the drugs that I take, current medicines that I take, what they’re for, when to take them. That was very good. Okay, I know when to take them, you know exactly when you take them, but if anything should happen to me out on the road, that’s in my pocket.” Patient Site E*

**Patients rarely discussed current social prescription.** Prescribed community exercise programmes were most commonly mentioned, but their perceived usefulness varied across individuals. However, involvement of the third sector being raised as an area of improvement suggest it may be more valued than expressed in interviews.

*“There’s no use in me going into a gym, being 76 years old and going onto treadmills or bicycles or rowing machines or weightlifting or anything like that. That’s not for me. But I can slowly walk a distance and say, “Right, that’ll do me”. Patient Site E*

*“I got referred into a gym and through the gym programme I’m probably more cardiovascularly fit than I was before I went in, but yeah.” Patient volunteer Site A*

**Patient participants discussed how carers benefited from the programme through receiving much needed psychological and social support through exposure to relatable stories of other participants and also an opportunity to be heard by participants and staff.** Several patients also discussed how an ICU visit was more essential for their carers than themselves, as unlike patients, they had memories of their loved ones stay at an ICU.

*“Plus, technically for me, it was a help to understand from the medical profession what happened because my family, my wife was my carer, my daughter’s attended, and everybody would remember something and tell you that, at one stage they were told I may have had a stroke and may have brain damage, or I may have to lose my leg. So, my family were cycling between very upset and apprehensive to feeling more positive.” Patient Site B*

**Return to employment was not viewed as a top priority for patients.** While in theory support to return to employment was on offer, it was only relevant for a handful of participants. Goal setting was viewed to be more appropriate, although only mentioned directly by one participant in the interviews (although this had been raised in the patient feedback sessions at sites).

*“I wouldn’t say there’s been a lot of return to employment. It has been talked about. I think the main focus, I think has been to get you on your feet and to give you more confidence and to get you doing your daily activities better so that you’re not as reliant on other people or other services, probably”. (Site C)*

**In terms of outcomes for patients and their carers, while InS:PIRE set out to help participants feel more ‘in control’, they speak themselves more of “coping” and “confidence”.** Being able to ‘deal with it properly’, know what to do and what not to do, not do too much and to take time, but not to avoid doing things and how much to get on and not rely on others, and being pushed to think about looking after themselves, were all mentioned. Aligning patients’ and carer/family expectations is one tangible outcome of an integrated programme.

*“I think it’s allowed him [the patient’s carer] to hear that actually it is really important to try and do things as well and get back to normality and not that, like, he was really holding me back but I think he was concerned about me doing too many things so I think it was quite good*

*for him, I suppose, to see that I was okay doing the sort of physio classes but also to hear that actually it's important to do these things and it is okay and you know, very much that we are, the aim is so that you will be exactly the same as before you went in, do you know, that it's not ... and that's not unrealistic so I suppose for both of us, it's quite reassuring to hear that as well". (Site C)*

**Patients reported that they 'got a lot out of it', and more mental than physical benefit, lessened anxiety and that "laughter was the best medicine".** Patients noted that InS:PIRE pays attention to all aspects of health and being treated not as a patient, but as a person was important. Seeing other people look well was also motivating/inspiring for participants. The programme was considered to be good for the carer too.

**As implementation matured, patients continued to perceive InS:PIRE staff as highly motivated and described how much they valued being cared for by highly motivated and positive staff.** One patient even expressed an opinion that the programme's very success depended on the participation of highly motivated staff.

*"...[T]he fact that they seem very happy to be there. I mean I don't know if this is their spare time that they're doing this in, if this is part of their shift, or is this [...]....how many people want to do that? How many people want to just put their coat on and get home? And the fact that they are taking the time to do this I think speaks volumes doesn't it, that they are willing to give up their time and... it shows how much they care, it shows how much they care." Patient site D*

**All patients reported being somewhat unsure about what InS:PIRE was when they were invited to attend and/or were unclear about the possible consequences of the programme.** Reported reasons for joining the programme (despite some having initial hesitations or uncertainties) included a need to share their experience with other ICU survivors, intrinsic motivation to try anything potentially helpful, trust in ICU staff knowing what's best for them or out of sense of gratitude to ICU staff for saving their lives.

*"Just self-thought, that basically that one, "Well I'll go along and see what it is and see if there is benefits there to be had from the programme", so I decided on that basis I would certainly try it out rather than totally discard it." Patient Site C*

*"I got the impression that it was a rehabilitation to get you back to how you were before" Patient Site D*

**The majority of patients felt that assessing 'readiness' and inviting patients when they are 'ready' was an important area for improvement (rather than a set time *per se* across all patients).** Most patients felt that they would benefit more from the programme if they were invited earlier, although not as early as up to a month after discharge (preferably between 2 to 3 months after discharge).

*"I think maybe between a month and two months after discharge, depending on how long they've been in and things like that. [...] Because I think at that point I was physically well enough to participate and at that point I probably would've got more out of the programme than two or three months later." Patient volunteer Site A*

*"I think that's why it should be sooner because if you're coming out of hospital you're obviously going to have a sick line, and if it incorporates this course your attendance is likely to be higher because you're not having to take more time off your week." Carer site C*

**Patients' approach to the idea of shorting the duration tended to be similar to that of the interviewed staff** in that they were cautious about the impact of shorting on patients' opportunities to interact with each other and staff.

*“I think they’ve changed the programme because I came five Mondays, and with 6-7 couples, and I think they [patients] ran out of steam [...] Well, we did it on a Monday at 12 noon until 4.00pm, and five weeks is a long time, so my group was very good, they all came for the five days, but the next group, half of them disappeared. They lost either difficulty travelling, or -- only three attended. [...] It was the patients, but I think what they’ve done is better. Slightly longer for a shorter period of time. Keeps the interest [...]” Patient volunteer Site B*

**Patients valued the opportunity to have follow up appointments, but did not necessarily express issues regarding coming to the end of the programme.** More prolonged support was regarded as perhaps being more needed by people with serious chronic illness underlying their hospitalisation (e.g. addiction).

*“But that would be like if I needed more help. I wouldn’t say that, that would be making you feel as if you were an alcoholic or something like that. You were going to be dependent on them. No, I wouldn’t say that. [...] I think if you had a more chronic, like an alcoholic or a drug addict, then you would have to go to these places..” Patient Site E*

## QUALITY IMPROVEMENT (QI) REFLECTIONS

**There was a recognition that InS:PIRE offered a totally new model of working for staff.** QI leads all reflected on how involvement with InS:PIRE is transforming staff – how they work with each other and work with patients. Having some autonomy over how they organise their intervention, spend budget and what they do for patients locally is motivating and rewarding. Cross-professional working in the ways promoted by the InS:PIRE programme was recognised to be “not routine”. It is resulting in system and cross-disciplinary learning. It was also noted that the types of staff involved in InS:PIRE were generally self-selecting with many highly organised and completer/finisher type staff engaged.

**It was recognised that InS:PIRE had a significant positive impact on staff morale.** Meeting patients/their carers again had a huge impact on staff – it allowed a more nuanced view of work, understanding of the patient journey and needs, and awareness of resources, including social as well as medical. Leads noted how InS:PIRE allowed the meaning of work for staff to be restored and staff are reconnecting with why it was they came to work for the NHS. Comments are positive and light:

- *“[people have a] spring in [their] step going into work”*
- *“How do you measure joy?”*
- *“There is a real buzz!”*

**QI thinking promoted in InS:PIRE was a catalyst for spreading QI approaches to other domains outside of ICU.** Immersion in QI thinking with regard to ICU care led to consideration of issues about post-ICU hospital care from the wards (this was an issue routinely raised after every cohort) as there are lots of issues with wards not being prepared for the transition that this necessitates for patients who have been used to being intensively nursed 1-1 moving into a 1-many model ‘overnight’. This led to the development of action plans to address transition to ward care at a number of sites.

*“We’ve opened a huge a can of worms...”*

These wider issues have raised the importance of having a “learning healthcare system” where wider system issues are raised and addressed routinely.

**One-to-one interactions and peer support were perceived to be the core InS:PIRE components.** The intervention components that QI leads perceived to be key (one to ones and peer support in particular) map to patient experiences

### 3.3.3 Ongoing sustainability and evolution of InS:PIRE over time

**There were widespread concerns amongst staff about the potential sustainability of the programme beyond the InS:PIRE grant.** The InS:PIRE intervention currently sits outside standard NHS structures was considered likely to be unsustainable in the longer term. There is broad recognition that funding for InS:PIRE will be “problematic” going forward and that there is a “need to streamline” the provision of the service to fit with the NHS. How best to communicate the benefits of InS:PIRE and to whom are concerns for the site teams. Various conversations are being instigated at local levels to explore how the learning from InS:PIRE can best be used for service improvement and patient recovery.

**InS:PIRE was viewed as a resource intensive intervention.** Although staff members valued being part of the programme and were clearly highly motivated, they nevertheless viewed engagement as laborious, often necessitating personal time sacrifices. The programme depends on the good will of hospital administrations, flexibility/availability of participating personnel and also the good will of hospital staff to cover for InS:PIRE staff time away from wards. Project management/administration was viewed as disproportionately time consuming, compared to the intervention.

*“So, for example, it’s difficult at times, for example we are running over the Easter holidays with lots of people off. So, actually I don’t think there is going to be anybody to cover my clinical session to let me come and do my clinic, so I’ll probably try and do both at the same time. So, it relies on people volunteering to do an extra session to cover me, and the same for everyone else.” ICU staff Site C*

*“And certainly each of us have tried to you know, to do a bit of research as well within the programme, to use the results that we’ve found and put that together, analyse that data, and that’s probably... some of that’s within our own time, and there’s not getting away from that. I think we’re just at that phase where we need to do it, as in we all want to do it, and once we have put those findings together and get them out there then it will be easier. But yeah, it certainly has taken a lot of time, and when we started the programme I don’t think any of us anticipated how much it would take” ICU staff site E*

**Implemented or hypothetical ideas for improving the feasibility and sustainability of the programme, were related to changes in the level of involvement of ‘costly’ staff.** The main strategy used across sites to date has been to stop group physiotherapy (exercise) classes, subsequently cutting out the need for a physio pre-assessment. In some sites this also resulted in the programme being shortened. In addition to physio involvement, some sites have reduced or contemplated reducing involvement of consultants (e.g. in the programme administration and delivery). Tailoring content to a cohort’s specific needs - to avoid unneeded content and subsequently associated human resources cost - was also discussed by both staff and patients.

*“And even though it probably gave us a lot of information for those that did come, we just found for the cost of staffing a pre-assessment, and actually the attendance as well, it wasn’t cost effective, but at this point we were thinking of dropping our exercise class anyway. And one of the main reasons other sites are doing it is for safety so that they can pre-assess patients for exercise. And one of the other sites, [site name], they’ve dropped their exercise component to see if that changes attendance, and also the cost of cohort, to maximise the benefit to patients, if it means you get more patients in who benefit more from it. So pre-assessment is something we trialled, but we found it didn’t really work for us.” MDT staff Site E*

**Staff also referred to strategies aimed at strengthening justification for the programme’s existence.** A primary focus seemed to be on participation rates, reflected in many changes to the programme’s structure, eligibility criteria and recruitment strategies. One interviewee also mentioned building on existing evidence demonstrating effectiveness of integrated or multidisciplinary models of care.

*“It’s that multidisciplinary team working element that’s the key bit of the evidence base that seems to be quite high up on the agenda that is a useful piece of evidence for this programme to get further funding I think. It’s worth bearing it in mind.”* MDT staff Site D

**Staff noted the option of expanding the scope of staff (e.g. by rotating nursing staff into InS:PIRE)** would assist in disseminating the educational values of the programme and therefore would be a good way to increase staff awareness of the programme.

*“But that’s something I think over time kind of creating awareness within our unit about what’s happening, and I think the plan for the next year is to have a nursing rotation into the programme, so nurses will rotate to come to the programme and see what it’s about so that they can tell patients about it as well. From a management point of view I’m not sure because I don’t really ...”* MDT staff Site E

**Staff discussed limitations in how patient motivation is currently being addressed by the programme.** There was a recognised need to enhance the programme’s strategies to motivate patients to engage (*i.e.* seek help), reflected in efforts to improve attendance rates. Several staff members also expressed their views on the issue of motivating patients beyond InS:PIRE. It was felt that currently the programme can encourage patients to make the best of provided care, but that a patient has to have an intrinsic motivation (e.g. willingness) to take on board those recommendations. One suggested strategy to improve patient motivation is through more informative and impactful goal setting.

*“It can only I think InS:PIRE and motivate people, but you can’t create the willingness, we can’t prescribe willingness. So I think patients have to be willing to take on the signposting and the motivation, and then have to be willing to take it themselves, so we can’t create that and we can’t prescribe that. So I don’t think InS:PIRE will ever create willingness, but it might encourage patients to become more willing, if that makes sense, and that boils down to probably personalities and life circumstances.”* ICU staff Site A

*“I think we could probably get a bit better at it [goal setting]. I think if we...looking at the common goals other people have said we could give people suggestions, this is what other people wanted to do, do any of these ring any bells with you? I think the goal setting is important. I think we all need a goal to get us out of bed in the morning, don’t we, whether it’s just to get to the afternoon off, or to get to the weekend, but goals are good. They keep you motivated.”* ICU staff Site C

**Some ideas for enhancing collaboration with health social care partners in the community emerged.** A need to improve communication with general practices was also discussed. Some staff members indicated that more involvement of third sector parties would be useful. One patient suggested improving the relevance to the local context of the information provided by the third sector partners.

*“Well the only thing, the only kind of big negative thing that I found was while they could tell me I was having anxiety issues, I had to get my GP to refer me to the... to get treatment, yeah, to get the cognitive behaviour therapy. They couldn’t [refer me], because it’s a funding thing that the referral comes from the GP, apparently they don’t have the funding to do the referral, that’s what I was told. [R - And was it difficult to get that referral from your GP?] Not for me personally because my GP you know, I see my GP quite a lot so he kind of knows me. But it might’ve been more troublesome for someone who’s less known to their GP perhaps, I don’t know.”* Patient Volunteer site A

*“Citizens Advice people, could be a little bit more informative as for the different regions and who to contact, because we are in north and south Lanarkshire you know, we’re actually in south Lanarkshire and Airdrie is in north Lanarkshire, and that does make a big difference”.* Patient Site C

### 3.4 Key findings

#### Key insights panel 2:

✚ **Three core aspects of the intervention were consistently highlighted as the most important: peer support; patient-centred care, and one-to-one time with the ICU staff** (Table). Other elements were deemed less important.

Value/benefit	Details	Exemplary quote
<b>An opportunity to hear from and share experiences with other ICU patients (including patient volunteers)</b>	<ul style="list-style-type: none"> <li>Understanding a range of negative side effects (bad dreams; panic attacks; anxiety; sore throats etc.)</li> <li>Realising that they were not alone in their experiences and in many ways seemed to 'normalise' their experiences</li> </ul>	<p><i>"And you could speak to others who related their story. You realise that it was more common than specific. So, from that point of view, InS:PIRE was a huge psychological benefit."</i></p> <p>Patient Site B</p>
<b>Patient-centred focus</b>	<ul style="list-style-type: none"> <li>Having their feelings heard</li> <li>Having dedicated time for asking questions without time constraints.</li> <li>An 'informal' setting that facilitated discussions and made patients feel comfortable discussing and sharing problems;</li> </ul>	<p><i>"I think it was very important just for me personally [to be able to ask questions]. I think just you know, having the time and saying, "No, not at all, sit down, sit down and we'll have a chat", and it was like, "Time..." "No, no, don't you worry, I'm not busy with anything else, you just sit down, you tell me what's wrong", I think is really, really important. They weren't in too much of a rush for you. But I don't mean just for me because every time you looked they were sitting with someone."</i></p> <p>Patient Site D</p>
<b>Opportunity to discuss the specifics of their ICU stay with actual ICU staff</b>	<ul style="list-style-type: none"> <li>Finding out exactly what happened to them in intensive care, which constituted an important part of coming in terms with what happened</li> </ul>	<p><i>"I mean, there's no point an outside agency taking it on, because they are not going to know what you went through. The ICU nurses that were here, the physiotherapists who were here, the doctor ... the nurse, they were all in ICU when I was in there. The physio came down to me to get me to move my arms and legs when I couldn't. I couldn't even wake up. So, they knew me. When I came in, there, it was a relief to see them, because I knew that they knew what I went through, and I could maybe get some answers. So, to have somebody else do it, I don't think you would have the same effect."</i></p> <p>Patient Site A</p>

## Key insights panel 2 continued ...

- ✚ **Moving forward, InS:PIRE, may benefit from focusing less on the elements that were not proactively identified as being helpful by patients.** For example, we know from staff interviews that engaging with the 3<sup>rd</sup> sector is time consuming (e.g. arranging external speakers) and these were not necessarily the things raised by patients when asked what they had got out of InS:PIRE. One way to deliver comprehensive and standardised talks, and to save human resources expense, would be to invite some of the current speakers to develop and deliver on-line talks tailored to specific needs of InS:PIRE participants with a possibility to have questions answered through a chat room.
- ✚ **Increasing the level of involvement of trained in psychology/mental health staff could be one area of improvement to be re-assessed according to needs (both staff and patient needs) and adjusted according to available resources.** That is due to reported staff benefits of extended involvement of psychology/mental health staff, a recognised need for extended psychological input and eligibility criteria being focused on patients with post intensive care syndrome.

The following possible limitations should, however, be noted:

- ✚ **There is the high likelihood of socially desirable responses in the studied sample,** given hospital setting and a sense of gratitude expressed by patients for ICU staff.
- ✚ **The interviewed patient group may be more biased towards positive engagers in the programme.** We did not talk to participants who chose not to engage or who dropped out and we were introduced to potential participants selected by site staff.

## CHAPTER 4: Formative Evaluation of the Implementation of the Improvement Programme: Behavioural diagnosis of delivery and scaling up of InS:PIRE

### 4.1 Specific aim

The aim of the wave 3 interviews was to understand the implementation of InS:PIRE in relation to the behaviour and the context in which it occurred, specifically to robustly identify contextual influences on the InS:PIRE scale up. In this part of the report, we focused on barriers and facilitators to the implementation of the InS:PIRE scale up project identified using a **behavioural theory**, based on perceptions, preferences and experiences of current QI and clinical leads with the delivery of the programme.

The purpose of this last part of formative evaluation was to comprehensively identify issues and potential solutions to be considered by future InS:PIRE sites; suggest priority areas for change to effectively facilitate the further scale up InS:PIRE; and to identify the core 'ingredients' of the programme's success, from the perspectives of InS:PIRE staff involved in the InS:PIRE model development (see Chapter 5 below re driver diagrams and logic models).

### 4.2 Evaluation strategy

Identifying barriers/facilitators to the implementation (or scaling up) of an intervention is facilitated through applying theories of behaviour change, given health care practice is a form of human behaviour. Barriers are related to 'not performing' the desired behaviour and facilitators are 'enablers' of behavioural performance.

One such rigorous behavioural framework is the Behaviour Change Wheel (BCW)<sup>15</sup> - a synthesis of 19 frameworks of behaviour change - developed to aid intervention design, to improve the process of intervention implementation (optimise/refine the intervention) and theory development. Developing such interventions is preceded by the need to identify what needs to change (i.e. barriers and facilitators) to ensure that the intervention is implemented as planned. By this we mean 'what needs to change in the person and/or environment in order to achieve the desired change in behaviour?' In his developmental evaluation framework, Patton<sup>16</sup> recommends identifying barriers and facilitators using a behavioural theory. This is because the more accurate the analysis of the target behaviour, the more likely it is that the intervention will change the behaviour in the desired direction. We can then develop strategies to minimise barriers and enhance facilitators to support behaviour change. In the BCW, intervention development stages involve identifying relevant types of intervention strategies and specific behaviour change techniques.

In this part of our evaluation, we are presenting the result of behavioural diagnosis of the scale-up of the InS:PIRE intervention. This systematically identifies what the primary perceived barriers and facilitators were to the scale up of InS:PIRE from a behavioural perspective. Having identified the barriers that are in play, this can then inform how the future development of InS:PIRE can be tailored to address these specific issues. To maximise the use of the behavioural diagnosis conducted, we

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<sup>15</sup> Michie S, Atkins L, West R. (2014) The Behaviour Change Wheel: A Guide to Designing Interventions. London: Silverback Publishing.

<sup>16</sup> Patton, M.Q. (2011) Developmental Evaluation. Applying complexity to enhance Innovation and Use. The Guildford Press. New York/London.



present a synthesis of contextual influences experienced at different InS:PIRE sites, and also present a compendium of likely challenges and proposed solutions.

## 4.3. Methods

### 4.3.1 Analytical approach

We used the Theoretical Domains Framework version 2 (TDF v2), a theoretical framework, developed by synthesising behavioural theories through a systematic consensus process, as a framework for investigating the barriers and facilitators to behaviour. The TDF v2 has 14 domains (outlined in Figure 4.1) which might act as barriers or facilitators to behaviour change including knowledge, environment, beliefs about consequences etc<sup>17</sup>. It has been applied across a range of healthcare systems and healthcare behaviours to successfully identify barriers and facilitators to the implementation of a range of interventions<sup>18</sup>.

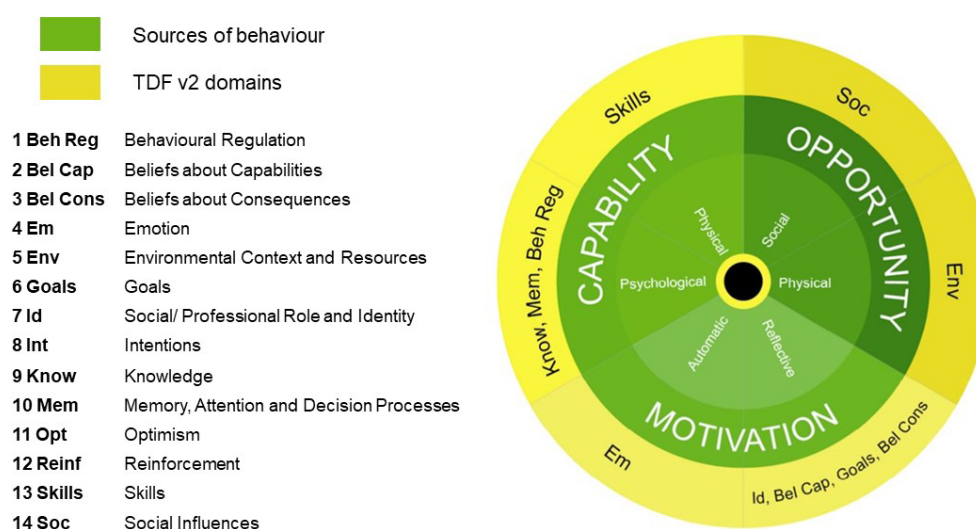


FIGURE 4.1: TDF v2 (MICHIE ET AL. IMPLEMENTATION SCIENCE 2011, 6:42)

### 4.3.2 Data collection

We interviewed QI and clinical leads from each of the scale up sites. Interviews were conducted in two parts. Section A of the interview related to participants' experiences of and views on the general successfulness of the InS:PIRE programme and elicited any important programme modifications, to capture any changes with those aspects since wave 2.

Section B of the interview used a topic guide based on the TDF to systematically explore the factors influencing delivery and scaling up of InS:PIRE. The interview guide was pilot tested with the InS:PIRE project manager. Following the pilot, we judged that the TDF domain 'memory attention and decision process' (defined as: the ability to retain information, focus selectively on aspects of the environment and choose between alternatives) was not relevant to the InS:PIRE scale up, hence no related

<sup>17</sup> Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implement Sci.* 2012;7(1):37.

<sup>18</sup> Atkins L, Francis J, Islam R, O'Connor D, Patey A, Ivers N, Foy R, Duncan EM, Colquhoun H, Grimshaw JM, Lawton R, Michie S. A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. *Implement Sci.* 2017 Jun 21;12(1):77. doi: 10.1186/s13012-017-0605-9.

questions were asked. Open-ended and closed-ended questions were used and the number of questions ranged from one to four for each TDF domain. Follow-up prompts were included when necessary to address specific constructs within the domains

### 4.3.3 Data analysis

Two researchers jointly coded the four transcripts into one or more of 13 relevant TDF domains. In the next step of analysis an inductive approach was used to identify subthemes (specific barriers and facilitators), within the coded domains of the TDF. Each extract was classified each extract as a perceived barrier ('obstacle'/'issue'/'problem'), perceived actual/hypothetical facilitator ('solution'/'helpful'/'good') or (neutral) description of a behaviour.

Frequent barriers and facilitators were identified based on the number of times they were reported (i.e. "frequently reported" was classified as  $\geq 3$  interviewees). Those domains in which barriers were most often identified should be the focus of efforts at current sites to inform future scaling up efforts. Those domains which included frequent facilitators – means of leveraging required changes – can be used to help ease the process of scaling up.

In this abridged version of the report we report only the most commonly identified barriers and facilitators that were identified (the full list of all identified barriers and facilitators grouped by TDF domains is reported in the full version of the report).

## 4.4 Findings

### 4.4.1 Common Facilitators

Actual and perceived facilitators categorised as high frequency ( $\geq 3$  interviewees) are listed in Tables 4.1 below. Twenty-three common facilitators were identified which mapped onto eleven TDF domains: 'Beliefs about consequences', 'Emotions', 'Environmental context and resources', 'Goals', 'Intentions', 'Knowledge', 'Optimism', 'Reinforcement', 'Skills', 'Social Influences' and 'Social/professional role and identity'.

Broadly speaking, a universal strong sense of positive impact of InS:PIRE on current staff and patients and post-ICU care in the future, associated with positive feelings and social influences (between staff, patients and staff, staff and a wider ICU community), acted as a positive reinforcement for staff to overcome the challenges of scaling up and to feel optimistic about the future of their programmes – these served as core enablers of delivering InS:PIRE at scale.

The Health Foundation's grant funding support has clearly been viewed as a pivotal enabler of environmental stressors, particularly with regards to two crucial resources - time to develop and amend their programmes through shared and experiential learning and associated costs (particularly staffing time - the main cost of InS:PIRE).

While personal satisfaction was an important driver, financial incentives were frequently viewed as an enabler of staff participation. Moreover, the needs of ICU survivors being recognised by a wider post-ICU care community acted as a facilitator, and these needs were viewed best served via a person-centred multi-disciplinary care approach – that is within the framework of a working relationship focused on patients' welfare and attainment of their goals. Future funders and scale up sites should consider those frequently reported enablers, as probable key 'ingredients' of InS:PIRE success.

<b>TDF domain</b>	<b>Facilitator</b>	<b>Sample quote</b>
Beliefs about consequences	Belief that the programme should be continued at current sites	<i>"[W]e haven't really discussed that yet because we're still very hopeful that we are going to get funding through service provision. I think something will continue in [name of the site]. I would really very much like it to be what we currently do." (L1)</i>
	Belief in the value of the programme for optimising the traditional model of care	<i>"I think it's also got us closer to understanding what the model of the service should be. Whereas before where there have been follow-up clinics after critical care, there wasn't really any great evidence base or agreement on what the model for that clinic should be." (Q12)</i>
	InS:PIRE was viewed as successfully scaled up and that there was scope for it to be transferable to other settings	<i>"I think we have achieved what we set out to achieve. I don't know how much -- I don't know that we feel that we've been that managed in a scaling way. I think we were given quite a free rein to make the programme specific and unique to Fife. So, I think that has been successful because I think we, as a team, have delivered that. But I think I haven't really felt that we've necessarily had an awful lot of direction in that sense." (L1)</i>
	A sense of doing something valuable for patients	<i>"I think the benefits for staff it's that motivational thing again about the business that they actually see the people get better; I think that's a very strong motivating thing. We're asking them to do something different, to work in a slightly different way, and they commit to doing it and they commit to doing it because I think they see the impact that it has on others". (Q11)</i>
Emotions	A sense of 'satisfaction' from seeing the programme having positive impact	<i>"Yeah, it feels good, yeah. Yeah, absolutely. And the fact you know, the fact that people, the staff members who are doing it feel good about it, that feels good. [...] Yeah, it's kind of the... so quite a satisfaction that it works and that people are engaged, and a nice warm glow about that. And you see them talk about work differently." (Q11)</i>
Environmental context and resources	Without the Health Foundation the programme would not be possible, as there is simply no funding available for these kind of initiatives	<i>"Yes, that's right. Once in a blue moon opportunity? Normally we would have great difficulty accessing innovation and R&amp;D type money to help us develop us anything and usually our first port of call is internal within our own -- but to have this kind of cash made available for something new is a very new experience." (Q12)</i>
	Currently InS:PIRE staff is paid for their clinic time	<i>"So what's been really easy for the health boards just now is the staff time for it has been funded out the health foundation money". (Q11)</i>
Goals	InS:PIRE being person-centred care - aligned with patients individual goals - viewed as a fundamental goal around which the programme evolves	<i>"So it isn't like this additional particularly medical healthcare model where you treat asthma, so it's quite different from that, and that's fundamental I think in the way that we set it up at the start when we asked people about what their personal goals are. And then after that, when that's done right at the start, that then helps us align everything else in their attainments(?) around helping them achieve their personal goals" (Q11)</i>
Intentions	Strong intrinsic motivation was critical to programmes' success (i.e. to overcome challenges)	<i>"They're all enthusiasts and I think the fact that they have received some support to explore this area of service development keeps them motivated. It's great, they think it's fantastic. Normally, they would be trying to develop services within their usual job but the fact that they're actually getting some support to do this they think is very valuable. " (Q12)</i>

Knowledge	Informing future efforts to scale up will depend on scientific data coming from InS:PIRE research/evaluation data	<i>The testing of a model in a site other than the initial pilot site again will generate useful information. So, certainly we're seeing some common themes between the different sites and we're seeing also maybe some differences that help us redesign the service as we scale up."</i> (Q12)
	Knowing how to scale up is a process developing over time though experiential learning	<i>"So, the delivery of the programme is almost the easiest bit because I think we've all worked together as a team and we've learnt as we've gone long. I think we all feel much more confident and comfortable with that aspect of the whole project."</i> (L1)
	Direct contact between team members and teams - e.g. learning sessions - facilitated knowledge transfer	<i>"I think the elements that InS:PIRE has brought the collaboration between sites and the learning sessions and so on, and the sharing of information, that's been useful."</i> (Q12)
Optimism	Reported levels of confidence ranged from moderately confident (e.g. 50/50 (Q1, Q2)) to very confident (e.g. 80% (L1, L2)) that InS:PIRE at least in some form will continue at their site. Overall interviewee felt relatively optimistic about the future of InS:PIRE at their site.	<i>"I'm 80% confident that it will [continue]. I think there is certainly great desire within the people who deliver it to continue delivering it. So, I think we've agreed that as much as we're pushing forward to try and achieve funding, if we don't get formal funding then we want to look at other ways of trying to continue. So, whether that involves looking at endowment funds or fundraising of some description, I don't know, we haven't really discussed that yet because we're still very hopeful that we are going to get funding through service provision. I think something will continue in [sute]"</i> (L1)
Reinforcement	Staff are paid per 'normal hour of work' or 'overtime' to take part in InS:PIRE. This sends a clear signal that InS:PIRE time is an additional role.	<i>"Going back to what I was saying earlier, that it would be something that would be very difficult to do within your existing job. I think recognition that this is an additional role is important, and therefore payment is an incentive for that."</i> (L2)
	The main reward is staff satisfaction gained through: feeling helpful and doing good for patients/gratitude from participants, being part of a team and getting 'positive attention'/recognition (e.g. staff newsletters)	<i>"I think the benefits for staff it's that motivational thing again about the business that they actually see the people get better; I think that's a very strong motivating thing. We're asking them to do something different, to work in a slightly different way, and they commit to doing it and they commit to doing it because I think they see the impact that it has on others"</i> (Q11)
Skills	New skills were learned by experiential learning - i.e. participating in the programme - over time from own team and through team-shared learning.	<i>"I suppose that the skills that we maybe didn't have in the beginning is the language of social care and accessing different services and support, and that is certainly something that we've had to learn. We've also, and I think this is something that I have learned since I started, when dealing with the patients, is for me to speak less and allow them to speak more, and that's actually a skill in itself."</i> (L2)
Social Influences	InS:PIRE seems was very well received by a wider ICU community	<i>"I think there is definitely interest within the ICU community in Scotland certainly. [...] I think people ask about it when you're elsewhere, they know that we do it at Fife and they do definitely show an interest in it. So, I think people are interested to know what it's all about. Yeah, I think there is interest in it."</i> (L1)

	Working with staff with whom one has a sense of proximity/familiarity built over time through shared experiences (i.e. having a network/team) is an important facilitator for programme delivery	<i>"[T]he very nature of them taking on some stuff that their colleagues do, and some of the stuff that they do be taken over by some of their colleagues. I think that's from the tightness of the working relationship over the course of the programme, yeah." (Q11)</i>
	Without the positive influence of enthusiastic or motivated staff on each other and patients, it would be difficult or even impossible to deliver InS:PIRE	<i>"I mean, I think we're hugely influenced by the members within the team and the attitudes within the team and the ability to think, "Well, why don't we just do it, why don't we just try it?" That is a really positive team environment to be in. I think it does help with relationships out with the InS:PIRE team as well, definitely. That's been a positive thing." (L2)</i>
	Patients' individual needs/goals have an important impact on the structure and content of the InS:PIRE programme.	<i>"We always have to adjust what we're doing to the needs of the people that are coming". (L2)</i>
	Positive feedback (i.e. feedback, videos) from patients acted as a facilitator for adoption and delivery of InS:PIRE	<i>"So, by showing them those videos and explicitly making it clear that that's what the programme was sort of about, we felt that that's helped to develop that conversation a little sooner in the programme". ( L1)</i>
Social/professional role and identity	Roles within multi-disciplinary InS:PIRE teams are blurred	<i>"Well I think... so yeah, because they do have their traditional roles and tasks, but the roles and tasks become a little bit blurred,." (Q11)</i>

**Table 4.1: Common facilitators to InS:PIRE delivery at scale.**

#### 4.4.2 Common Barriers

The most commonly identified barriers are listed in Table 4.2 below. We identified nine common barriers which mapped onto five separate TDF domains: 'behavioural regulation', 'beliefs about consequences', 'environmental context and resources', 'optimism' and 'social influences'. Those five TDF domains therefore should be targets of change – i.e. priorities for future intervention efforts<sup>19</sup>.

These findings suggest that many barriers were context dependent; so, despite some commonly shared main difficulties, overall sites had partially dissimilar experiences with InS:PIRE. The majority of common barriers were codified into 'environmental context and resources' suggesting that environmental stressors (e.g. limited financial resources, the burden of the administrative and project management, difficulties with access to a clinic) universally hindered opportunities to deliver InS:PIRE. Favourable financial conditions were perceived as necessary to further scale up, and therefore the current climate of severe fiscal constraint would have to change for staff to feel more optimistic about further scaling up.

Future intervention efforts will also need to address a lack of locally relevant guidance for post-ICU care that limited staff capability to deliver InS:PIRE. A lack of objective evidence for outcomes of scaling up will need to be addressed to inform staff on the consequences of scaling up. Initial resistance of some patients towards InS:PIRE, attributing to traumatic experiences with ICU recovery and previous negative experiences with health care services, should also be a priority target of change.

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<sup>19</sup> Michie S, Atkins L, West R. (2014) *The Behaviour Change Wheel: A Guide to Designing Interventions*. London: Silverback Publishing.

<b>TDF domain</b>	<b>Barrier</b>	<b>Sample quote</b>
Behavioural regulation	A lack of locally relevant guidelines and specific to post-ICU care	<i>"There's nothing local. There are national guidelines, or there are national statements from Intensive Care Society and the Faculty of Intensive Care Medicine, and that's great. But that's not been translated into a local model at all or any local guideline." (Q12)</i>
Beliefs about consequences	Not possible to confidently comment on effectiveness of scaling up, given the analysis report was not available at time of interview	<i>"So I think we'll have to wait until the final evaluation report for that, so I've got to be kind of uncertain about that just now. Superficially you know, for what you see at the learning sessions, national ones where people come together, you get a sense that that has happened well. But if I stood back and said, "Well what is it that we've done that made this happen?" I might be a little less certain about certainly putting my finger on things that would really help. I've got a few ideas but I don't know if they're right." (Q1)</i>
Environmental context and resources	Based on their experience, required financial resources to support further scaling up do not exist	<i>"For me, it's not something that can be done within existing budgets. I know that it would take money to make that happen, and it's whether somebody will produce that money to make that happen." (L2)</i>
	NHS boards' resources are in general limited and competitive, with ongoing projects having priority over newly established services, so there are major difficulties with taking over costs: paying InS:PIRE staff working hours, project team and scaling up activities	<i>"I think there is just a lot of pressure on resources full stop in the NHS. We're currently being tasked with finding X tens of thousands of savings within NHS Fife and so there is resistance to funding new projects. I think that's the main problem really." (L1)</i>
	Managing project workload was challenging, specifically working in time-constrained environment, multi-tasking and dealing with new tasks (administrative, recruitment, retention tasks; seeking funding)	<i>"I think the downsides are that it is time pressure. It's the same as everything; it's an additional job to do. So, you sometimes do feel that you've got a lot of plates spinning and it's difficult to keep on top of three different things. Because I do InS:PIRE, but I also do intensive care and I also do anaesthesia. So, it's just time to manage all of those things." (L1)</i>
	Practical difficulties with accessing an InS:PIRE clinic (e.g. long distance, lack of transport, difficulties with finding parking spaces) Patients missing InS:PIRE clinic due to hospitalisation (i.e. ill-health)	<i>"There were some transport issues; some people lived a bit further away. Some people were ill, acutely ill in hospital at the time they were supposed to be coming to InS:PIRE, so they had other things going on." (Q12)</i>
Optimism	Given current financial climate, compared to perceived future of InS:PIRE at the current sites, interviewees felt much less certain (more pessimistic) about further scaling up	<i>"I'm less certain about that [scaling up to news sites]. And the reason for being less certain about that probably... or principally a method of scaling it up. The very nature of the programme got us five sites to scale up to, it got as funded. Whereas the next... say if we were hypothetically going to go and scale it up to another 5 intensive care units in Scotland, or 15 in England, that might just be... we would have to do it in a slightly different format from the way we've done it this time." (Q1)</i>
Social Influences	Some patients entered the programme carrying lots of 'difficult feelings' that created resistance. Those were related to the traumatic process of ICU stay and	<i>"Initially when people come they don't really know what to expect, and sometimes they can be a little bit angry or they can be a little bit apprehensive or cautious. We very much have to judge and take our lead from them and find out what it is that they're thinking at that time."</i>

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recovery or previous negative experience healthcare services

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*Often we don't know what's happened, we don't know how difficult it's been for them, patients' personalities can change after an ICU stay. " (L2)*

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**Table 4.2: Common barriers to InS:PIRE delivery at scale.**



## 4.5 Key insights

### Key insights panel 3:

- ✚ **Key facilitators for the success of any future scale-up are:** staff's satisfaction related to feeling very positive about the value (e.g. patient outcomes and/or own experiences) of the InS:PIRE programme; delivered through person-centred interdisciplinary post-ICU care (further encouraged by being well-received by a wider ICU community); and adequate financial support to afford sufficient time to learn through experiential and shared learning.
- ✚ **InS:PIRE teams have shared experiences of barriers.** Frequently experienced were issues around environmental stressors (that is responsibility for sustaining on-going funding to enable the continued running of the InS:PIRE programme locally beyond the scale up project and the burden of the administrative and project management, which was a new role for many clinical site leads); a lack of locally relevant guidance for post-ICU care; a lack of demonstrable evidence of InS:PIRE effects still to be presented and overcoming patients' initial resistance to take part (attributed to post-ICU trauma or previous negative experiences with health care services or lifestyle or situation). These could be priority targets for behaviour change interventions.
- ✚ **While valuable generalisable lessons were learned from frequently experienced barriers, it should not lead to downplaying the fact that InS:PIRE staff have experienced many dissimilar context-dependant problems.** As suggested by interviewees themselves, while shared and experience-based learning successfully narrowed information gaps between InS:PIRE teams, there are further opportunities to better inform future scaling up processes (of InS:PIRE and/or others). Amongst proposed areas of improvement were organising learning sessions around site-specific needs and developing a strategy to systematically learn from and share information on the scaling up process.
- ✚ **Overall, many contextual factors influenced InS:PIRE,** with the programme being so highly context-dependent, sustaining it in complex and uncertain environments will be challenging. Clearly, individual and team determination of InS:PIRE staff to meet that challenge so far was considerable and this personal drive can be further spread.

## CHAPTER 5: Summative Evaluation

### 5.1 Specific aim

A summative evaluation took place at the end of evaluation cycle to objectively measure the perceived underpinning theories of change and the potential influence of context on scale up using quantitative measures of change.

### 5.2 Evaluation strategy

The guiding research questions for the summative evaluation included:

- Is there evidence that the hypothesised theory of change holds when the intervention is scaled up?
- Did context mediate the effects of scale up?

*Is there evidence that the underpinning hypothesised theory of change holds when the intervention is scaled up?* The original theory of change model underpinning the InS:PIRE intervention suggested that the intervention would first result in increased patient self-efficacy which would then translate into improved quality of life. The summative evaluation investigated whether there was any evidence in the patient collected outcomes to support the hypothesised mechanism of change across sites, i.e. was there any evidence of the hypothesised direction of change (e.g. increase in self-efficacy measures in patient reported measures).

*Is there any evidence to suggest context mediates the effect across centres?* Context has long been noted to influence the scale and spread of complex interventions. Local drivers can influence how a complex intervention is locally implemented, which can result in changes to the underlying model of change (and also to the potential mechanisms of change). The InS:PIRE programme is, in essence, a complex intervention and it was therefore important to assess whether, and how, the scale up of the intervention influenced the local implementation of the intervention at multiple sites. In Chapters 3 and 4 we reported identified many contextual influences on the delivery of InS:PIRE at scale. Evidence for heterogeneity of effects across centres was explored to capture the impact of contextual influences on participants' outcomes

### 5.3 Methods

Data from one full cohort of InS:PIRE patients four sites were collated by the main study team as per study protocol. Data for a complete cohort at a site included:

- Throughput data (number approached, attended, completed the InS:PIRE intervention); patient outcome data – patient reported outcomes at the start and at three months after the intervention
- Carer data – carer reported outcomes at the start and at three months after the intervention

Patient outcome data included self-reported measures of self-efficacy score (as measured by the General Self- Efficacy Scale<sup>20</sup>, GSE), anxiety and depression (the Hospital Anxiety and Depression Scale<sup>21</sup>, HADS-anxiety and depression subscales), quality of life (the EQ-5D-5L<sup>22</sup> scale) and pain severity and inference (as measured by the Brief Pain Inventory<sup>23</sup>- Short form, BPI-SF).

Carer data included self-reported measures of carer strain (as measured by the Caregiver Strain index<sup>24</sup>, CSI), anxiety and depression (HADS) and insomnia (the Insomnia Severity Index<sup>25</sup>, ISI).

Outcomes were available at baseline and at three months follow-up (a further measure of outcomes at twelve months is currently being collected by the project team and will be analysed by them when this data is complete late in 2019).

Given the very small numbers finally available from each site, it was inappropriate to undertake any formal statistical analysis of heterogeneity.

Full detail of the analysis strategy are presented in the full report.

## 5.4 Findings

### 5.4.1 Throughput

Data were collected on throughput from three of the sites where data was available for the index cohort – one site did not provide throughput information. Data are presented in Table 5.1 below:

Centre	Eligible	Invited	Agreed to attend	Week 1	Week 2	Week 3	Week 4	Week 5
1	~22	13	5	3	5	4	3	n/a
2	~ 25	N/A	N/A	10	8	9	9	7
3	~30	23	11	4	4	3	4	4

**TABLE 5.1: THROUGHPUT OF PATIENTS AT EACH SITE (NUMBERS OF PATIENTS REPORTED)**

The primary reasons noted why patients who were notionally eligible, but who were subsequently not invited, included patients who were deemed unfit to attend and those patients who were deemed likely not to “need” the intervention. Approximately half of those invited went on to agree to attend, with further drop out (again around half) before the first clinic session. These data suggest, therefore, that only 50% (and sometimes less) of those patients who were invited attended and completed the InS:PIRE intervention.

<sup>20</sup> Schwarzer, R., & Jerusalem, M. (1995). Generalized Self-Efficacy scale. In J. Weinman, S. Wright, & M. Johnston, Measures in health psychology: A user’s portfolio. Causal and control beliefs (pp. 35-37). Windsor, UK: NFER-NELSON.

<sup>21</sup> Zigmond, A.S. and Snaith, R.P. (1983) The hospital anxiety and depression scale. Acta Psychiatrica Scandinavica, 67, 361-370

<sup>22</sup> EuroQol Group (1990) EuroQol A New Facility for the Measurement of Health-Related Quality of Life. Health Policy, 16, 199-208.

<sup>23</sup> Daut, R..L., Cleeland, C.S. and Flanery, R.C. (1983) Development of the Wisconsin Brief Pain Questionnaire to Assess Pain in Cancer and Other Diseases. Pain, 17, 197-210

<sup>24</sup> Robinson, B.C. (1983) Validation of a caregiver strain index. The Journals of Gerontology, 38, 344-348

<sup>25</sup> Morin CM. Insomnia: Psychological assessment and management. New York: Guilford Press; 1993.

## 5.4.2 Data on patient and carer reported outcomes

Patient and carer reported data were available on a total of 49 patients and carers (27 patients and 22 carers) from the four participating sites

## 5.4.3 Patient reported outcomes

Patient reported outcomes data at baseline are summarised in Table 5.2 below.

Measure (score range)	n	Mean Score (SD)
<b>HADS:</b>		
• Anxiety subscale (0-21)	26	10.73 (5.50)
• Depression subscale (0-21)	26	10.0 (4.81)
Self-efficacy score (10-40)	27	24.8 (8.2)
<b>EQ5D:</b>		
• Visual analogue score (0- 100)	24	54.96 (19.18)
• EQ-5D-5L index value (-0.594-1)	23	0.40 (0.30)
<b>BPI-SF:</b>		
• Pain severity (0-10)	20	4.7 (2.1)
• Pain interference (0-10)	20	5.9 (2.4)

*Footnotes:*

*HADS anxiety & depression scores: a lower score indicates less severe anxiety or depression symptoms*

*Self-efficacy scores: a higher score indicates greater levels of self-efficacy*

*EQ5D visual analogue score: a higher score indicates better overall quality of life*

*EQ-5D-5L quality of life index value: a higher score indicates higher quality of life*

*BPI-SF pain severity and inference components: higher scores indicate grater pain severity and levels of pain interference with activities*

**TABLE 5.2: PATIENT OUTCOME MEASURES AT BASELINE**

Changes in score from baseline to three months are summarised in Table 5.3below.

Measure	n	Mean (95% CI)
<b>HADS:</b>		
• Anxiety	12	-1.67 (-4.49, 1.15)
• Depression	12	-2.42 (-4.45, -0.38)
General self-efficacy scale	13	-0.07 (-4.5, 4.4)
<b>EQ5D:</b>		
• Visual analogue score	11	9.09 (-2.33, 20.51)
• EQ-5D-5L index value	12	0.15 (-0.003, 0.30)
<b>BPI-SF (in those with remaining pain):</b>		
• Pain severity (0-10)	4	0.25 (-3.03, 3.53)
• Pain interference (0-10)	4	-0.73 (-2.99, 1.54)

**TABLE 5.3: CHANGES IN PATIENT OUTCOME MEASURES FROM BASELINE TO 3 MONTHS**

#### 5.4.4 Carer outcomes

Carer reported outcomes data at baseline are summarised in Table 5.4 below.

Measure (score range)	n	Mean (SD)
HADS:		
• Anxiety (0-21)	21	9.19 (5.61)
• Depression (0-21)	21	5.67 (4.86)
Carer strain Index (0-13)	22	5.45 (3.72)
Insomnia Severity Score (0-28)	18	9.11 (6.57)

*Footnotes:*

*HADS anxiety & depression scores: a lower score indicates less severe anxiety/depression symptoms*

*Carer strain index: a higher score indicates a higher level of strain*

*Insomnia Severity Score: a higher score indicates more severe problems*

**TABLE 5.4: CARER OUTCOME MEASURES AT BASELINE**

Changes in score from baseline to three months are summarised in Table 5.5 below.

Measure	n	Mean (95% CI)
HADS:		
• Anxiety	9	-3.22 (-6.48, 0.03)
• depression	9	-1.02 (-2.29, 1.63)
Carer strain Index	9	-1.56 (-2.72, -.040)
Insomnia Severity Score	7	-0.14 (-4.78, 4.49)

**TABLE 5.5: CHANGE IN CARER OUTCOME MEASURES FROM BASELINE TO 3 MONTHS**

## 5.5 Key insights from summative evaluation

### Key insights panel 4:

- Findings from the cohort study suggest that a substantial proportion of potentially eligible and invited patients do not attend and complete the InS:PIRE intervention.** Our data suggest that 50% (and sometimes less) of those invited attend the InS:PIRE intervention – with further drop out over the course of the intervention. These data are similar to those reported in the original single centre pilot of the InS:PIRE intervention<sup>1</sup> which reported that about 50% of those invited attended. Thus, the InS:PIRE intervention is not unanimously seen as an useful and attractive intervention for the entire target population. These findings also suggest that we must, therefore, be cautious in assuming the interpretation of the patient/carer outcome data is generalisable to the fully eligible ICU population.
- Data from the different sites' cohorts indicated that the average change in the majority of patient outcomes between baseline and three months were in the anticipated direction (towards improvement) – towards improvement in quality of life, reduction of anxiety and depression.** These directional changes were consistent with previously reported patterns in response in the original project pilot. Data on changes in quality of life data are also in keeping with previously reported estimates of quality of life following ICU discharge. For example, data from the standard care arm of the PRACTICAL trial of ICU follow-up (which can provide a proxy for expected recovery trajectory over time) reported a baseline mean (SD) value of EQ5D index of 0.44 (0.3) rising to 0.62 (0.32) by six months. Whether these observed changes are clinically and statistically significant and whether they are maintained across the full sample needs to be addressed in the full effectiveness evaluation. This effectiveness evaluation is due to be carried out by the InS:PIRE team after full twelve month data is collected.
- Patient ratings of self-efficacy at three months in this sample, however, appeared to be unchanged.** This raises some questions about the proposed mechanism of effect of the intervention – which had previously been postulated to be through improvements in self-efficacy leading to improved patient outcomes. These data are in contrast to the measures of self-efficacy reported in the original project pilot where marked improvements in self-efficacy scores were observed from baseline to five weeks and then onwards to one year. This has implications for the overall logic model underpinning the intervention.

### Key insights panel 4 continued ...

- ✚ **The sample size was small so there is a high degree of variability around the estimates of effect on outcomes and care must be taken around the interpretation (and possible over-interpretation) of these data.** Estimates of effect may change when the whole InS:PIRE dataset is available for review and the longer term (one year) data is available – that will be addressed in the full effectiveness analysis to be carried out by the InS:PIRE team next year. Additionally, there was a high level of patients for which three-month questionnaires were not available. The interview data presented in Chapter 3 suggests that drop-out before the end of the programme was associated with patients completing the programme early because they realised that the programme was not for them and/or not needing the programme any longer. As such, the three month data which is available is likely to be an underestimate of the underlying benefit of the intervention. The implications of incomplete data returns has been stressed to the InS:PIRE team who have been strongly encouraged to actively promote 100% return of the one year data to ensure that their analysis of effectiveness will be scientifically robust.
- ✚ **There was no control group to provide data on the counterfactual.** This part of the evaluation is primarily an evaluation of the processes of scale-up. There is no control group against which to measure whether improvements observed would have happened anyway. This is an important consideration for the planned full twelve month effectiveness evaluation. We have compared data estimates observed to relevant external literature (e.g. the SHINE pilot report, the PRACTICAL trial report) as a form of external benchmark.
- ✚ **Due to small numbers we were not able to analyse for the presence of heterogeneity in a robust manner.** Numbers at individual site level were very small, thus a formal analysis to look for evidence of heterogeneity was not possible. It would be useful for the project team to consider exploring for any effects of heterogeneity when the full twelve-month dataset becomes available.

## CHAPTER 6: Summary, discussion and conclusions

### 6.1 Summary of main findings

Evidence collected throughout the evaluation suggested the InS:PIRE was successfully scaled up to the other five sites across Scotland. InS:PIRE as an intervention had a transformative effect on the staff engaged with it – resulting in them working in completely different ways to their normal clinical activities – which was viewed as highly valued and rewarding. Patients perceived the programme to be useful and early evidence suggested that patient and carer reported outcomes had moved in the expected direction – towards reductions in anxiety and depression and towards an increase in quality of life. Patients consistently rated three elements of the InS:PIRE intervention as core to them – the opportunity to go through their ICU journey with the clinical staff who had cared for them; the peer support; and the cross-disciplinary focus on their problems.

InS:PIRE also developed a high external profile over the course of the scale-up – winning multiple awards and was quoted in a number of government policy documents including the Chief Medical Officer’s report. It was also showcased on television and was the subject of numerous national and international conference presentations. These external markers of esteem significantly helped to develop the InS:PIRE “brand” and added useful prestige and legitimacy to the product.

The evaluation suggested, however, that the scale up process was somewhat unsystematic and the implementation of the InS:PIRE intervention at sites was highly variable and changed over time. Most sites adapted the package over time to provide what was most feasible and suitable in their context – but this was not consistent across sites. The process of developing ‘customised models’ was felt to be challenging, as guidance and practical support in the due course for scale up sites were somehow suboptimal. In addition, there was little evidence to support the originally hypothesised mechanism of action – that InS:PIRE would lead to increases in self-efficacy which would then result in increased quality of life.

Staff noted that the organisation and delivery of the intervention was resource-intensive requiring highly motivated staff and staff who were willing to work outside and across traditionally professional boundaries. The level of administration required to organise and deliver InS:PIRE was also noted to be burdensome and, despite intensive efforts at all sites, only about 50% of those invited (and around 20% of those potentially eligible for the intervention) actually attended the clinics.

The evidence collected suggested that there were a number of elements which contributed to facilitating scale-up at sites. At an individual health professional level this included a sense that they were doing something valuable for individual patients, commitment to working across professional and disciplinary boundaries and a personal sense of satisfaction in seeing improvement in patients and witnessing the growth of the programme and its staff. System enablers also included the recognition by employers that staff roles within InS:PIRE were additional to their routine NHS roles and which were remunerated accordingly. This was greatly facilitated by the external funding the Health Foundation grant provided.

Conversely, trying to scale-up InS:PIRE against a background of fiscal constraint within the NHS was a barrier as was the large extra administrative burden of organising venues, attendance of patients etc., and managing the sometimes chaotic circumstances of patients (e.g. managing transport, parking, non-attendance, etc.).



## 6.2 Discussion of findings

### 6.2.1 What are the active components of the intervention?

It was clear from the evaluation that the implementation of the intervention was heavily influenced by shared and experiential learning that was viewed as an enabler for narrowing information gaps between sites. As such it is difficult to now characterise what the “InS:PIRE intervention” specifically consists of as the implementation of the original InS:PIRE package was highly variable and subject to regular adaptation. The quote from one of the clinical leads at the sites describes this lack of specificity well: *“InS:PIRE is an ethos not a thing: it is doing the best by your patients”*. New centres that might be wishing to now commence an InS:PIRE clinic may, therefore, have difficulty knowing what that service should look like.

InS:PIRE is a complex intervention – formed of multiple interacting components. The MRC complex intervention framework<sup>26</sup> suggests that for such interventions, extensive development, feasibility and evaluation phases should be designed in with the opportunity to iterate between the phases until the intervention is suitably well characterised and stable enough to enable large-scale evaluation. The evaluation presented here was primarily formative in nature and thus could be classified as an enactment of this development-evaluation loop.

The evidence that we collected within this evaluation suggests that any future characterisation of InS:PIRE be formulated around three core “active ingredients” (defined as those consistently most valued components by patients and staff) – provision of one-on-one time with the ICU clinical staff to discuss their ICU journey; provision of peer support; and the provision of patient-centred care facilitated by blurring of professional boundaries to solve patient problems. Other activities (which were outlined in the original InS:PIRE programme as essential components) appear to have less salience.

### 6.2.2 Underlying theory of change

Throughout the scale-up process the project team were encouraged to regularly review and update their driver diagrams (which outlined the underlying theory of change that underpinned their conceptualisation of the InS:PIRE intervention) in the light of emergent findings. This resulted in several changes, including a shift of emphasis away from return to employment, a greater emphasis on the impact on staff and changes in emphasis on the intervention components.

From the outset, a primary hypothesised mechanism of change for the intervention was that it would result in improvements in self-efficacy, which in turn would lead to improvements in quality of life. A highly positive effect on self-efficacy was noted in the successful pilot of the InS:PIRE intervention (the SHINE<sup>27</sup> project) and was thus hypothesised to continue in the larger InS:PIRE programme.

In our evaluation, however, we did not find strong support for this proposal – the quantitative data (although based on small numbers) demonstrated no signal in the hypothesised direction of effect and interviews with patients did not raise this as a strong component. What was more suggestive in

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<sup>26</sup> Medical Research Council. [A framework for the development and evaluation of RCTs for complex interventions to improve health](#). London: MRC, 2000.

<sup>27</sup> McPeake J, Shaw M, Iwashyna TJ, et al. Intensive Care Syndrome: Promoting Independence and Return to Employment (InS:PIRE). Early evaluation of a complex intervention. [PLoS One](#). 2017 Nov 29 ; 12(11): e0188028

the interview data was a notion of benefit being realised through positive reinforcement with a stronger emphasis on positive emotional responses underpinning the patient outcome. We recognise that our sample is small, however, and would suggest ongoing work by the project team to continue to seek to unpack the true underlying mechanisms. As currently understood, there may be a partial failure of the theory to explain the results (see Table 6.1<sup>28</sup>).

Intervention available	Intervention delivered	Mechanism observed	Outcome achieved	Interpretation
✗	✗	✗	✗	Implementation Failure
✓	✗	✗	✗	Engagement Failure (first causal link)
✓	✓	✗	✗	Theory Failure (early causal link)
✓	✓	✓	✓	Consistent with theory
✓	✓	✓/✗	✓	Theory Failure (later causal link)
✓	✓	✓/✗	✓/✗	Partial Theory Failure Works in some contexts
✓	✓	✗	✓	Theory Failure (different causal path)
InS:PIRE available?	InS:PIRE delivered?	Self-efficacy raised?	Improved QoL?	Interpretation
✓	✓/✗	✗	✓	InS:PIRE scaled up; variably delivered; perceived mechanisms unclear; QoL apparently increasing

**Table 6.1: DELIVERY AND INTERPRETATION OF InS:PIRE SCALE-UP**

### 6.2.3 Discussion of InS:PIRE in the light of previous literature?

The fact that many patients continue to suffer significant physical, social and psychological problems in the months following ICU discharge has been well recognised in the literature<sup>29</sup>. This has prompted the development and testing of many interventions in an attempt to address this continuing problem. Despite many different interventions targeted at different time points following discharge most interventions have to date failed to show significant improvement in patient outcomes<sup>30</sup>. This has included a number of recent trials which have included many similar components to the InS:PIRE intervention including the PRACTICAL trial of a nurse-led post-discharge clinic with integrated physical

<sup>28</sup> Adapted from Mohammed M et al. Sharing our experience of evaluating scaling up projects. Health Foundation Evaluators Day, October 2017

<sup>29</sup> Cuthbertson BH, Roughton S, Jenkinson D, et al. Quality of life in the five years after intensive care: a cohort study. *Crit Care*. 2010;14(1):R6.

<sup>30</sup> Hodgson C, Cuthbertson BH. Improving outcomes after critical illness: harder than we thought. *Intensive Care Med* 2016; 42:1772–1774

and psychological interventions<sup>31</sup>, the RECOVER trial – again a complex intervention including a rehabilitation practitioner<sup>32</sup>, and the POPPI trial which completed at the end of 2018 (which was again a nurse-led intervention, this time starting in ICU, with associated psychological support)<sup>33</sup> – all of which have shown no evidence of effect on patient outcomes,

None of these previous interventions, however, specifically prioritised peer support as a core component – and it is, thus, particularly noteworthy that patients viewed this aspect of the InS:PIRE intervention as one of the most important, allowing patients to normalise their experience in the light of the experiences of others.

Patients and staff also highlighted the importance within InS:PIRE of staff being able to work across blurred disciplinary boundaries (and how the setting of the InS:PIRE clinic outside of the normal health service structures had enabled this, with staff attending InS:PIRE whilst not in uniform and interacting on first name terms). None of the previous interventions has set their clinic outside of the standard health service structures and again may be an important explanatory factor if the InS:PIRE intervention is finally found to be effective.

Previous commentaries<sup>34</sup> have also indicated the importance of identifying and only targeting patients who have the potential to benefit from an intervention such as InS:PIRE – those who have so called “treatable traits”. It is widely accepted that a follow-up intervention would be unlikely to transform the patient outcomes for patients who had significant pre-existing, pre-ICU psychological or physical problems. Appropriate selection of an appropriate patient group with potentially modifiable factors is key. In this regard, it is interesting to note that the cohort data would suggest that the patient group who attended the InS:PIRE clinics tended to present with moderate levels of anxiety and depression (with carers who were mildly anxious, but no symptoms of depression) thus potentially amenable to intervention. Again, it will be interesting to explore the relation of presenting traits with the final outcome of the InS:PIRE effectiveness analysis (due later in 2019).

The importance of measuring appropriate outcomes in evaluations of interventions post-ICU discharge has also been stressed widely in the literature. Needham and colleagues recently published a core outcome set that all trials involving ICU follow-up should report (albeit the focus of the core outcome set was post-acute respiratory distress syndrome (ARDS))<sup>35</sup>. This outcome set suggests that any evaluation should include survival, health related quality of life, mental health, pain, cognition, physical functioning and (for post-respiratory patients) respiratory function. It is, therefore, reassuring to note that these domains are covered in the outcome set used in InS:PIRE (albeit with some collected as sub-domains within the EQ-5D instrument).

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<sup>31</sup> Cuthbertson, BH, Rattray, J, Campbell, MK, et al The PRACTICAL study of nurse led, intensive care follow up programmes for improving long term outcomes for critical illness: a pragmatic randomised controlled trial. BMJ 2009; 339:b3723

<sup>32</sup> Walsh, TS, Salisbury, LG, Merriweather, J, et al Increased hospital based physical rehabilitation and information provision after intensive care unit discharge. The RECOVER Randomized clinical trial. JAMA; 2015; 175(6):901-910

<sup>33</sup> Richards-Belle A, Mouncey PR, Wade D On behalf of the POPPI Trial Investigators, et al. Psychological Outcomes following a nurse-led Preventative Psychological Intervention for critically ill patients (POPPI): protocol for a cluster-randomised clinical trial of a complex intervention. BMJ Open 2018;8: e020908.

<sup>34</sup> Iwashyna TJ, Burke JF, Sussman JB, et al. Implications of heterogeneity of treatment effect for reporting and analysis of randomized trials in critical care. Am J Respir Crit Care Med 2015; 192:1045–1051

<sup>35</sup> Needham DM, Sepulveda KA, Dinglas VD, et al. Core Outcome Measures for Clinical Research in Acute Respiratory Failure Survivors. An International Modified Delphi Consensus Study. Am J Respir Crit Care Med. 2017; 196(9): 1122-1130.

#### 6.2.4 InS:PIRE – the “brand”

The scale-up of InS:PIRE also benefitted from the many external markers of success awarded to the programme over the scale up period. From the outset of the scale up process, InS:PIRE was receiving positive external recognition (starting with a highly prestigious BMJ award) and this continued throughout the scale up period - with local team awards and high profile placement of the InS:PIRE programme in high-level government documents including the Chief Medical Officer’s Report and the NHS Scotland annual report. These high-level external markers of peer esteem significantly helped to develop the InS:PIRE “brand” and added useful prestige and legitimacy to the InS:PIRE product, which in turn provided useful evidence for the teams to support their bids to have the InS:PIRE intervention supported over the longer term. The importance of, and high positive influence of, a strong brand is widely acknowledged in the marketing literature (as is the importance of gaining signals of product “worthiness” such as that provided by inclusion in high-level government documents)<sup>36</sup>. The project team had commendably ensured fully integrated Scottish Government stakeholder engagement from the outset - a factor which the literature would also suggest would facilitate the take up of the study aims and outputs externally.

### 6.3 Strengths of evaluation

The evaluation had a number of strengths that are worthy of comment. Most importantly, although there was routine interaction between the evaluation team and the project team, the evaluation team were, and remained, independent of the actual scale-up process. As such, the perspectives and interpretations presented by the evaluation team can be judged to be independent and objective. This is a key strength in any evaluation of an intervention that has been developed by the project team as this minimises any bias, or perceived bias, in the evaluation findings. The possibility of bias in a non-independent evaluation has been noted repeatedly in the quality improvement literature – the “conspiracy of enthusiasm” that may creep into the interpretation of results<sup>37</sup>. In this regard, the project team should also be commended for opening their intervention to independent scrutiny.

The triangulation of qualitative and quantitative data in this evaluation is also a strength. Findings observed in the early interview data were followed up in later waves of interviewing to ensure consistency of interpretation. Additionally, observations noted in the qualitative interviews were also able to be confirmed independently both through the cohort data, but also through observations at learning sessions, through dialogue noted through Twitter and through photographic capture of learning at sites.

We also used a combination of theory-informed and theory-generating analysis to inform the evaluation. Early interviews were fully inductive allowing issues deemed pertinent to the individual interviewees to be raised and discussed. This was particularly useful in developing the initial feedback to the project team on the perceived benefits/problems with initial scale up in a wide-ranging and fulsome manner. The thematic analysis of these interviewees then allowed key themes to be further investigated in later interviews and also highlighted key learning across staff and patients. For the assessment of barriers and facilitators to scale-up and sustainability, a theory of behaviour change-based approach to the interviews was taken. This adopted the Theoretical Domains Framework – an integrative framework approach to the interviews - and thus allow a comprehensive and evidence-

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<sup>36</sup> McDonald M, Wilson H: The New Marketing: Transforming the Corporate Future. 2002, Oxford, Butterworth-Heinemann

<sup>37</sup> The Health Foundation. Evaluating healthcare quality improvement: A summary of learning from a Health Foundation roundtable, 6 June 2011

based exploration of the possible barriers and facilitators around the full set of theoretical domains. This comprehensive diagnosis of potential behavioural impediments to successful scale up and sustainability is particularly useful to allow generalisable lessons to be generated for future scale up proposals.

## 6.4 Limitations of evaluation

The evaluation did have a number of limitations, however. The number of sites involved in the scale up was small and sites were part of the scale-up because they wished to develop an InS:PIRE service and were, therefore, favourably disposed to the intervention from the outset.

In addition, it is important to acknowledge that although patients and staff were interviewed from across all sites, the numbers of staff and patients included in this evaluation is small. Additionally, we were only able to interview patients who were volunteered to the evaluation team as suitable and we only spoke to staff who were willing to speak to us. We also didn't have the ability to interview patients who chose not to engage with the InS:PIRE intervention nor those who dropped out. As such, it is likely that our evaluation does not represent the full range of opinions on InS:PIRE.

The evaluation also only had limited quantitative data available to more objectively assess the likely direction of effect of InS:PIRE on outcomes. There was only ethics approval to capture information at four of the five sites, and cohort numbers were small. Additionally, there was a high rate of missing questionnaires at three months, further diminishing the usefulness of the data. The importance of ensuring complete follow-up for the future twelve month assessment has been stressed to the project team.

Comparison is the main way in which evaluation helps users to attribute value (in other words we can only judge value if we make a comparison), and, together with valuation, is what distinguishes evaluation from some other types of research<sup>38</sup>. In case of InS:PIRE we could only compare the objectives of the intervention to the actual achievements. Our evaluation of the scale up process, however, did not have the benefit of any counter-factual data (there was no control or comparator group). As such, any improvements we may have noted, may have happened not as a result of the InS:PIRE intervention. This is another important issue for the future assessment of outcome at twelve months. However, one could also argue, given that the intervention is still evolving, it is still too early for a fully controlled comparison. For example, the IDEAL evaluation framework,<sup>39,40</sup> which was developed to aid the appropriate evaluation of surgical interventions, which evolve as they develop, suggests that a fully controlled evaluation (IDEAL stage 3 evaluation) is only appropriate once an intervention is fully stable and further refinement is not expected. The IDEAL framework has many parallels with the development and scale-up of quality improvement interventions, where continued iteration and refinement is expected in the earlier phases of development and scale-up. Thus the InS:PIRE scale-up evaluation reported here could be construed more as an IDEAL stage 2a/2b study, where the purpose of this evaluation phase is to consolidate learning as the intervention is rolled out

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<sup>38</sup> Øvretveit, J. (2014) Evaluating Improvement and Implementation for Health. Open University Press, New York.

<sup>39</sup> McCulloch P, Altman DG, Campbell WB, Flum DR, Glasziou P, Marshall JC, Nicholl J; Balliol Collaboration. No surgical innovation without evaluation: the IDEAL recommendations. Lancet. 2009 26;374(9695):1105-12

<sup>40</sup> Hirst A, Philippou Y, Blazeby J, Campbell B, Campbell M, et al. No Surgical Innovation Without Evaluation: Evolution and Further Development of the IDEAL Framework and Recommendations. Ann Surg. 2019 Feb; 269(2):211-220.

to a wider set of practitioners (in our case sites). Only when the intervention has become more stable would a full (potentially randomised) evaluation be appropriate.

Finally, the evaluation team did not have access to any cost-effectiveness data (this is being assessed by a different external group). The InS:PIRE intervention was noted in our evaluation to be highly resource intensive; thus the cost-effectiveness analysis will be highly relevant to any health authority wishing to set up an InS:PIRE intervention in the future.

## 6.5 Conclusion

Our evaluation suggests that the InS:PIRE programme could be successfully scaled up to other clinical sites; however, the implementation of InS:PIRE was highly variable and changed repeatedly over time. InS:PIRE had a transformative effect on the staff engaged with it and patients perceived the programme very positively and early indications suggested improvement in outcomes. Our findings suggest that InS:PIRE is perceived to be driven by three core “active ingredients” – provision of one-to-one time with the ICU clinical staff to discuss their ICU journey; provision of peer support; and the provision of patient-centred care facilitated by blurring of professional boundaries to solve patient problems. Implementation was greatly facilitated through staff commitment to working across traditional professional and disciplinary boundaries and their beliefs that they were engaging in something of value to patients (reinforced through satisfaction in seeing improvement in patients).

The organisation and delivery of the intervention was resource-intensive, however, requiring high level of staff buy-in and administrative input. In addition, only a small proportion of potentially eligible patients receive the intervention and the perceived mechanism of change is unclear. Implementation was significantly facilitated by the external resource provided through the scale-up grant and the fact that the InS:PIRE clinics sat somewhat out with routine NHS services. Against a background of fiscal constraint within the NHS, future embedding of an InS:PIRE service must address these issues.