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Sharing the patient's story: co-designing primary care discharge summaries for patients leaving the ICU

Dr Suzanne Bench

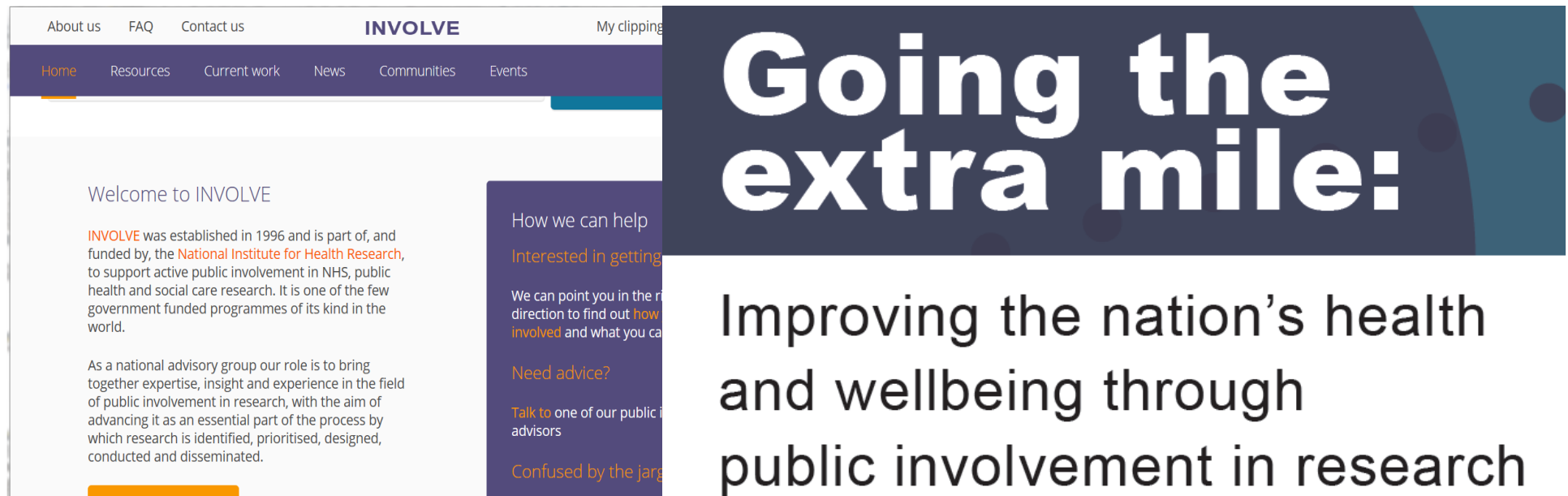
Hippocrates (1849)

The physician “*must not only be prepared to do what is right [himself] but also make the patient...cooperate*”

Public and Patient Involvement (PPI)

- Research carried out '*with*' or '*by*' members of the public rather than '*to*', '*about*' or '*for*' them (INVOLVE).

Denegri (2015)



The image shows a screenshot of the INVOLVE website. The website header includes navigation links: 'About us', 'FAQ', 'Contact us', 'INVOLVE', and 'My clipping'. Below this is a secondary navigation bar with 'Home', 'Resources', 'Current work', 'News', 'Communities', and 'Events'. The main content area on the left has a 'Welcome to INVOLVE' section, followed by a paragraph explaining that INVOLVE was established in 1996 and is part of the National Institute for Health Research. Below this is another paragraph describing the organization's role as a national advisory group. On the right side of the screenshot, there is a dark blue overlay with white text that reads 'Going the extra mile: Improving the nation's health and wellbeing through public involvement in research'. The overlay also contains a list of services: 'How we can help', 'Interested in getting...', 'Need advice?', 'Talk to one of our public i advisors', and 'Confused by the jarg...'. The text 'Interested in getting...' is partially cut off.

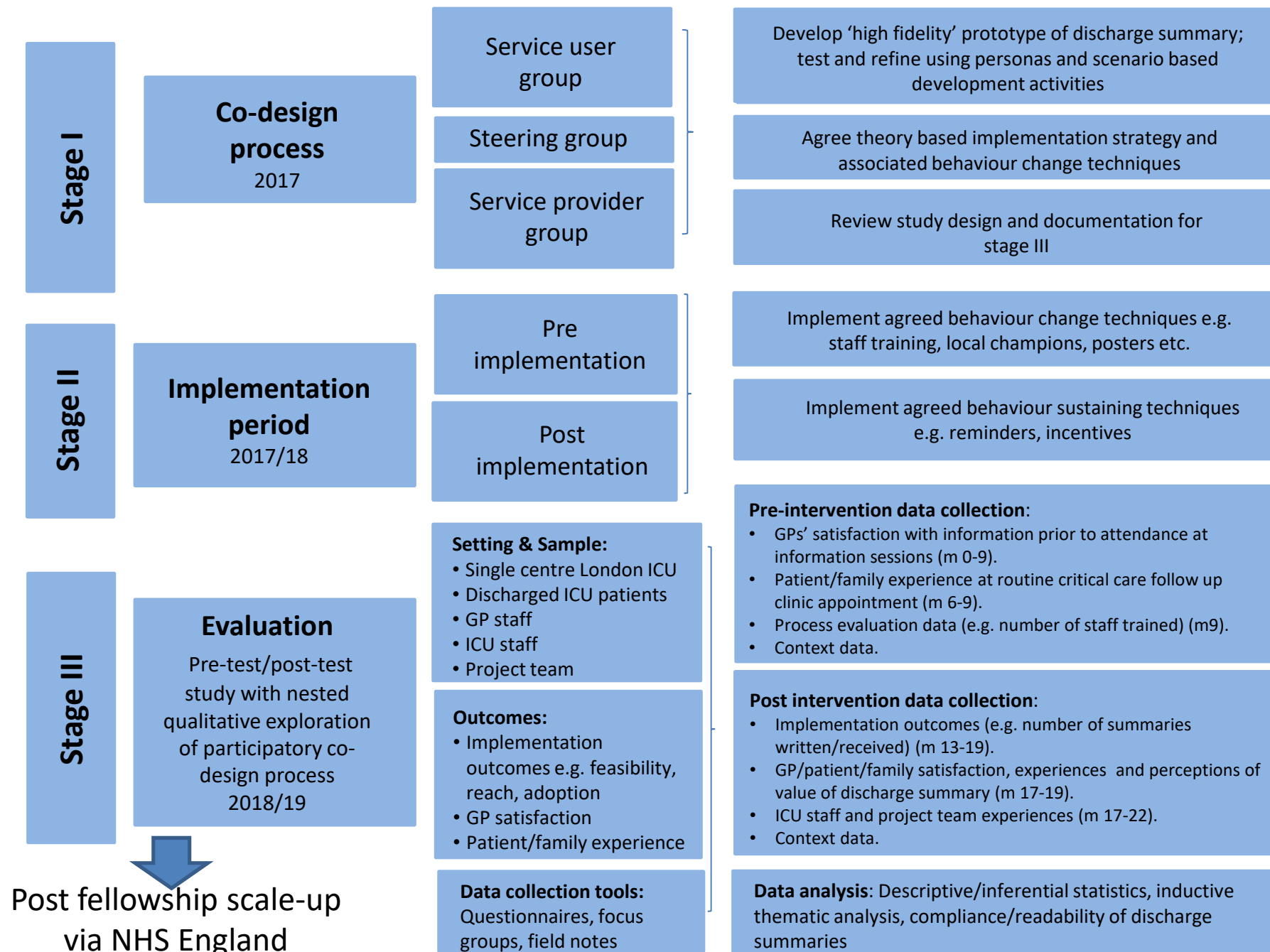
Going the extra mile:
Improving the nation's health and wellbeing through public involvement in research

Project aims

To:

- Co-design an ICU-primary care transfer of care communication intervention and implementation strategy.
- Implement the behaviour change intervention, which requires ICU staff to provide GP staff and patients with a critical care discharge summary).
- Evaluate the implementation of the ICU staff behaviour change intervention.
- Evaluate the model of service user involvement utilised for the project.

Figure I: Overview of Project Design



Participatory Research and Quality improvement

- Geared towards planning and conducting projects *with* those people whose life-world is affected
- Comprises a range of methodological approaches and technique
- Moves beyond a model of service user consultation

Determining the research question and designing the study

- Use of previously collated experience data (Bench *et al.* 2014)
- National focus group study (Bench *et al.* 2016)
- Project steering group includes service users and providers
- Work with ICU steps Charity trustees
- INVOLVE advice

Critical care patient discharge summary training pack



Produced on behalf of the UCCDIP project team by:
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Suzanne Bench

Intensive and Critical Care Nursing (2014) 30, 69-76



Available online at www.sciencedirect.com

ScienceDirect

Journal homepage: www.elsevier.com/locate/icc



ORIGINAL ARTICLE

Providing critical care patients with a personalised discharge summary: A questionnaire survey and retrospective analysis exploring feasibility and effectiveness

Suzanne D. Bench^{a,*}, Karina Heelas^b, Catherine White^c, Peter Griffiths^d

needs and get the information you require to support your recovery on the ward.

Name:

Why was I in critical care? What happened to me?

You have been in intensive care at King's College Hospital. You arrived on Friday 12th August 2011. You arrived early evening by helicopter because you had fallen 20 feet from scaffolding onto concrete.

You sustained many injuries = broken ribs, collapsed lung, a hole cut to the back of your head. You also had some bleeds in your brain.

Despite your many injuries you didn't need any surgery. You were put on a breathing machine and kept asleep for 24 hours, also a tube was put in your lung to help inflate it.

You have suffered some pain in your ribs and wounds have caused discomfort. You have been confused whilst in intensive care, but you have not seemed upset to be here. You have had a good sense of humour and many visitors, both family and friends.

Completed by: Nurse (Print name and position)

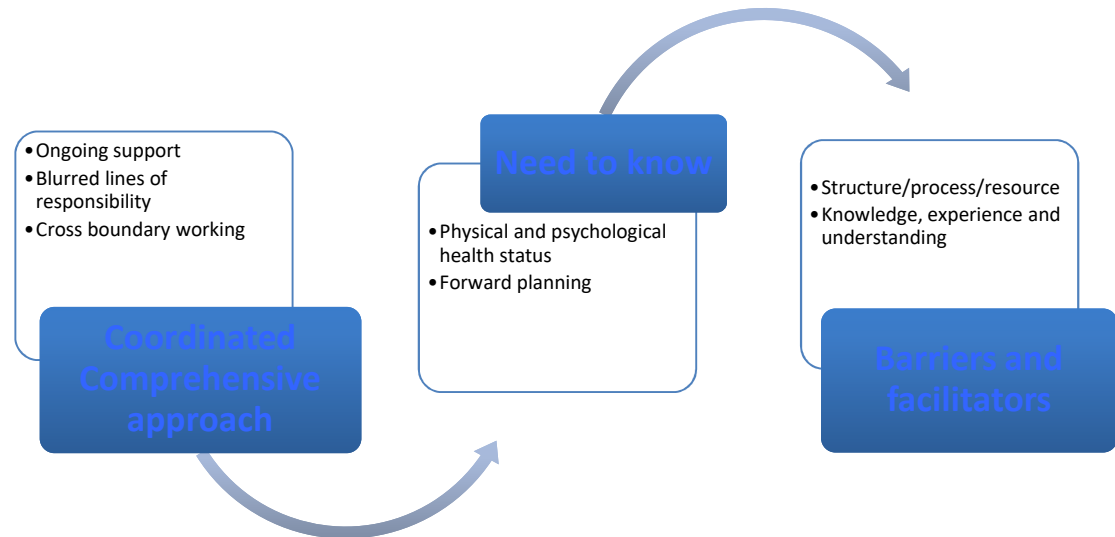
Date of discharge from critical care:

Ward: 602

Name of Ward sister/Charge Nurse:

Ward Tel no:

An exploration of the information General Practitioner (GP) staff require to successfully coordinate the rehabilitation of critically ill patients after hospital discharge (Bench et al. 2016)



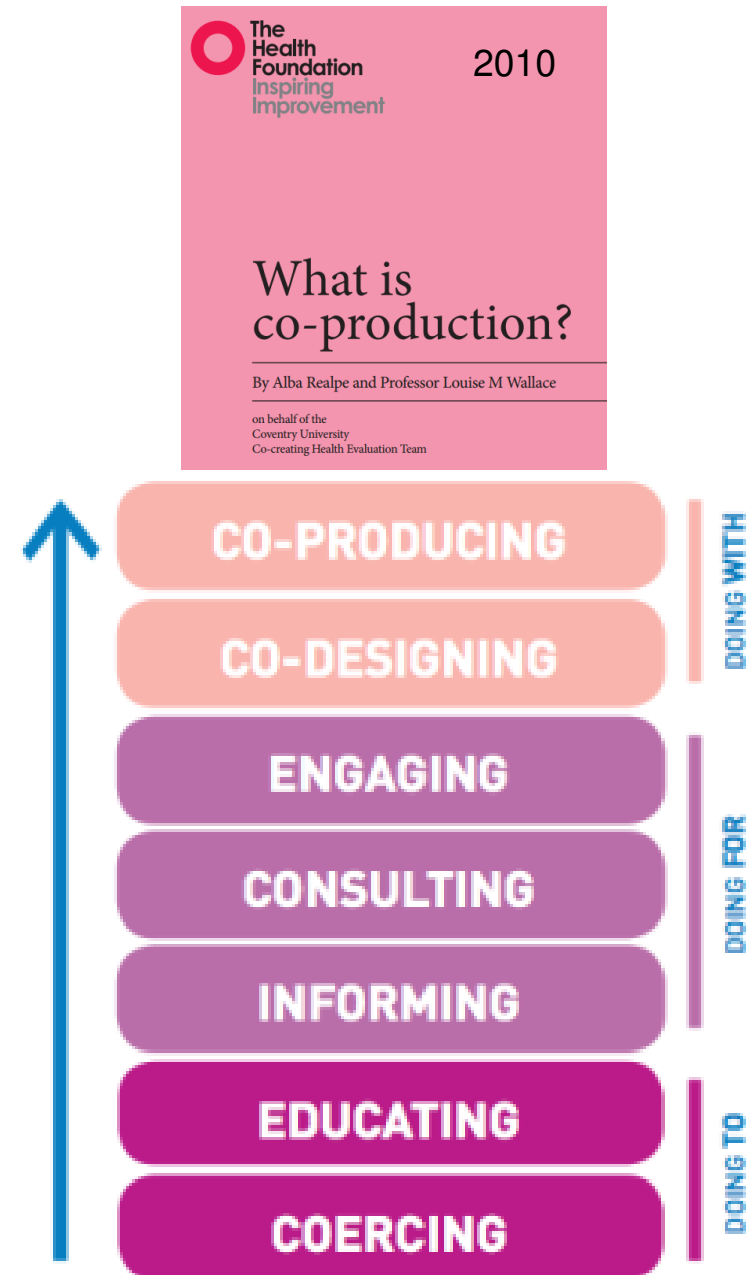
TR

Co-designing the intervention and implementation strategy

- Draft prototype
- Service user and provider advisory groups and researchers will co-design
 - An ideal ICU-primary care transfer of care communication template
 - behaviour change techniques, which will support implementation of the intervention
- Personas-pretend users of discharge summary
- Scenario based development-mocked up narrative descriptions about people and experiences

- Co-design addresses the problem and a solution
- Co-production embeds the solution into reality
- Co-creation is identified as the way in which both of these are addressed

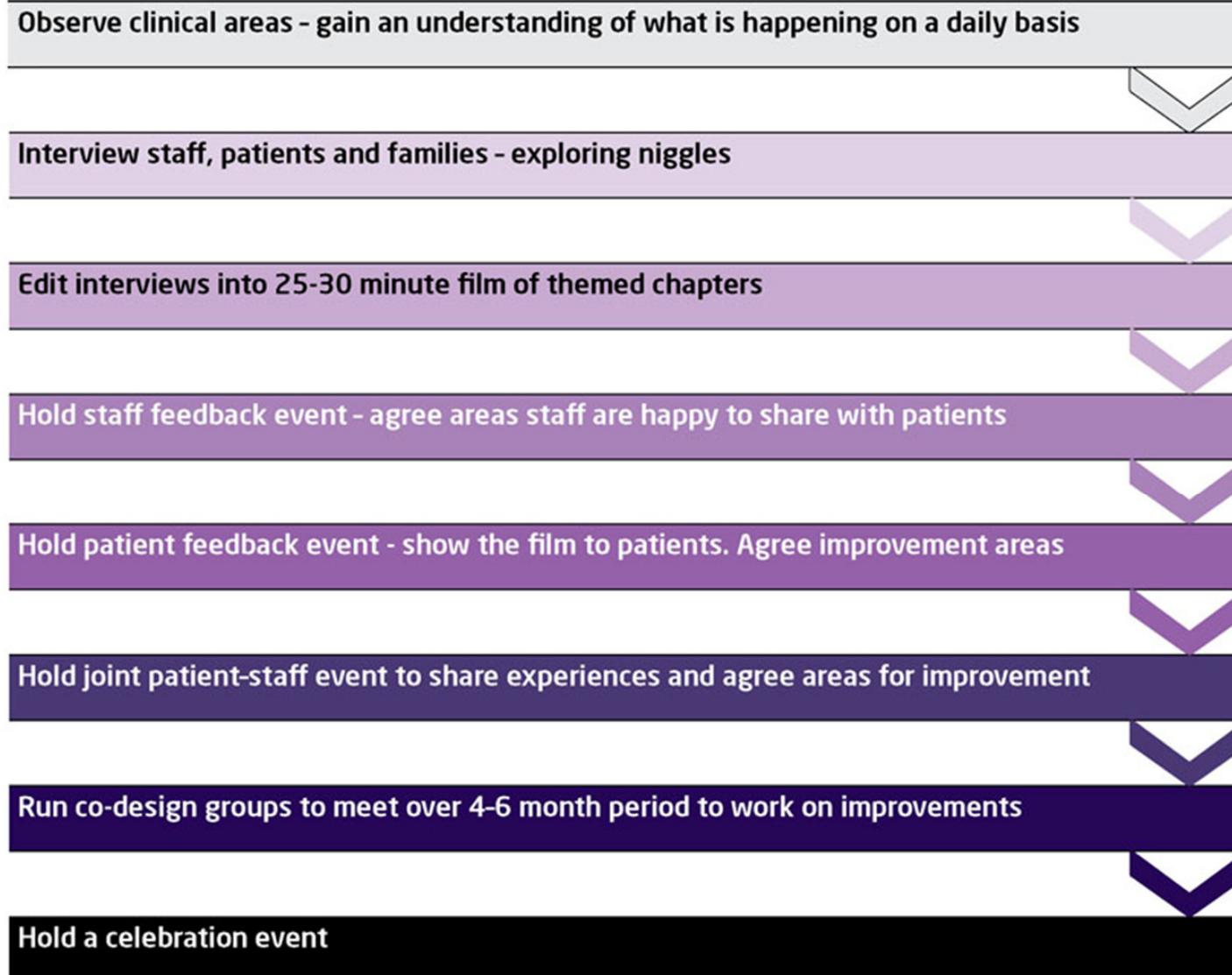
McDougall (2012)

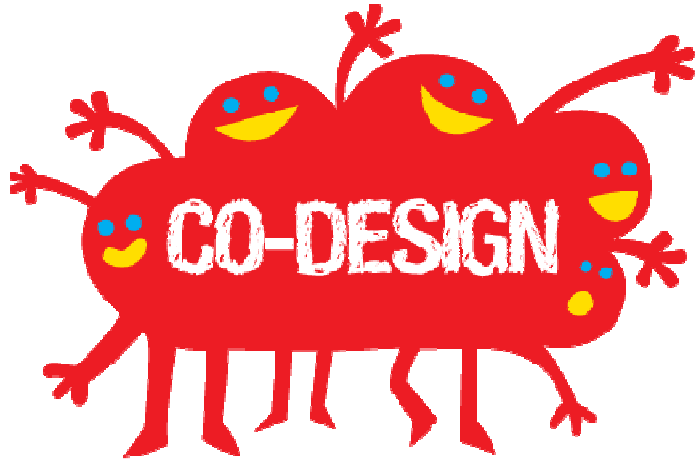


Source: new economics foundation

Experience-Based Co-design

(King's Fund)





“shift the balance of power...transforming the role of the user from that of an informant to a legitimate and acknowledged participant in the design process”

(Donetto et al. 2013)

Challenges/Limitations

- Not everyone has the desire or capacity to be an active participant
- Not always possible nor desirable to share power and responsibility equitably
- Resistant healthcare culture

Batalten et al. (2015)

Other involvement activities

- Review of study documents
- Service users to facilitate a focus group discussion (after training) with the internal service user stakeholder advisory group at the end of the project
- Disseminating project findings through co-delivered oral presentations and co-authored publications

The nature and extent of service user involvement in critical care research and service improvement; a scoping review of the literature



Bench S., Eassom E. & Poursanidou K. (2016b)

Identification

Records identified via 11 online databases
(*n* = 5747)

Additional records identified from websites, conference proceedings, experts and snowballing (*n* = 39)

Screening

Records after duplicates removed
(*n* = 4654)

Records screened
(*n* = 4654)

Records excluded
(*n* = 4616)

Eligibility

Full-text articles assessed for eligibility
(*n* = 38)

Full-text articles excluded
(*n* = 3)

1. Barnato et al. (2007): no detail of patient involvement
2. Field et al. (2008): did not meet inclusion criteria
3. Hinton et al. (2015): Detail of service user involvement not included in paper, only on website

Included

Included in narrative synthesis
(*n* = 35)

Full text papers
(*n* = 20)

Abstracts/summaries
(*n* = 15)

Research

- Locock et al. (2014a, 2014b): ethnographic evaluation of an Accelerated experience based co-design (AEBCD) project in 2 adult ICUs in the UK
- Trajkovski et al. (2015a, 2015b): Qualitative evaluation of Appreciative Inquiry (AI) in a neonatal ICU in Australia
- Nasenbeny et al. (2014) questionnaire survey evaluating impact of PPI on service improvement

Overview of findings

- Diverse projects- Most data related to service improvement rather than research and all designed by academics or service providers
- Limited data evaluating PPI, poor reporting of processes and inconsistent use of terminology
- Difficult to determine if projects outputs would have occurred without service user input or the extent of impact service users actually had
- **Scarcity of information makes it difficult to fully understand and appreciate PPI in critical care service improvement and research projects and its likely impact**


Levels of involvement

(Denegri 2015)

- **User-led/user-controlled:** where research/SI is actively driven, directed and managed (controlled) by service users and/or family members
- **Collaboration:** when service users/carers are actively and collaboratively involved in research or service development as members of research or project implementation teams, as co-researchers, co-implementers and co-authors of academic publications
- **Consultation:** when service users are consulted, asked for advice, and/or provide information that is used to inform decision making by others in research or service development

Which service users to involve and how to do so?

- Huge variation in number of people involved in projects
- Limited details regarding demographic characteristics- predominantly white British
- Involvement based on 'convenience'
- Same people commonly involved in projects



"The hardest challenge for us has been finding people for individual projects"

Derbyshire (no date)

Bench *et al.* (2016b)

Processes

- Time involved (1 day-15 months)
- Payment/incentives: often unpaid

“travel expenses were reimbursed, and lunch and refreshments were provided at meetings”

Locock et al. (2014b)

“sample patients at different points in their journey, but...[not to] actively seek to reproduce our local demographics”

Wilcock et al. (2003)

“given a xmas present”

Hamil & Heslop (2010)

Barriers & Facilitators

“we need to develop the skills to effectively work with families to get the best possible outcomes”

Trajkovski *et al.* (2015)

“a physical and mental space that encouraged dialogue, built trust and created links between health professionals and parents...”

“conflict and tension—often relating to issues of power...”

Robert *et al.* (2015)

Key points

- PPI is strongly endorsed by the DH
- Participatory approaches shift the balance of power, but their impact and the most effective methods are currently unclear
- Our project uses and evaluates a participatory approach adding to the limited body of improvement/implementation science knowledge

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Any questions?
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