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

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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)

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.
Review study design and documentation for stage III.

Stage I: Co-design process 2017
- Service user group
- Steering group
- Service provider group

Stage II: Implementation period 2017/18
- Pre implementation
- Post implementation

Stage III: Evaluation
- Pre-test/post-test study with nested qualitative exploration of participatory co-design process 2018/19

Outcomes:
- Implementation outcomes e.g. feasibility, reach, adoption
- GP satisfaction
- Patient/family experience

Data collection tools:
- Questionnaires, focus groups, field notes

Data analysis: Descriptive/inferential statistics, inductive thematic analysis, compliance/readability of discharge summaries

Pre-intervention data collection:
- GPs’ satisfaction with information prior to attendance at information sessions (m 0-9).
- Patient/family experience at routine critical care follow up clinic appointment (m 6-9).
- Process evaluation data (e.g. number of staff trained) (m9).
- Context data.

Post intervention data collection:
- Implementation outcomes (e.g. number of summaries written/received) (m 13-19).
- GP/patient/family satisfaction, experiences and perceptions of value of discharge summary (m 17-19).
- ICU staff and project team experiences (m 17-22).
- Context data.

Post fellowship scale-up via NHS England
Participatory Research and Quality improvement

• Geared towards planning and conducting projects \textit{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
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)
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)
Experience-Based Co-design
(King’s Fund)

- Observe clinical areas - gain an understanding of what is happening on a daily basis
- Interview staff, patients and families - exploring niggles
- Edit interviews into 25-30 minute film of themed chapters
- Hold staff feedback event - agree areas staff are happy to share with patients
- Hold patient feedback event - show the film to patients. Agree improvement areas
- Hold joint patient-staff event to share experiences and agree areas for improvement
- Run co-design groups to meet over 4-6 month period to work on improvements
- Hold a celebration event
“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)
Records identified via 11 online databases (n=747)

Records after duplicates removed (n=4654)

Records screened (n=4654)

Full-text articles assessed for eligibility (n=58)

Full-text articles included in narrative synthesis (n=35)

Full-text papers (n=20)

Abstracts/summaries (n=15)

Additional records identified from websites, conference proceedings, experts, and snowballing (n=179)
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)

“given a xmas present”
Hamil & Heslop (2010)

“sample patients at different points in their journey, but…[not to] actively seek to reproduce our local demographics”
Wilcock et al. (2003)
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...”

Robert et al. (2015)

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

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