Co-design: what’s the evidence?
Toward More User-Centric OD
Lessons From the Field of Experience-Based Design and a Case Study

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This article argues that the design and delivery of healthcare services is a unique and timely opportunity for user-centered design. The authors draw on their experience as designers of healthcare services, involving patients and healthcare professionals in the design process, to illustrate how user-centered design can be applied to healthcare services. They describe a case study where they worked with a hospital to redesign its patient experience, focusing on the physical and emotional aspects of the service. The case study demonstrates how user-centered design can lead to improvements in patient satisfaction and outcomes.

Keywords: user-centered design, healthcare services, patient experience, service design

A frequently quoted quote in the field of user-centered design is: "Design is not only about making things look good, it's about making them work. It's about understanding the needs of the users and designing solutions that meet those needs. Design is not just about making things pretty, it's about making things effective." - Paul Bate

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References:

In conclusion, user-centered design is an essential aspect of healthcare services. By involving patients and healthcare professionals in the design process, we can create services that are not only effective but also personalized to meet the needs of the users.
Enhancing the experience of carers in the chemotherapy outpatient setting: an exploratory randomised controlled trial to test impact, acceptability and feasibility of a complex intervention co-designed by carers and staff

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Abstract

Purpose Supporting someone through chemotherapy can be emotionally and physically demanding. However, research has yet to establish the type of support carers require or the best way to provide this. This study tested the feasibility and acceptability of a complex intervention for carers that was co-designed by staff and carers of patients starting chemotherapy. Methods Forty-seven carers were recruited, randomised between the intervention (n = 24) and control (n = 23) groups. A questionnaire was completed pre- and post-intervention measuring knowledge of chemotherapy and its side effects, experience of care, satisfaction with outpatient services, coping and emotional wellbeing. The intervention process was evaluated by carers and healthcare professionals (HCPs) in focus groups. Results Recruitment to the study was unproblematic and attrition from it was low, suggesting the intervention and study processes were acceptable to patients and carers. Carers in receipt of the ‘Take Care’ intervention reported statistically significantly better understanding of symptoms and side effects and their information needs being more frequently met than carers in the control. Confidence in coping improved between baseline and follow-up for the intervention group and declined for the control although differences were insufficient to achieve statistical significance. There was no significant difference between the two groups’ emotional wellbeing. HCP and carer focus groups confirmed the feasibility and acceptability of the intervention. Conclusions The ‘Take Care’ intervention proved acceptable to carers and HCPs and demonstrates considerable promise and utility in practice. Study findings support the conduct of a fully powered RCT to determine the intervention’s effectiveness and cost-effectiveness.

Keywords Carers · Chemotherapy · Support · Intervention
Published research

- Clarke D, Jones F, Harris R et al. (2017) What outcomes are associated with developing and implementing co-produced interventions in acute healthcare settings? A rapid evidence synthesis. *BMJ Open* 2017;7 http://bmjopen.bmj.com/content/7/7/e014650


What does the evidence tell us?

- Projects achieve changes in services
- Projects achieve positive outcomes for patients
- The co-design process is motivating for staff and engaging for patients
- The co-design process can be adapted to different settings
- Projects achieve sustainable change
Examples of improvements for patients

- Full time cleaner in ED
- Porters remove waste at a different time in ICU
- New templates for patient appointment letters
- Customer care training for reception staff
- New layout of roads surrounding outpatient building
- New design mammography gown
- More comfortable V shaped pillows
- New private room for communicating diagnosis
- Information leaflets, folders, posters, DVDs
- Appointment for surgery given on day of diagnosis
- Patient-held records
- Redesigned discharge summary
- Clock in ICU
EBCD in mental health settings (Springham et al. 2015 BMJ Quality Improvement)

**Toolkit uses patient experiences to improve mental health services**

The toolkit captures the experiences of patients, carers and staff through discussion, observation and filmed interviews

Neil Springham and Ami Woods
Guardian Professional, Tuesday 7 January 2014 05:05 GMT

- Went from being ward with highest number of complaints to no complaints for 23 months

- Co-design groups for admissions; ‘blanket’ rules; and conflict between service users and staff

- The approach was adapted for mental health setting through Researchnet group

**Mental health** acute wards are frightening for patients and stressful for staff.

Patients feel at their worst and are often terrified about what is happening. Staff must process a high volume of admissions, many of which come with additional complications relating to factors such as housing or benefits.

For these reasons, the patient experience team at Odeas NHS foundation trust decided to take a new approach to these pressures. The experience-based co-design (EBCD) toolkit is a distinctive approach, which captures the experiences of patients, carers and staff through discussion, observation and filmed interviews; then brings them together.
EBCD with family carers (Tsianakas et al 2015 Supportive Cancer Care) – feasibility study for a RCT
Developing and testing feasibility of complex interventions

To develop and test a carer support package in the chemotherapy outpatient setting using EBCD:

- understand support provided by healthcare professionals to carers
- develop a short film depicting carers’ experiences
- bring healthcare professionals and carers together in co-designing components of an intervention for carers
- develop and implement a carer intervention.
- explore feasibility and acceptability, impact on carers’ knowledge of chemotherapy and on their experiences of providing informal care

Tsianakas V, Robert G, Richardson A et al. (In press) ‘Enhancing the experience of carers in the chemotherapy outpatient setting: an exploratory randomised controlled trial to test the impact, acceptability and feasibility of a complex intervention co-designed by carers and staff’, Supportive Care in Cancer
‘Take care’ intervention
Co-designed DVD and booklet and group consultation

Intervention group reported:
• Statistically significantly better understanding of symptoms and side effects, and information needs being met
• Confidence in coping improved between baseline and follow-up (control group’s went down)
• Emotional wellbeing same for intervention and control groups
• Feasibility and acceptability of intervention confirmed
EBCD in a rural clinic in South Africa (VanDeventer 2016 BMC Health Services Research)

3 Co-design groups:
Waiting
Practical issues
Attitudes and communication

Results:
- Examples of improvements
- Ill children taken straight to ward from ED without waiting for results
- Queue marshals at clinic and hospital reception
- Mattresses for mothers on the ward
- Tea in the morning for mothers
- Soundproof room
- Positive attitude workshop for staff
Positive for staff and patients taking part

Accountability

‘I wondered what, if anything, will be taken on board. To be honest with you, everything has been taken on board, and that in itself was a complete surprise [contrasted with previous project] where it was people say I’ll do this, I’ll do that, and nothing happens’
(Patient interview)

‘Because of hearing patients’ relatives’ and staff experience it acts as a catalyst and gives you energy to keep going and make the change, and make sure it happens’
(Staff interview)

‘I felt I was really listened to’
(Patient interview)

‘I have already changed the way I think and care for patients even though we haven’t started implementing changes yet. I have a better understanding now of how things are from the patients’ perspective’
(Staff interview)

Acceptability
Sustainability; case study in breast and lung cancer services

7 co-design groups

‘Quick fix’ solutions: 28 with 24 sustained

‘Process redesign’ solutions: 9 with 5 sustained

56 quality improvements implemented

Cross service/interdisciplinary solutions: 14 with 8 sustained

Organisational level solutions: 5 with 2 sustained

19-22 months after initial implementation
66% of improvements sustained

Crucial role of facilitators in staff experiences of EBCD approach

Getting to the CORE: testing a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness

Los Angeles

New project to:

- Pilot test the experience-based co-design approach with recently incarcerated individuals to help improve fragmented safety net services

- Develop a practical road map and practice guide describing system changes necessary to support formerly incarcerated individuals and their families.
• Patient focused quality improvements reported in the identified 12 studies:
  • *Simple practical changes ‘sweating the small things’*
  • *BUT from the patients’ perspective these issues made care and treatment more humane and person-centred*
  • *And made their journeys easier to engage with and negotiate*

• One study looked at cost and found it was possible to significantly reduce the cost of the project by using ready-made films

• Patients and staff reported positive experiences of participation
  • *Took direct responsibility for the work and its outcomes – this was a success factor linked to the EBCD process itself*
  • *The active involvement of patients in this way gave both legitimacy and urgency to service improvement plans, particularly where managers were involved in or actively supported the co-design project*
  • *Powerful impact on some staff*