Experience Based Co-design

a toolkit for Australia

Australian Healthcare and Hospitals Association (AHHA) and Consumers Forum of Australia (CHF) are delighted to make available this toolkit on Experience Based Co-design.

As our health system moves to becoming even more patient centric it is critical we use tools and approaches to design the system to meet the needs of our population. Experience based co-design offers a methodology that brings health workers and consumers together in an authentic and equal partnership to co-design care to deliver an improved experience. In doing so, the approach not only improves the experience of patients but also of the workforce. The combined benefit is an overall improvement in quality of care.

This toolkit brings together existing resources from the UK and New Zealand and with Australian case studies provides a context that will support Australian health services to utilise the approach.

We would like to thank our colleagues in UK at the Point of Care Foundation and in New Zealand at Healthcare co-design who have been generous with permission to use their resources.

PwC Australia has provided financial support for this toolkit, which has been developed by Adjunct Prof Paresh Dawda of Prestantia Health and Dr Andrew Knight.

We hope the toolkit inspires positive examples of co-design activities in Australian health service. We invite you to share case studies of your work with us, for sharing with others who may also be embarking on the co-design journey.

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Experience based co-design - a toolkit for Australia was developed by Prestantia Health.
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Content and resources produced by the Point of Care Foundation in the UK and the Health Care co-design website hosted by Waitemata District Heath Board in New Zealand have strongly influenced this project. We would like to express our sincere gratitude to both organisations for their generosity in providing permission to use their resources and adapt them for this toolkit.

Health Care Co-design

- http://www.healthcodesign.org.nz/index.html

Point of Care Foundation

- https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/

Case studies were identified from a search of the literature as well as invitations for submission. We are grateful to all the Australian health services and organisations that submitted case studies for inclusion in this tool kit. Their contribution has been critical to adding value and helping to bring this toolkit to life. Case studies from the following organisation have been used:

- NSW Agency for Clinical Innovation
- Sydney Children's Hospital
- Illawarra Shoalhaven Local Health District (NSW)
- Victoria University, Australian National University and Western Health
- Ochre Health (ACT)
- NSW Emergency Departments (from publication)

Paresh Dawda
on behalf of Prestantia Health

Foreword

I'm a great believer that if you help people to create purposeful relationships and share their respective expertise; amazing things happen. Many health and care services from around the world are achieving this through partnerships where consumers, families, staff and other stakeholders use co-design methods to better understand how it feels to deliver and receive care and then make improvements together. The need for these skills has increasingly come into sharp focus as those working in health and care services strive to provide excellence every day. Pooling the considerable expertise of health and care staff along with the unique expertise of those who have 'lived experience' of health and care services is a recipe for success.

I have had the pleasure of working with Dr. Paresh Dawda and over the years have witnessed his unwavering passion to support teams to increase quality and safety. He uses an analogy of a golden thread to describe his vision of meaningfully involving patients and families alongside staff to achieve this.

I am delighted to have been invited to write the foreword to this Experience Based Co-Design Toolkit which is specifically orientated for Australia. It is an excellent resource, hosted by the Australian Hospitals and Healthcare Association (AHHA) and Consumer Health Forum (CHF) of Australia, which sets the context for working differently and provides a wealth of tools, tips and case studies from organisations and teams across Australia and beyond. The toolkit also points you to a range of sources where you can find how teams have improved safety, environments and clinical outcomes, reduced waste and enriched both staff and consumer experiences.

I know it will inspire you to put co-design at the heart of what you do.

Dr. Lynne Maher

Director of Innovation, Ko Awatea, Counties Manuaku Health, Auckland
Associate Honorary Professor of Nursing, University of Auckland
Adjunct Associate Professor, School of Medicine, University of Tasmania

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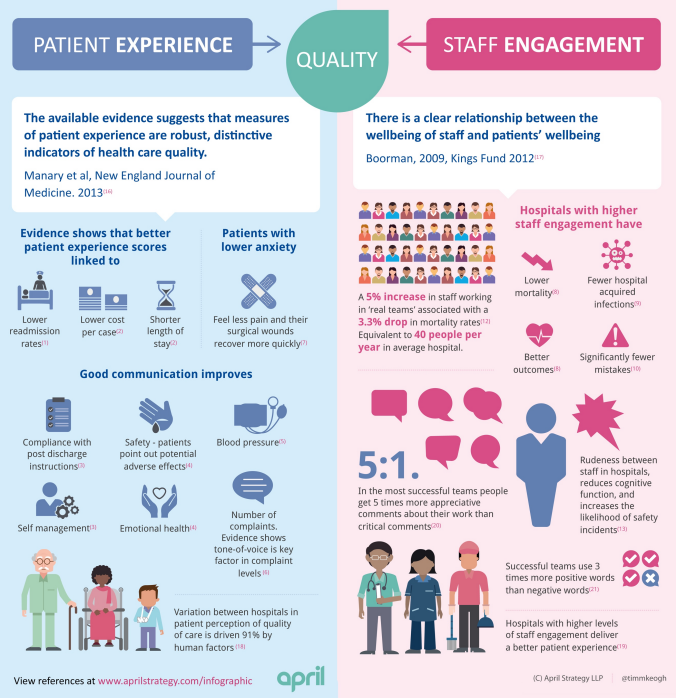
Introduction

Health care systems around the world are striving towards achieving the quadruple aim.[1] That is improving clinical outcomes, unit cost of delivery, staff experience and patient experience. The co-design process brings together a focus on both the patient experience and staff experience. It also brings together other stakeholders. This leads to an end result that meets all stakeholders needs. Studies demonstrate the link between staff experience and patient experience,[2] [3] and their impact on quality is summarised by the infographic in figure below.



Source Tim Keogh, April Strategy LLP. The references in the infographic are available at http://www.aprilstrategy.com/infographic/.

Achieving the quadruple aim requires good design of healthcare service delivery. Good design considers three aspects: Performance, Engineering and Aesthetics.[4] [5]

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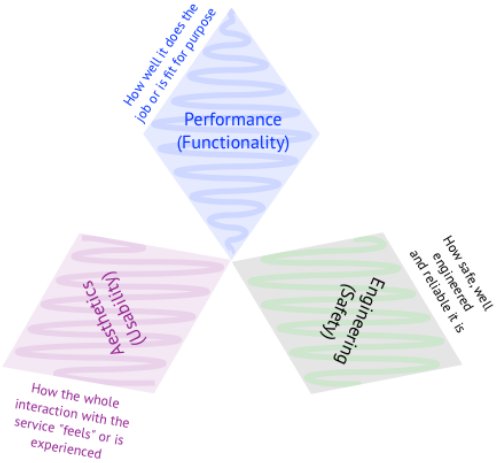
[1] Bodenheimer, T., & Sinsky, C. (2014). From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider. *The Annals of Family Medicine,12*(6), 573-576. doi:10.1370/afm.1713

[2] West, M., Dawson, J. (2012). Employee engagement and NHS performance. The Kings Fund. UK. Reporting on the NHS Staff Survey. Available at https://www.kingsfund.org.uk/sites/default/files/employee-engagement-nhs-performance-west-dawson-leadership-review2012-paper.pdf

[3] Maben, J., Adams, M., Peccei, R., Murrells, T., & Robert, G. (2012). 'Poppets and parcels': the links between staff experience of work and acutely ill older peoples' experience of hospital care. International Journal Of Older People Nursing, 7(2), 83-94. doi:10.1111/j.1748-3743.2012.00326.x

[4] Berkun, S. (2004) Programmers, designers, and the Brooklyn bridge. Available at http://scottberkun.com/essays/30-programmers-designers-and-the-brooklyn-bridge/.

[5] Bate S P, Robert G, Bevan H. The next phase of health care improvement: what can we learn from social movements? Qual Safety Health Care 20041362–66.



For many years, the primary focus in healthcare had been on performance. In recent years, safety and reliability has gained momentum. Even more recently increasing attention is being paid to the aesthetics of experience, that is, how the whole interaction with the service is experienced by consumers and staff. To truly achieve an improved experience requires going beyond the usual approaches of seeking patient feedback to one that brings people together and helps capture the very essence of the experience from multiple perspectives.

The continuum of patient influence
Adapted from Bate and Robert (2006)[6]

Experience is an inner subjective, immaterial phenomenon, it cannot be accessed or observed directly, but only indirectly through the words and language people use to describe it.[7]

[6] Bate, P. and Robert, G. (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. Quality and Safety in Health Care, 15(5), pp.307-310.

[7] Saul Alinsky, Rules for Radicals, quoted by Henry Mintzberg in "The Five Minds of a Manager" HBR 11/03

'Happenings become experiences when they are digested, when they are reflected on, related to general patterns and synthesised' (Alinksy)

Experience Based Co-Design (EBCD) is a methodology that goes beyond user views, attitudes, needs and perceptions to a focus on designing experiences using a methodology that brings together the 'user centred orientation' (experience base) and a collaborative change process (co-design). It has been deliberately developed by bringing together the worlds of design thinking and quality improvement.

A recent article in the Harvard Business Review by authors at John Hopkins Hospital and University Business school concluded:[8]

"It's every health care leader's mission to improve patient experiences. Design thinking is a useful process for doing so, as it requires decision makers to empathize with patients, think creatively, prototype, and continually test solutions to these problems."

We trust this toolkit will help you as leaders in your health service or organisation to make a positive difference to the experience of your consumers.

[8] Sharon H, Kim C, Myers L A. Health Care Providers Can Use Design Thinking to Improve Patient Experiences. HBR (2017). Available at: https://hbr.org/2017/08/health-care-providers-can-use-design-thinking-to-improve-patient-experiences

Background

> Co-design is a way of bringing consumers, carers, families and health workers together to improve health services. Giving people an equal voice as active partners in health care improvement leads to better outcomes for all.
>
> *NSW Agency for Clinical Innovation*

While the use of design thinking is widely used in many industries, the application of design thinking in health care is relatively young. It has already led to a range of publications and toolkits and a number of research studies. It was piloted in a head and neck service at a hospital in England in 2005-2006. This led to the 'ebd approach', a resource and toolkit developed by the NHS Institute for Innovation and Improvement.[1] A book was also published about bringing user experience to healthcare.[2]

In early iterations, it was simply called "experience based design". Whilst early sites were capturing patient experience it became increasingly clear that they were paying insufficient attention to the co-design phase. The inclusion of "co-design" in the name emphasises the crucial nature of this element to achieving successful patient oriented outcomes.

The approach has gained increasing popularity and a global survey in 2013 discovered that experienced based co-design (EBCD) projects had been or planned to be implemented in over 60 health care organisations, in countries including Australia, Canada, England, the Netherlands, New Zealand, Sweden, and the United States.[3] The projects addressed a broad range of clinical areas including emergency medicine, drug and alcohol services, cancer services, paediatric diabetes care and mental health care.

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[1] The **EBD** approach. NHS Institute for Innovation and Improvement. Available at https://improvement.nhs.uk/resources/the-experience-based-design-approach/

[2] Bate, P., & Robert, G. (2009). Bringing user experience to healthcare improvement: the concepts, methods and practices of experience-based design. Oxford: Radcliffe.

[3] Donetto S, Pierri P, Tsianakas V and Robert G. (2015) 'Experience-based Co-design and healthcare improvement: realising participatory design in the public sector', The Design Journal, 18(2): 227-248 http://www.tandfonline.com/doi/abs/10.2752/175630615X14212498964312?journalCode=rfdj20

In 2011 The King's Fund developed an EBCD toolkit which is now hosted by the Point of Care Foundation.[4] The toolkit with downloadable resources - including films of facilitators and participants providing lessons and tips - was updated in 2013, by incorporating learning from the growing international experience and includes several case studies. A key element of EBCD is the use of film to capture the patient narrative, which is subsequently edited and used as trigger material during co-design events. Early sites found this approach resource intensive. Others in the meantime tested the use of an existing archive of filmed patient/carer narratives in the process and found it to be effective and less resource intensive.[5] They called it 'accelerated' EBCD (AEBCD).

In New Zealand, the approach has been supported by the Health Quality & Safety Commission who has run a Partners in Care co-design programme since 2012 based on the NHS Institutes experience based design programme. Fourteen of the nineteen DHBs in New Zealand and over 60 project teams have been involved. Waitemata District Health Board also host a health service co-design[6] website.

Impact of EBCD

An increasing number of healthcare services worldwide are using the EBCD approach.

Benefits described by users and proponents of EBCD include[7]:
(a) the value of patient and staff involvement in co-production processes
(b) the generation of ideas for changes to processes, practices and clinical environments
(c) tangible service changes and impacts on patient experiences

There are other potential benefits that include:

- from a patient perspective, improved satisfaction with the experience of care, reduction in complications associated with treatment and improved health outcomes[8]
- from a staff and organisational perspective, the case for co-production may include improvements in staff well-being, increased recognition of the need for a better

[4] Experience Based Co-Design Toolkit. Point of Care Foundation.
https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/

[5] Locock L, Robert G, Boaz A, Vougioukalou S, Shuldham C, Fielden J, et al. Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. Health Serv Deliv Res 2014;2(4)

[6] Health Service Co-Design. Waitemata District Health Board. http://www.healthcodesign.org.nz/index.html

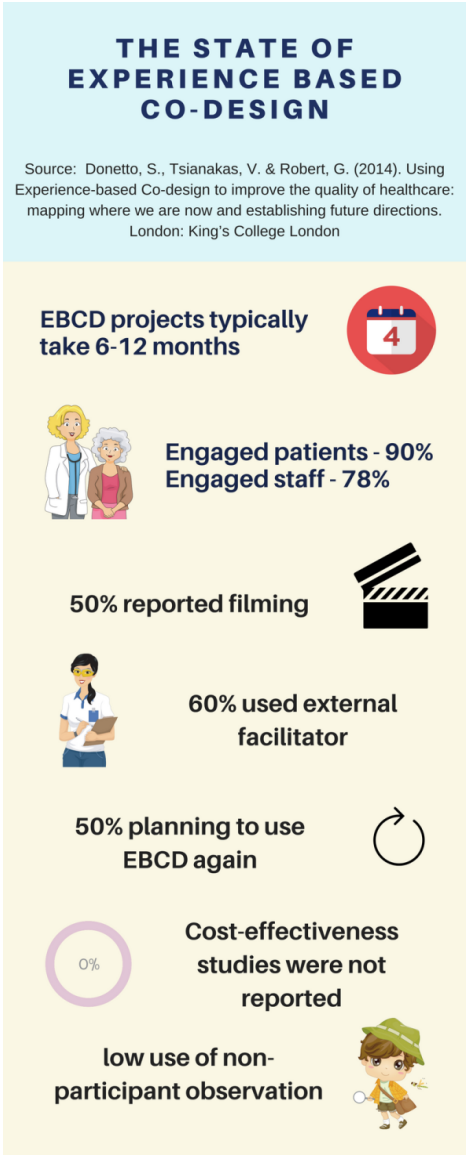
[7] Clarke D, Jones F, Harris R and Robert G. (2017) 'What outcomes are associated with developing and implementing co-produced interventions in acute healthcare settings? A rapid evidence synthesis', BMJ Open 2017;7:e014650. doi:10.1136/ bmjopen-2016-014650

[8] Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open 2013;3:e001570. doi:10.1136/bmjopen-2012-001570

understanding of patient perspectives and changes in attitudes toward working with patients as partners in quality improvement.

In the many EBCD projects around the world the majority have had some form of evaluation, however, rigorous studies of EBCD are lacking.

A key finding from research on EBCD projects found many of these projects had used the approach in a flexible manner and modified elements of it.[9] Whilst EBCD is an adaptable approach, there are some key elements and concepts, the loss of which can result in reduced impact. Services particularly seemed to find the co-design element challenging. This appears to be related to operationalising a shift to equality of power and is discussed further in the section on principles of co-design.



In Victoria, a large study[10] is underway that will evaluate the impact of a modified version of Mental Health Experience Co-Design on improving psychosocial recovery outcomes for people with severe mental illness.

In those organisations that have had positive experiences and impact using EBCD, success appears to ultimately be about three things:

- The mind-set and a way of thinking
- The methodology
- The tools

[9] Donetto S, Pierri P, Tsianakas V and Robert G. (2015) 'Experience-based Co-design and healthcare improvement: realising participatory design in the public sector', The Design Journal, 18(2): 227-248 http://www.tandfonline.com/doi/abs/10.2752/175630615X14212498964312?journalCode=rfdj20

[10] Palmer VJ, Chondros P, Piper D, et al. The CORE study protocol: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness in the community mental health setting. BMJ Open 2015;5: e006688. doi:10.1136/bmjopen-2014-006688

Mindset - a way of thinking

"Co-design practice reflects more a way of thinking than it does a process. It can be done in a multitude of different ways, and therefore cannot be delineated in a concrete step-by-step process. This is because people, problems and contexts are always going to be variable; as will the organisations and practitioners who work with them." (Quote from Co-Design Initiative report[13])

So, what is co-design? Definitions and principles

Approaches have used the model variably and in the literature different terminology is used (see Box). But given this variation it is important to start with a common and shared purpose of the what and why. The lack of a shared purpose and understanding in your organisation risks not optimising the benefits of the approach; at the same time making it too narrow will stifle creativity and innovation.

Co-production[11] (Osborne)	Co-production is defined as the voluntary or involuntary involvement of users in the design, management, delivery and/or evaluation of services.
Co-Creation[12]	Collaborative knowledge generation by academics working alongside other stakeholders. This was described in a research context but the authors noted that the concept emerged independently in several fields: • value co-creation – business studies • experience-based co-design - design science • technology co-design - computer science • participatory research - community development.

[11] Stephen P Osborne, Zoe Radnor & Kirsty Strokosch (2016) Co-Production and the Co-Creation of Value in Public Services: A suitable case for treatment? Public Management Review, 18:5, 639-653, DOI: 10.1080/14719037.2015.1111927

[12] Greenhalgh, T., Jackson, C., Shaw, S. and Janamian, T. (2016), Achieving Research Impact Through Co-creation in Community-Based Health Services: Literature Review and Case Study. The Milbank Quarterly, 94: 392–429. doi:10.1111/1468-0009.12197

Co-design	Co-design is an approach to participatory design (although traditionally of a new product) that seeks to actively involve all stakeholders (e.g. staff, patients, citizens) in a process to help ensure the result meets their needs and is usable. Designing and delivering services and systems in an equal and reciprocal relationship between professionals, people using services, their families and their community. (New Economics Foundation)
Experience Based Design (EBD) Experience Based Co-Design (EBCD)	Experience based design was the initial terminology used but was later modified when it was observed there was insufficient focus on the co-design element. Experience-based co-design involves gathering experiences from patients and staff through in-depth interviewing, observations and group discussions, identifying key "touch points" (emotionally significant points) and assigning positive or negative feelings. A short edited film is created from the patient interviews. This is shown to staff and patients, conveying in an impactful way about how patients experience the service. Staff and patients are then brought together to explore the findings and to work in small groups to identify and implement activities that will improve the service or the care pathway. The NSW Agency for Clinical Innovation defines it as a way of bringing consumers, carers, families and health workers together to improve health services. Giving people an equal voice as active partners in health care improvement leads to better outcomes for all.

Accelerated Experience Based Co-Design (AEBCD)	A modified version of EBCD in which a pre-recorded trigger film is used as the trigger material during co-design events.

Terminology

This animated video on a hypothetical scenario offers a useful oversight of the co-design approach and the required mind set of bringing together user experience and equal partnership in co-designing.

https://www.youtube.com/embed/HWgJlwTDIRQ
Duration: 3:45 minutes Source: Think Public

Now you've seen what it is, hear from some services users about it.

https://www.youtube.com/embed/qG5F1rC_dN4
Duration: 3 minutes Source: Social Care Institute for Excellence

Principles and values

The way of thinking when considering co-design can be thought of as a set of values and principles. The Social Care Institute for Excellence (SCIE) in the UK have identified four critical values:

- Equality – everyone has assets
  - The principle is that everyone has skills, abilities and time to contribute and that no-one group or person is more or less important than another.
- Diversity
  - The process is inclusive and diverse to represent all the stakeholders. This may require special efforts and alternative approaches to ensure seldom heard and hard to reach groups are included.
- Accessibility
  - Attention to accessibility is required to ensure everyone has an equal opportunity to participate as fully as they can in an activity in a way that suits them best.

- Reciprocity
  - Reciprocity means people get something back for putting something in. These can be using formal methods and sometimes can be met from achieving equal relationships between participants and the organisation.

These values are articulated in the following video.

https://www.youtube.com/embed/gum8WtameVs
Duration: 20 minutes. Source: Social Care Institute for Excellence

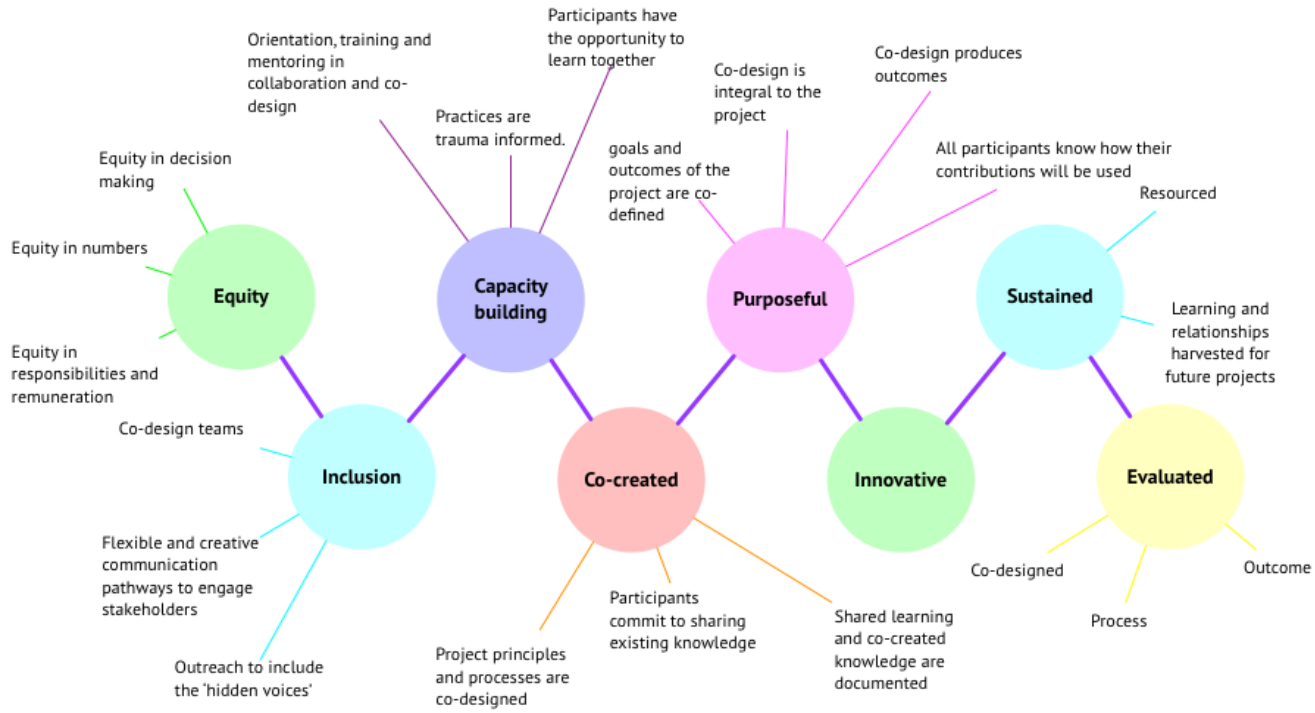
During 2016, the Co-design Initiative[13] invited a broad cross section of stakeholders to participate in two co-design symposia in Victoria. It was a voluntary carer and consumer led project and a planned response to the review and reforms of the Australian mental health system. The output was a set of principles for authentic co-design. A couple of principles are identical to those from SCIE and others have implicit overlaps. These principles were developed in the Australian context and together with those of SCIE are relevant to any EBCD project:

- Equity
  - Co-design is collaborative promoting an equitable partnership between stakeholders
- Inclusion
  - Co-design is inclusive, supporting the involvement of all stakeholders
- Capacity building
  - Co-design initiatives ensure skill development and capability building for all participants
- Co-created
  - Participants commit to learning from each other
- Purposeful
  - Co-design works towards real outcomes that are meaningful to all participants
- Innovative
  - There are opportunities to explore and experiment with alternative solutions
- Sustained
  - There are opportunities to build on the co-design process for future initiatives

[13] Codesign – shared perspectives on authentic co-design. 2016. https://auspwn.files.wordpress.com/2016/05/codesign-shared-perspectives-report-vf1-5-040616.pdf

- Evaluated
    - Evaluation is integral to all co-design projects

The diagram illustrates each of the principles with more details.



Principles of authentic co-design (Developed by Prestantia Health from content of the Co-Design Initiative Report)

More recently, the NSW Agency for Clinical Innovation has identified a set of principles that encapsulate much of the intent of the process of experience based co-design:[14]

- Equal partnerships - consumers, families and staff work together from the beginning with an equal voice and shared ownership and control
- Openness - work together on a shared goal, trust the process and learn together
- Respect - acknowledge and value the views, experiences and diversity of consumers, families and staff
- Empathy - practise empathy and maintain an environment which feels safe and brings confidence to everyone
- Design together - consumers, families and staff work together to design, implement and evaluate improvements, activities, products and services.

Principles and values in conducting research with Aboriginal and Torres Strait Islander people and communities have been articulated and should be considered for EBCD projects too. These are Spirit and Integrity, Reciprocity, Respect, Equality, Survival and Protection, and Responsibility (https://www.lowitja.org.au/ethics/guidelines).

[14] Experience Based Co-Design Approach. (2017). Available at https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0003/390126/ACI-Experience-Based-Co-design-Infographic.pdf

The Methodology

Experience based co-design is composed of two key components.

1. A user-centred orientation - '**experience based**'
2. A collaborative change process - '**co-design'**

The features[15] of EBCD methodology and tools used are a way of operationalising the principles and augment the mind-set. They are based on:

- A focus on designing experiences, not just improving performance or increasing safety
- Putting patients and staff at the heart of the effort
- Together they do the designing
- In the process, improving the day to day experiences of giving and receiving care

There are a range of tools that can be used when gathering experience and their core purpose is on deeply understanding patient and staff **experiences and emotions** rather than relying upon attitudes or opinions. Qualitative methods play a central role and ethnographic methods such as conversations and storytelling (narrative based approaches), and in-depth observation are used. Key '*touchpoints'*, that is the point of a process where a person experiences an emotional reaction with the health care service are identified, and emotions at those touch points are mapped.

The **co-design** element is equally critical. A criticism of many EBCD projects is that they have not paid enough attention to the four key components that lead to effective co-design[16]:

- Participation
  - co-design is a collaborative process in which as many stakeholders as possible have input;
- Development
  - co-design evolves as a process, maturing and adapting as it takes place;
- Ownership and power
  - co-design involves a transformation of ordinary power relations between stakeholders and aims to generate collective ownership; and
- Outcomes and intent
  - co-design has a practical focus, notwithstanding that unplanned processes and transformations are likely to occur as collateral effects of the process.

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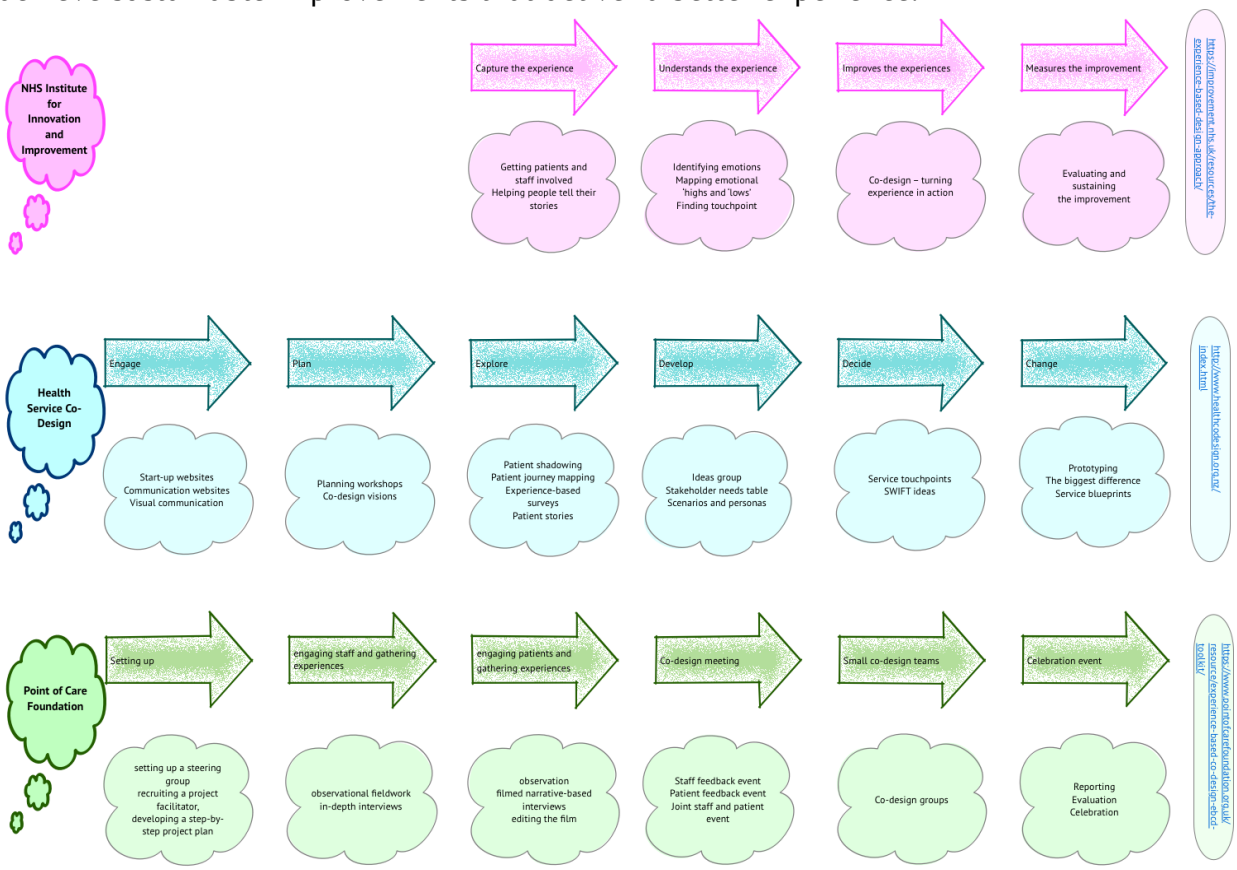
[15] Robert, G., Cornwell, J., Locock, L., Purushotham, A., Sturmey, G. and Gager, M. (2015). Patients and staff as codesigners of healthcare services. BMJ, 350(feb10 14), pp.g7714-g7714.

[16] Sara Donetto, Paola Pierri, Vicki Tsianakas & Glenn Robert (2015) Experience-based Co-design and Healthcare Improvement: Realizing Participatory Design in the Public Sector, The Design Journal, 18:2, 227-248

The tools

There are three influential experience based co-design resources in health. The diagram illustrates the three different resources and the tools offered by each of them. Each resource shares fundamental similarities but each also has subtle differences. The Point of Care Foundation and New Zealand include preparatory steps around planning and engaging. The Point of Care Foundation places a strong emphasis on capturing the story using videos (or using pre-recorded videos as in AEBCD).

The tools are designed to help manage the project aspects of EBCD, to gather and understand the experience, to support the co-design aspects of the methodology to achieve sustainable improvements that deliver a better experience.



Influential healthcare related EBCD resources

The Australian toolkit

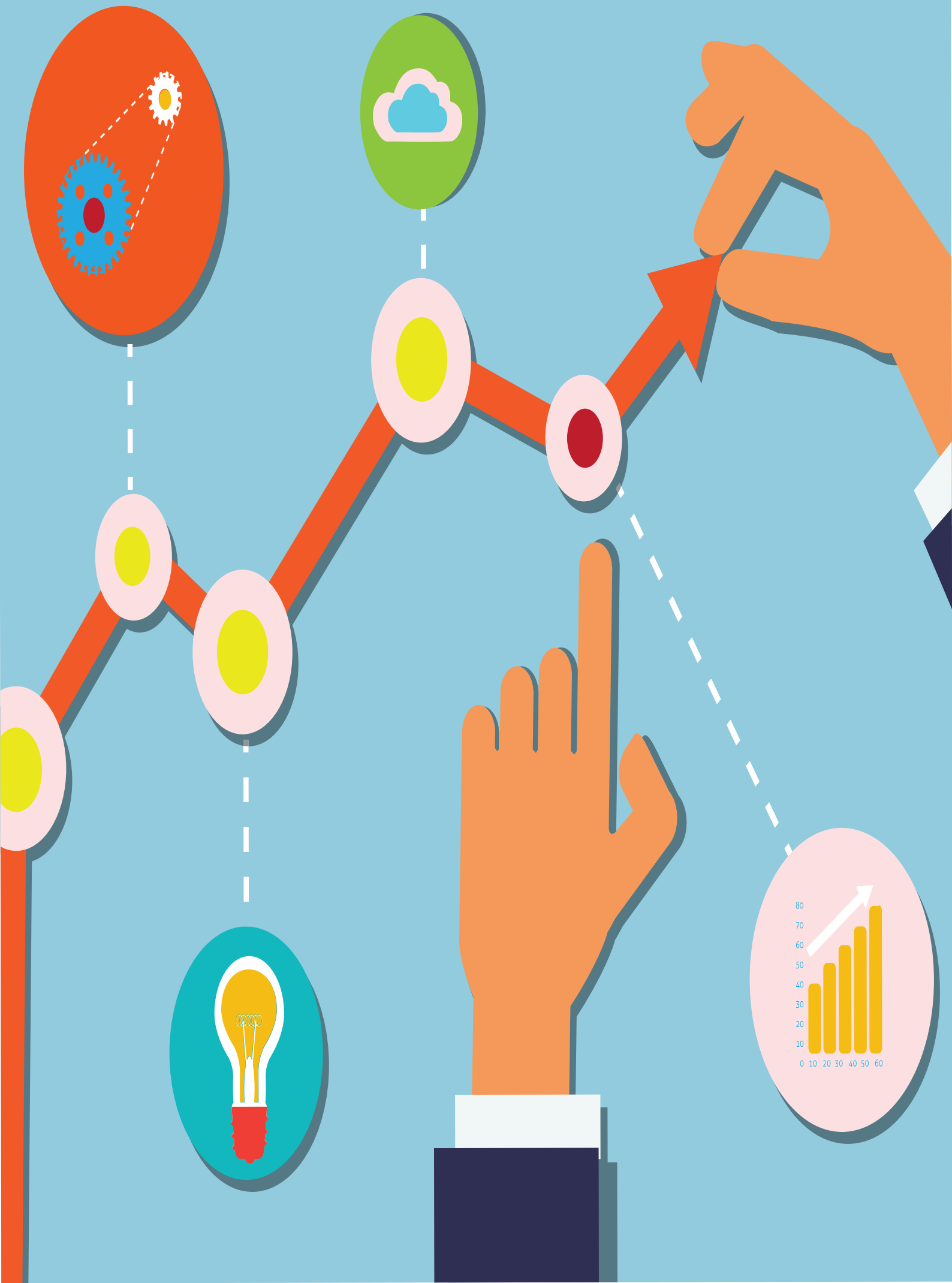
In this next section, we take you through five different stages of EBCD and use illustrative examples from Australian case studies. The tools used in each of the stages are described and for each tool more detailed instructions are provided with implementation aids such as spreadsheets, agenda planners and interactive pdfs.

We start with:

- an emphasis on planning and setting up for success as an incredibly important precursor for any EBCD project.

This is followed by four more steps:

- gather the experience
- understand the experience
- improve the experience
- monitor and maintain the experience.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Set up for
success

Set up for success

Many improvement projects are not sustained. The sustainability may be improved by understanding the factors that contribute to success, and then planning and investing effort into optimising those factors. The NHS Institute for Innovation and Improvement developed a sustainability tool for improvement projects which identified three groups of factors that contribute to sustainability.

Process factors

- real or perceived benefits beyond helping patients
- credibility of evidence for the change
- adaptability of the improved process
- effectiveness of the system to monitor progress

Staff factors

- staff involvement and training to sustain the process
- staff behaviours towards sustaining change
- engagement by senior and clinical leaders

Organisation factors

- fit with the organisation's strategic aims and culture
- the existence of infrastructure for sustaining change

In a New Zealand analysis[1] of EBCD projects (Partners in Care) authors found relevance and applicability between the categories from the Sustainability Model and the sustainability requirements of EBCD projects. The following ideas were reported to support sustainability:

- Promoting the projects and increasing visibility of the work and patient voices within healthcare services to support cultural change around consumer voices
- Disseminating skills more widely across healthcare systems by creating opportunities for experiential learning, or learning through observation with new co-design projects
- Building 'people power' through engagement with students, volunteers or others who could be involved in projects
- Increasing buy-in from sponsors or other senior leaders to enable or endorse (i) patients engagement approaches, and (ii) changes recommended by project teams
- Involving more patients and team members in project teams to maintain momentum and mitigate staff turnover and consumer attrition from projects
- Continue building relationships with patients and other health professionals to share the co-design approach with an opportunity-based, rather than a fear-based, response

[1] Maher, Lynne; Hayward, Brooke; Hayward, Patricia; and Walsh, Chris (2017) Increasing sustainability in co-design projects: A qualitative evaluation of a co-design programme in New Zealand Patient Experience Journal: Vol. 4 : Iss. 2, Article 7. Available at:

- Align projects with broader/wider projects or strategic directions of healthcare services
- Embed the approach within policy, procedure or other system changes
- Embed the approach in existing training and development opportunities that are already funded for patients and healthcare professionals
- Seek funding opportunities to secure time of clinical staff to contribute to quality projects around patient stories/patient voices
- Dedicate adequate resources for funding of interventions
- Increase staff and leadership engagement in the masterclass training for increased buy-in and understanding of the value of patient voices

The first step in any EBCD project involves planning the project and considering how you will address the factors that will contribute to maximise the benefit you achieve from your project and its longer-term sustainability. The following are a list of items and resources for you to consider in setting up for success.

Strategy/Tool	Description
Engagement	Engagement is critical to the success of any EBCD project. This requires engagement from all stakeholders including patients, staff and others that will be impacted by the project. The New Zealand health service co-design website has made engagement the first step in the EBCD pathway. It's a critical part of setting up for success. It is recommended relationships with patients are established before beginning your improvement work. This will help establish patients see a need for change, their interest in being involved and the best mechanism to involved them. They identified tools including start-up workshops, communication websites and visual communication which are discussed further below.
Deciding on your EBCD approach	There is no single one way to perform EBCD. As discussed in previous chapter it is fundamental about a way of thinking and applying principles. The key elements of the methodology are: 1. A user-centred orientation - '**experience based**' 2. A collaborative change process - '**co-design**' Health Service Co-Design in New Zealand have

produced route maps. These route maps are simple flowcharts suggesting tools to consider based on one of three scenarios:

1. I want to develop a new service
2. I want to improve an existing service
3. I want to solve a specific issue

Please visit for further information

- http://www.healthcodesign.org.nz/how_to.html

NHS Sustainability Tool

This is a diagnostic tool that is used to predict the likelihood of sustainability for your improvement project. It can be used by individuals or teams and is best used at the beginning, near to the middle and about four weeks before the end of your project.

- https://www.qualitasconsortium.com/index.cfm/programs-services/sustainability/

Sustaining improved outcomes

In this publication which drew strongly from the NHS documents above authors define sustainability to be "when new ways of working and improved outcomes become the norm". They identify 12 factors which impact on sustainability and provide examples of how they might be operationalised. They suggest three or four factors may be most relevant for any one project.

- https://nyshealthfoundation.org/uploads/general/sustaining-improved-outcomes-toolkit.pdf

Senior leadership support

The New Zealand analysis[1] found the need for senior leadership was critically important. An effective sponsor was necessary and they identified key attributes for an effective sponsor and senior leader.

- Position
  - In a position of influence to provide an authorising environment for staff time committed to projects, to support proposed interventions/changes to systems or services, and establish ongoing organisational development in co-design approaches.

- People
  - Existing relationships and network knowledge of the relevant healthcare system.
- Passion
  - Passionate and energetic about the co-design approach; a vested interest in the project.
- Presence
  - Availability to meet regularly with the project team to maintain engagement and visibility and to show support; proactive in checking on progress; approachable for direction and advice when needed.
- Problem solver
  - Engage with project teams to find solutions to barriers encountered throughout project phases.

A video from Point of Care Foundation on making the case.
https://www.youtube.com/embed/9EI9XnEt03U

Source: Point of Care Foundation Duration: 3:11

Key messages that are helpful will include:

- EBCD is a cutting-edge approach and offers promise of change and has growing evidence base
- Use case studies from other sites
- Patient stories and material generated can be used more broadly (Case Study 3)

Project Management

A video from Point of Care Foundation on getting started and the project team
https://www.youtube.com/embed/3xc9HtIsUpw
Source: Point of Care Foundation Duration: 2:26

This guide to project management is from an archive of the NHS Institute's website and is a recommended resource from the Point Care Foundation. In using this tool it is important to understand the problem or opportunity from multiple perspectives: organisational data related to the perceived problem or opportunity and experience data form patients/family and staff. Once the team is clear about the problem then they can use the creativity tools described in this resource to identify potential solutions.

The guide contains a six-step approach to project management:

Outline of the six stages:

- Start out
- Define and scope
- Measure and understand
- Design and plan
- Pilot and implement
- Sustain and share

It also identifies critical elements to success:

- Stakeholder engagement and involvement
- Sustainability
- Measurement
- Risk and issues management
- Project documentation and gateway criteria

It is comprehensive and for each of the six stages it

describes several steps and provides hyperlinks to further tools and resources.

You should consider a project steering group. This should include key members of staff from the service and their management and a key senior person (see senior leadership support). Meetings should be at least scheduled for:

- before the project begins
- before the first feedback event
- before the joint patient–staff event
- after the celebration event

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/project_management_guide.html

Start-up workshop

Health Service Co-design in New Zealand recommend start up workshops as an engaging method.

These workshops involve gathering a wide variety of people together in one place to discuss different points of view about issues, learn together and make decisions about next steps. In doing so they help you develop relationships with a variety of stakeholders and reach a common understanding about the way forward.

Start-up workshop

Start-up workshop summary template

Planning workshops

This is a workshop that brings interested people in the project together and develop and own a plan together.

This tool invites you to take a bigger picture and longer term view of the health conditions and services you are working with.

Planning Workshop

Planning workshop template

Co-designing visions

Developing a vision and articulating it in a written statement can help maintain the focus on patient experience and supports developing a shared purpose for the project. It is critically important that the vision does not jump directly to a solution.

Co-designing vision

Co-designing vision template

A communication strategy

Communication is an important aspect of engaging and maintaining momentum before, during and after your project.

NSW Health have an online communications strategy template which offers an opportunity to consider how you will manage your communications. Tools you may already have used e.g. co-designing vision and outputs from your start-up and planning workshop may be helpful to incorporate into this document.

- Communications Strategy - WOHP
  Communications Strategy Template - NSW Health

More specifically, Health Service Co-design in New Zealand recommend a communication website and visual communication.

Communication websites are a social networking tool where you can share information online about your work with other stakeholders.

Communication websites

Visual communication is a way of conveying ideas to people using aids such as pictures, diagrams and colours rather than just words.

Visual communication

Recruiting staff

The recruitment and maintaining engagement of staff is critical to the success of any EBCD project. In case study 2, when asked what they would do differently the improvement team said:

"If we were to do it again we would actively recruit a few ward champions to drive the project on the floor. We would also involve ward staff in asking patients and families about the boards, to hear about their experience first-hand."

In case study 7, which is a published and evaluated EBCD project the team noted that EBCD activities were viewed as an additional burden by staff. Lack of dedicated time may have reduced the impact and sustainability of the programs.

The process of EBCD is designed to be engaging, however, there are no specific tools to assist with recruiting of staff. In your recruiting effort, the following tips will be useful:

- Develop a simple 'elevator pitch' stating why teams want to work on this project and how a staff member can become involved (what can they do) and what is 'in it' for them (exposed to new ideas and a new methodology)
- Enlist key support from an influential member of the team (not necessarily the most senior) and from those who commissioned the work in the first place, to explain the reasons for undertaking the project (specifically note advice above on leadership support)
- Explain that the process does not imply anything negative about the service
- Agree dates well in advance, at a time when people tend to be able to meet
- Make sure everyone has all the information they need, so that no one can claim not to have known about it
- Starting by gathering staff members experiences of delivering a service often gets them interested and can be a time to engage them to help with other tasks
- Send through interview questions in advance to give them time to prepare. Also, consider inviting staff members to influence some of

the questions

Recruiting patients

Case Study 1 on NSW Brain Injury Rehabilitation Model of Care experienced delays in recruitment of and access to consumers and their families. This resulted in an initial analysis of a more limited set of consumer experiences than planned. They also noted difficulty connecting with consumers. They found that those who had a more positive experience were more likely to respond. This created a bias towards positive experiences and is one of challenges in meeting the equity principle of EBCD.

In your recruiting efforts for patients and their carers the following tips will be useful:

- Use staff you've recruited to help you recruit patients
- Try and include a diverse range of patients (age, sex, ethnicity) but also different services and treatments
- If you need to recruit particularly vulnerable groups you may need to allow additional time and leverage of existing groups to build trust and rapport
- Try and recruit early and use multiple modes to try and recruit e.g. direct invitations, posters, leaflets, local patient groups
- Be clear that the approach is not about focusing on negative experiences – it's about working together to find solutions

Working with Aboriginal People and Communities

The NSW Department of Community Services has developed a practice resource to provide a consistent approach to working with Aboriginal people and communities. It contains information and practice tips all of which are relevant to EBCD projects.

- Working with Aboriginal People and Communities. A Practice Resource. http://bit.ly/2jEMOR6

Ethics and EBCD

There is an overarching responsibility to ensure that the rights and dignity of patients are protected always. This includes ensuring patients understand what is being done, can withdraw from participation at any time without impact on the care they receive and that these conditions continue as a project proceeds. Patients should not be exposed to harm by the activity.

In 2007, the National Health Service in the United Kingdom issued an ethical statement specifically for staff involved in EBCD work. The seven principles of good practice it describes are:

1. The improvement initiative should be designed and undertaken in a way that ensures its integrity and quality
2. All people who are involved, including staff patients and carers must be informed fully about the purpose, methods and intended possible uses of any information they provide
3. All participants must formally consent to the use of any information they provide including attribution of quotations, film extracts etc
4. All people involved participate on a strictly voluntary basis free form any coercion and able to withdraw at any time without need for explanation
5. All people involved must not be knowingly exposed to harm or distress
6. Provision must be made for responding to queries and complaints about the work
7. Privacy and confidentiality must be respected as requested.

Does your project require approval by an ethics committee?

Any improvement activity must be conducted in a way that is ethical. In general quality assurance and quality improvement work, such as EBCD projects, does not require ethical approval provided it meets certain criteria.

The NHMRC document "Ethical Considerations in Quality Assurance and Evaluation Activities" lists several triggers which may indicate a need for formal ethical review. The triggers are:

- ☒ Where the activity potentially infringes the privacy or professional reputation of participants, providers or organisations
- ☒ Secondary use of data - using data or analysis from QA or evaluation activities for another purpose
- ☒ Gathering information about the participant beyond that which is collected routinely. Information may include biospecimens or additional investigations
- ☒ Testing of non-standard (innovative) protocols or equipment
- ☒ Comparison of cohorts
- ☒ Randomisation or the use of control groups or placebos

☒ Targeted analysis of data involving minority/vulnerable groups whose data is to be separated out of that data collected or analysed as part of the main QA/evaluation activity.

Triggers which may indicate need for ethical review

If one of these triggers applies the NHMRC National Statement on Ethical Conduct in Human Research 2007 should be consulted. If ethical review is not required and publication is being contemplated strong consideration should still be given to obtaining ethics approval or if that's not possible a statement affirming that an alternative approach to ethical review is deemed appropriate. The resource list below contains links to definitive NHMRC documents and examples of state government and university guidelines for ethical approval of quality assurance activities. There are also resources AND guidelines relevant for working with Aboriginal and Torres Strait Islander people.

Irrespective of whether ethics is sought or not depending on the outcome of the above process you should consider:

- Some form of social support in case anyone involved in the project is affected by the issues that arise. This could include patients, interviewers, staff, facilitators and those involved in filming and editing
- When using EBCD with potentially vulnerable groups, the ethical issues arising from the process can be more complex – particularly when it comes to preparing them for, and supporting them through, the co-design stage. The process can be extremely rewarding, but patients, families and staff can find it challenging too, so you need extra preparation. When working with these groups, the steering group or project team should include someone with experience of dealing with the psychological and ethical issues that may arise, such as a clinical psychologist

Resources

- Ethical Considerations in Quality Assurance and Evaluation Activities. NHMRC. 2014. http://bit.ly/2AyxPCP
- Human Research Ethics Committees- Quality Improvement & Ethical Review: A Practical Guide. NSW Government. Health. 2007. http://bit.ly/2BCo0RM
- Do Quality Improvement/Assurance Activities Need Ethical Approval? ACT Government. Health. 2007. http://bit.ly/2ANLjuQ
- Human Research Ethic Committee. Quality Assurance Guidelines. University of Newcastle. 2008. http://bit.ly/2jEJ8ib
- National Statement on Ethical Conduct in Human Research. NHMRC. 2007. http://bit.ly/2BCoCH4
- NHMRC guidelines for Aboriginal and Torres Strait Islander health research. 2003. http://bit.ly/2ANfCC1
- Aboriginal peoples participation in their health care: a patient right and an obligation for health care providers. http://bit.ly/2i9dOHW
- The Lowitja Institute. https://www.lowitja.org.au/research

START-UP WORKSHOPS

WHAT

These workshops involve gathering a wide variety of people together in one place to discuss different points of view about issues, learn together and make decisions about next steps.

WHY

Start-up workshops help you develop relationships with a variety of stakeholders and reach a common understanding about the way forward.

WHEN

Use this tool during the early stages of your work to help you to make key decisions about your service improvement project.

HOW

1. Identify your key people

- Identify the owners of the project and the key decision-makers
- Identify the people and groups who have a stake in the results of the work
- Identify who else needs to be informed of the project and its results
- Identify a named person who can be a point of contact for consumers.
- Review your lists and decide who should be invited to the workshop. Get a second opinion on whether the invitation list covers everybody. Make a separate list of those who do not need to attend but should be informed of progress.

2. Develop a workshop agenda

3. Invite attendees

- Invite people to attend the workshop and send them an agenda. For consumers a personal discussion may be helpful.
- Make arrangements for the venue, transport, refreshments and any other needs.

4. Hold the workshop

Key discussion items should include:

- Start with a welcome and a brief round of introductions. Agree ground rules and specifically that everything said in the workshop remains confidential and reporting will focus on agreed improvements only
- Prepare to present agenda in a very brief (bullet points if written) draft form
- If the group is large then ask for discussions to take place in sub-groups and then report back. Be prepared to develop a master list of comments on these topics
- Move through the agenda, providing five-minute breaks every 45 minutes or so to avoid fatigue
- At the end of the workshop, thank attendees and arrange for a brief draft report to be sent out for final comments. If appropriate, commit to the next stage of the project at this time and outline any likely steps.

Adapted with permission from healthcodesign.org.nz

5. Circulate and finalise the report as appropriate

- You can use the workshop summary template to assist you.

6. Stakeholder updates

- Update stakeholders on progress regularly and hold further workshops to work together on shared concerns, ideas and decision-making as required.

OTHER CONSIDERATIONS

- Allow at least two hours for this workshop
- Consider how the output from the workshop will be captured
- Consider who will facilitate the workshop and develop a flexible plan for the workshop
- Have a staff member available at the workshop that can support. Introduce this person at the beginning of the workshop.
- Ensure all attendees feel free to share concerns and ideas throughout the workshop. Remind people all comments are made in confidence and should not be reported outside the workshop.
- Remind patients that discussing their concerns and ideas is vital to the workshop.
- Remind staff the aim is to improve service processes for them as much as for patients. Prepare a way to involve the whole workshop in confirming any final decisions to end the workshop.

NEED FOR PROJECT	**OVERVIEW OF PROPOSED PLAN AND METHODS**
NEED FOR STAKEHOLDER INVOLVEMENT	**DECISIONS REQUIRED**

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PLANNING WORKSHOPS

WHAT

Planning workshops are where people with an interest in the improvement work you want to do, to meet up for a set time to share information and come up with a plan for how the work can be done. They usually require someone skills/experience and involve lots of discussion.

WHY

Service improvement work is often defined by what an organisation wants to do and/or what it thinks will work. This tool invites you to take a bigger picture and longer term view of the health conditions and services you are working with.

A planning workshop will help you:

- Involve consumers from the beginning and get buy-in and ownership from everyone early on
- Understand where to focus your efforts and understand what data/information you already have and what more you will need. It helps clarify what your organisation can and should do, what it can do but is not a priority, and what it can't do that remains important
- Build a robust and focused plan for your service improvement work
- Ensure the plan is clearly understood by the project team and stakeholders

WHEN

Use this tool when you need to plan how you are going to do your service improvement work and what your data needs are.

HOW

1. Identify the key participants

- Identify the owners of the project and the key decision-makers
- Identify the people and groups who have a stake in the results of the work
- Identify who else needs to be informed of the project and its results
- Now review your lists and decide who should be invited to the workshop. Make a separate list of those who do not need to attend but should be informed of progress.

2. Develop a workshop agenda

- For example, you might suggest it will cover project outcomes that could improve things from the perspective of patients, staff and the service or organisation

3. Invite attendees

- Invite people to attend the workshop and send them an agenda.
- Make arrangements for the venue, transport, refreshments and any other needs.

4. Use the planning workshop template to run the workshop

5. Review the contents of the planning workshop template and agree on a final version

Adapted with permission from healthcodesign.org.nz

OTHER CONSIDERATIONS

- Include stakeholders from a variety of backgrounds and disciplines
- Encourage external stakeholder input during discussion of outcomes
- Work visually as much as possible. This simplifies the workshop process and encourages active participation throughout
- Use the planning workshop template to communicate progress and issues throughout the project

Template Instructions:

1. Identify the desired patient and staff outcomes

- What are the desired outcomes of this work for the patients and their communities?
- Patient outcomes are both personal and community health outcomes, measurable in terms of the health status of individuals and populations. These may take years or decades to establish, so they imply sustained service provision.
- Patient outcomes may be expressed as qualitative and/or quantitative targets.

2. Identify the desired service outputs

- What outputs are needed in the next few years to achieve the patient outcomes identified above?
- Outputs are immediate and direct results of the service delivery.

3. Identify the improvement goals

- What goals are needed to achieve the service outputs?
- Include improvements in existing services or possible new service elements.
- Identify as many specific goals as you want, then narrow these down to two or three key goals.

3. Project Goals
What goals are needed to achieve the service outputs?

2. Service Outputs
What outputs are needed to achieve patient outcomes?

1. Patient Outcomes
What are the desired outcomes for patients and their communities

Statement

Statement

Statement

Planning Workshop Template

Adapted with permission from healthcodesign.org.nz

CO-DESIGN VISIONS

WHAT

A vision is a written statement about what your health service aspires to achieve. It includes both what your service will deliver to patients (the service promise) and what patients can expect as a result (patient outcomes).

WHY

Improvement work can sometimes resolve system issues without improving patient experiences. Even when considered, patient experiences may still be overshadowed by other elements. Having a vision helps keep the patient in focus.

WHEN

Use this tool in the early stages of your co-design work. It is particularly useful when developing a new service but can be used in other contexts too. This tools is not about creating the solution but the vision and expectations of what it might deliver.

HOW

1. Use the four-box template to help you develop your vision

- This section will require information about data about experiences that has been gathered

2. Develop a draft service promise and patient outcome statement to communicate your project vision

- This will help people understand why the improvement work is being done.

3. Finalise your service promise and patient outcome statement

- Use these as a reference point for all your improvement ideas and developments. Does the improvement contribute to the promise and its outcomes?

Definitions:

- *The **service promise** commits the service to providing a specific experience for patients. It begins with the words 'we will…' and says what the service will do.*
- *The **patient outcomes statement** commits you to providing specific outcomes for patients.*

OTHER CONSIDERATIONS

- Make the vision as tangible, practical and patient-oriented as possible.
- Don't use medical or system jargon in your promise or outcome statements. Instead use simple words and phrases a patient can understand.
- Try not to debate words and semantics. Remember, this is a draft and as you learn through the project, these statements should evolve.
- Always use patients as your reference-point. If patients are not involved in developing the vision, make sure you run it past them afterwards and reword if necessary.

You can include your completed four-box template as a reference diagram in your planning documentation.

01 How **do** patients want to experience the service? How **do** they want to feel during service delivery?

02 How **don't** patients want to experience the service? How **don't** they want to feel during service delivery?

04 What outcomes **don't** patients and communities want?

03 What outcomes **do** patients and communities want?

Four box template

Adapted with permission from healthcodesign.org.nz

COMMUNICATION WEBSITES

WHAT

Communication websites are a social networking tool where you can share information online about your work with other stakeholders.

WHY

Communication websites enable ongoing communication between patients, staff and other people involved in your service improvement work. This tool helps people to share their ideas and get fast feedback. It can also be useful for staff to gain an insight into patients' perspectives or develop specific concepts and ideas.

WHEN

You can use this at any stage during your work.

HOW

1. Decide on the website's purpose

For example, as a tool to communicate with people on the project's progress or to seek specific comments on an improvement idea.

2. Choose an online site to host your social network

Examples of social networking hosts designed specifically for groups include ning.com, bigtent.com and Google Groups.
Note: It is free to set up your social network site with many of the hosts.

3. Develop your content

This may include discussion forums, photos, videos, blogs and events.

4. Invite participants to join

Most social networking host sites will include a way of doing this from within the site.

OTHER CONSIDERATIONS

- Make sure the people you want to communicate with are computer savvy, have internet access and can afford the data.
- Update your website regularly and ensure that information is current.
- Make sure you check the privacy settings of the site carefully. If your project has confidential information that you don't want available to the public, limit access accordingly.
- Online communication is an effective way of communicating with stakeholders but it can't replace the richness of information gained from talking or meeting with people in person. Use this tool to supplement other communication and feedback methods.

VISUAL COMMUNICATION

WHAT

Visual communication is a way of conveying ideas to people using aids such as pictures, diagrams and colours rather than just words.

WHY

The purpose of visual communication is to help create accessible, tangible ways of talking about and designing better service experiences. Visual communication is useful for making abstract things – such as needs, issues, ideas, processes and outcomes – tangible, and can help span the different perspectives of patients, staff and other stakeholders. This tool can also capture complex interactions between people, processes, and ideas.

WHEN

You can use visual communication at any time during your project when you need to express key concepts in simple and practical ways. For example, you may want to use a visual map to explain a patient's journey through a health service.

HOW

1. Identify the topic

- Do this as clearly as possible, focusing on defining what you mean and what you don't mean.

2. Identify who the communication is from (usually your organisation) and who it is for (usually patients)

Distinguish between how the organisation and the patients think and speak about the topic. Focus on the patients' point of view including:

- Things they might understand already, and the ways they typically talk about them
- Things they can agree with easily
- Questions they might ask
- Things they might by confused by and/or disagree with.

3. Explore similes and metaphors for communicating the topic

- For example, patients often say their journey is 'like a roller coaster' (a simile) or a staff member 'has become a rock' (a metaphor).
- Select a few options you think will work well in communicating the topic. Note that you may need to balance accuracy (in relation to service processes or clinical diagnoses) with the views, existing knowledge and needs of your audience.

Adapted with permission from healthcodesign.org.nz

4. Sketch out drafts of your ideas

- Keep your sketches rough. This encourages people to engage with them and comment on them, and to try drawing ideas themselves. Ignore criticisms about the roughness of the drawing – it's not the point.
- Others find using images from magazines or clipart on PowerPoint useful too

5. Use the following test to see how easy the sketches are to understand

- Show the drawing to a patient
- Ask them to explain in their own words what it is telling them
- Explain what you meant
- Discuss ways to improve the sketch so it communicates effectively and efficiently.

6. Select a draft

- Select the version and specific elements that communicate best and document these
- Develop a 'good' draft
- Trial your draft in a real setting such as a clinic or ward.

7. Decide on the final version and use as appropriate.

- You can ask a graphic designer or illustrator to help you complete the final version so you have a professional looking piece of work.

There are many online tools that can help you with visual communication. Some of these are free, others charge depending on what you would like. For example, https://elearningindustry.com/the-5-best-free-cartoon-making-tools-for-teachers describes five such sites.

OTHER CONSIDERATIONS

- Make sure you do your development in the sketch phase – it's simple, quick and gets you 90% of the way to effective and efficient communication.

Gather the
experience

Gather the experience

Initially, you will want to get a sense of what the current experience is. There are many ways to gather the experience. The statement by Steve Rogers, responsible for designing the BBC's home page, is even more relevant for service industries i.e. designing a service is designing a relationship. Relationships are founded on feelings and emotions experienced. Therefore, when gathering the experience, you really want to get a sense of those feelings and emotions. There are many ways you can do this and you may want to use more than one way.

> "Designing a product is designing a relationship"
>
> Steve Rogers

> "Several techniques were used to capture our consumer's experiences in including surveys, interviews and focus groups. We used these techniques to capture both the range of consumer experiences and the detail of specific experiences across that range. Interviews and focus groups were a powerful way to learn and discover insights about people's experiences and their stories." Case Study 5

Patient Shadowing and Observation

Patient shadowing and observation are important tools that have been underutilised in EBCD.[1] It can help you really understand different perspectives and highlights issues that are unlikely to arise through any of the other activities. It can be helpful to do undertake observation before any patient or staff interviews as it may help inform your questions during that stage.

Patient shadowing and observation tool

https://www.youtube.com/embed/cJsDzuD9EmQ
Source: Point of Care Foundation Duration: <3 mins

[1] Donetto S., Tsinakas V., Robert G. (2014) Using experience-based co-design (EBCD) to improve the quality of healthcare: Mapping where we are now and establishing future directions, London: King's College.

"You never really understand a person until you consider things from his point of view... until you climb inside of his skin and walk around in it."
—Atticus Finch, in Harper Lee"s To Kill a Mockingbird

https://www.youtube.com/embed/1rZoyKHLXAI
Source: Patient and family centred care (PFCC), Duration 12 mins.

Patient and Family Shadowing – A resource from PFCC

Design students from University of Canberra attended a GP clinic to undertake observation in the waiting room. After a careful analysis of activities students identified potential problems to tackle. The observation process informed a separate project that and was used as trigger material at a consumer workshop developed an interactive pod in the waiting room. (Case Study 6)

Patient Stories

Storytelling is at the heart of EBCD. Gathering the richness of experiences from stories is a critical element of the methodology.

In the design of communication boards in a paediatric was the project teams identified "listening to patients and families to incorporate their ideas and suggestions" was a success factor. At the same time when asked what they would do differently they said, "we would do more interviews, and if possible, record these for use in staff focus groups" (Case Study 2)

Stories can be gathered by interviewing patients as a group or individually or with their families and carers. Patient will often share information in an interview they might not otherwise share. They are best gathered at this stage and then can be used at a number subsequent stages of the project.

https://www.youtube.com/embed/HoNXAuZlXeI

Source: Point of Care Foundation Duration: 2 mins

To optimise the value from stories requires preparation before the interview, skilful interviewing and preparedness and support following the interview. Detailed guidance on approaching gathering of patient stories are provided in the tool on patient interviews and the interview guide. A template information and consent form is also provided.

Patient Stories Guidance

Interview Guide

Information and Consent Sheet

The Consumers Health Forum of Australia have produced a tool called Real People Real Data. The tool captures patient stories and presents it as a patient experience wheel. It offers an engaging and interactive way of presenting the narrative in a visual way.

Real People, Real Data tool

- https://ourhealth.org.au/content/real-people-real-data-toolkit#.Wauvqa1L2sw

Video

The Point of Care Foundation and a review of EBCD projects have found that taking videos of patient interviews is a powerful and perhaps a critical element. However, it should be noted that the process of video production requires considerable skill and is resource intensive and time consuming.

https://www.youtube.com/embed/sdA_cS4JQZA

Source: Point of Care Foundation Duration: 2:15 mins

Guide to Filming Interviews

A modified version of EBCD called Accelerated EBCD (AEBCD) has been developed and tested in lung cancer services and intensive care units in England.[2] In this approach pre-recorded videos are used as trigger films and have been found to be acceptable by staff and patients. They offer a more cost-effective alternative. The evaluation found that even though the films did not include relevant local detail, they still served the purpose of 'triggering' discussion. However, it is not known whether the same library of films would serve the same utility in a completely different healthcare system in Australia.

The trigger films are available from the following link.

https://www.youtube.com/user/Healthtalkonline

[2] Locock L, Robert G, Boaz A, Vougioukalou S, Shuldham C, Fielden J, et al. Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. Health Serv Deliv Res 2014;2(4).

Filmed interviews with consumers of a mental health service were conducted over a three-month period. Themes were extracted from the transcripts and a short film was created depicting the consumer experience. Those involved in filming, reviewing and editing the consumer interviews also reported how powerful it was to be directly involved in capturing consumers' experiences and seeing them as 'real people'. The films of patient interviews which were developed for this project have become a resource for highlighting consumer views on hospital and inpatient experiences, and ambulance and emergency department experiences. (Case Study 3)

Interview staff

Staff interviews are an essential strategy for gathering the experience of the service from all perspectives. An online video that discusses factors to consider when interviewing staff:

https://www.youtube.com/embed/qklEIPxQEi4
Source: Point of Care Foundation Duration: 2:16 mins

Staff Interviews

Experience Based Surveys

Experience questionnaires can be simple and valuable approaches to capture feelings and experience. The focus is on capturing feelings and experience at 'touchpoint' in the service. Those touch points may have been identified by one of the other tools.

The patient experience survey can be modified and used to capture staff experiences and feelings in a similar way.

Experience Based Surveys

Experience Based Survey template

Conversation cards

These are cards that patients and family members can look through and choose a topic that is of most interest or concern to them e.g. Parking or waiting time. They are then given the opportunity to meet

and discuss that area with a manager.

Here is a link to an online Webinar describing the concept and its benefits

- http://www.prccustomresearch.com/webinars/care-cards-impact-meaningful-conversation-understanding-patient-preference/

OBSERVATION and SHADOWING

WHAT

Observation and shadowing are very important tools when working with patient and staff experience. In observation events, activities, and interactions are observed with the aim of gaining a direct understanding of the area being explored in its natural context.
Shadowing is being beside someone going through the process, giving you the ability to ask them questions as they go along.

WHY

It can help you really understand different perspectives and highlights issues that is unlikely to arise through any of the other activities. It is used to identify exactly what happens during a patient visit to a service, including:

- Learning about people's movements through the service
- Observing behaviours
- Helping you see things through the eyes of a patient.

WHEN

Use this tool during the gathering of experience stage when you want to identify existing experiences and behaviours. It can be helpful to do it before any staff or patient interviews as it may help inform your questions during that stage. It can be used again later to check the impact improvements have had.

WHAT

- The observation process is a three-stage funnel:
  - beginning with descriptive observation (broad scope observation to get an overview of the setting)
  - moving to focused observation (attention to a narrower portion of the activities of most interest)
  - selected observation (investigate relations among the elements have selected as being of greatest interest).
- The shadowing process is accompanying a patient on their journey, observing but also taking the opportunity to ask questions as they are accompanied.

HOW

1. Decide on your approach

- *What are you aiming to learn?*
  - List your questions.

- *Decide on whether you are going to observe or shadow or will you need to do both.*
  - Pick aspects of the service that are practical to observe
  - Choose a time when you are likely to observe the areas of interest

- Examples of what to observe include:
  - How easy or difficult it is for patients to find their way around the hospital
  - How long patients have to wait to be seen
  - How patients are treated by members of staff
  - What questions patients ask
  - What forms patients are asked to fill in
  - How many staff members patients interact with.
- Shadowing is most useful for assessing variability. You can learn a lot by shadowing a small number of people carefully selected to represent the extremes of patients, conditions and/or staff. Identify extreme examples (that challenge the service elements you are exploring) alongside a few 'average' ones. List the types of people you should shadow to answer your questions.

How many people do you need to shadow?

- Determine the minimum number of people you need to shadow by assuming you will need 2-3 of each extreme example. Note: it is better to keep numbers small and focus on the quality and depth of shadowing sessions.

How will you make records and document your results?

- List the recording and documentation options and develop a recording template.
  - Take detailed notes to record what has been observed
  - Audio recording, video recording or photographs can be helpful (but may need consent to be sought specifically for the purpose)
- Now review your outline and streamline your approach as much as possible.

2. Invite patients/staff to participate and obtain their consent

- See ethics for further information.

3. Set up, carry out and document

- If possible, talk to patients about their experiences of the service during or after the shadowing session.
- **Avoid jumping to conclusions or solutions**
- Keep an open mind – someone experience is their experience and their truth, even if you disagree
- Use all your senses. Look out for pauses, obstacles and body language.
- Ask people to show you what they do rather than tell you what they do
- Focus on the meaning of service events and interactions for them, and explore what they meant by their own behaviours. Use non-specific open-ended questions such as 'what was going on for you at that moment?' and 'what did it mean for you to do that/act that way?'
- Ask for ideas for service improvements as appropriate

Adapted with permission from healthcodesign.org.nz

OTHER CONSIDERATIONS

- Make sure patient stories remain confidential no matter what the setting (interview, group or workshop).
- Patients can often experience highs and lows while telling their story. Be prepared to provide appropriate support if required.
- Be prepared to be moved yourself. This is normal and important for understanding how and why experiences arise and how best to resolve them.
- Make sure people are comfortable with being observed/shadowed.
- Do a number of trial observations/shadows with colleagues to ensure it works for you and will give you the information you need to know.
- You can use the tool to follow staff as well as patients.

PATIENT STORIES

WHAT

Patient stories are an opportunity for patients to talk about their experiences, either individually or in a group setting.

WHY

The purpose of patient stories is to explore and understand patient experiences of their condition and of health services over time. Patient stories can help other patients make sense of their experiences and help services understand how these might be improved.

One or more stories can be used as reference case studies or evolved into patient journey mapping or scenarios and personas to help guide your improvement work.

WHEN

Patient stories are best gathered early on in your co-design work to help you identify and develop improvements. They can also be useful later on when you are designing changes such as during prototyping and monitoring the effects of improvements such as with the biggest difference tool.

Deciding your approach:

There are two main ways of gathering patient stories: individual interviews and group sessions.

1. Interviewing individual patients with their families and other supporters:

- Such interviews provide considerable detail about the patient experience of both their condition and the service. They are useful for exploring subtle nuances, though identifying these can depend on a researcher's familiarity with general or expected experiences.

2. Talking to patients in groups (with similar conditions or service experiences):

- Patients typically have few opportunities to 'share and compare' experiences with other patients in any detail, so group discussions can help explore common experiences. (Group discussions are also useful for brainstorming improvements that can make a big difference to patient experiences.)
- Patient stories can be analysed in a number of ways, depending on the scope of your project and your own approach to service improvement:
    - The structure of the story – typically the story is organised around the phases of their condition and/or the service steps they went through, with emotional highs and lows interwoven with these
    - The content of the story – such as the experiences they went through, with attention to the nature and intensity of different experiences over time

- The language patients use – such as the ideas they use to make sense of their experiences and their own responses
- The service elements or incidents that had a particular impact – these may be communications, attitudes, behaviours and/or people.

The steps below can be used in both individual interviews and group discussions.

HOW

1. Make sure patients are physically comfortable and at ease

- Consider and prepare for how you are going to capture the story e.g. second person going to take notes, videoing, audio recording.
- For interviews, ask consumers about their preferred place to meet. For some, it helps to conduct sessions in their homes where they can feel free to be themselves and express their experiences fully. However, others may find this uncomfortable.
- Be prepared for moments of deep emotion for patients as they tell the story and re-live particular moments, or discover things they had not noticed previously, or re-experience feelings they thought were past. It can be important to have family and friends as part of the interview to provide support, as well as ready access to formal support services. Be prepared for patients who are emotionally very strong as well – most grow in some way through their experiences.
- As a researcher, it is also important to be prepared for intense emotions, and to be able to articulate these in full empathetic support of the patient. It is common to recall one's own experiences as well, and it is important to hold these carefully during the interview. A calm, quiet, deeply empathetic manner is completely appropriate.
- Give patients the time to tell things their way. Gathering stories can be exhausting for both the patient and the researcher. Be aware of exhaustion. Agree a timeline before the meeting and if the time line is reached ask if they would like to carry on and be prepared to conduct the interview over more than one meeting. The principle here is not to rush the story telling at the same time as managing the effectiveness of the process by avoiding exhaustion.

2. Briefly explain the purpose and format of the interview/discussion

Before you begin:

- Make sure patients understand and have given their consent to participate.
- Emphasise that the session is unstructured and designed to give them free reign to talk about their experiences.
- There are usually three different aspects to a storytelling session:
  - Patients telling their story and talking about their experiences.
  - Patients reflecting on what their experiences meant for them.
  - Patients reflecting on what their experiences suggest about services and how they can be improved.
- These are typically intertwined in the telling, and it is better to let people manage the session in their own way.

3. Encourage patients to tell their own stories on their own terms and at their own pace

- Start by asking open-ended questions such as "how did things start for you?" or "when did you first notice anything unusual?"
- Continue to use open-ended questions such as "what happened next?" and "what was going on for you at that time?" until they have reached the end of their story.
- In group discussions, it can be useful to ask people to tell their stories in groups of two or three to develop shared stories. They may then summarise and write these down as three to five 'chapters' (describing the major phases) with key experiences summarised under each.

4. Invite patients to reflect on their own experiences

- Start by asking open-ended general questions such as "overall, what do you make of your experiences?" before moving into specific examples.
- Continue to use open-ended questions such as "what specific experiences stand out for you as particularly good or bad?", "what did you make of X experience?", "how did you deal with X experience?" and "what did X experience suggest to you about the service?" until they have reflected as much as they want.
- Patients may have reflected on their experiences already, so encourage a deeper exploration while avoiding repetition at this time.
- One way to encourage deeper reflection is to offer comments other patients have made and invite discussion from their own experience.
- In group discussions, it can be useful to summarise their reflections on specific experiences under the relevant phases.

5. Invite patients to suggest improvements

- Focus on things that would have made all the difference to patients' own specific experiences. Start with an open question, such as, "what could have been different for you?" or "what changes in the service would make a difference for you?"
- Remind patients of any ideas they have already mentioned.
- Include any ideas you want to check at this stage.
- When the ideas have all been covered summarise by asking, "if all these things were done what difference would that have made for you?"

6. Paraphrase patient experiences, their reflections and their suggestions

- Check you have understood correctly and that you aren't missing anything out. Invite them to comment on, or add anything, to what you have paraphrased.

7. Give a simple, concise outline of the next few steps in the project

- Including when and how any improvements will be made.
- Patients will want to know they are making a tangible difference to service quality and to the experiences of future patients. You may also need to share contact details so you can review any details of their experience and/or provide patients with a summary of the research, and so they can follow-up with you at any time.

Adapted with permission from healthcodesign.org.nz

OTHER CONSIDERATIONS

- Remember to consider positive stories. Patients may be able to identify "bright spots" and solutions that may form the core of improvement strategies that can be spread.
- Even a single patient story about a negative experience can be useful in developing improvements. What matters is that the cause of the experience is explored and the probability of a repeat experience reduced. Specific aspects of stories (such as critical events and feelings) can also be quantified using experience-based surveys.
- Make sure the session is focused on patients and their experiences. Minimise any need to ask structured questions and to cover topics of little or no relevance to them.
- Patients may often hold values that are not relevant to their service experiences, but respect their views nonetheless. Don't debate the correctness of their views in any way. If the patient has extreme views of the service, accept these. If the patient's experience includes a significant misunderstanding, carefully suggest this and explore what difference this information make for them.
- Make an offer to provide more accurate information. If the patient is abusive of service staff in any way, try to understand the cause (such as the specific behaviour) without agreeing or disagreeing with their view.
- If patient experiences include any examples of unethical service or staff behaviour, or unresolved problems, carefully point this out (they may not realise this) and offer to help the patient address these. Be proactive and don't use the research as a barrier to improving patient outcomes. Make sure you fulfil any commitments to act on their behalf.
- Conduct the interview in a culturally sensitive and appropriate manner. Storytelling is a feature of Indigenous societies and is sometimes known as '*yarning*'. The Lowitja Institute have produced a guide for researching Indigenous Health.
  - http://bit.ly/2nlEdId

Interview Guide

Be Prepared		
Pen and Paper	Stimulus Questions	audio or video equipment

Prepare the enviornment	
Comfortable room/seating	Remove/reduce noise

Explanation		
Explain purpose	Explain format	Seek consent

Three elements of interview		
Patients telling their story	Patients refecting on what their experiences mean for them	Patients reflecting on what their experiences mean for the service

Enable the story teller to do just that – tell you their story, in their own way, their own terms, their own pace		
Start with open-ended questions	facilitate patients to reflect on their own experiences	invite patients to suggest improvements

Give a simple, concise outline of the next steps in the project including when and how any improvements will be made

Close		
Manage the time and steer the interview to a natural close.	Remember to thank the story teller for their time and for sharing their story with you.	Make sure that they feel OK before they leave.

Adapted from the ebd approach, NHS Institute for Innovation and Improvement and Health Service Co-Design

Organisation Name

Talking about your health experience

Organisation Name invites you to take part in an interview about your health and healthcare. Your participation is voluntary. This means you do not have to take part in any of these activities.

This sheet tells you what taking part involves. This will help you to decide if you want to take part.

Organisation Name will use what you tell us in our Project Name project. This project aims to:

Enter Project Aims Here

The purpose of the interview is to learn more about your experience of health and healthcare so we can make change to improve it.

Part or all of what you say may appear in public reports and resources that we produce as part of the this project. You will NOT be identified by name. Any videos will not be shown other than at events described below.

What is involved?

You'll take part in a face to face interview. The aim is to learn about your experience of health and healthcare. It will take between 1-2 hours.

You'll talk with *Interviewer Name*, whose role is Interviewer Role. She may ask questions about things like noticing a change in your health, seeking medical assistance, diagnosis, treatment, living with your condition and your experience of health services.

She may ask about what has worked well in your healthcare, and what may be improved.

We want you to tell us your story in your way. However, if you would like to you can request a list of possible questions beforehand.

Talking about these topics could be upsetting. Please only talk about things you feel comfortable to talk about. If you'd rather not answer a question or questions, that's fine. You can stop the interview any time.

☐ We will record the interview with a video camera. After the interview, we will edit the video into a shorter version (about 10 minutes). We will focus on the

'touchpoints' of your experience where either you had high or low points in your experience.

You will be able to review this and check that you are happy for us to use the video. The video will be shown at future staff, patient and combined events related to this project to allow participants to understand your experience using your words and emotions.

☐ We will record the interview with a voice recorder. After the interview, we will convert this into a transcript. We will focus on the 'touchpoints' of your experience where either you had high or low points in your experience. The content of the interview may also be analysed so we can depict your story as a patient experience journey map.

You will be able to review this and check that you are happy for us to use those elements. You may be quoted as per the records in the transcript. These may be shown or played at future staff, patient and combined events related to this project to allow participants to understand your experience using your words and emotions.

If the details of your interview are to be used for any other purpose than described above we will come back to your for your consent.

What if I change my mind?

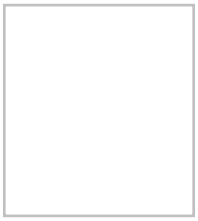
You can withdraw from the project at any time. Please be aware that if you withdraw *after* you approve the final record of your interview, your story may already have been used for the project.

What if my story includes a difficult experience?

It can be upsetting to share a story about a difficult health experience. Before you decide to take part you may like to:

- Talk about it with your health consumer organisation.
- Talk about it with someone you trust.
- Let us now so we can explore providing additional support.

The method used in this project is used internationally and particularly in the United Kingdom where it was developed.



Organisation Name

Project Name

Consent for interview and Audio/Video Recording

This consent form tells Organisation Name that you understand and agree to being interviewed and recorded. Please tick the following if appropriate:

☐ I have read and understood the information sheet about this project and have had the opportunity to ask questions

☐ I understand that my comments (or part of them) may be used in different formats such as video, paper and/or electronic to share with others for the benefits of designing services that are based on patient experience

☐ I understand that my participation is voluntary and I am free to withdraw at any time

☐ I know that I can ask for any comments I have made on tape, or in writing or on film to be removed

☐ I understand that any of my comments used may be transcribed and will appear anonymously.

I agree to take part in the above project.

☐ Yes ☐ No

Signing below indicates you agree.

Patient Name:	Interviewer Name:
Signature:	Signature:
Date:	Date:

FILMING INTERVIEWS

WHAT

Videoing is a powerful strategy for capturing patient experiences and then presenting it back at future events. Many exponents of EBCD see video as essential to the method. The video needs to be edited.

WHY

The use of video captures the experience in the patients/carers own words and language with their non-verbal cues. Patients/care will often feedback aspects on a video that they might not otherwise. It is a powerful way of capturing the information and then reflecting it back at co-design events.

WHEN

This is used during the gather experience phase.

TIPS

- Ensure you have sought informed consent from the patient
- Be familiar with the equipment otherwise it can become a distraction
- If a separate camera operator is involved then encourage them to stand some distance from the interviewee to be less intrusive
- Seek some basic training in filming skills so that the angle, framing and lighting are right
- Audio quality can be variable. Consider using an external microphone or take an audio recorder as well
- The whole interview/discussion may take an hour or more. The aim is to edit the video footage to 10 minutes per interviewee
- When editing the video pick out the key 'touch points' – e.g. arriving for the appointment, getting your diagnosis
- Divide up clips into those themes, interweaving the various patients' quotes with each other
- The aim for the end product is to have footage where several patient quotes will be captured for each theme
- The final video will usually present experiences following the clinical pathway chronologically
- Balance out negative comments with positive ones
- Send each patient a DVD with all their own quotes that you would like to include or alternatively send the unedited film and ask them which aspect they do not want to include

Adapted with permission from Point of Care Foundation

STAFF INTERVIEWS

WHAT

Interviewing staff involved in a patient journey across the entire pathway.

WHY

Staff interviews like patient interviews help identify the touchpoints in the journey and the factors contributing to a negative experience.

WHEN

Use this tool during the capture of experience stage. It is often helpful to do it after observation and any start-up and planning workshops.

TIPS

- People may be suspicious about the agenda, uncomfortable about criticising their workplace or worried about receiving criticism from patients
- Present the project clearly to the entire group, explaining what the project is for, how it will benefit staff and patients, and what sort of commitment is required, to allay any fears
- Ask them what is working well as well as what is not working so well from their perspective
- Having conducted start-up workshops and planning workshops will help as staff will have been involved in the process
- Conducting observation prior to staff interviews will also be helpful and provides a further opportunity to build trust and allay any concerns
- Draw interviewees from roles across the entire patient pathway
- Aim, where possible, for one-to-one interviews – preferably face-to-face as people often feel more comfortable
- Think about how you will capture the conversation such as audio recording or making notes on a template.

Adapted with permission from Point of Care Foundation

EXPERIENCE-BASED SURVEYS

WHAT

Experience-based surveys are simple surveys to find out how patients experience a specific part of the hospital healthcare journey and allow patients to come up with specific suggestions for improving their experiences.

WHY

It is a simple, easy-to-complete survey that can quickly give you an understanding of which parts of the journey are most problematic for patients and what changes can be made to improve it.

WHEN

Experience-based surveys can be used early on in service improvement work to understand experiences, identify areas for improvement and establish baseline measures. They can also be used again after changes have been implemented as a way of quantifying the impact of these on patients' experiences.

HOW

1. Choose a clinic or service to survey

- Choose an area to survey, it may be a clinic visit, having a dressing undertaken at home or a journey through a particular service for example.
- Break down the patient journey into about five or six typical steps or stages that a patient will go through. Make sure you use non-technical language that is easy for patients to understand.
- For example, a typical visit to a clinic may involve the following steps:
- Arriving/checking in - Waiting - Clinic appointment - Information - Leaving

2. Agree on the details of undertaking the survey, including:

- How long a clinic will be surveyed for? (a week, a fortnight, a month). See other considerations.
- Who will give out the survey forms? (staff at reception, nurses).
- Who will collect the completed forms?
- Who will be responsible for compiling the results?
- Whether a summary of the results will be sent to patients (and who will do this).
- Who is responsible for implementing the recommendations?

3. Develop the survey using the experience-based survey template or your own design

4. Prepare for the survey

- Brief all staff involved about the survey.
- Get surveys printed and addressed pre-paid envelopes to return them. Ideally, the surveys will be collected before the patient leaves.

Adapted with permission from healthcodesign.org.nz

- Print information posters about the survey and put up on clinic walls.
- Set up survey boxes (for people who want to complete the survey and hand it in immediately).

5. Conduct the survey

6. Analyse and present the data

OTHER CONSIDERATIONS

The duration of your survey (and your sample size) should be long enough (and large enough) to cover as much variation between patients as possible.

Things to consider might be:

- the number of patients over a given duration
- gaining the best representation of a variety of patients
- avoiding atypical times such as public holidays
- gaining expert advice on statistical robustness

Experience Survey

Project Name

This experience questionnaire will help you think about how you feel at different stages

	Arriving/Checking in	Information	Waiting	Going to theatre	Recovery	Check ups	Leaving	How do you feel overall about your
Circle the words that best describe you you feel at different stages of your journey	happy supported safe good comfortable in pain worried lonely sad	happy supported good comfortable worried sad relief curiosity apprehensive	happy supported safe good comfortable in pain worried lonely sad	happy supported safe good comfortable in pain worried lonely sad	happy supported safe good comfortable in pain worried lonely sad	happy supported safe good comfortable in pain worried lonely sad	happy supported safe good comfortable in pain worried lonely sad	happy supported safe good comfortable in pain worried lonely sad
Write your own words here								
Why? We'd like to know why you felt like this. Whatever it is we'd like to know.								
How can we make it better?								

Adapted from NHS Institute for Innovation and Improvement

LOGO
SLIDER

Understand the
experience

Understand the experience

You have 'gathered the experience'. You may have used several different methods. The next step is to get a deep understanding of those experiences. Understanding requires using the material you have collected in the 'gather' phase to create further discussion and dialogue.

> "Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it is the only thing that ever has." Margaret Mead, Anthropologist

Point of Care Foundation recommend three types of events for building greater understanding of the experience:

- Staff feedback events
- Patient feedback events
- Joint patient-staff events

These events are used to help all participants understand the patient experience and to build empathy with the consumer. They provide an opportunity to share the information gathered with all the stakeholders and to validate the information. Particularly seek to understand the emotions experienced by patients and staff and to explore the causes of these feelings in preparation for the next stage of improvement.

Patient feedback event

This event is the point at which patient participants come together for the first time. They watch the edited film and discuss their views on the key priorities for service improvement.

https://www.youtube.com/embed/_zIbiN1Yu3k Source: Point of Foundation Duration: 3:02

The meeting is facilitated by someone with the required skillset to facilitate and:

- invites patients who have already been interviewed as part of the project to develop their collective feedback about the service
- brings the patients together as a group to build their confidence about speaking in a meeting environment before they meet with the staff
- presents the synthesised material from the 'gather' phase back to participants to stimulate further dialogue
- may use tools such as emotional mapping and identification of touch points (see below)

The excel spreadsheet includes templates for

- patient invitation letter
- agenda for event
- feedback form for event

Staff feedback event

The event aims to enable staff to highlight their priorities for improvements within their service. It is also a key opportunity to show staff that the project seeks to form a genuine partnership between staff and patients. Some groups have found it is important to have a separate staff event to allow processing of the patient feedback in a safe environment prior to contact with patients.

In Case Study 3, there was an initial joint event. However, several staff who attended the joint workshop reported that it had been confronting to see the film for the first time. While the main purpose of the film in EBCD is to trigger discussion the result in this project was that most staff participants at the workshop spoke very little during the post-film discussion. A second workshop was held with staff to review the film and debrief the experience.

https://www.youtube.com/embed/5JLzkL-lLZ8
Source: Point of Foundation Duration: 2:20

The meeting is facilitated by someone with the required skillset to facilitate. The aims of the day are to:

- Feedback and validate the staff experience findings
- Agree work to be taken forward jointly with patients
- Agree next steps moving forward to joint patient-staff event

The excel spreadsheet includes templates for

- agenda for event
- feedback form for event

Joint event

This event brings together the patients and staff to hear each other's perspectives on the service and identify the key priorities to tackle together to make improvements.

The aims of the meeting are to:

- Feedback the staff experience and patient experience findings.
- Agree jointly priorities for patients and staff working together.
- Form co-design groups to begin improvement work in priority areas.

The excel spreadsheet included as a resource in this section includes templates for

- agenda for event
- feedback form for event

Patient Journey Mapping

A patient journey map is a diagram summarising the service experiences patients have over time.

A patient journey map is similar to a process map which is a common tool used in quality improvement. The key difference is that at each of the touchpoint of the journey map the objective is to capture positive and negative experiences and emotions.

"*Experience mapping was used to develop a visual depiction of the emotions and touch points related to the various stages within a journey. A focus on emotions promoted greater empathy and understanding.*"
(Case Study 5)

This tool developed from Health Design New Zealand and Point of Care Foundation resources describes the approach.

Patient Journey Mapping

The Improvement Foundation undertook a mapping journey of one patient to understand integration concepts. This video whilst does not specifically demonstrate emotional mapping illustrates the power of process mapping particularly from a staff perspective.

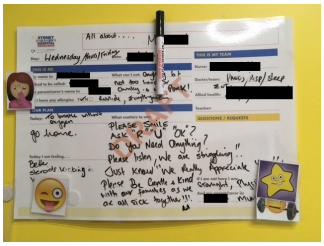
https://vimeo.com/147399549
Source: Improvement Foundation Australia, Duration: 12:45 mins

Service touchpoints and hotspots

A touchpoint is any point of contact patients have with your service. A hotspot is a high value touchpoint. This tool helps you understand exactly what makes your service work for patients. Knowing which touchpoints patients value most helps you decide which areas to prioritise for improvement, and how best to do so.

Service touchpoints and hotspots

Case Study 2 describes a project to improve communication in an inpatient adolescent ward. It focussed on clinical handover which is a very important high-value touch point. Effective improvement at this touchpoint led to an enormous improvement evidenced by the following quote:



Communication Board from Case Study 2

"ever since we started this [communication board], the levels [of communication] just gone through the roof [...] maybe the nurses are getting to know us better"

PATIENT JOURNEY MAPPING

WHAT

A patient journey map is a diagram summarising the service experiences patients have over time.

WHY

You can use patient journey mapping to identify, map and plan patient experiences of services. The tool can be applied to improving patient experiences of health services, specialist units, or encounters with individual staff.

WHEN

Use this tool during the early stages of your co-design work to understand the patient journey and their parallel experiences of services. With stakeholder input, it then becomes a template for identifying key service touchpoints and improvements.

Deciding your approach:

There are two main ways of developing patient journey maps: individual interviews and group sessions:

1. Interviewing individual patients with their families and other supporters:

These will give you the deepest understanding of the patient's journey and experiences. Interviews are suitable for more in-depth improvement work.

2. Talking to patients with similar conditions or service experiences in groups:

This will give you the best overview of the journey, key experiences and key improvements. This suits full co-design projects where prior work has been done (such as interviews or surveys) or where time and budget are limited.

note: You will need to organise recording methods appropriate to the approach you use. All approaches rely on note-taking by or on behalf of patients, so this needs to be managed carefully by facilitators. Audio or video recording may also be appropriate.

HOW

1. Start your interview or workshop by exploring the patient journey

Do this from the perspective of patients, their families and their other supporters (noting families and supporters have significant journeys of their own).

Elicit patient stories about their journey from the beginning (such as when they first noted symptoms) to the present day.

Ask participants to divide their stories into phases (these can be visualised as sections, chapters or scenes) to help others understand how the journey changes.

Adapted with permission from healthcodesign.org.nz

Between three and five phases is usually practical from a patient perspective but use as many as you need.

Write down the phases on a large sheet of butcher paper. This is known as a journey sheet.

2. Ask participants to describe their overall experience of each phase in more detail

You may start this by using a scale from one to ten to rate how high or low participants felt during this phase. Note this against each phase on the sheet.

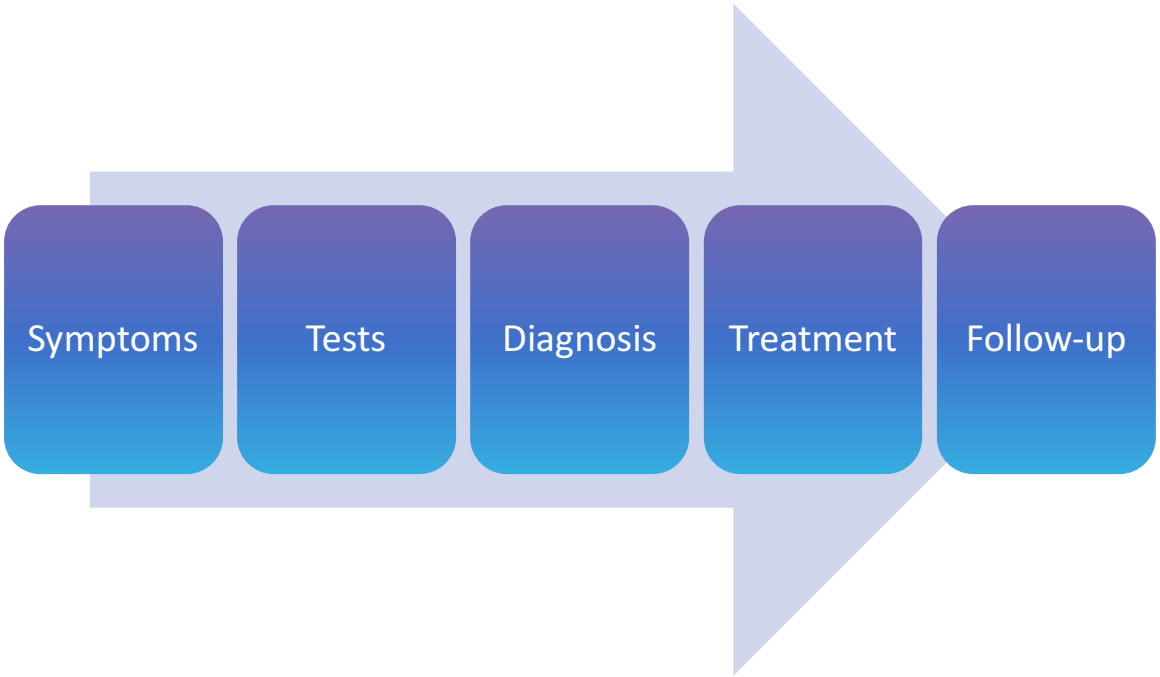
Then prompt for the feelings and emotions experienced during their highs and lows, noting these on the sheet. You can prepare a set of 12 – 24 words covering a range of positive and negative feelings and emotions to help them with this. Work through the whole journey this way.

You can use the mapping template and improvement opportunities template to help you.

3. Ask participants to highlight any especially good and bad service experiences in each phase

Note the emphasis falls on both (avoid asking for negatives only). Summarise the experience on the journey sheet and record any details about specific service elements on a separate sheet.

Example of patient journey phases:



4. Ask participants to suggest the values and actions that led to these positive and negative experiences

Adapted with permission from healthcodesign.org.nz

Emphasise the need to learn from both good and bad experiences. Summarise these on the journey sheet under appropriate phases with any details on a separate sheet. Then summarise 'do's and don'ts' to guide any improvements, detailing these on a separate sheet as well.

5. Ask for improvement ideas and suggestions

Note this includes applying values and actions from the good experiences as well as developing new ways of providing services and meeting desired experiences. Again, these can be summarised on the journey sheet and detailed on separate sheets.

6. Reflection

Congratulate the patient(s) on the 'map' of their journey through the service and on the insights and opportunities it affords. Ask them to reflect on anything they see in the map or that occurs to them as a result of creating it. Add any observations of your own, asking for their comments on these as well.

7. Develop the patient journey map

Take photos of the maps and develop a master version integrating all the different versions you have. If patients want to keep their maps, make sure you have an accurate record (for example, take additional photos).

Start your master with an inclusive draft (this will be messy and complex) and then simplify it until key improvements are clearly contextualised in the journey phases and related experiences of patients. If you can, carry out this step with patients.

Finally, identify your organisation's service parameters (the phases in the journey it has a responsibility for) within the patient journey, perhaps highlighting any critical improvements here in particular. Make sure you understand these phases clearly. For example, if your service covers only some of the phases described by patients, you may create a separate and more specific diagram to detail patient experiences within your service.

Note: this final diagram commonly becomes a central reference for improvement teams and future work. It is important to make sure it is accurate, emotionally rich and visually simple.

8. Summarise your specific improvement opportunities

This is useful when working with other tools, such as service touchpoints and hotspots and SWIFT ideas.

ALTERNATIVE OPTION FOR MAPPING EXERCISE

(from Point of Care Foundation)

Facilitating the emotional mapping exercise:

- Listen to the interviews and pick out the key moments along the patients' experience of their journey – moments raised by a number of patients. Write those moments down on pieces of paper constructed into a long, straight line on a wall – much like a process map.
- Then, ask the patients to approach the wall wherever they want to, look at those moments, and raise the position of that piece of paper if it was a positive moment or lower it if it was negative.
- Next, ask the patients to write words on sticky notes to describe the emotions they associate with each of the moments. Again, people can begin with whichever element of the journey they wish to and carry on until they have said as much as they wish to about their overall journey.
- Once everyone has contributed all they wish to the map, lead the group in looking at the map as a whole. In particular, look at aspects that attract a range of views and those where there are many comments, whether positive or negative.
- This tool highlights those moments or aspects of the service that could be handled better.
- Discuss the map and help the group narrow the points down to four or five areas for improvement to be taken to the joint patient–staff event.

Example of emotional mapping touch points – lung cancer:

Receiving the diagnosis

- How you were told you had lung cancer
- Support and information at time of diagnosis

Moving through the service

- Waiting for results
- Delays in starting treatment
- Speed of moving through the service
- Seeing lots of different doctors
- Seeing more than one clinical nurse specialist
- Waiting times in clinics
- Transfer from one hospital to another

Being an inpatient

- Attitudes of nurses on the ward
- Staff available when needed on the ward
- Communication on the ward
- Mixed-ward experience
- Going to theatre

Having chemotherapy

- Chemotherapy day unit experience
- Staff available when needed on chemotherapy unit
- Staff attitudes

Adapted with permission from healthcodesign.org.nz

Having radiotherapy

- Radiotherapy department environment
- Radiotherapy staff
- Music played during radiotherapy

Understanding what's happening

- Information about patient journey – who you would see, when, where and why
- Information about treatments
- Information about what to expect after treatment
- Information about home care
- Information about financial benefits
- Patient Information Centre

Receiving support

- Clinical nurse specialist support
- Psychological support
- Support from other patients

MAPPING TEMPLATE

	Symptoms	Tests	Diagnosis	Treatment	Follow up
Experiences • Scale • Words • Highlighted					
Values & Actions **Do's & Don'ts**					
Ideas and Suggestions					

Journey Focus

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IMPROVEMENT OPPORTUNITIES TEMPLATE

Experiences of good and bad service	Improvement Criteria	Opportunities to improve
patient experiences	Service criteria for improvements	Key opportunities for actual improvements

Adapted with permission from healthcodesign.org.nz

SERVICE TOUCHPOINTS AND HOTSPOTS

WHAT

A **touchpoint** is any moment where a user interacts in some way with the service. Examples could be; arriving on the ward, talking with a nurse, waking up after surgery, mealtimes, being discharged. They include letters and brochures, websites, signage, equipment for patients (such as gowns) and even the appearance of facilities. Personal interactions (both words and actions) are often important touchpoints too, because they are crucial to service experiences.

A **hotspot** is a high value touchpoint that you can improve quickly and easily and has significant impact on patient experiences of the service.

In healthcare services, improvement ideas often involve changes to an existing touchpoint, such as using better pictures in an existing brochure. They may also involve new touchpoints, such as using videos instead of brochures to communicate with patients.

WHY

This tool helps you understand exactly what makes your service work for patients.
Knowing which touchpoints patients value most helps you decide which areas to prioritise for improvement, and how best to do so.

WHEN

The best time to use this tool is after you have developed an understanding of patient experiences and a selection of improvement ideas.

Touchpoints and emotions
"...these [touchpoints] are the points of contact with the service that are intensely 'personal' points on the journey, where one recalls being touched emotionally (feelings) or cognitively (deep and lasting memories) in some indelible kind of way".
(Bate and Robert, 2007).

HOW

1. Summarise what you know so far about the patient journey

Using the information from your exploration of patient experiences and improvement ideas, fill in the first three columns of the touchpoint development template, starting with good and bad patient experiences of services. For each experience, note the values and actions that contribute to it, then any relevant improvements. Note: this might take a few sheets of paper.

2. Identify possible touchpoints

Review the completed touchpoint development template for each experience and identify existing and/or possible touchpoint ideas.
These touchpoints may be:

(a) the way service is currently delivered or
(b) ways it could be delivered better.

It is likely interaction-based touchpoints (words and actions) are already listed in the 'values and actions' column, but it is important to include them in the touchpoint ideas column too.

3. Analysis

Using the touchpoint analysis template, analyse each touchpoint idea for its value to both patients and your organisation. To do this, simply take each touchpoint in your list and position it on the diagram.

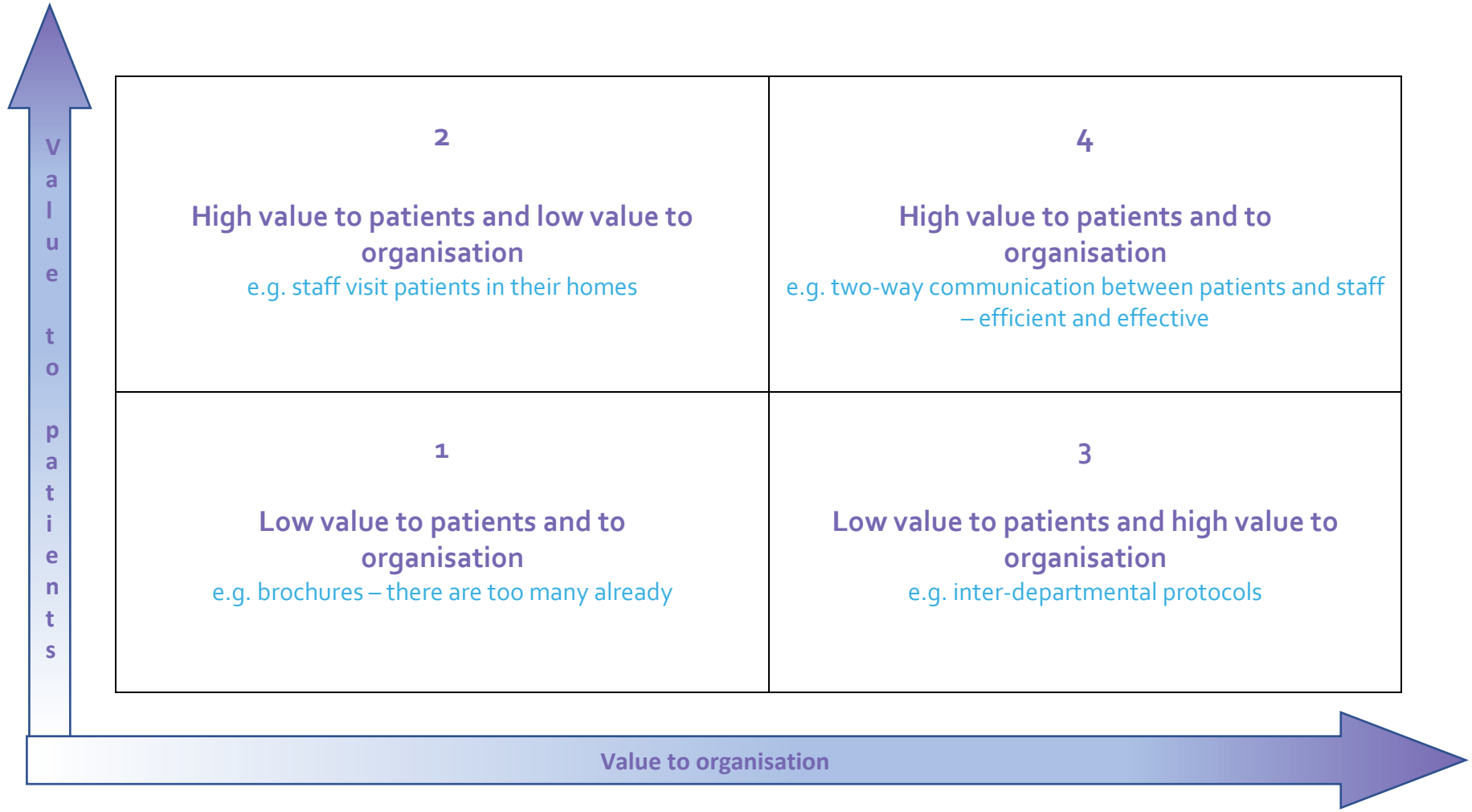
This will involve some discussion over the merits of each touchpoint, and it is important not to rush this. As you do this, you may find it useful to note the criteria or rules-of-thumb you are using to decide, as this helps you keep your decisions consistent. When you have covered all the touchpoints, review your decisions one last time for consistency.

If you discover new improvement ideas and approaches during the analysis, add these to the touchpoint analysis template.

4. Identify which touchpoints to focus on

Shortlist the higher value touchpoints (Boxes 2 and 4) and prioritise those in Box 4. These are your hotspots for immediate attention.

TOUCHPOINT ANALYSIS TABLE



2 **High value to patients and low value to organisation** e.g. staff visit patients in their homes	**4** **High value to patients and to organisation** e.g. two-way communication between patients and staff – efficient and effective
1 **Low value to patients and to organisation** e.g. brochures – there are too many already	**3** **Low value to patients and high value to organisation** e.g. inter-departmental protocols

TOUCHPOINT DEVELOPMENT TABLE

experiences	values and actions	improvements	touchpoint ideas
☺			
☹			

Adapted with permission from healthcodesign.org.nz

A
B
C
D
E
CONTINUOUS
IMPROVEMENT

Improve the
experience

Improve the experience

The next step in the journey is to translate the understanding of current experiences into meaningful improvements. Throughout the 'gather' and 'understand' phases you identified the current state of experience, expectations and potential areas for improvement. You and your team may already have identified many ideas for improvement. There may also be broader concepts with the potential to improve the experience which need further work and exploration.

"No design without co-design"

https://www.youtube.com/embed/MvoAk1ODLYI
A video from Point of Care Foundation on the experience of co-design groups

Improving the experience has the objectives of continuing an authentic co-design process by bringing patients and staff together to work on:

- generating further ideas
- scoping them further
- selecting and prioritising those to be taken forward
- piloting and/or implementing of those ideas

"We had a fantastic full-day multi team co-design workshop where the app developers met with staff and patients to nut out our ideas." (Case Study 4)

Such co-design groups can be enormously powerful but may need expert facilitation. They can be greatly enhanced if facilitators use a range of skills and tools to meet the objectives.

In Illawara Shoalhaven LHD members of the surgery service with input from patients came together in co-design teams with app designers to co-design an app that led to improved patient experience of day surgery, improved staff experience by reducing work arising from cancellation and this translated into enhanced efficiency. (Case Study 4)

There are many resources to help support the project management aspect of this phase. Other tools to help generate ideas and creativity. Others help you to view these ideas through the lens and perspective of different stakeholders. The goal ultimately is to improve the

experience of service users. Using personas and scenarios when employing these tools can help to sharpen your team focus on end-user experience.

Deciding on which improvements to implement and where to make changes can be difficult. The key again is to maintain a consumer focus. Understanding the consumer journey and the **touchpoints** patients have with the service, as described in the section on understanding experience, can assist with the decision making. Within these touchpoints the '**hotspots**', a high value touchpoint, which if improved can have a dramatic impact on the experience of the service. Other strategies for prioritising use a considered approach where a tool helps assess each improvement against set criteria (e.g. the SWIFT approach).

> The NSW Agency Clinical Innovation in an EBCD project on improving day rehabilitation held an initial co-design workshop. The priorities for improvement were explored and collectively agreed upon at the workshop. They were categorised into a matrix: easy, hard, high impact and low impact. Service information was identified as a key priority. (Case Study 5)

Once ideas have been selected to take forward they need to be translated into action. Some of the resources below can help you 'manage' the action stage. The aim is to have a change that results in the desired impact and for that impact to be sustained. Prototyping was used by three of the case studies cited in this toolkit. The purpose of prototyping is to test the hypotheses generated in the 'gather' and 'understand' phases of your EBCD project. The prototyping activities will have informed the ideas you are using in this 'improvement' phase. Other tools can help you capture the improvement experience commitment made by individuals and collectively by groups

Tool	Description
Ideas group	Ideas groups come together to brainstorm improvement ideas and ways of resourcing and implementing them. They offer an easy, fast, fun way of scoping potential improvements and innovations.
	Ideas group
Stakeholder needs table	A stakeholder needs table shows you what two different stakeholders need and what improvements will most effectively help more than each. It helps build a balanced view of potential improvement areas and improvement ideas.
	Stakeholder needs table
	Stakeholder needs matrix template
	Stakeholder needs benefits template

Scenarios and Personas

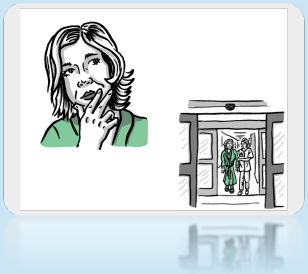
A **scenario** is a realistic description of how a service works. A **persona** is a realistic description of a type of client.

The following animation on YouTube offers a fun way to understand what a persona is:

https://www.youtube.com/embed/W1kw5xK1C30
Source: YouTube, MJV Technology & Innovation

Scenarios and Personas

Persona checklist



Julie, a persona from Case Study 1

In NSW, the Agency for Clinical Innovation facilitated an EBCD project to in the redesign of Brain Injury Rehabilitation Model of Care (Case Study 1). The team built five personas using the expertise within the project team; each persona differing in their needs based on age, type of injury, age and location. The team used the tool to stimulate discussion during semi-structured interviews. Interviewees could connect to the persona and narrative, highlight comparisons or differences and share their experiences more openly and freely. Their use of this during the gathering phase highlights the flexibility of the tool.

SWIFT ideas

Each improvement idea is assessed for its **s**trengths and **w**eaknesses, and its **i**ndividuality (what makes it different). **F**ixes (solutions to the

weaknesses) are identified and the improvement idea is transformed (changed).

It helps to facilitate a considered approach to all improvement ideas including out of the box ones and assessing your ideas against set criteria.

Swift ideas

Swift ideas template

Prototyping

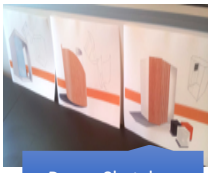
Prototyping simply means using a 'rough draft' of an improvement or a touchpoint to learn more about it. It is extensively used in the technology industry. The three videos below from Google offer insight into how prototyping is used in a technology industry. The lessons can easily be applied to health.

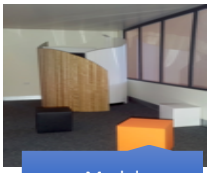
Sketching and Paper Prototyping
https://www.youtube.com/embed/JMjozqJS44M
Source: YouTube, Google

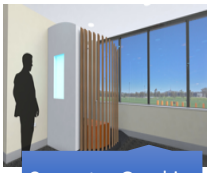
Digital Prototyping
https://www.youtube.com/embed/KWGBGTGryFk
Source: YouTube, Google

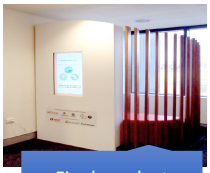
Native Prototyping
https://www.youtube.com/embed/lusOgox4xMI
Source: YouTube, Google

Three of our case studies all used prototyping in their EBCD approach. The communication board in Case Study 2 was developed using rapid prototyping approach. Case Study 5 describes an improved provision of service information for a day rehabilitation service. Consumers, families and staff worked together to design the layout and content of an information brochure and online presence for the community. Prototyping was used to test the layout and content in an iterative way. Case Study 6 aimed to develop a patient pod to be used in the waiting area whilst patients waited for their appointment. The project team first designed the Pod on paper, then built small models. The team then used computer assisted graphics to refine the selected model which were then used in building the final product.


Paper Sketches


Model


Computer Graphics


Final product

Prototyping information and templates

Experience Improvement sheet

Changes to a service can be recorded and tracked against experiences. This sheet provides a way of capturing the group's improvement efforts.

Experience improvement sheet

Group Action Statement

A group action statement lists the different team members and what their improvement project aims are. The statement is used to record group and individual actions. It serves as a communication tool, facilitates ownership of actions and promotes accountability. It can be given to all individuals as well as shared on a project display board.

Group action statement

Group action statement template

Individual action statement template

"Not every change is an improvement, but every improvement is a change"

Harry Potter and the Methods of Rationality

IDEAS GROUPS

WHAT

Ideas groups come together to brainstorm improvement ideas and ways of resourcing and implementing them.

WHY

Using ideas groups will help you to brainstorm issues and related ideas for improvements. It is an easy, fast, fun way of scoping potential improvements and innovations.

WHEN

Use this tool when you need to scope initial solutions to a problem or opportunity.

Note: You will need to organise a whiteboard, sheets of paper and/or Post-it pads to record people's ideas.
Always emphasise the need to write down all ideas!

HOW

1. Identify the key problems and any benefits for patients if they are resolved

- Write a sentence describing each problem with the benefits of resolving it (the outcomes) in plain, simple language. (Avoid any descriptions that suggest a solution, as this will block further ideas.)
  Example:
  "*reducing miscommunication between patient and staff would save time, prevent errors, and help patients feel more in control of their situation*"
- Make a list of the problems to focus the session.

2. Identify who needs to be in the session

- Make sure you include anyone who is an active stakeholder in addressing the problems and opportunities.
- Set up the session and invite attendees.
- Consider appointing an independent facilitator.
- Before you hold the session, circulate a list of problems, inviting people to think of others and contribute them during the session.

3. Begin the session

- Briefly review the initial problems list and check all attendees have a clear understanding of the challenge each problem poses.
- Brainstorm any additional problems if these arise.
- Ask attendees to reflect on the list and note any patterns and themes they find.
- Discuss these and review the list, grouping any that seem similar. Finalise the list.

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4. Develop success criteria

- For each problem ask: How would a patient want to experience this once the problem was resolved? What would a patient's experience of success be?
- This exercise can be done in subgroups, with each team allocated a specific problem. Another way to group people is around touchpoints.
- Once this is complete take a brief break and prepare for a high-energy brainstorm!

5. Brainstorm ideas for resolving each problem on a separate sheet of paper

- If there are many problems, split into smaller groups and allocate a set to each group.
- The brainstorming question is: "How might we resolve this successfully for patients (or for its key users, if not patients)?"
- Stay focused on brainstorming ideas and avoid judging ideas.
- When each problem has been brainstormed, take another break.

6. Review the lists of ideas and allow 5-15 minutes of reflection and discussion

- This works best if the sheets of paper are arranged around the walls of the room and group members can circulate to view them. Provide each group member with three 'sticky dots' (or a small number of other items they can stick to the brainstorming sheets).
- Invite participants to vote for the three ideas they consider will make the biggest difference for patients (or whichever stakeholder group is the primary focus).

7. End the session by listing the ideas that are being put forward on a fresh sheet of paper

- Review this list and reflect on the themes and priorities. Avoid making any decisions, keeping the ideas open for further assessment and development.

OTHER CONSIDERATIONS

- When brainstorming, the more diverse the participant group the better.
- Be tolerant of ideas that are off the mark, even if silly – write these up as well. They are useful for stimulating more ideas!
- Encourage fun and silly ideas as these helps keep people's creative energies flowing.

Handy items for workshops:

- *Ballpoint pens - 10 each of blue, black and red*
- *Permanent markers -16 each of blue, black, red & green*
- *Whiteboard markers - 3 each of blue, black, red, green & purple*
- *Highlighter - 1 each of blue, pink, yellow and orange*
- *Pencils and colouring pencils*
- *Two rulers*
- *Post-it pads - assorted colours*
- *Blue Tac ,Thumbnail tacks*
- *Scissors*
- *Sellotape*
- *Post-it flags - 2 each of blue, red, orange yellow*
- *Stress balls*

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STAKEHOLDER NEEDS TABLE

WHAT

A stakeholder needs table focusses on two stakeholders listing what their needs are. It will help identify improvements that will help both stakeholders most effectively.

WHY

You can use this tool to compare one stakeholder's needs against those of another. For example, patient needs and ideas can be identified and compared to managerial, clinical and other stakeholder needs.

Healthcare services often identify potential improvements before a project starts. As a result, they may inadvertently exclude other stakeholders' needs and useful improvement ideas. This tool helps build a balanced view of potential improvement areas and improvement ideas.

WHEN

A stakeholder needs table is a useful tool for sketching out possible improvements near the start of your co-design work, as well as deciding on key areas for improvement and specific improvements later in your work.

HOW

1. Identify key needs and areas of improvement from the perspective of each stakeholder group

- Key stakeholders might be management (a financial perspective), clinicians (a health perspective), administration (a logistics perspective) and patients (an experiential perspective). Try to focus on areas for improvement rather than specific improvement ideas at this point. Jumping to solutions too early can prevent other ideas arising.

2. Group improvement ideas

- Review the needs and areas of improvement for each stakeholder group. For each stakeholder, organise and group these into between three and six key areas that summarise the major concerns. Express these in the language of the stakeholder group.

3. Complete the stakeholder needs template

4. Create a summary diagram

- When you have completed the stakeholder needs template for all stakeholders, create a summary diagram to identify the key improvements that provide the greatest benefits for the most stakeholders.

OTHER CONSIDERATIONS

- Keep your brainstorming focused on improvements that benefit multiple stakeholders.

Adapted with permission from healthcodesign.org.nz

- Focus on identifying the improvement and its benefits, then move on to the next. Do not discuss or detail improvements beyond mutual benefits. For example, do not discuss how practical an improvement is, just whether it meets the 'mutual benefit' criterion.

Template Instructions:

- Using a large whiteboard or sheet of paper, list the needs of the key stakeholder group (usually patients) across the top. Then list the needs of another stakeholder group down the side.
- Work across and down the empty squares in the table, placing a tick in each one where stakeholder needs clearly coincide (it doesn't matter how many ticks there are). Then number each tick.
- Using a separate sheet of paper for each, brainstorm specific improvements for that square from the perspectives of both stakeholders, noting its benefits for each stakeholder alongside. Use the improvements and benefits template to record improvements in each square and how they benefit each stakeholder.
- Identify the key improvements that provide the greater benefits for both stakeholders. As you flesh out the improvements, you may notice patterns in the types of improvements being suggested. Review these and look for improvements that address multiple issues and/or achieve benefits for multiple stakeholders. These are likely to be the highest-value improvements and the most important to focus on.
- Repeat this for any other stakeholders, keeping the primary stakeholder (such as patients) across the top of the template.

STAKEHOLDER NEEDS TEMPLATE

What we want Patients						
What we want Other Stakholder		A	B	C	D	E
	Z					
	Y					
	X					

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IMPROVEMENTS AND BENEFITS TEMPLATE

Improvement Ideas	Benefits to .... Patients	Benefits to ... Enter other stakeholder here
1.		
2.		
3.		
4.		
5.		
6.		
7.		

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SCENARIOS AND PERSONAS

WHAT

A scenario is a realistic description of how a service works. A persona is a realistic description of a type of client.

Example:
Imagine an elderly patient with poor eyesight arriving by taxi at the front door of an outpatient clinic. He moves slowly inside (he has a walking stick) and sees a long queue in front of the reception.

The fuller persona would give more detail about his condition, needs, abilities and so his likely response to the queue.

A full scenario would describe the different things that might happen next as he tries to get the service he needs. For example, does he join the queue without question, or does he stop and look around to see if it is the right queue? If he looks around, what signage might he be able to see, if any? Or does a staff member greet him and offer help?

Scenarios and personas work best when based on realistic 'extremes', as in the example given.

They help you notice and amplify experiences that otherwise go un-noticed. They also prevent you defaulting to the 'average' patient or 'average' service delivery, which inevitably leads you to making merely 'average' improvements!

WHY

Scenario and persona descriptions:

- Help you determine exactly who your improvement needs to work for as well as when, where and how it needs to work to be successful.
- Give you simple, cheap, quick ways to develop improvements.
- Help you experiment with different improvement ideas, judging their value in a realistic and useful way, but without the need to involve staff and patients.

WHEN

Use scenarios and personas when:

- You have a solid understanding of different types of patients and their experiences (you may have used patient shadowing, patient journey mapping and/or patient stories to gain this).
- Developing any improvement ideas to keep improvements focused and grounded.
- During the early stages of prototyping.

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HOW

1. Identify and profile service scenarios of interest

Identify the service times and places where the issues occur or where you would like to make improvements. If you have explored patient experiences, you will be aware of the times and places where difficult experiences occur.

To create a scenario, simply list the elements of the scene, including anything that contributes to patient difficulties. To help, you might imagine you are setting up a film or stage set. What things and people need to be there, and how are they arranged? What happens in the scenario?

It is useful to avoid 'average' or 'typical' scenarios – be more specific and use extremes to accentuate and explore issues. For example, if the scenario is based on an outpatient clinic, make it very busy – noisy, full, long queues, stressed staff, anxious patients and so on.

Focus on the exact time and place. For example, if you are exploring letters written to patients, base your scenario in a kitchen or living room where the letter might be read.

It can be very helpful to quickly draw the scene and make notes next to it – this helps document what it is and why you are exploring it. Then evolve the sketch as you learn – it's a very easy way to record your learnings. Keep your sketches very basic – don't worry how pretty the sketch looks.

2. Identify and profile patient and staff personas of interest

When you have your scenarios, develop your patient and staff personas.

Start by giving the person a name and then bring them to life. List their demographic qualities (age, gender, ethnicity and education); their physique with their physical abilities; their psychological state and abilities and their social supports. Do this for both patients and staff.

It can be very useful to sketch the persona (stick figures with a bit of detail are fine). Sketching often helps make the person more real.

3. Create full scenarios with personas

To create a full scenario with personas, start by taking a basic scenario and putting the relevant personas into it to develop a brief story about how things would normally work. As you do this, include issues and how staff and patient personas react to them.

Example: Scenario with persona:

Scenario: a patient is in bed on a shared ward. It is visiting hours and the room is full of visitors.

Persona: The patient has had a sleepless night and is distressed by the noise and activity of the visitors. She calls a stressed staff member and complains. The staff member feels powerless and somewhat annoyed but tries to respond positively.

4. Insert an improvement and experiment with it

To use the scenarios and personas to evolve an improvement, start by inserting the idea into the scenario. For example, the improvement might be a heavy, sound-deadening curtain that closes around a patient's bed space.

Example: adding an improvement

The patient might ask a visitor to close the curtain for them. Or the staff member might agree that the room is noisy and close the curtain. Or the patient might try to get out of bed and close the curtain themselves.

Each of the variations in the scenario helps you to explore an idea and its implications. For example, a curtain might need to be especially high to help block out noise. It might need a special track to make it easy for a patient to open and close. Its outer face might feature a request for visitors to talk quietly.

Scenarios and personas allow you to experiment, create, learn and evolve your improvement ideas in a realistic way quickly and easily. There are no right or wrong answers, so be brave and explore freely.

5. Document your work

Make sure you document your scenarios and any implications or new ideas. It often helps to have a note-taker observing the 'scenario team' as they imagine the scenario, so the latter can concentrate fully on this.

The scenario template can be used to develop a comprehensive range of scenarios and personas that explore an issue or improvement idea fully.

OTHER CONSIDERATIONS

- Make your scenarios and personas realistic. Be consistent with the scenario and persona – don't 'change the rules' halfway.
- Go for extreme scenarios and personas, using these to amplify the pros and cons of a problem, its possible solutions and the implications of these.
- Make your sessions relaxed and fun. Encourage experimenting and playing with different options. Prevent any judgement about whether an idea is right or wrong – just try it out and see what happens.

If you can, use role-plays rather than just discussion. Even very simple role-plays are useful. Are you shy or reluctant? Be brave!

Role plays

One of the best ways to experiment with scenarios and personas is to use role-plays and simple models of any technologies or improvements (such as cardboard cut-outs).

Role-plays are especially important when exploring intangible improvements and touchpoints (such as staff behaviours or communication) and times when people's interactions are central to the service experience.

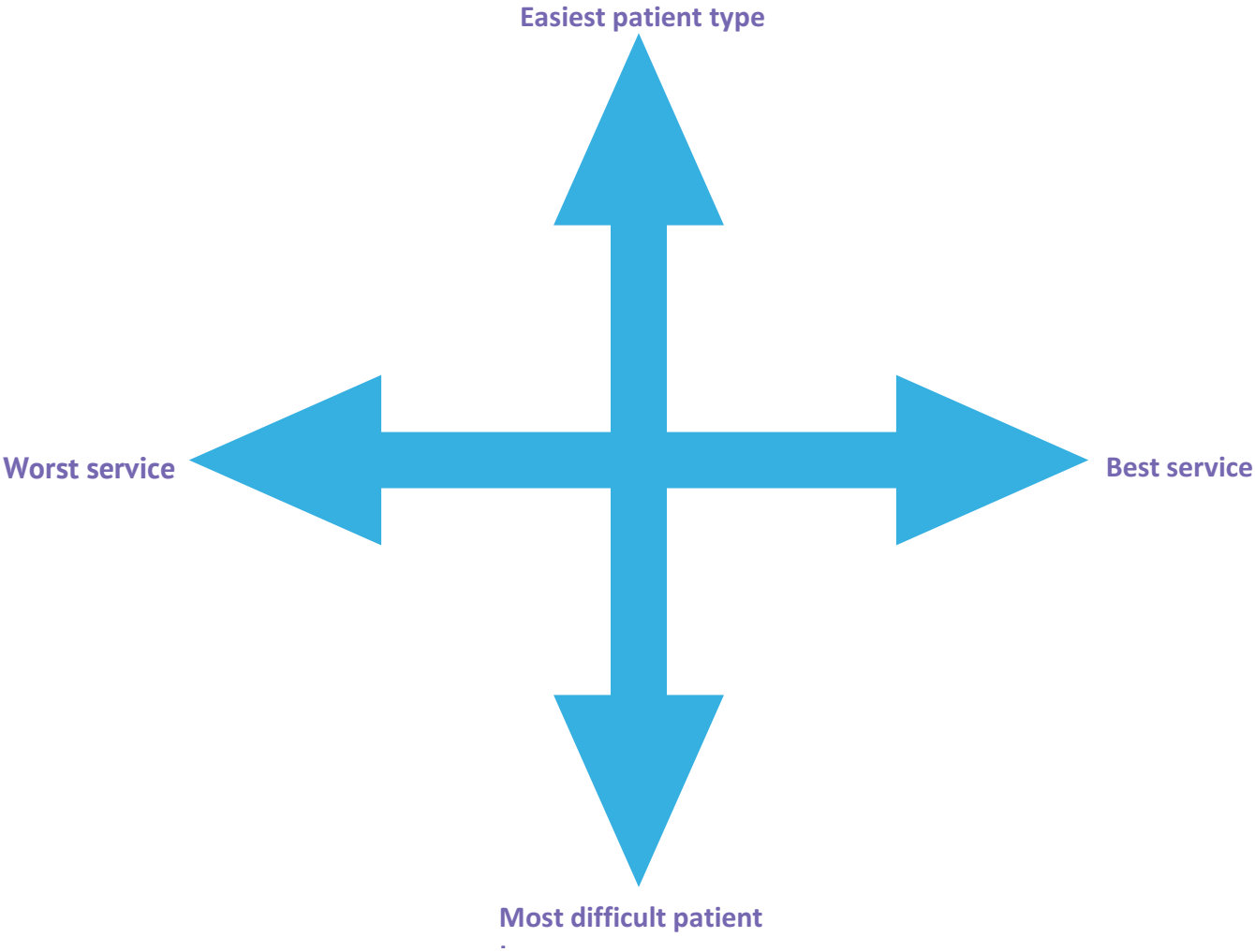
The major advantage is that you get to experience the kind of emotions that the patient or staff member has in that scenario. For example, an acted scenario produces spontaneous reactions and behaviours by the actors – ones that wouldn't come to light without acting it out. You can then explore ways to improve the service experience for both staff and patients.

When using role-plays have someone observing/taking notes/time keeping so the rest of the team can concentrate on acting and staying in role. When the scenario is finished, make sure you talk about the experience of being each person in the scenario – what it felt like to be that person, why things did and didn't work for them, and so on. If you have an audience, ask them to make observations about what they saw happening and what they understood from this. Summarise what you learned from the scenario and document it before moving on.

SCENARIO TEMPLATE

Template Instructions:

- identify the issue you wish to explore. Identify worst and best service extremes of the issue. Give each one a short, easy name
- Identify the easiest and most difficult patient types. Name these too.
- Combine your extremes of service delivery and patients into scenarios. Give these scenarios names.
- Plot these on the diagram. Try to have one in each quadrant. For example, you might combine a worst service with an easiest patient type.
- Flesh out each scenario with details.
- Introduce the improvement into each scenario and experiment with them!
- Document your learnings as you go.



Adapted with permission from healthcodesign.org.nz

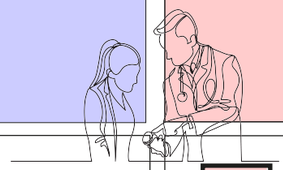
Persona Checklist

adapted from https://common-good.co/wp-content/uploads/2016/11/Persona-Checklist.pdf

Name, Sex, Age, Job, Location, Marital status

These details help focus on a specific individual, be specific. Think about their physique, psychological state, social supports

Sketch



Service use behaviour

Which services do they use?

Relationship with Service

What relationship do they have with the service?
Do they know the service? Are they new to the service?

Overview

Write a couple of paragraphs about who this person is to help get into the mind of the persona

Where do they access those services?

Quotes / attitudes

What would they say? What are their beliefs & attitudes?

How do they access those services?

Barriers

Why they might not engage with your service?

Underlying motivations / goals

What drives them? Why do they crave those needs?

Frustrations / concerns

If they already engage with you service, what are the negatives?

Opportunities

What specific opportunities are there for this persona?

Key Needs

What do they primarily need from the service?

Relevant Content

What specific content would this person be interested in?

Primary Actions

What do we want them to do first? (This helps give focus)

SWIFT IDEAS

WHAT

SWIFT stands for Strengths, Weaknesses, Individuality, Fixes and Transformation.

Each improvement idea is assessed for its strengths and weaknesses, and its individuality (what makes it different). Fixes (solutions to the weaknesses) are identified and the improvement idea is transformed (changed).

WHY

The SWIFT tool enables you to:

- Take a considered approach to all improvement ideas including out of the box ones.
- Assess your ideas against set criteria.
- Make robust, well-informed and transparent decisions about service improvements.
- Select the most viable improvements from a larger list and improve them.

WHEN

Use the SWIFT approach when you have several good potential improvements you need to develop and prioritise.

HOW

1. Identify and list your improvements

2. For each improvement complete the swift analysis template

3. Identify which improvements to prioritise

Review the list for improvements that are higher value for both patients and staff.

OTHER CONSIDERATIONS

- Have someone own and champion each improvement during the session.
- Keep your descriptions of strengths, weaknesses, individuality and fixes succinct – a few words at most.
- Allow anything from 15 minutes to an hour per improvement (it depends on both the improvement and the size of your team).
- Split your SWIFT exercise into a few brief sessions rather than an extended one if possible (this keeps people fresh).

Make sure your focus on strengths and individuality is balanced with weaknesses and fixes.

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SWIFT ANALYSIS TEMPLATE

Improvement idea	Strengths	Weaknesses
Individuality	**Fixes**	**Transformation**

Adapted with permission from healthcodesign.org.nz

Template Instructions:

- Identify key strengths and weaknesses of each improvement. Strengths are typically the qualities that make the idea attractive, while weaknesses are those that may cause difficulty and/or include elements that may need to be prevented or resolved. Beware of emphasising weaknesses and difficulties over strengths - be positive about the idea.
- Explore what makes each improvement especially individual – new, different, better and/or original.
- Prioritise the weaknesses and brainstorm ways to fix the key ones, then others.
- Be specific in addressing each weakness – avoid combining them under one fix. The aim is to strengthen, evolve and develop the improvement (not to find further reasons why it can't work). Beware of assuming any weakness is impossible to solve, and note any circumstances where weaknesses might not apply or be easier to resolve.
- 'Transform' the improvement into its final form. To do this, review your work on it (as above) and rewrite in a single simple statement.

PROTOTYPING

WHAT

A prototype is a rough draft of an improvement. Many kinds of prototypes are used throughout improvement work ranging from a simple verbal description of the improvement through to a full mock-up.

Prototypes can even be made just to help you learn. The key with all prototypes is to be clear about what you need to learn and who from.

Prototyping simply means using a 'rough draft' of an improvement or a touchpoint to learn more about it. Prototyping for services can seem difficult because they rely on intangible processes, such as relationships with people. For example, patients want to experience touchpoints such as warm smiles, informative conversations and helpful actions. But in fact, processes typically involve many tangible touchpoints, such as letters, gowns, signage and information booklets.

WHY

Prototyping can be used to test new processes, products or services to see if they will work.

WHEN

Prototyping is used throughout the design process. Early prototypes (such as concepts, descriptions, sketches and diagrams) are very useful for learning more about ideas and how best to develop them further. Later prototypes (such as drafts, role plays or physical mock-ups) are critical for making sure improvements are working as they should to improve patient experiences. Prototyping is a very useful way of engaging in learning with stakeholders and stimulating creativity.

HOW

1. Specify whom the improvement idea is for and what you want to learn

Start prototyping by clarifying who exactly the improvement idea is for - be as specific as you can. For example, when developing a patient brochure, your archetypal (target?) patient might be a person who has very little health knowledge and is confused. The next step is to specify what you want to learn by creating the prototype. Even if you have a lot of questions, focus on one or two at a time. For example, if you have a draft brochure for patients who have little health knowledge, find an appropriate patient and ask them to help you with one element such as the pictures and diagrams.

2. Select and develop the simplest prototype

Use the prototype selection template to help you find the simplest possible prototype. Note: the earlier you start prototyping the better your later prototypes are likely to be.

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You can develop tangible prototypes using materials such as paper, cardboard, cloth, plastic, lego, polystyrene and so on. You can develop intangible prototypes using diagrams and role-plays.

3. Develop the prototype as quickly and cheaply as possible

4. Test the prototype

Test the prototype as many times as you need until you notice a pattern in the ways people respond to it. You can adapt tools such as SWIFT ideas and the biggest difference to assess the prototypes. The interaction design foundation suggests three tools that help to maximise learning from testing.

a. Feedback Capture Grid – a structured way of obtaining feedback during testing or afterward to organise the feedback
   - https://public-media.interaction-design.org/pdf/Feedback-Capture-Grid.pdf

b. I like, I wish, what if – invites structured open honest feedback framing it in a way so that it can be provided in a constructive and positive manner, enabling an open discussion
   - https://public-media.interaction-design.org/pdf/I-Like-I-Wish-What-If.pdf

c. Sharing inspiring stories – a technique where team members share stories from prototyping in turn and each story is captured onto a post-it or similar. Each of these are displayed on a story wall and reviewed for common threads and insights to translate into actions for the next iteration
   - https://public-media.interaction-design.org/pdf/Sharing-Inspiring-Stories.pdf

Depending on the complexity of the prototype the feedback from the different tools can be synthesised on to a single prototype evaluation template to help you document your findings.

5. While you are fresh from your findings with this prototype, brainstorm ideas for the next one

OTHER CONSIDERATIONS

- In co-design work, it is a good idea not to spend a lot of time and money on individual prototypes. When working with stakeholders, a prototype only needs to be good enough for everyone to learn from.
- Prototyping is best when the exercise itself is very focused – the more focused the faster and easier learning is.
- Prototyping is best when people can play with and easily alter the prototype to reflect their findings and allow them to try out new ideas. The result might be an improvement or an idea for a new and better prototype.

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Feedback Capture Grid

Likes	Criticisms
Questions	Ideas

Developed by Prestantia Health based on content from https://public-media.interaction-design.org/pdf/Feedback-Capture-Grid.pdf

I like, I wish, what if

I like...	I wish...	What if..?

Developed by Prestantia Health based on content from https://public-media.interaction-design.org/pdf/I-Like-I-Wish-What-If.pdf

PROTOTYPE SELECTION TEMPLATE

1 **Prototype:** Just an initial idea (perhaps from a brainstorm) **Learning:** Asking stakeholders what they make of it	**2** **Prototype:** A concept description – a well-developed idea with some detail **Learning:** Asking stakeholders to assess it	**3** **Prototype:** A draft or sketch – a rough visual such as a sketch, diagram or map **Learning:** Asking stakeholders to imagine how it would work
4 **Prototype:** A rough tangible version – a rough written, visual or physical form **Learning:** Asking stakeholders to act out doing/using it	**5** **Prototype:** A full version – an example of the final version **Learning:** Asking stakeholders to use/do it in actual contents	**6** **Prototype:** The real thing – anything from a basic to a full version **Learning:** Asking stakeholders to use/do it in actual contents

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PROTOTYPE EVALUATION TEMPLATE

Key user(s)	Key questions/learnings needed	Key weaknesses
e.g. patient having a mammogram	e.g. what design works best for patients and staff	e.g. falls open too easily, one size only, makes patients feel uncomfortable
Key usage scenario(s)	**Key strengths**	**Ideas to improve prototype/criteria for next prototype**
e.g. patient seated while waiting, patient having a mammogram	e.g. easy to launder, durable material	e.g. different sleeve design, better ties, more attractive to patients, helps retain patient dignity

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Experience Improvement

WHAT

A place to record changes to the services and facilitate tracking of improvements against experiences.

WHY

It records the actions of the group and becomes a project management tool.

WHEN

To monitor and keep track of the different actions.

HOW

1. Record the name of the group
2. Record the experience that needs improving
3. Record the actions
4. Record who is responsible
5. Record the date agreed, when the action is due and status of the actions

Experience Improvement

Group Name:

Experience to be improved:

Improvement focus – what we will do:

Who is involved:

Who is responsible:

Today's date:

By When:

Status:

Group action statement

WHAT

A group action statement records the different team members and what their aims are.

WHY

Group action statements are a simple way of capturing group and individual actions. They serve as a communication tool and facilitate accountability. They can be given to all individuals and shared on a project display.

WHEN

Use this tool as a working document to ensure momentum is maintained. They can be useful if your group or some members are not achieving agreed activities

HOW

1. The group decides on their action statement and this is documented in the central box
2. Each member writes their name in the surrounding boxes together with their individual tasks
3. The date for completion of each individual task is written below the individual actions
4. Each member signs the document
5. Additional each member can also have an individual action postcard. These can be collated, photocopied and sent out a few days later as a reminder

Group Actions

Name: Individual actions: By when:	Name: Individual actions: By when:	Name: Individual actions: By when:
Name: Individual actions: By when:	Group Action Statement	Name: Individual actions: By when:
Name: Individual actions: By when:	Name: Individual actions: By when:	Name: Individual actions: By when:

Each group member signs here:

_____ _____ _____

_____ _____ _____

_____ _____ _____

Adapted from the ebd approach, NHS Institute for Innovation and Improvement

Individual Actions

Name:

My Individual Actions from _____ are:

Adapted from the ebd approach, NHS Institute for Innovation and Improvement

Monitor and
maintain the
experience

Monitor and maintain

Experience based co-design initiatives should be measured to see if the changes have had the desired effect, and monitored to help maintain improvements; ideally to support ongoing continuous improvement.

Measuring the improvement can take subjective and objective approaches. For example, the techniques from gathering information may be used to subjectively measure improvements. In the introduction, data was presented to show how improved experience can lead to better quality outcomes and safety. Measuring these outcomes is a more objective approach. Proxy outcomes or indicators, such as staff absence rates, can also be used. Examples of objective measures from the case studies are shown in the box.

Case Study 2

- Audits at 3 and 6 months after the project found 50-80% of boards in use, and pre-packed emojis were introduced 7 months into the project.

Case Study3

- Response times and referral patterns between services were monitored before and after the intervention

Case Study 4

- Staff surveys demonstrated reduced reactive work for nursing staff on the morning of the surgery, because patients were better prepared. For clerical staff reduced unnecessary paperwork because of fewer cancellations
- Patient-related day-of-surgery cancellations are reported daily and have slowly improved towards our goal of <2%

Examples of objective measures from case studies

Use any of the 'gather' and 'understand' tools, and comparing before and after, provides assessments of the impact of EBCD initiatives. For example:

- Running the experience questionnaire
- Patient and staff interviews
- Emotional mapping

In 'set up for success', the literature on sustainability was discussed with a range of strategies and tools to support efforts to enhance the impact and sustainability of your EBCD project. This discussed engagement, having a communication strategy and also the use of a sustainability tool. The same strategies and tools can be used to support maintaining and continuous improvement efforts. Additional tools and strategies are described below.

Tool	Description
Dissemination	Your communication strategy should include strategies to support dissemination of your findings. In 'set up for success' communication websites and visual communication were described. Other communication approaches may include newspaper or newsletters about your project and social media.

Your communication should be as engaging as possible. Consider including (subject to consent) photographs of people and events, write down what people say and quote them, include before and after stories, games and puzzles about the project.

Celebration Events

One important group of people who need to hear these project outcomes is project participants themselves. EBCD requires emotional investment from staff and patients alike. Holding a celebratory event for everyone involved, six to nine months after the joint patient–staff event, is a simple but important way of thanking participants, reporting back on what has been achieved, and providing a clear ending point to this part of the project. It may also act as a catalyst for future projects.

> In case study 4, the project team held a celebration event when the project went live with the app they co-designed. They also arranged publicity with national media coverage showing a patient and her family using the app and reading the magazine.

Make the celebration event as informal as possible. Ask someone to give a short talk to summarise the project and to thank everyone involved at the various stages. Use this opportunity to collate everything that has been achieved into one document.

PowerPoint Template

At the celebration event, make sure everyone feels comfortable. Assign people the role of facilitating informal chats, to help less confident guests circulate. Put up posters showing project achievements. This provides a useful focal point to help guests break the ice.

The Biggest Difference

The biggest difference tool illustrates the difference an improvement has made to a patient's experience.

It also helps identify the key aspects of the experience that have been changed and what part of the service made the difference.

- The biggest difference tool
- The biggest difference template

Service blueprints

A service blueprint is a document summarising key learnings and decisions arising from your EBCD project.

It communicates to all interested parties, including managers, why the service exists for patients, how it works best for them, and what it does now (or needs to be able to do soon). In this sense, it is a guide to the current and future state of the service from the perspective of patients and other stakeholders. It is very much like an architectural blueprint (hence the name).

A good service blueprint is important because it communicates on behalf of patients to other stakeholders within and beyond the organisation. It demonstrates a patient-based mandate and rationale for change, showing how to deliver great experiences and how to then continue evolving them.

- Service blueprint
- Service blueprint structure template
- Service blueprint future improvements template

Experience Based Co-Design
Project: [Insert Name]

Celebration Event

Background

- Enter the background details of the project here

Our aims and goals

Enter the aims and goals

What we learnt about our service

- Enter the learnings from the capture phase here
- Share stories/quotes/videos (Ensure consent is satisfactory)

The changes we made?

Describe the changes you made here

The impact of those changes

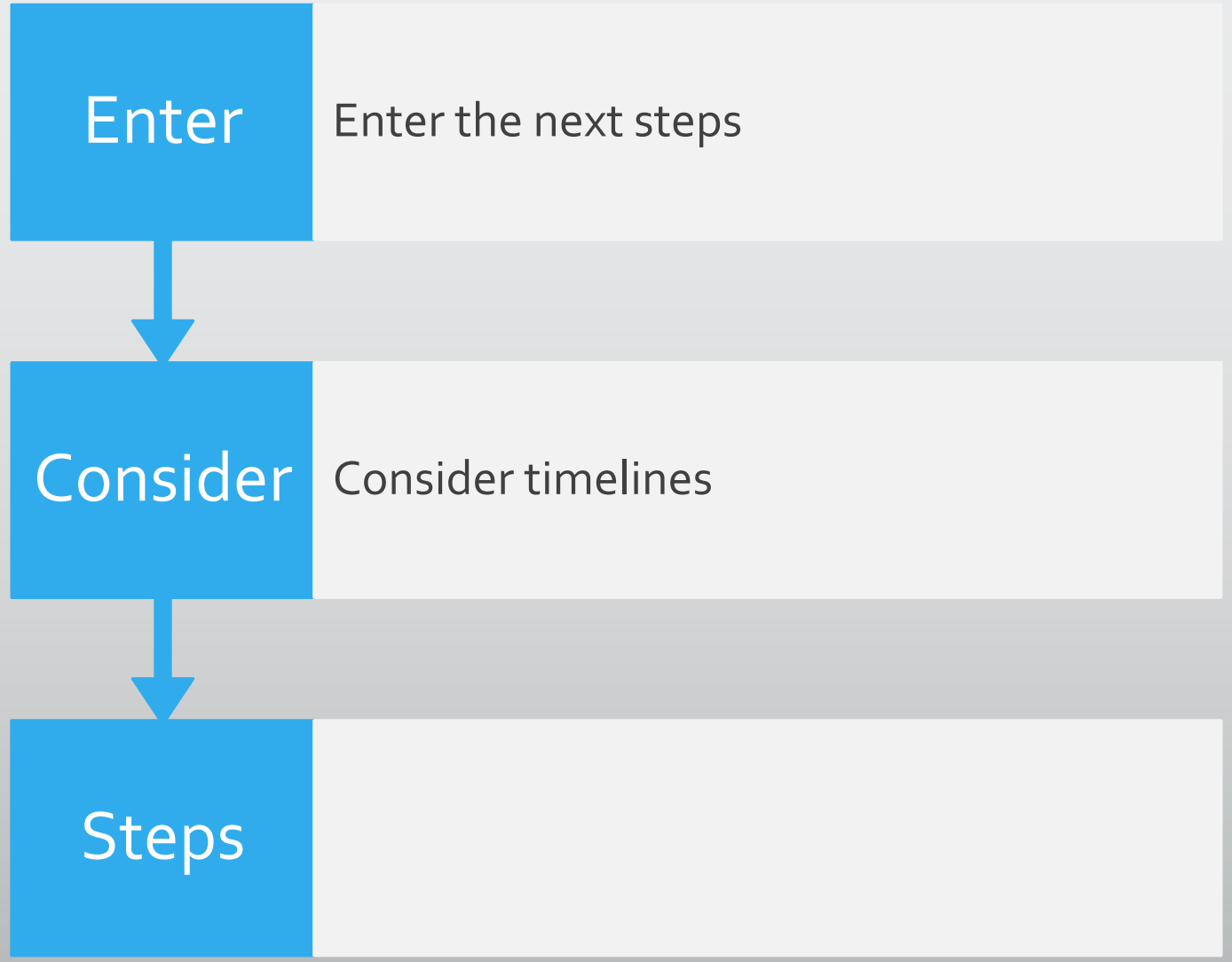
1. Describe the impact of those changes
2. Consider using quotes and stories
3. Consider staff experience as well as patient experience
4. Consider other benefits e.g. cost saving or improvement in clinical outcomes

Reflections on EBCD

Discuss the co-design process

Discuss what work well, what could be done differently

Next steps


Enter
Enter the next steps
Consider
Consider timelines
Steps

Thank you

THE BIGGEST DIFFERENCE

WHAT

The biggest difference tool provides evidence of what difference an improvement has made (or will make) to a patient's experience.

It also helps identify the key aspects of the experience that have been (or will be) changed and what part of the service made (or is likely to make) the difference.

WHY

This tool is important because it focuses on the patient's experience. It is designed to allow you to explore an improvement without needing detailed knowledge of the 'original' (pre-improvement) experience. But with this knowledge, it does allow you to compare and contrast the new experiences with the original.

WHEN

You can use this tool to evaluate a prototype or pilot version of an improvement, or to monitor the performance of an improvement after implementation.

Questions to ask about improvements:

- What is different about this improvement for you?
- Was anything else different? [Repeat until they say 'no'.]
- What effects, good and bad, did [name one difference they mentioned] have for you? [Repeat until all differences have been checked.]
- What was the biggest difference the improvement made for you?
- What effects, good and bad, did this biggest difference have for you? What were the effects during your times at home and in the rest of your life, as well as in the service?
- What ideas and suggestions do you have about making this difference even bigger and better for you?

HOW

1. Identify the key users of the improvement (patients are used as a general group in the steps below)

Make sure you have identified the types of patients an improvement is designed for. It pays to select a range of types to check the improvement is working equally well for all, or to assess that it is working best for those who need it most (without compromising the service for others).

2. Have patients experience the improvement

You can set up the experience by using prototyping, or by working with patients who have experienced the improvement during actual service delivery. Either way, it helps to observe them having the experience (see patient shadowing, to learn first-hand what happens).

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3. Have patients tell you about their experience and then reflect on the improvement

Ask patients to tell you the story of their experiences with the improvement. Use open-ended, non-specific questions inviting the patient to re-experience it fully.

Recording patient stories on video is a very useful way of capturing critical aspects of the experience. Tools for this are available in the capture section of this toolkit.

4. Encourage patients to reflect on the improvement

Work carefully with patients through the questions to help them evaluate the improvement. The questions need to be paced carefully so patients have time to reflect on and answer them fully. Some paraphrasing and much encouragement should be used.

5. Document your findings about the experiences carefully

Use the biggest difference template to help you do this.

6. Identify changes to improve experience

Review your findings. Identify ways to reduce negative effects and accentuate positive effects of the improvement.

OTHER CONSIDERATIONS

- Use this tool to explore with the patient and avoid making them do all the work. The questions focus a great deal of attention on the patient and make great demands of their time, energy and emotional resilience. So, encourage patients (whatever their replies), and contribute your own and others' ideas in support of those of patients you are working with.

- Focus on learning about the effects and impacts of the prototype or actual service improvement. If you are worried about biasing the evaluation, ask a researcher or colleague to lead the session for you. However, avoid stepping away from the process; it is better to witness patients directly, and in so doing make yourself accountable, than to miss out on critical findings.

- Having patients recall their experiences can be traumatic so make sure appropriate family and professional support is available.

THE BIGGEST DIFFERENCE

Project Name

Key Users	What was different about improvement?	What effects this had?
List key users	List differences	List effects of each difference
	What made the biggest difference?	**What effects this had?**
	Detail the biggest difference	Detail the effects this had

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SERVICE BLUEPRINTS

WHAT

A service blueprint is a document summarising key learnings and decisions arising from the co-design work you have done within a service.

It communicates to managers (and other readers) why the service exists for patients, how it works best for them, and what it does now (or needs to be able to do soon). In this sense, it is a guide to the current and future state of the service from the perspective of patients and other stakeholders. It is very much like an architectural blueprint (hence the name).

WHY

A good service blueprint is important because it communicates on behalf of patients to other stakeholders within and beyond the organisation. It demonstrates a patient-based mandate and rationale for change, showing how to deliver great experiences and how to then continue evolving them.

WHEN

Use this tool at the end of your co-design work to summarise the 'why, how and what' of the patient experience and the resulting service improvements.

As you read other tools, you will notice the emphasis on using diagrams to record your learnings, development work and decisions. That is, the emphasis falls on reporting progress often and in a brief, casual format. This saves a lot of time and keeps your co-design work moving.

Developing a more formal report or blueprint at the end of a project is easy because most of the work is done. It may be as simple as compiling your finalised diagrams and summarising the project using these to illustrate tools used, learnings gained and resulting improvements.

Sometimes you need to provide a rationale, strategy or plan for future development. This is easy as you can point people to the appropriate sections of the toolkit and to individual tools.

HOW

1. Collate your co-design work documentation and arrange it in an order that works for your organisation

Key tools to include if possible are:

- Planning workshops
- Co-design vision

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- Patient journey mapping
- Scenarios and personas
- Service touchpoints and hotspots

2. Develop a brief formal description of the service

- Use the service structure template, to help you.
- Simply complete the boxes from left to right, drawing on diagrams and project work to illustrate each section in concrete detail.

3. Use the future improvements template, to develop a more detailed discussion of improvements that could or should be made

- Use your knowledge of potential improvements by working column by
- column across the page template.

4. Add any other information developed during your improvement work

- This may include process maps, value chain analysis, reduction analysis, Six Sigma documentation, and so on.

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Stakeholders	Desired experiences	Outcomes
Key stakeholders	Desired service experiences for each stakeholder	Outcomes of great service experiences for each stakeholder
Touchpoints	**Recent Improvements**	**Future Improvements**
Key touchpoints for each stakeholder	Improvements recently made during the project	Improvements that should or could be made

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FUTURE IMPROVEMENTS TEMPLATE

01 Who is it for?	**02** Why it works for them?	**03** How it works for them?
04 What can go wrong?	**05** How can it be fixed?	**06** How might it be improved?

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CASE
STUDY

Case Study 1 – NSW Brain Injury Rehabilitation Model of Care

Organisation: NSW Agency for Clinical Innovation
Website: https://www.aci.health.nsw.gov.au/
Contact Person: Tara Dimopoulos-Bick, Manager Patient Experience and Consumer Engagement Email: tara.dimopoulosbick@health.nsw.gov.au

What were the goals and aims of our project?

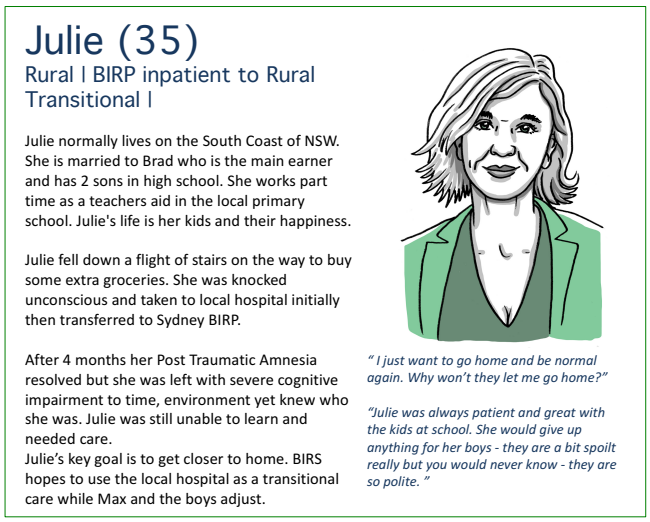
The aim of the Brain Injury Rehabilitation Program Model of Care review was to engage consumers and families to understand their experiences of receiving care through the Brain Injury Rehabilitation Program (BIRP) in NSW. This was intended to complement the diagnostic report in a project focused on redesigning the model of care.

What did we do and what EBCD tools did we use?

The key tools used to capture consumer and families' experiences and insights were personas, visual narratives, semi structured interviewing and thematic analysis.

Personas are a representation of the goals and behavior of a group of users linked by their motivations and needs. We built five personas from the expertise within the project team – differing in their needs based on age, type of injury, age and location.

Persona example



By referencing the clinician perspective of the service, we built a journey for each persona from injury to accessing services in the community. This became our narrative and was used to inform a semi structured interview when talking with consumers and their families. The data collected (written and audio recordings) were thematically analyzed and patterns across and within the personas were identified.

What was the impact?

The use of personas and narratives enabled the project team to interview and safely engage families and consumers. Consumers and families were able to share their experiences, feelings and needs rather than just a factual review of the process. They could connect to the persona and narrative, highlight comparisons or differences and share their experiences more openly and freely.

This process revealed many unmet consumer and family concerns. These included the need for more information and support in relation to emotional needs. The concerns were summarised into seventeen key themes for the project to focus on together. The experience also initiated ongoing co-design activities between clinicians, consumers and families.

Reflections

What went well?

The consumer engagement activity unearthed additional needs not identified in the initial diagnostic report. Consumers could share their potentially traumatic experiences safely. In addition to data, this method of consumer engagement encouraged involvement in subsequent co-design workshops and working parties.

What were the challenges?

The key challenges included:

1. Delays in recruitment of and access to consumers and their families. This resulted in an initial analysis of a more limited set of consumer experiences than planned
2. Difficulty connecting with consumers. We found that those who had a more positive experience were more likely to respond. This created a bias towards positive experiences

Extensive geographical distribution and time constraints resulted in a majority of phone interviews rather than preferred face to face engagement.

If we were to do it again what we would do the same?

The narratives including visual illustrations are a powerful tool to gather experiences through interviews with consumers and families. They were shown to be a safe and gentle way to engage with consumers and families. The narratives enabled the collection of stories, direct quotations and memories. We would use the same process to build, deliver and analyse narratives in other projects requiring consumer engagement.

Case Study 2 - Co-designing a patient communication board – the paediatric experience

Organisation: Sydney Children's Hospital, Randwick NSW
Contact Person(s): Maria Brien and Laurel Mimmo

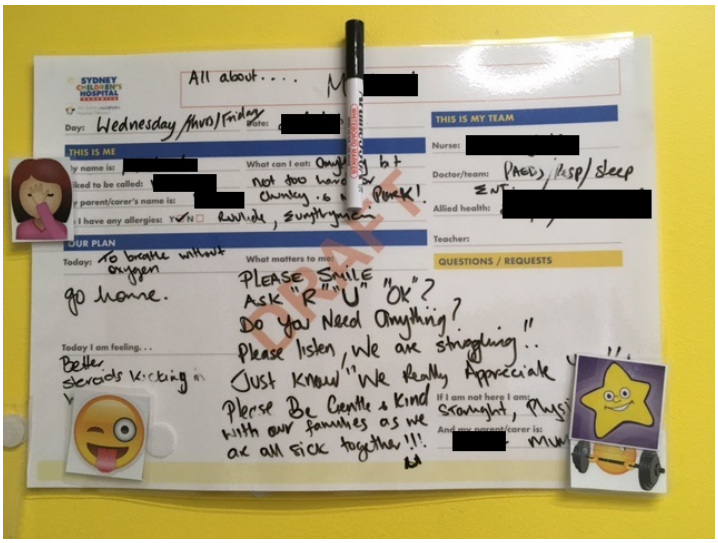
What were the goals and aims of our project?

Within three months, to co-design and develop a communication board with patients that facilitates patient and family engagement in clinical handover in an inpatient adolescent ward.

What did we do and what EBCD tools did we use?

We initially began our project as a quality improvement project. After sourcing several different communication boards used at other hospitals, we asked our Graphic Design team to mock up a basic template. We showed this to several of our patients who have regular admissions to our unit, and asked them what they think would be important to tell us. One patient told us to us emojis, as that's how she communicates with her friends.

With this information, a prototype was developed. One of our patients, Tony*, was asked to trial the prototype during his stay:



The experience for Tony and his family using the prototype was shared with nursing staff during staff education sessions of 2-3 nurses. Our intention was for nursing staff to reflect on what was written on the board and what they thought about their own practice, and how the board could improve communication with our patients and families.

* Pseudonym

After a few sessions, we conducted semi-structured, in-depth interviews with Tony, his mother and sister to tell us about their experience of using the board, and how they felt this improved communication with staff. These were audio recorded and transcribed verbatim. Quotes from these interviews were incorporated into subsequent educational sessions and focus groups.

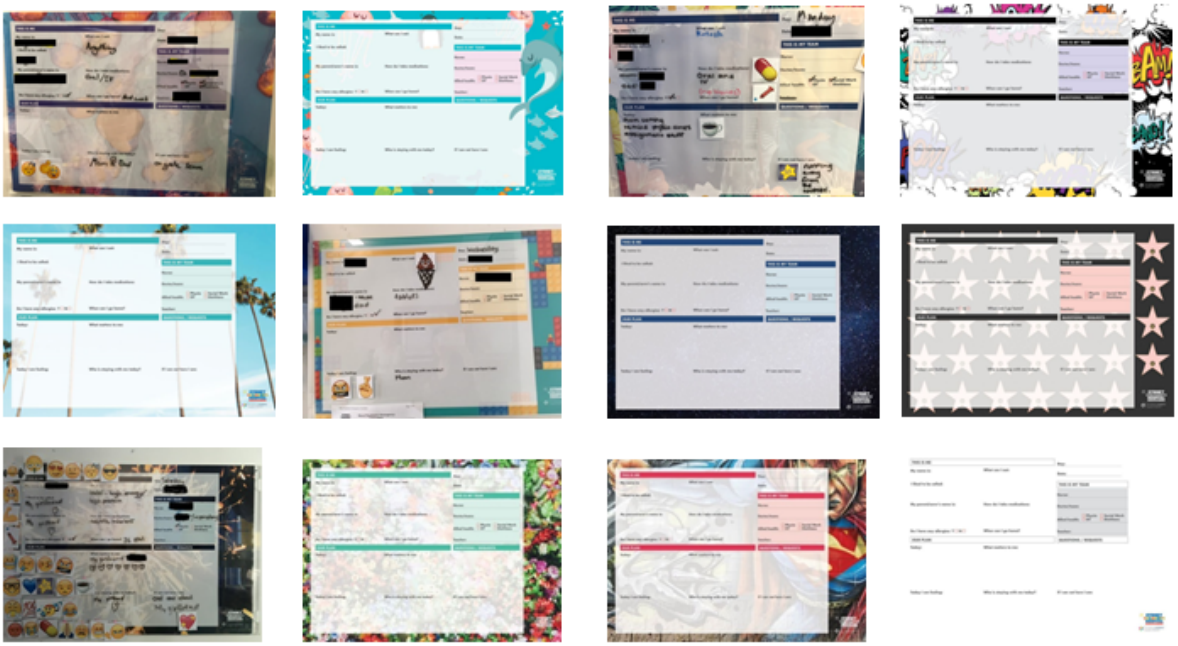
As we could only have 2-3 nurses in the focus groups, we found this approach enabled honest, thoughtful and sometimes an emotional reflection from nursing staff about how they communicate with their adolescent patients and families.

In presentations to senior nursing staff and committees, we display Tony's board, allowing our audience to read his family's comments in silence, which has initiated some heartfelt conversations within these groups.

Step One: First board trialled

Step Two: Rapid cycle PDSAs - changes over four weeks

Step Three: Sustaining Change - final templates and Perspex boards installed March 2017



Using rapid PDSA cycles over a period of four weeks, increasing numbers of patients were asked to use the board to communicate with staff and further iterations of the board were produced. We took regular photos of the boards in use and asked patients and families directly about their experience. To incorporate this input Graphic Design delivered 11 modifications over three months.

What was the impact?

"It makes me feel happy, it gives me something to do."

Many patients were using the board as were an increasing number of staff too. A patient/family survey reported 75% used the board, with 25% saying staff used the board. Overall, feedback was very positive:

Tony's mother said:

"I have to admit, ever since we started this [communication board], the levels [of communication] just gone through the roof [...] maybe the nurses are getting to know us better. "They're getting more comfortable now [...] And you can be comfortable with them."

"Good way of writing down the nurses name for the shift. Parents name also. The emoji cards are great visuals. The board covers all aspects of A___'s care"

Barriers to use included lack of access to permanent boards, emojis were not available, and lack of orientation to the board. Audits at 3 and 6 months after the project started found 50-80% of boards in use, and pre-packed emojis were introduced 7 months into the project.

Reflections

What went well?

- Listening to patients and families to incorporate their ideas and suggestions

- The emojis that were suggested, prompt conversations with and between the patient and family, and are especially significant for those patients with communication difficulties
- Using a prototype to trial and adapt the board in use

What were the challenges?

- Engaging nursing staff to use the board
- Board placement. The boards have been installed behind the patient bed and access can be difficult. We are working with our maintenance team to change the position
- Sourcing pre-prepared emoji packets for sustainability

If we were to do it again what we would do the same?

- Using the prototype and in-depth interviews. In particular, we would do more interviews, and if possible, record these for use in staff focus groups
- We would use the staff focus groups more, with a focus on these as a strategy for staff engagement

If we were to do it again what we would do the differently?

- Actively recruit a few ward champions to drive the project on the floor. We would also involve ward staff in asking patients and families about the boards, to hear about their experience firsthand

Case Study 3 – Join the conversation: Evaluating the effectiveness of experience-based co-design in improving the client experience of mental health transition across health sector interfaces

Organisations: Victoria University, Australian National University, Western Health
Website: http://aphcri.anu.edu.au/files/Experience-based-full-report.pdf
Contact person: Kate Cranwell (Kathryn.cranwell@wh.org.au)
Source
Cranwell, K., McCann, TV and Polacsek, M. Join the conversation: Evaluating the effectiveness of experience-based co-design in improving the client experience of mental health transition across health sector interfaces. 2015. APHCRI.

What were the goals and aims of our project?

Overall Aim:
To use Experience Based Co- Design (EBCD) to improve consumers' experiences of mental health services as they transition through tertiary services to primary care and self-management support.

Objectives:

- To understand the experiences of consumers as they transition through tertiary services to primary care and self-management support
- To Identify opportunities for service redesign and integration, to improve consumers' service transitions
- To develop, trial and evaluate service redesign initiatives aimed at improving consumer experiences of transitions
- To promote greater understanding of services, more integrated care across the system, and more effective communication between stakeholders.

Why they did it?

Health services, including mental health services, tend to be fragmented and slow to respond, leading to poor health outcomes for consumers. The Fourth National Mental Health Plan recommended improving coordination between primary care and specialist mental health services, and suggested that emergency and community services develop protocols that support care transitions between services. The Fourth National Mental Health Plan also recommended that health provider staff should engage actively with consumers at all levels, including research, policy development and service delivery.

What did they do and what EBCD tools did they use?

Consumers with mental health conditions who were frequent attenders at three emergency departments across Melbourne were recruited to participate. Staff from regional mental and community health services and GPs were also invited. Filmed interviews with consumers were conducted over a three-month period. Focus groups

and semi-structured interviews were conducted with providers. Themes were extracted from the transcripts and a short film was created depicting the consumer experience. A joint co-design workshop was conducted with regional service providers and consumers in partnership in which the short film was viewed and priorities for improvement were identified. Surveys of all participants regarding the EBCD process were conducted. Response times and referral patterns between services were monitored before and after the intervention.

Three main projects were developed from the joint workshop

- Design and develop consumer information
- Design implement and evaluate a consistent post discharge follow up process
- Increase awareness and understanding of the role of the community mental health integration project

What was the impact?

All consumers reported

- the new brochure would have improved their understanding and would be useful for new clients
- a post discharge phone call would be useful (one raised the need for a readmission process if required)
- the EBCD process was effective in involving them.

Analysis of referral patterns appeared to indicate improvements in appropriateness and timeliness.

Reflections

The project provided a forum in which consumers and staff collaborated to generate service improvements. The experience in this project was that EBCD is an effective means of capturing consumer and staff experiences, as it provided a framework for understanding the impact of duplication and fragmentation of care. It provided valuable insights into the experiences of consumers with complex mental, medical and social health care needs.

Approximately 50% of consumers approached agreed to participate in the EBCD project and positive consumer response was supported by evaluation survey results.

Those involved in filming, reviewing and editing the consumer interviews also reported how powerful it was to be directly involved in capturing consumers' experiences and seeing them as 'real people'.

Several staff who attended the joint workshop reported that it had been confronting to see the film for the first time. While the main purpose of the film in EBCD is to trigger discussion the result in this project was that most staff participants at the workshop spoke very little during the post-film discussion. A second workshop was held with staff to review the film and debrief the experience. Future projects might benefit from

engaging consumers and front-line staff in the development of the project, not just during implementation.

The films of patient interviews which were developed for this project have become a resource for highlighting consumer views on hospital and inpatient experiences, and ambulance and emergency department experiences. In order to maximise effectiveness the project team developed speaking notes that introduce and contextualise the films.

One of the reported strengths of this project was that it allowed consumer participants to feel that their views had been heard. More time is needed to determine whether tangible and sustainable improvements to service delivery and integration have been achieved through this project. Nevertheless, it provided impetus to expand and support consumer involvement in future service improvement and planning.

Case Study 4 – Improving the patients' experience of surgery

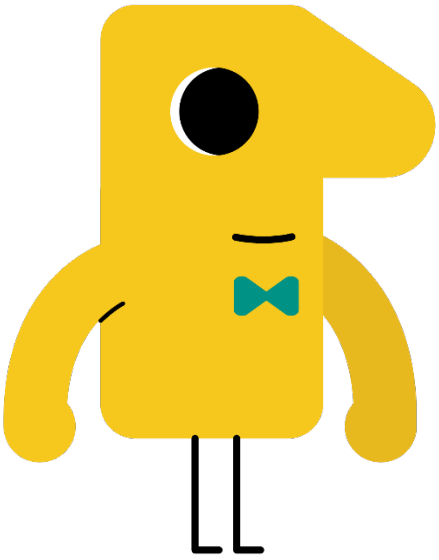
Organisation: Illawarra Shoalhaven Local Health District (NSW)
Websites:
http://www.mysurgery.mobi/
http://www.islhd.health.nsw.gov.au/Surgery/docs/MySurgeryJourneymagazine.pdf
Contact Person: James Brinton Email: james.brinton@health.nsw.gov.au Clinical Nurse Consultant Surgery

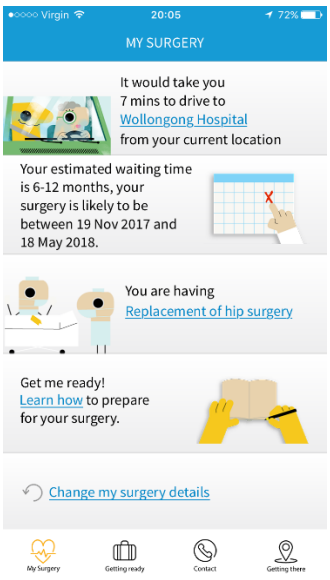
What were the goals and aims of our project?

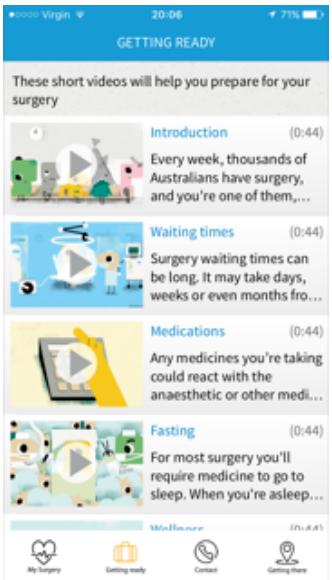
To reduce patient-related day of surgery cancellations and improve the patients' experience of surgery. Additionally, we wanted to improve in-hospital efficiencies and reduce 'waste' by improving utilisation.

What did we do and what EBCD tools did we use?

We started with pre- and post-operative patient and family surveys asking about the amount of information patients were given. Then we produced the magazine and tested with patient focus groups. Next, we developed the app and tested with patients and their families.







We used the following tool:

- Staff interviews - frequent and repeated staff liaison
- Patient interviews - pre and post-op interviews followed by patient-led focus groups
- Group dialogue - focus groups with patients who had experienced surgery led by patients
- Co-design meetings - Met with app designers and clinicians with input from our patients

- Celebration events – A celebration when we went live, with national media coverage showing a patient and her family using the app and reading the magazine

http://www.illawarramercury.com.au/story/4791051/wollongong-app-the-first-of-its-kind-for-nations-public-hospitals/

What was the impact?

- Improve the patient experience of surgery
- Staff surveys demonstrated reduced reactive work for nursing staff on the morning of the surgery, because patients were better prepared. For clerical staff reduced unnecessary paperwork because of fewer cancellations
- Patient-related day-of-surgery cancellations are reported daily and have slowly improved towards our goal of <2%

Reflections

What went well?

Fantastic clinician engagement and great response from patients and their families to develop an Australian-first solution

What were the challenges?

The initial challenge was simple: money! When that was secured, the next challenge was matching the amount we had to the reality of producing a product within budget. Our newest challenge is to on-sell the idea to some of the 700 other Australian hospitals who experience the same problem.

If we were to do it again what we would do the same?

We had a fantastic full-day multi team co-design workshop where the app developers met with staff and patients to nut out our ideas.

If we were to do it again what we would do differently?

Set a more realistic budget before pitching for funding- we were off by a considerable amount and were fortunate enough that the developer, Capuchin Digital, were well aligned with our dream.

Case Study 5 - Day Rehabilitation Services (Local Service Improvement)

Organisation: Agency for Clinical Innovation
Website: https://www.aci.health.nsw.gov.au/
Contact Person: Tara Dimopoulos-Bick, Manager Patient Experience and Consumer Engagement Email: tara.dimopoulosbick@health.nsw.gov.au

What were the goals and aims of our project?

The goals and aims of the project were to improve the patient and carer experience for people receiving day rehabilitation services.

What did we do and what EBCD tools did we use?

A range of Experience-Based Co-design resources were utilised throughout the project including: capturing experiences through interviews, focus groups and surveys; theming; experience mapping; and prioritising, designing and testing solutions with consumers, families and staff. Education and training in EBCD was given to consumers, families and staff at regular intervals during the project.

Several techniques were used to capture our consumer's experiences in including surveys, interviews and focus groups. We used these techniques to capture both the range of consumer experiences and the detail of specific experiences across that range. Interviews and focus groups were a powerful way to learn and discover insights about people's experiences and their stories. The service routinely captured feedback through surveys and the last two years of this data was reviewed collectively with the insights captured through interviews and focus groups. The results were displayed publicly and consumers, families and staff were invited to contribute comments using post-it notes.

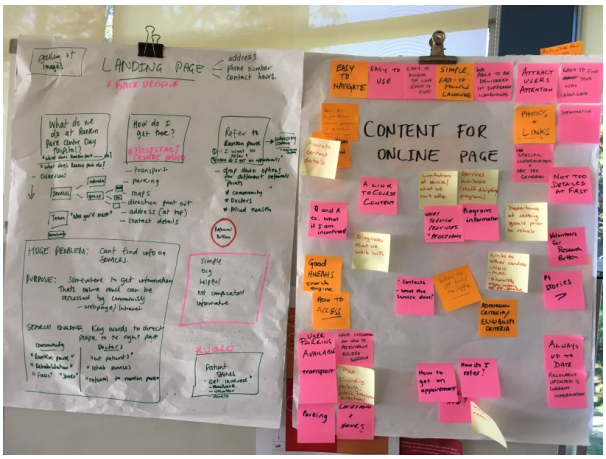
Experience mapping was used to develop a visual depiction of the emotions and touch points related to the various stages within a journey. A focus on emotions promoted greater empathy and understanding.

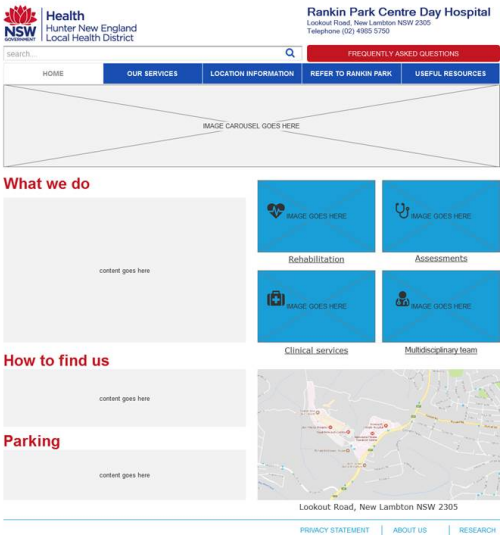
Theming was used to organise all the data captured, discover patterns and focus improvement on what mattered most to the people using and delivering day rehabilitation services locally. The priorities for improvement were explored and collectively agreed upon a co-design workshop. The priorities were categorised into a matrix: easy, hard, high impact and low impact.

Service information was identified as a key priority. Following the initial co-design workshop; consumers, families and staff worked together to design the layout and content of an information brochure and online presence for the community. Prototyping was used to test the layout and content.

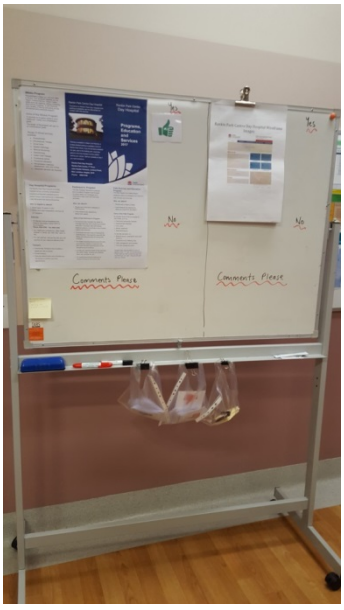
Prototypes are an effective way to generate quality feedback and foster engagement. It decreases risk of failure and enables you to learn and make solutions richer with minimal effort and cost.

Prototyping an online presence (different iterations)





The prototypes included wireframes for an online presence and a hardcopy of an information brochure. Testing occurred through facilitated discussions and both prototypes were made available in the activities room, which encouraged greater and more diverse input and feedback.



What was the impact?

More than 135 consumers, families and staff shared their experiences and their insights have led to several service improvements. In addition to the brochure and online presence, a short film was co-designed to raise public awareness of rehabilitation and educate people on how to access services.

Reflections

What went well?

Consumers, families and staff were passionate about improving the access to services and the solution development. Using an iterative process to design the brochure and

online presence ensured it was responsive to the needs of consumers, families and staff and allowed for strengthened trusting partnerships to occur.

What were the challenges?

The time taken to develop the prototypes was a challenge and it was difficult to maintain consumer, family and staff engagement over a prolonged period of time.

If we were to do it again what we would do the same?

Utilising a variety of methods to capture the experience including survey data, focus groups and interviews gave richness to the project that would otherwise have been lacking. Including consumers, families and staff on the Project Steering Committee ensured equal partnership and collaboration from the start and throughout.
It was important that the initial prototypes were simple, rough and very draft. People are less likely to engage with a prototype if it looks and feels like a final product.

What would you do differently?

There were two key areas:

- Ensuring that the governance and ethics responsibilities are fully understood and approval has been established prior to the project
- Ensuring that the Project Steering Committee are familiar with the approach and have opportunities for revising throughout the project. Check-in points would have been beneficial
- Understanding the NSW and local guidelines for working with consumers prior to commencement of the project.

Case Study 6 - Development of the 3P Pod - a Patient EmPowerment Pod

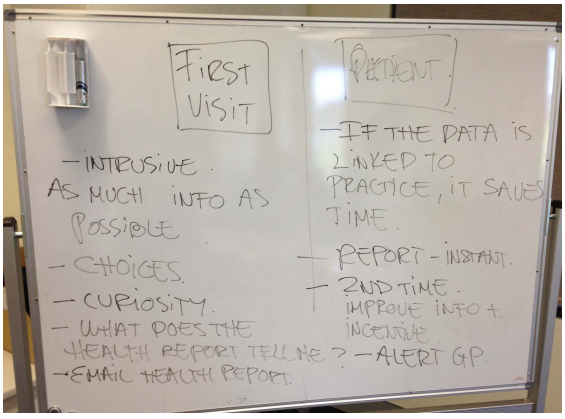
Organisation: Ochre Health and University of Canberra
Contact Name: Vincent Learnihan
(Vincent.Learnihan@canberra.edu.au)
Acknowledgment: This project was funded by a grant from HCF and RACGP.

What were the goals and aims of our project?

We wanted to explore whether the time spend by patients whilst waiting for their GP or nurse appointment could be used in a constructive way to help the clinicians but also empower patients and motivate them to act to support themselves.

The project was focused on a purpose built Patient Empowerment Pod (3P) that would easily and non-intrusively collect a range of measureable data from patients and then offer them with a tailored health report card and appropriate signposting.

What do we do and what EBCD tools did we use?



Consumer Design Meeting

Firstly, we had a multi-disciplinary team that included practicing clinicians, members from Health faculty but also members from marketing, design and information technology disciplines.

The experience was gathered in multiple ways through observation (many design students over different days and time periods observed the waiting room). Focus groups with consumers and with staff were held.

A working group consisting of the multi-disciplinary team members also fulfilled the role of a co-design group.

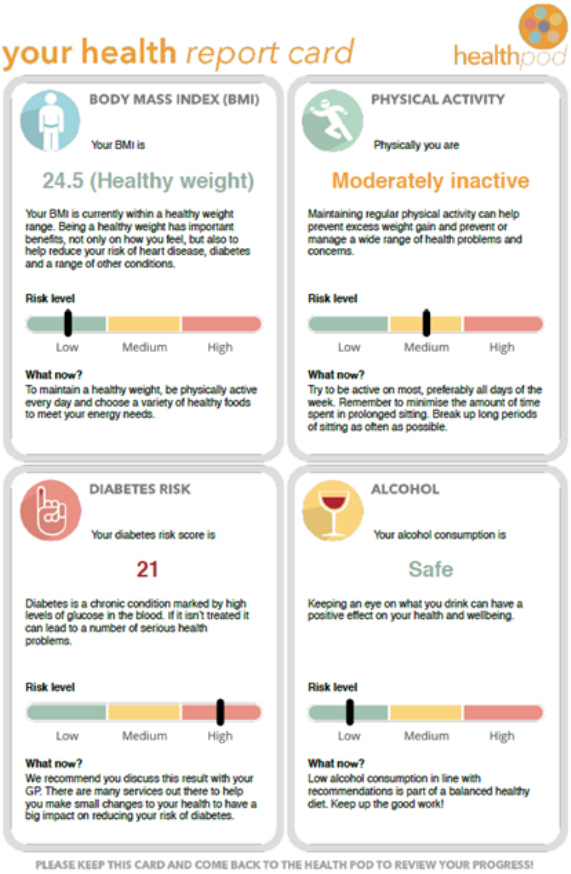
The project had three main outputs.

1. The building of a private yet inviting and aesthetically pleasing Pod.
2. An interactive screen and equipment that asked patients four key groups of questions (A video of screenshots of all four modules is available at https://www.youtube.com/embed/NC1yMVLeRao):
    a. Basic health check module including an automated height and weight capture to calculate BMI
    b. Questions on alcohol intake

c. Questions to calculate a diabetes risk assessment using a variation of the Australian Diabetes Risk Score
d. Questions on physical activity

3. A report card that participants were presented with signposting to a website (http://www.ochrehealth.com.au/healthpod/) for further resources.

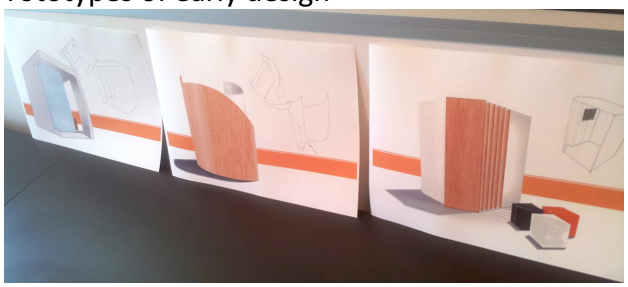
Front Page of Report Card



Reverse Side of Report Card

Prototyping in both the build of the Pod itself, software/technology and report card were utilized. The picture below illustrates the different prototypes of the Pod and a video of the construction of the Pod can be viewed at https://www.youtube.com/embed/JkKR5fyBYbI

Prototypes of early design



Picture of final 3P Pod design

What was the impact?

> "*A useful trigger and reminder about health issues that you have a vague sense of needing to change but seeing the report card was salutary*"

250 participants used the 3P Pod during the pilot period. 89% completed basic health check and 38% completed all four within a mean time of 4 minutes. The majority described a positive user experience of the Pod with 72% citing they would like to use the Pod more frequently and confirming that the Pod increased awareness of their health. 20% did not discuss their report card with anyone. 15% of users took further action because of recommendations on their report card.

Reflections

What went well?

- The value of a multi-disciplinary team who brought design expertise
- The engagement of participants and consumers who described positive experiences once they used the Pod
- Senior leadership sponsorship of the project

What were the challenges?

- The lack of integration with the clinical system proved to be a barrier
- Front line reception who were having to prioritise reactive front desk duties with a proactive approach

If we were to do it again what we would do the same?

- Maintain the multi-disciplinary nature of the design team
- Use the same approach

If we were to do it again what we would do the differently?

- Integrate with clinical system at outset
- Identify more resources to allow reception staff to be released to act as concierge for the 'pod'

Case Study 7 - Utilizing experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals

Organisation: The emergency departments of seven NSW hospitals
Contact person: Donella Piper. dpiper@une.edu.au
Source
Piper D, Iedema R, Gray J, Verma R, Holmes L, Manning N. Utilizing experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals: an evaluation study. Health Serv Manage Res. 2012 Nov;25(4):162-72.

What were the goals and aims of our project?

Overall Aim: To improve patient experience of emergency departments (ED) through the use of experience based co-design

Initial 3 Emergency Departments

Program 1, Stage 1.
Aim: to strongly engage frontline staff, patients and carers in identifying the best and worst aspects of their experience, and to co-design solutions to improve that experience within the ED.
Program 1, Stage 2.
Aim: to re-visit the Stage 1 sites 24 months after the initial deployment of EBCD to determine whether the aims of Stage v1 were achieved and whether or not the improvements brought about at the EBCD sites were sustained

Further Emergency Departments

Program 2.
Aim: to deliver improvements in patient, carer and staff experience

Why they did it?

The Garling Report, released in 2008 inquired into the shortcomings of acute care services within the NSW health systems. High among the shortcomings noted was a lack of "patient centredness". This project sought to address the problem through the use of EBCD.

What they did and what EBCD tools did they use?

NSW Health in partnership with the NSW Department of Premier and Cabinet commissioned an EBCD project in 3 emergency departments in 2007 which was extended to a second stage in 2009. The project was extended simultaneously in a 'second stage' to a further 4 emergency departments in 2009. In Program 1 the improvement efforts were confined to emergency departments. In Program 2 efforts included a Medical Assessment Units, an acute cardiology service, a radiology service

and orthopaedic teams in order to build on previous local work and improve the patient experience of flow between emergency and specific specialist teams.

How they did it?

Project governance teams were formed at each site as well as working groups. The intention was to implement five phases of EBCD. All sites carried out phase 1 (planning and startup) however there was considerable variation between sites in implementing phases 2-5. All sites used staff and patient interviews and video. Interviews with external stakeholders, observations, tag alongs, patient and staff surveys and diagnostic workshops were used variably across the seven sites. All sites conducted co-design workshops and all sites developed implementation plans based on priority areas identified in the co-design phase. Despite difference in implementation all sites reported similar challenges and achieved similar outcomes.

What was the impact?

Evaluations indicated participants felt that EBCD work had improved operational efficiency and interpersonal dynamics in their units. Staff and patients reported a deepened understanding of each other's experiences. EBCD appeared to produce change that mattered to patients which in turn raised clinician morale. Practical changes were made in all seven sites. Areas of change included: improving patient and carer comfort and privacy; improving physical space for staff and patients; and improving communication between staff and between staff, patients and carers.

Follow up after 24 months in program 1 sites (stage 2) indicated all sites had sustained and extended improvements. Specifically, evaluation of the follow-up programme reinforced the earlier finding that EBCD:

- taught project staff new skills
- enabled frontline staff to appreciate better the impact of health-care practices and environments on patients and carers
- enabled frontline staff to appreciate better the impact of health-care practices and environments on patients and carers;
- engaged consumers in 'deliberative' processes that were qualitatively different from conventional consultation and feedback
- achieved practical solutions that realize the wishes, advice and insights of consumers and frontline staff.

Reflections

- EBCD activities were viewed as an additional burden by staff. Lack of dedicated time may have reduced the impact and sustainability of the programs.
- Project staff reported a need for increased support and reporting opportunities.
- Project staff reported patient recruitment was sometimes extremely difficult in the ED setting. There was high turnover of patients between the diagnostic and solution co-design phase perhaps indicative of the transient relationship of patients with EDs. Recruiting a small number of patients required a very large

investment of time in some sites. A consumer retention strategy appeared to be successful at one site ensuring greater continuity and engagement throughout the project. The appointment of a consumer to the project governance committee had a positive impact. Program 2 sites learnt from this challenge in Program 1. They recruited a higher number of patients initially and found that progressive daily recruitment was more effective than contacting patients after their health event was completed.

Experience Based
Co-design
a toolkit for Australia