



# Improving the experience of people who are blind or have low vision in hospital

## An Experience based co-design project

**Badge H, Thomson S, Smith C, Thompson K, Fuller C, Waller S-J, Kovacic C, Jacobs N, Dimopoulos-Bick T**

### Low Vision EBCD Project Partner Organisations



**Health**  
South Western Sydney  
Local Health District

H Badge  
S Thomson  
C Smith  
K Thompson  
C Fuller  
S-J Waller  
C Kovacic  
N Jacobs  
T Dimopoulos-Bick



# Stroke







# Glaucoma







Diabetic Retinopathy

Diabetic retinopathy

NSW GOVERNMENT | AGENCY FOR CLINICAL INNOVATION

Vision Australia  
Blindness, Low Vision, Opportunity

Improving the Experience of people who are blind or have low vision in hospital



AGENCY FOR  
CLINICAL  
INNOVATION

**25%** of patients in hospitals  
are blind or have low  
vision

with numbers set to



# Experience-based Codesign (EBCD)

<https://www.aci.health.nsw.gov.au/networks/peace>



## Aims:



AGENCY FOR  
CLINICAL  
INNOVATION

Use experience-based codesign to

1. Understand the experiences of people who are blind or have low vision when they are in hospital and those who care for them
2. To use these narratives to co-design, test and implement solutions together to improve the experience of patients, carers and staff

## Project timelines

Timelines	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	March	April	May	June	July
<b>Engage</b>														
<b>Gather</b>														
<b>Understand</b>														
<b>Improve</b>														
<b>Measure</b>														



## Start up & Engage

- 1. START-UP AND ENGAGE**  
Frame the challenge or opportunity

### PART 1



### PART 2



Create a project plan and engage with decision makers early

### PART 3



Learn from **real-world experiences**, adapt ways of engaging with people and communities



## EOI to NGO and Consumers



### Project Partners

- Vision Australia
- LHD Consumer and Community Participation Managers
- LHD Disability group
- Community Stroke Recovery group
- Blind Citizen's Australia

## HOW we are working TOGETHER



- Ethical / QI approvals
- Terminology
- EBCD capability
- Willingness to partner as equals
- Consumers vs service users

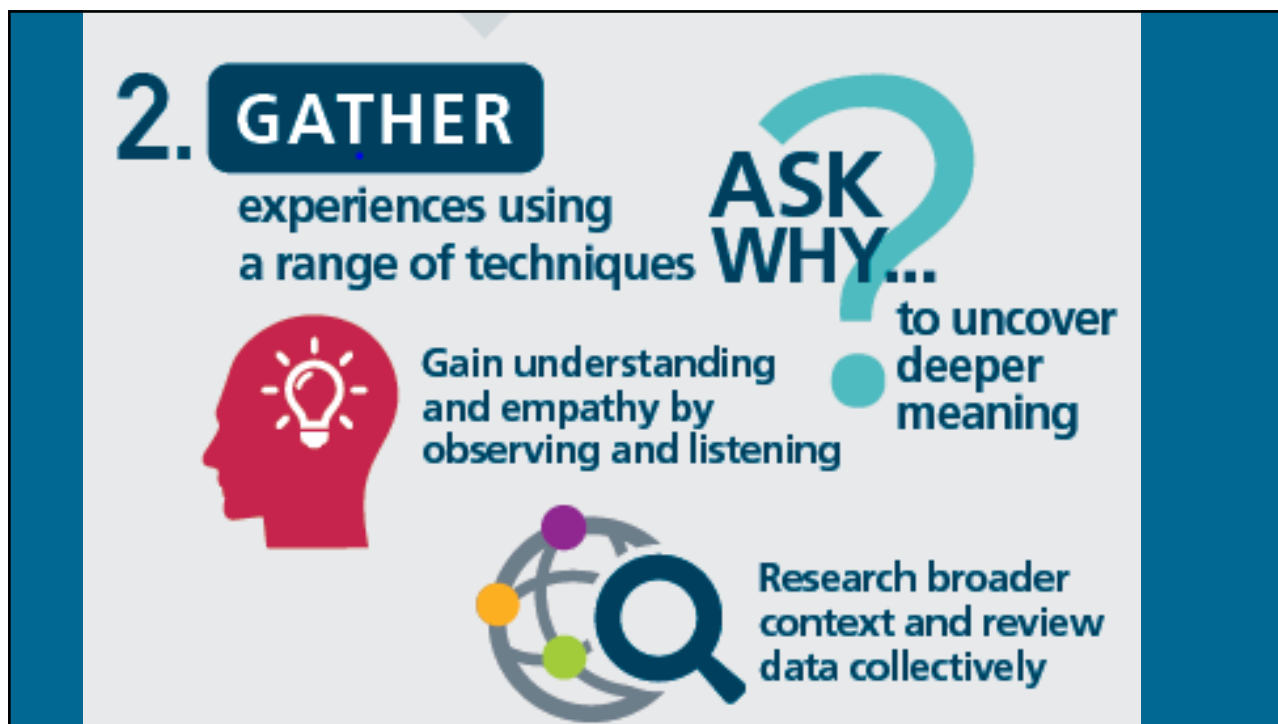


## HOW we are working TOGETHER



AGENCY FOR  
CLINICAL  
INNOVATION

- Supporting equal partnership
- New ways of working (no templates, share power)
- Accessibility: Information, processes, decision making
- Adapting EBCD - Flexibility
- Never losing 'sight' of experiences



## How did we gather stories?



Interviews	6 consumers (2 before focus groups) 5 staff
Focus Groups	2 x 6 – 10 people Live theming
Validated via Consultation	Staff workshop / emails / staff room Consumers – via email / phone

## Touch points

1. Hospital Admission and Giving Consent
2. Communication between patients and hospital staff
3. Staff Awareness and Understanding
4. Orientation to the Ward and Hospital Environment
5. Looking after yourself, independence and mobility
6. Preparing for and being Discharged from Hospital



## Admission and Consent



- Can't read or complete the forms, no support is offered and there is no digital form available
- Need somewhere private to read otherwise disability is on show
- Paper form? How does that work for people who can't see?

## Touch point: Consent



*As I person who is blind...  
I kept getting asked if I  
recognised the signature  
on the consent form*

## Touch point: Communication



*“Staff should always tell you  
who they are and what they’re  
doing.*

*Gosh that made a difference  
when they remember to tell me  
every time”*







Retinitis Pigmentosa

Vision Australia  
Sightless. Live Vision. Open hearts.

Touch point: Communication



*‘The nurse asked my mum,  
“How old is he?”  
He answered,  
“He is 27”.’*

## Touch point: Communication



*“It might only take 2 minutes to read a form. They’d help if you were in a wheelchair, why not if you are blind?”*

*“I was calmed by a nurse who spent the extra time explaining things”*

## Touch point: Staff awareness



I had an anaphylactic shock during a day procedure  
When I woke up I had a tube in my throat...

*“All I got told was that I was in the intensive care unit  
.... I couldn’t see (or talk),  
.....I didn’t know why until they took the tube out of my  
throat’*

*And can’t read the paper they tells me what to do*

## Staff awareness



*“When you are operating on my hands remember you are operating on my eyes”*

## Communication



*“You need the audio”*

*“You need to be informed all the time about  
where you are,  
what is happening,  
and what is about to happen”*

## Orientation



*“I had someone put me in a corner and leave me there”*

*“They should not move your stuff. You want to find something but can’t if they’ve moved it and haven’t told you”*

## Getting around & Self care



*No-one told me the meal was there or came to help me eat meals*

*I didn’t shower for two days*

*I say to the patient, I want you to do as much as you can, but I’m here to help*

## Looking after yourself



*“You lose the independence you have at home”*

*“You struggle”*

*“I felt forgotten”*

*“I felt vulnerable”*

### 3. UNDERSTAND



#### PART 1

Identify the emotions and touch-points

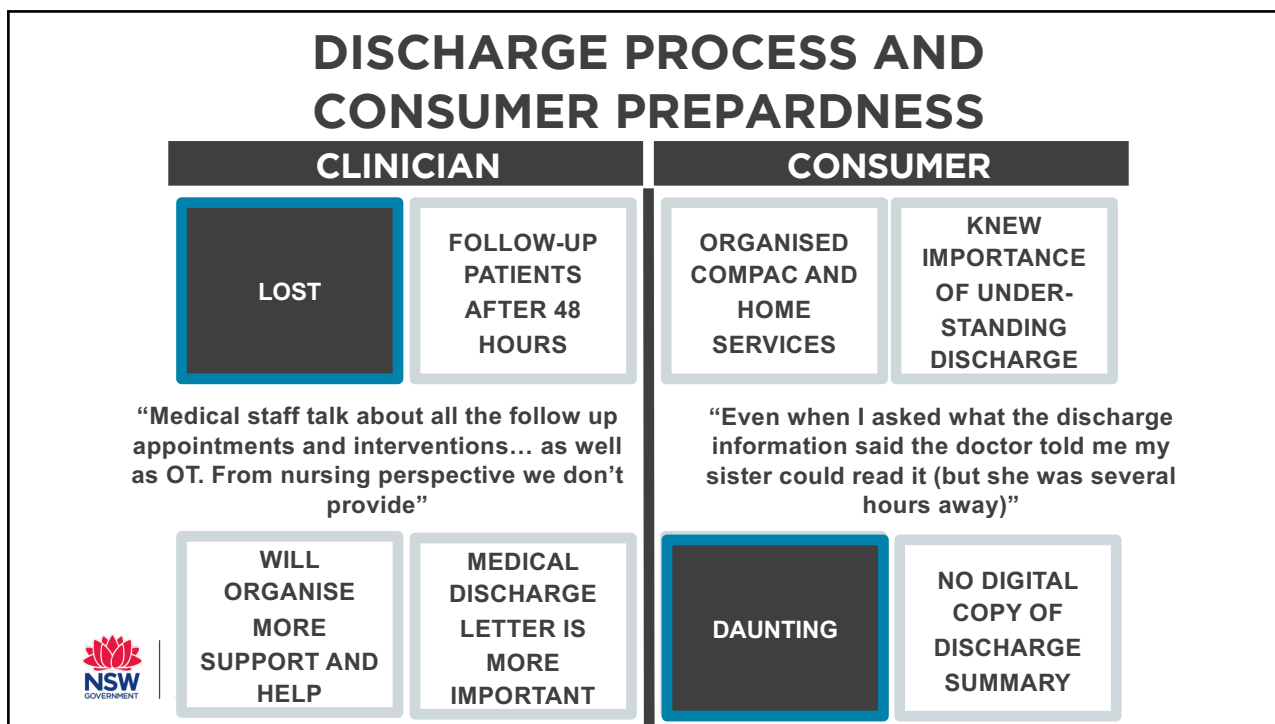


#### PART 2

Map the emotions to the touch-points

#### PART 3

Create and interact with a journey map



## Multiple formats



1. Please listen and comment on the following audio surrounding the first touchpoint - 'Admission and Consent Practice'



Cookie policy



mjenvo

Experience Map Recording Touch Point 1 - Low - Vision Inpatient Management

SOUNDCLOUD



2:21

- Do you agree with the issues and emotions raised?
- Have we missed anything?
- Does anything really stand out as being important to you?

<http://bit.ly/aciblindlowv>.

## Moving to co-design – defining success



### 1<sup>st</sup> Codesign Workshop >>> Voting priorities

Hospital staff are able to provide adequate audio description of what's happening so that people who are blind or have low vision understand

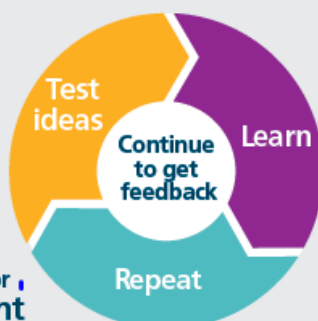
People are blind or have low vision are provided with discharge information they can access themselves (for example letter, verbal recording, email, plain text large print document).

## 4. IMPROVE

Use collective experiences and include everyone in identifying opportunities for improvement



Prioritise and agree on areas for improvement together



**Finalise priorities  
29 April 2019**

**Co-design  
Workshop  
MAY 2019**

**Develop & test  
solutions**

## Final Thoughts



- Shifting power – we don't know what we don't know
- Co-design everything!
- Anyone can do EBCD but you need some with knowledge, skills and who 'get it'
- EBCD powerful & rewarding
- Can't wait to see solutions and improvements