

Leveraging Lived Experience Using Experience Based Co-Design

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Patient Family Engagement



Direct Care

Patients being surveyed

Patient Family Advisory Councils

PFA serving throughout organization

Experience Based Co-Design

Experience-Based Co-Design Process



Donetto S, Pierri P, Tsiannakas 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



Benefits of Using EBCD

- Does not need to be part of a larger Patient and Family Engagement program
- Does not require “vetting” patients
- Includes diverse patients and staff
- Able to focus on specific topic and population
- For SUD can (and should) include individuals still using
- Identifies problems and solutions including all voices



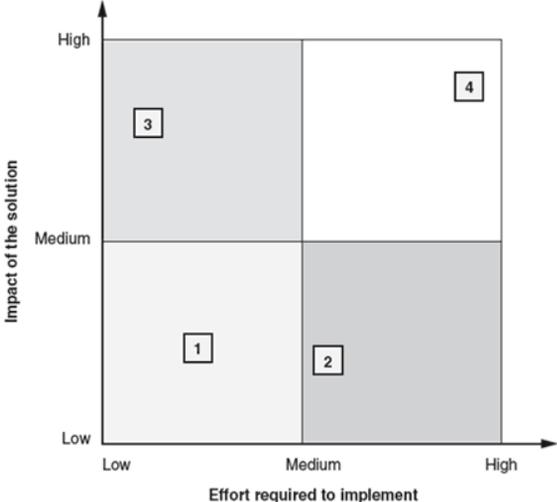
Co-Design Meeting

- Creative Matrix

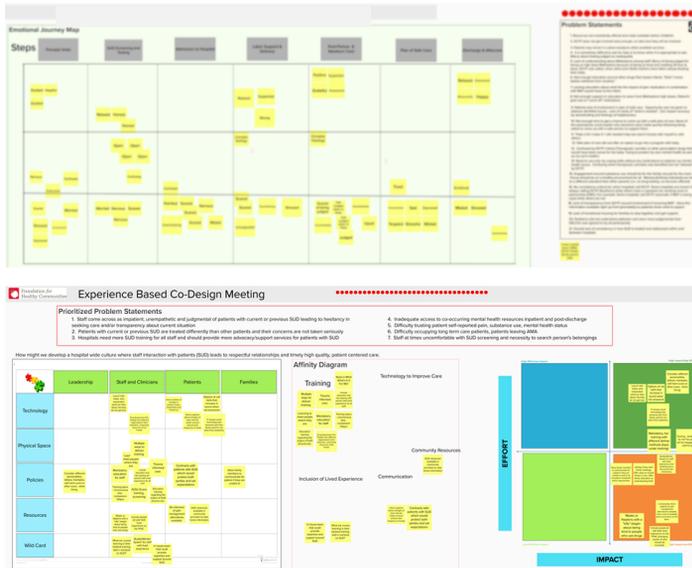


Co-Design Meeting: Impact/Effort Grid

- An impact effort matrix is a **decision-making tool**. Each potential idea, strategy or project is assessed based on the level of effort required and the potential impact or benefits they will have.



EBCD: Virtual

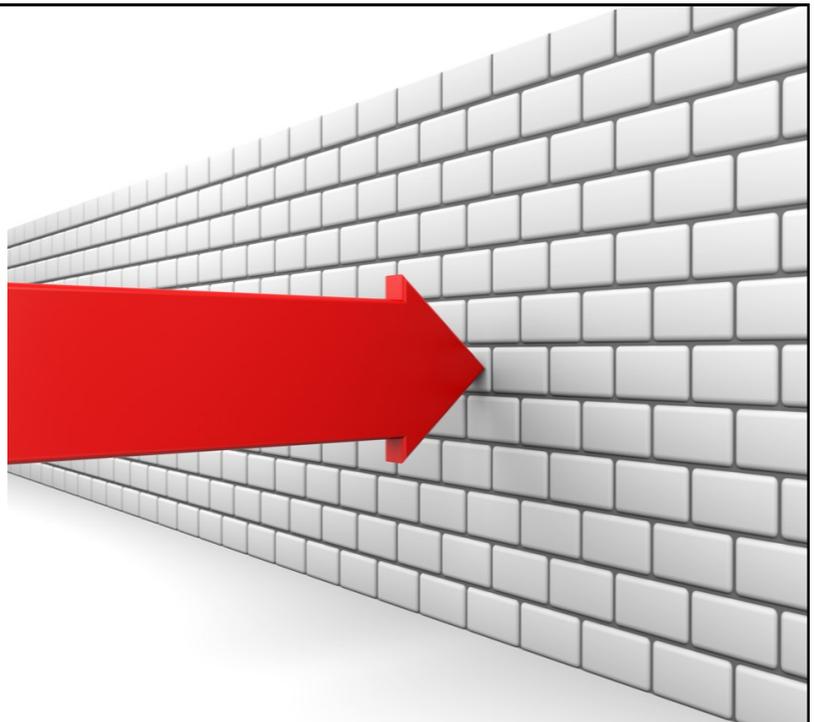


M U R A L



Challenges

- It is unfamiliar to not start with an identified problem or objective
- Length of the process
- Conflicts or intense emotions within the sessions
- The designed process or program may not satisfy everyone



Use EBCD When...

- The problem is not clear or hasn't been defined
- A current process or policy isn't working, and you are not sure why
- Buy-in is needed from multiple stakeholders
- A new process or initiative is being designed
- Many individuals will be impacted by the new or revised process



NH FORE Project

Improving Hospital Inpatient Management of Opioid Use Disorders in Rural Communities

- 2 Years (Extended 6 months)
- Using Experience Based Co-Design method to bring all perspectives to the design, implementation and evaluation of initiatives
- Four rural hospital pilot



**Foundation for
Opioid Response Efforts**



Recruiting Patients

- Strategy
 - Flier development
 - Outreach by email, phone and social media
 - Shared with:
 - Governors Task Force
 - Director RCO mee
 - Administrator at th Drugs and Alcohol .
 - Peer Networks
 - Family Support Netw



We Want to Hear From You!

Help to improve care in rural hospitals for people who have used alcohol or drugs

Whether your experience was good or bad

JOIN OUR FOCUS GROUPS
Carrie at 603-731-0032

You Will Receive
A \$50 Amazon Gift Card for each meeting you attend

Help Others
By sharing your experience

...patient during a hospital stay, your insight will the way care is delivered.
...32 or email at cmcfadden@healthynh.org for information.
...shared for any purpose other than for use of this project.

Foundation for Healthy Communities
Partnership to improve health for all.

Peer Champions



- Lived Experience
- A trusted:
 - Harm Reduction Worker
 - Peer Supporter
 - Member of other grassroots recovery organizations



Lessons Learned: Recruitment

- Have a dedicated phone
- Identify a single contact person
- Establish trust
- Use direct, In-person connection
- Develop a screening tool and script
- Communicate as needed
- Reassure often
- Providing alternatives
- Expect last minute changes
- Plan multiple connections
- Check your own bias...often!



Virtual Focus Groups: Results

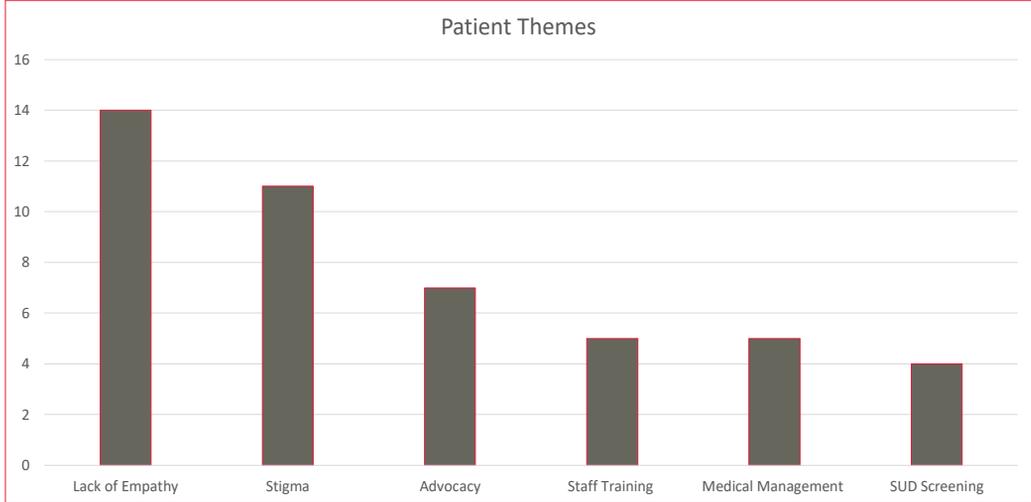


Staff and Clinician Problem Statement Themes

Hospital 1	Hospital 2	Hospital 3	Hospital 4
Community Resources	Community Resources	Community Resources	Community Resources
Patient Behaviors	Patient Behaviors	Patient Behaviors	
Medical Management	Medical Management	Medical Management	Medical Management
Empathy			Empathy
Staff Education			Staff Education
Compassion Fatigue			Compassion Fatigue
	Security Issues		
	SUD Screening	SUD Screening	
		Stigma	Stigma
		Insurance Issues	



Patient Problem Statement Themes



The Primary Finding: Patients

stigma

/ˈstɪgmə/

noun

1. a mark of disgrace associated with a particular circumstance, quality, or person.
"the stigma of mental disorder"
synonyms: [shame](#), [disgrace](#), [dishonour](#), [More](#)



Stigma

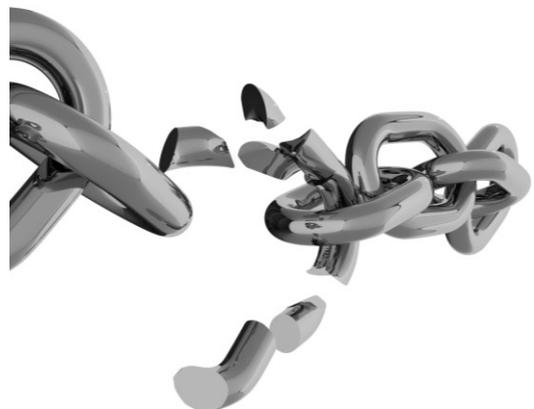
- Did not stand out as the top results for all hospitals
- **However....Survey Results:**

"They don't want to help themselves"

"They can't be trusted to tell us the truth"

"They lie 95% of the time and don't tell the truth the other 5%"

"Why are we spending money on people who do not want to be helped"

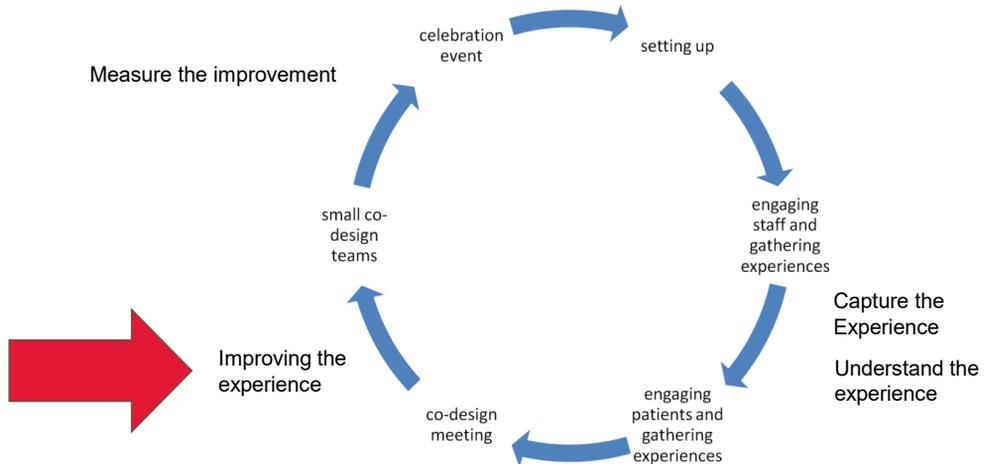


How Might We

How Might We...	
Hospital 1	create a trusting culture where staff, clinicians and patients are comfortable and educated addressing SUD (treatment and non-treatment), other medical and behavioral health concerns, including pain management, in an effective, respectful manner.
Hospital 2	create a trusted environment that allows patients and staff to effectively discuss substance use and care planning?
Hospital 3	develop a hospital wide culture where staff interaction with patients (SUD) leads to respectful relationships and timely high quality, patient centered care.
Hospital 4	create a screening process that is consistent, non-judgmental and comfortable for staff and patients and includes follow up plan for identified issues.



Experience Based Co-Design



Source: <https://www.kingsfund.org.uk/projects/ebcd>



Hospital Initiatives

Hospital 1	Hospital 2	Hospital 3	Hospital 4
Establish an improved interaction and scope of services amongst the individual behavioral health teams at Cheshire Medical Center.	Increase coverage from ED to Med/Surg and Medical Practices	Recruit a minimum of one community member with SUD lived experience to join the PFAC	Screen 100% patients coming through ED/admitted to floor; refer to appropriate resource if positive
Complete, promote, and distribute Virtual Training Video regarding SUDs and Stigma to team leaders for use in staff meetings.	Offer professional training using various methods (online, live, experiential, etc.)	Purchase Neuma Clamp-catheter safety device that deters purposeful abuse, decrease expensive reinfections and potential overdoses. Educate staff and patients. Develop patient contract	Complete staff trainings on SUD/ODU
Expand the outpatient capabilities of MAT and Psychiatric Care in the community.	Identify best SUD screening and implement	Develop an anti-sigma video that includes individuals with SUD lived experience. The target audience would be nursing.	
	Create "Discussion Starter" cards for Pt rooms that will be used as a symbol that Pt would like a private discussion	Explore updated software for call bell monitoring—the new software will help to see where and when the delays in answering call bells occur.	



The opposite of addiction is not recovery, it is connection.





Thank you!

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