Reclaiming relationships as a legitimate tool for systems change: A Change Laboratory approach to palliative care

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What is the problem?

If someone you care about experiences serious mental or physical illness

- What would be worst versus ideal care?
- Who would be involved?
- How? when? where? what doing?

How would you describe safety or risk?

We need to know about hidden work mediated through collaborative relationships

When and how is this work valued?

What does good look like and how can we get there?

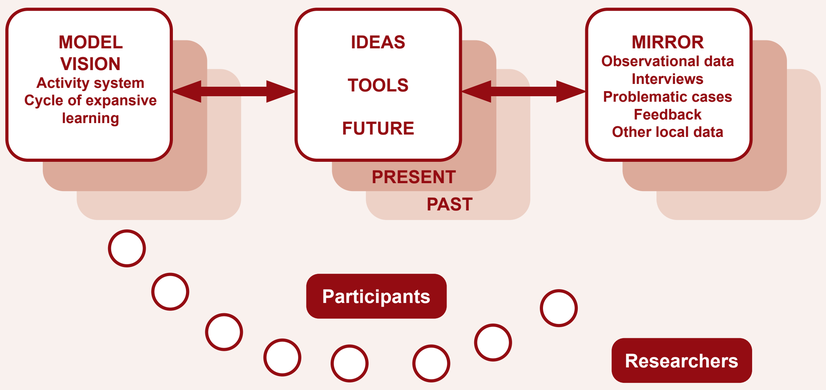
Our research questions

Can a Change Laboratory workshop create a:

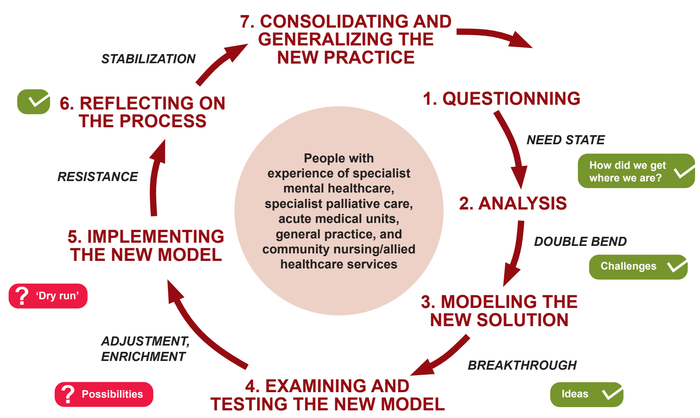
- **Multivoiced vision** for how the system can be improved, and what success would look like?
- **Scaffolding framework** for future socioculturally mediated improvement initiatives

Why Change Laboratory?

- Change Laboratory is a formative intervention based on Cultural-Historical-Activity-Theory.
- Analysis is directed to how/what people think/feel relates to what they do.
- We wanted to:
  - Focus on hidden work that people do to address gaps in the structural organisation of healthcare systems
  - Move from problems to ideas for future practice
  - Look at two areas of healthcare critically dependent on relationships: Palliative Care and Mental Healthcare



Change Laboratory workshops followed a cycle from describing problems to identifying potential solutions



Green and Red bubbles show progress made in our single cycle

Cycle of expansive learning (Engeström, 1999, p389). Reproduced with permission from Cambridge University Press

> "Working in an organisation offers a different challenge from being on the outside… managing hierarchies, keeping on the right side of those in power... On the other hand, carers are deeply affected by what happens to the person they care for and in some ways are freer to ask for 'more' but often don't know how the system works"
>
> **Carer participant**

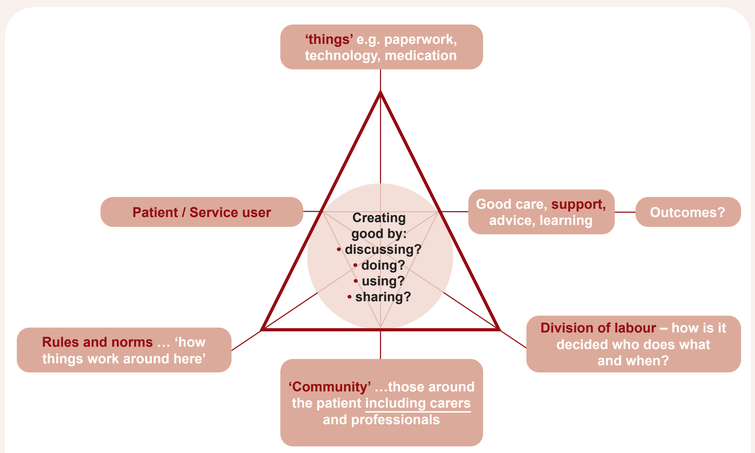
> "…interesting that everyone [is] struggling … really useful to know that they want to help … but we need to work with the team rather than blaming the team so if I have concerns that so and so team haven't done certain things, I should pick up a phone and follow up, try and build relationship as well as respect each others input more"
>
> **Professional participant**

Reclaiming relationships for systems change:

patients, carers and professionals co-developed the concept of Collective Social Safety with the research team

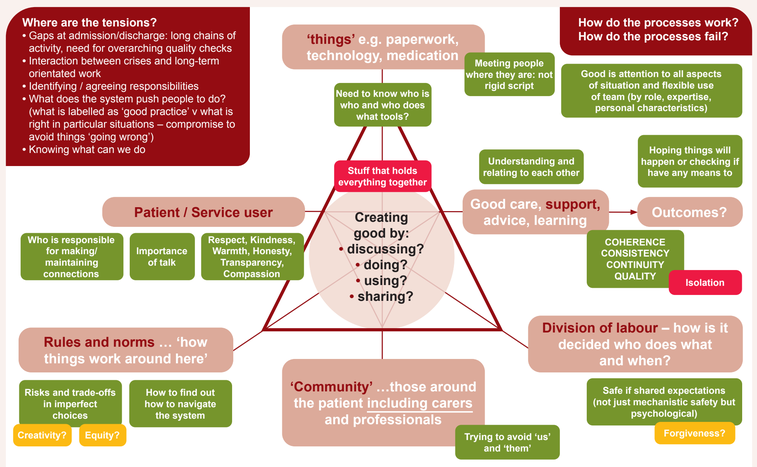
- Collective social safety means being safe with each other in a common purpose: it is much more than the physical or psychological safety of the individuals involved
- Collective social safety is founded on trust and negotiation of shared understandings generated through dialogue that develops shared language and meanings through shared activities and experiences
- Relationship-based work and care can flourish when collective social safety allows people to act with appropriate flexibility and nuance in face of changing circumstances/needs

Our starting framework



What is happening in the healthcare system?

Populating the framework with data



What have we identified?

What next?

Our findings demonstrate the need to think differently about people and relationships within systems-based approaches to healthcare improvement.

In palliative care much attention is paid to individual relationships (e.g. the therapeutic relationship between patient and professional) and communication between individuals but this is not enough.

When we think about people in systems we need to picture an open ecosystem, such as an archipelago.

Instead of trying to construct systems that don't rely on people knowing each other our energies should be focused on creating systems that facilitate relational working through equitable opportunities for knowing and multiple dimensions of proximity.

More attention is needed in systems-approaches to

- **'relational reach'** (bridging work to link people across systems and hold complex situations)
- **'relational glue'** (support constructed between people, mediated by trust)

Multiple dimensions of proximity that help or hinder building relationship-centred work and care include

- Moral (sense of closeness, resonance, responsibility to identifiable person)
- Temporal (dialogue rather than 'transmit-receipt-check' cycles of communication)
- Linguistic (speaking the 'same language', developing the same meaning)
- Psychological and social (focus on function not form/mode)
- Geographical/physical

We would love to hear your feedback

This study considered situations when people needed palliative care or care for serious mental illness. The findings presented hold true for both groups.

For more information please contact **sarah.yardley@ucl.ac.uk** or use the QR code below:

A recent presentation of more detailed findings is available via:

Want to know more?

Systemic problems

- In the UK, healthcare models require consultative, collaborative working between specialist/generalist healthcare professionals (across community and acute hospital services)
- People experience multiple transitions, boundaries and interfaces between locations and providers
- Technico-clinical work is necessary but not sufficient for safe healthcare - good care is critically dependent on relationships between people yet inadequate attention to people in system design is common
- Institutions and organisations weigh different risks differently with taxonomies (classifications) of harms tending to relative overvaluing of the technico-clinical and undervaluing of the relational including psychological, social, and existential (spiritual)
- Prioritising the needs and choices of individuals, or specific groups of people can create tensions with structural safety standards but failure to consider these can result in avoidable harms
- Education and service delivery plans lack recognition of complexity in how to enact shared responsibilities

What did we do?

Preparation	Change Laboratory Workshops (Jan-Jul 22)	Research Data

Identified an absence of work synthesising palliative care practices with common safety, risk, improvement approaches
• Co-designed the study with a public engagement group (n=11)
• Collected ethnographic data from 148 people including patients, carers and healthcare staff with experience of specialist mental health, specialist palliative care, acute medical unit, general practice and community nursing/allied healthcare teams
https://q.health.org.uk/resource/creative-approaches-to-problem-solving/
	• Online, six sessions, two researcher-facilitators
	• 18 people with multiple roles (patient, carer, healthcare professional) from across organisational boundaries within a system of service provision in London, UK (94% attendance in five/six sessions).
	Creative quality improvement activities to help participants:
	• Explore prompts (mirror data) derived from anonymised interviews and observations (ethnographic data)
	• Question system tensions/gaps
	  • analyse challenges
	  • model new ideas
	  • consider transferability into practice
		• Sessions audio-recorded for transcription
		• Researcher fieldnotes, reflexive notes and task artefacts feed forward from session to session
		• Concurrent (preliminary) analysis
		Recognising when people address gaps in systemic approaches to system design
		• Not just in crises/within organisational boundaries
		• Expansive learning cycle with people in exemplar roles
		• Level of abstraction from immediate personal practices and experiences to consider 'big picture' issues

Workshop experience

How did the Change Laboratory group function?	What were the group's priorities for change?
The group • Rapidly formed into 'us' with othering of 'the system' which all participants felt ill-equipped to challenge. • Were highly motivated to entrust the researchers with 'things that otherwise cannot be said' in the hope of representation to 'decision-makers'. • Enjoyed taking part **"Thank you for such a creative, interesting and mentally stimulating piece of work. It was a respectful and shared two way process and has been a really meaningful engagement in research."** **"The workshop has been adventurous, interesting and relevant."**	• Opportunities to develop shared values/goals so that people feel 'close' across wider systems • Easy modes and mechanisms to communicate in real time • Time and other system resources to be viewed as collective resources • Lowered triggers and benchmarks for expending resource on tailored solutions before crisis points are reached • Trust in ability of patients, carers and professionals who have developed a sense of collective social safety use practical wisdom and judgement for meeting healthcare needs

No conflicts of interest