UCL Division of Psychiatry

Marie Curie Palliative Care Research Department

How can we meet the palliative care needs of people living with severe mental illness and advanced incurable physical illness?

Sarah Yardley, Madeline Li, Daniel Shalev

PROUD TO BE A 2024 CHURCHILL FELLOW

Marie Curie RESEARCH DEPARTMENT, UNIVERSITY COLLEGE LONDON

Getting involved:

- Join a movement for change
- Partner in practice-based local project
- Support inclusive research to grow the evidence base

sarah.yardley@ucl.ac.uk
sarahychurchillfellow2024@gmail.com

People and populations

Severe mental illness (SMI)	Psychological problems severely impairing functional & occupational activities (includes schizophrenia, bipolar disorder, and other psychotic illnesses)
Palliative Care	Supportive care and symptom control: physical, psychological, social, spiritual. Not just very end of life.

- Taking a wider approach: “severe and enduring non-organic mental and behavioural disorders” (ICD-11)
- Challenging ideas behind mental models such as “people whose needs don’t fit the system”, “good” or “difficult” people

Severe mental illness

Advanced incurable physical illness

"Inclusivity is about meaningful choice"

Diagnostic overshadowing

Capacity questioned

Stigma & bias

"he's not a piece of cake"

Li

Hig

Hal

lon

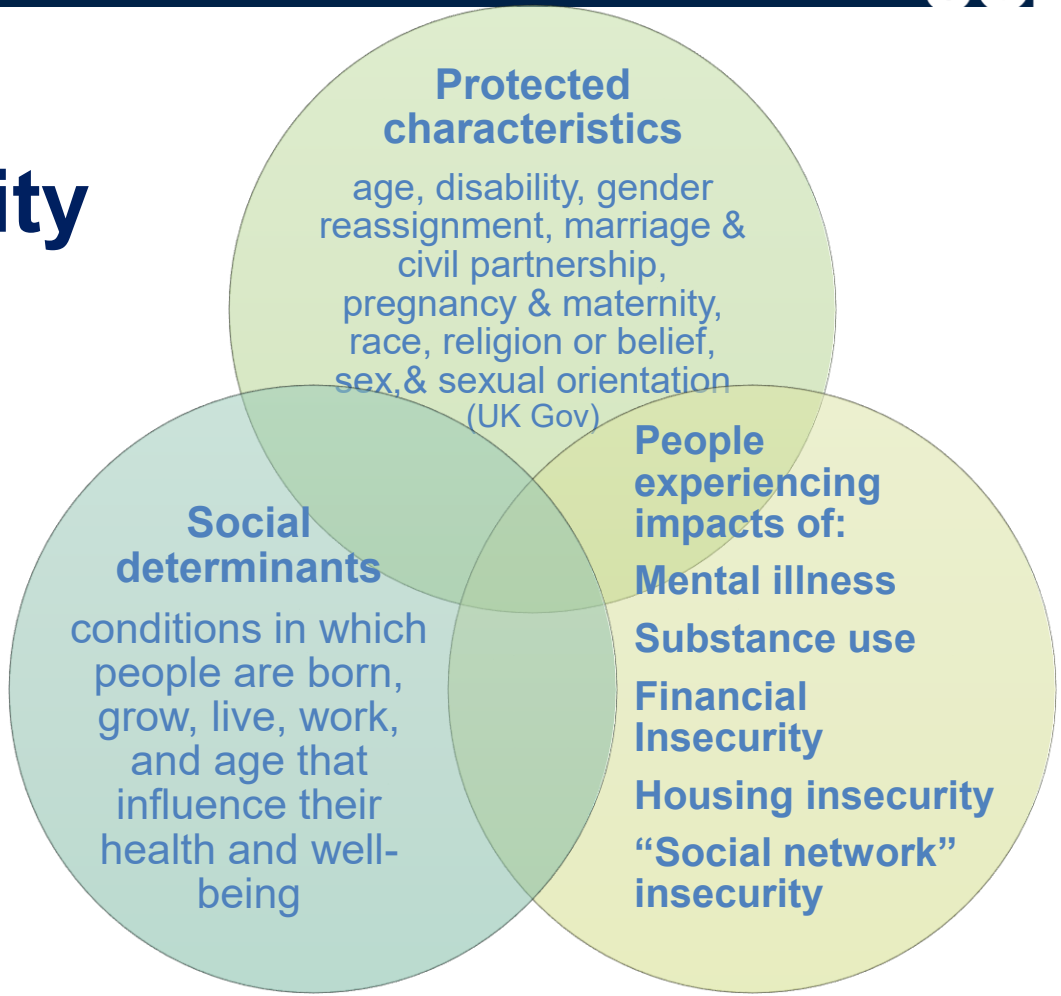
Lac inclusion in clinical

d cussions and research

Parity of esteem = care of equal quality

Social justice & resource stewardship issue

Getting healthcare right for those with the least, and in the most difficult circumstances, holds potential to improve care for all of us



Intersectionality (Multiple characteristics/features of identity impacting adversely on life experience)

People from ethnic minority backgrounds are:

- less likely to access palliative care services,
- in cancer services less likely to get prescriptions for analgesia, and less likely to have doses titrated (Koffman)
- more likely to see unplanned care and have higher rates of hospital admissions in the last 3 months of life

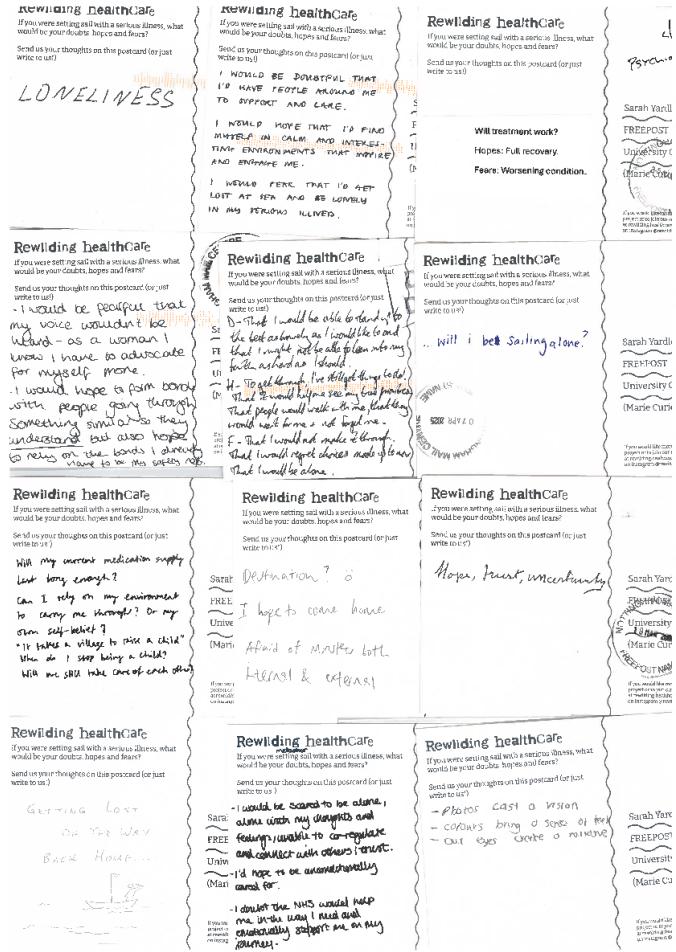
Rewilding healthCare

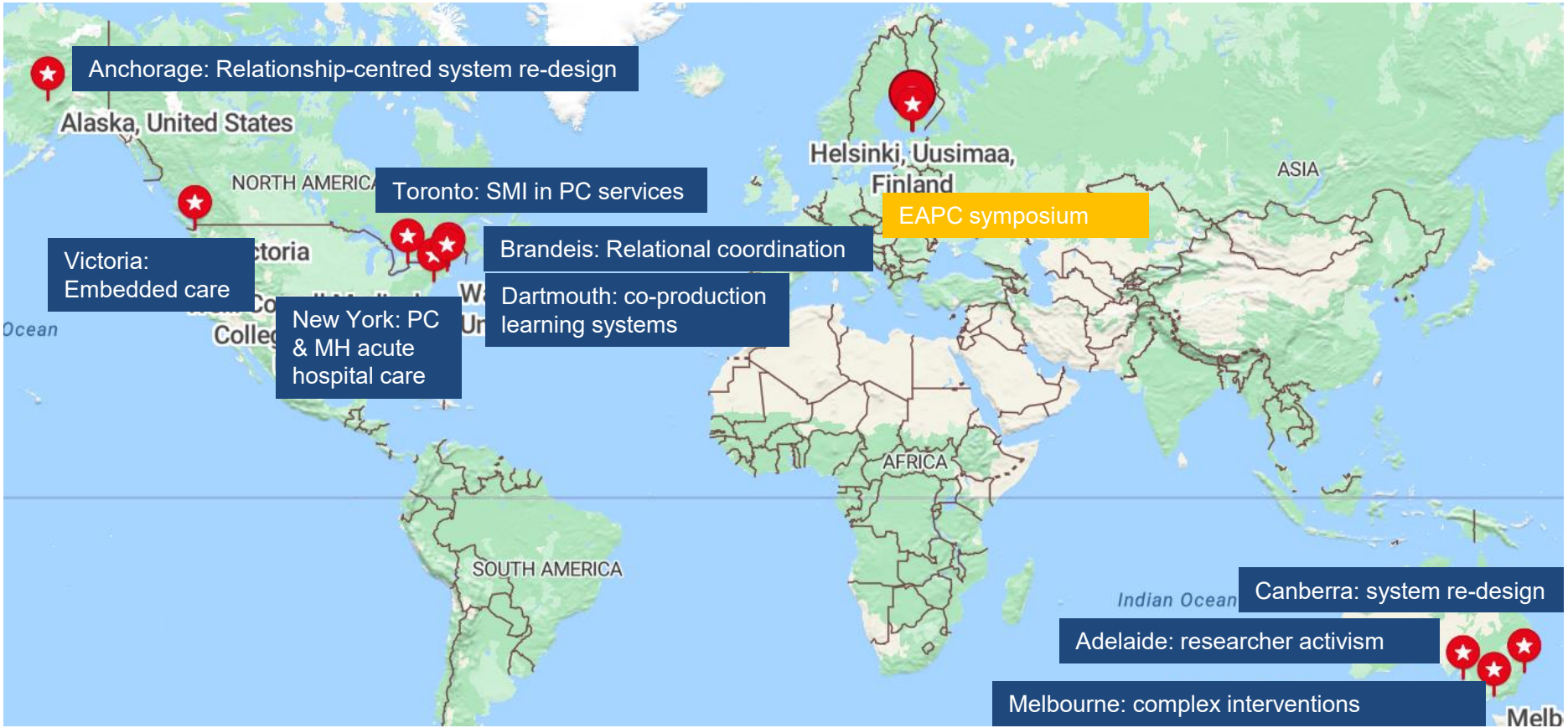
If you were setting sail with a serious illness, what would be your doubts, hopes and fears?

Send us your thoughts on this postcard (or just write to us!)

Sarah Yardley
FREEPOST
University College London
(Marie Curie PCRD)

If you would like more information about the project or to join our mailing list - get in touch at rewilding.healthcare@gmail.com or follow us on instagram @rewilding.healthcare - thanks!

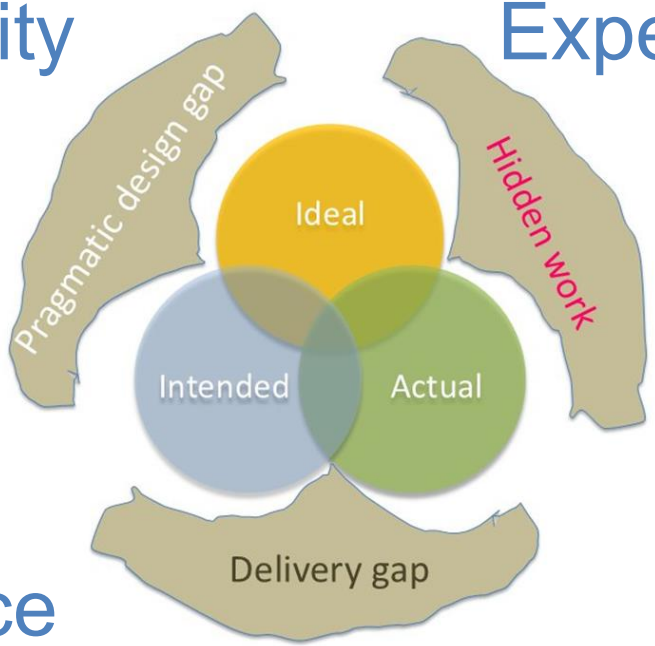



Anchorage: Relationship-centred system re-design
Alaska, United States
NORTH AMERICA
Toronto: SMI in PC services
Victoria: Embedded care
Brandeis: Relational coordination
Dartmouth: co-production learning systems
New York: PC & MH acute hospital care
Helsinki, Uusimaa, Finland
EAPC symposium
ASIA
AFRICA
SOUTH AMERICA
Indian Ocean
Canberra: system re-design
Adelaide: researcher activism
Melbourne: complex interventions

From system gaps to systemic change

Rhetoric-reality

Expectation-experience



Policy-practice

Relationship

"Shared understanding between people about meaningful use of resources, and willingness to change one another through genuine exchange"

(Jay,D. Relationality: How Moving From Transactional to Transformational Relationships Can Reshape Our Lonely World. USA, North Atlantic Books, 2024)

If we want shared practices, we first need shared language and shared meaning

(Carlile PR. A Pragmatic View of Knowledge and Boundaries: Boundary Objects in New Product Development Organization Science: 2002, 13:4:442-455)


“Our sy
e for people
who are ver
gs …people
who are v
hard. It’s
“The safety is in the coherent relationship …coherent, mutual understanding”

Collective Social Safety =

"Best care [was] when people took risks, to try and respond … a human moment outside of the churning… synchronicity"

- Permits flexib[illegible] nuance in face of changing circumstances/needs

"How much better would it be to get the most effective behaviours wrong every now and then rather than get the least effective behaviours right most of the time?"

(David Robinson)

Who is in the team?

- Do you know, work with, or look after people who die?
- Are some of them living with severe mental illness?

- How does the experience of advanced incurable physical illness play out?
- Whose involvement is “legitimised”?
- Is care organised to needs and convenience?
- Do people have tools to talk with each other quickly and securely?

Anchorage

MAKE IT EASY TO DO THE RIGHT THING

Redesign – thinking relationally

- Outcome not input: whole system effectiveness
- Person not disease: managing distress
- Population not process: remove low value tasks
- Service not practice: convenient care

Victoria, BC

INCREASE WORKFORCE MOBILITY

Naoko Fukumaru. Beauty of Mending: Kintsugi and beyond

Mobile workforce, legitimised boundary- crossing

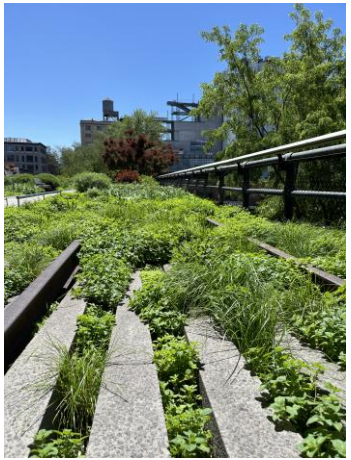
- Who is already working with people in need?
- How can we work with them?
- Permissions and preapprovals
- “Warm handovers” of trusted relationships
- “Mending is relational and starts with purposeful listening”

Toronto

FROM SPECIAL CASE TO MAINSTREAM CARE

Prioritise meeting needs over setting service criteria

- Assess distress in everyone
- Experiment with inclusion quotas for structurally vulnerable populations in mainstream services
- Peer support worker roles



New York City

INCREASE WORKFORCE SKILL MIX

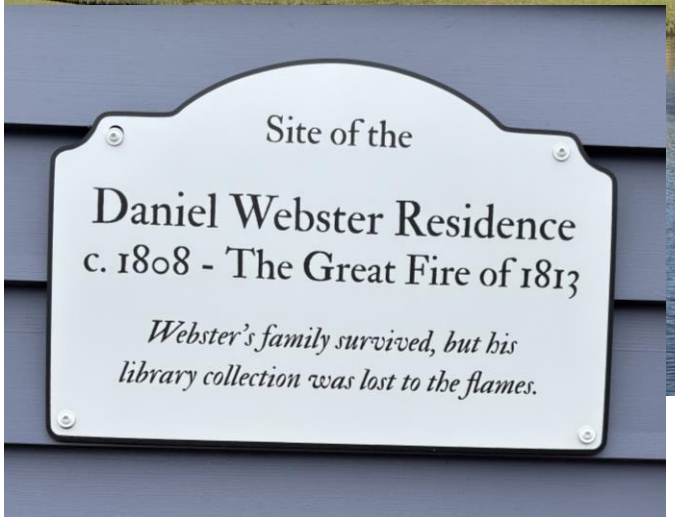
Exchange, extend, upskill roles

- Chaplaincy, psychology, social work, cultural and language interpreters
- Reducing fear of the unfamiliar: exchange and co-working

What I Want to Say at Parties
Jessica Smith

So, what do you *do*?
I'm a chaplain at a hospital…

"I hope that I'm the life vest
on the boat when the storm
story starts to creep across the blackened
sky, waves hissing at the quaking hull."

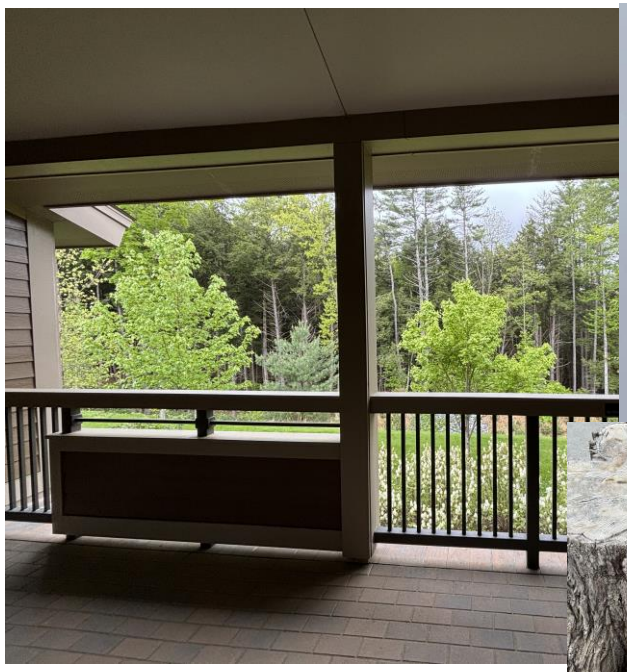


Brandeis

THINK OF SYSTEMS AS RELATIONAL CONTAINERS

Coordinating for relational interdependence

- Relational job design
- Invest in work rituals that deliver because building relationship an expected part of “work”
- Partnership models of care with clarity and transparency about distributed responsibilities
- Services that are flexible and connected, with fewer barriers between teams and organisations



Dartmouth

EVALUATE FOR SUCCESS AS EVIDENCE THAT RELATIONSHIPS ARE PRODUCING GOOD OUTCOMES

Reduce, reward, recognise

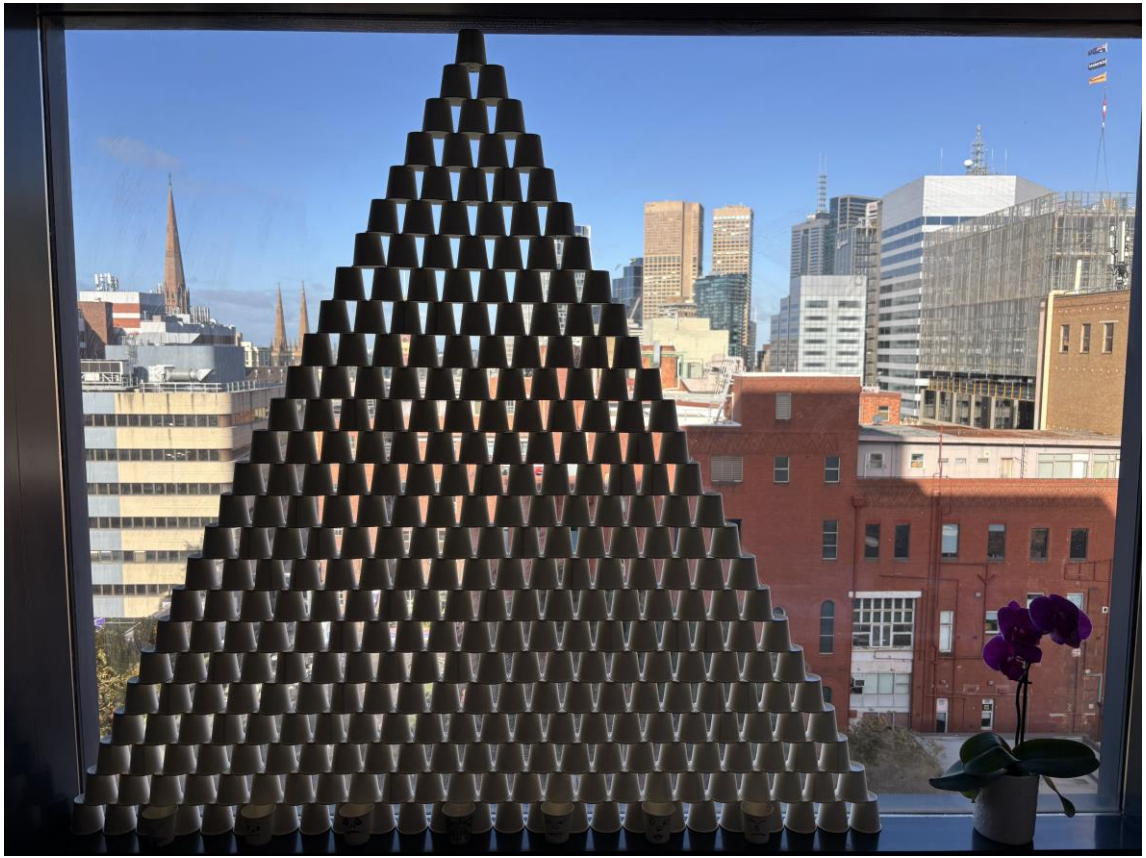
- Reduce processes (removing or automating low value tasks) as much as possible
  - referral criteria and triage are prime targets for simplification / shifts to doing not deferring work
- Reward “doing what is right” rather than only demonstrating harm avoidance
  - support people doing what is needed because “they can / if not them then who?”
- Recognise and support people who step up to help
  - train to care competently not only with permission

Adelaide

ASK THE RIGHT QUESTIONS TO MAKE THE RIGHT DECISIONS

Participatory in-situ change and evidence building

- Research advocacy and activism
  - Video-Reflexive Ethnography: care, collaboration, exnovation, and joint reflexive work
- Working upstream
- Dignity of risk in balance with duty of care
- Inclusive positive-risk taking

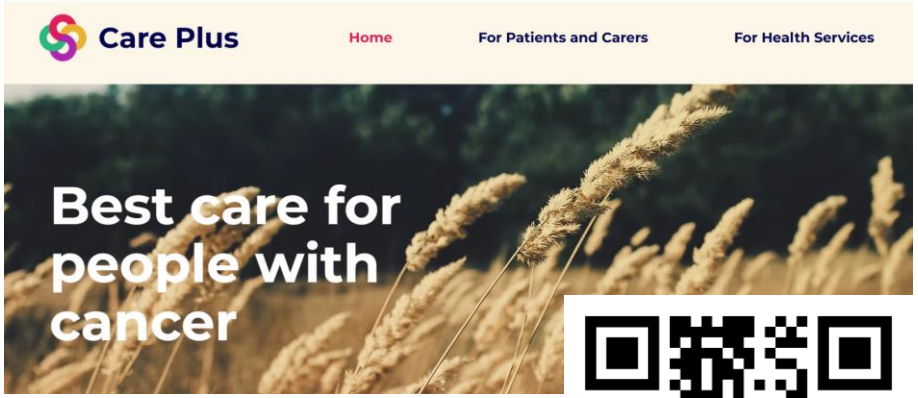


Melbourne

INCLUSIVE RESEARCH TO GROW AN EVIDENCE-BASED APPROACH

https://www.careplusau.org/

- Turning practice-embedded understandings into evidence
- Co-owned intervention triggers



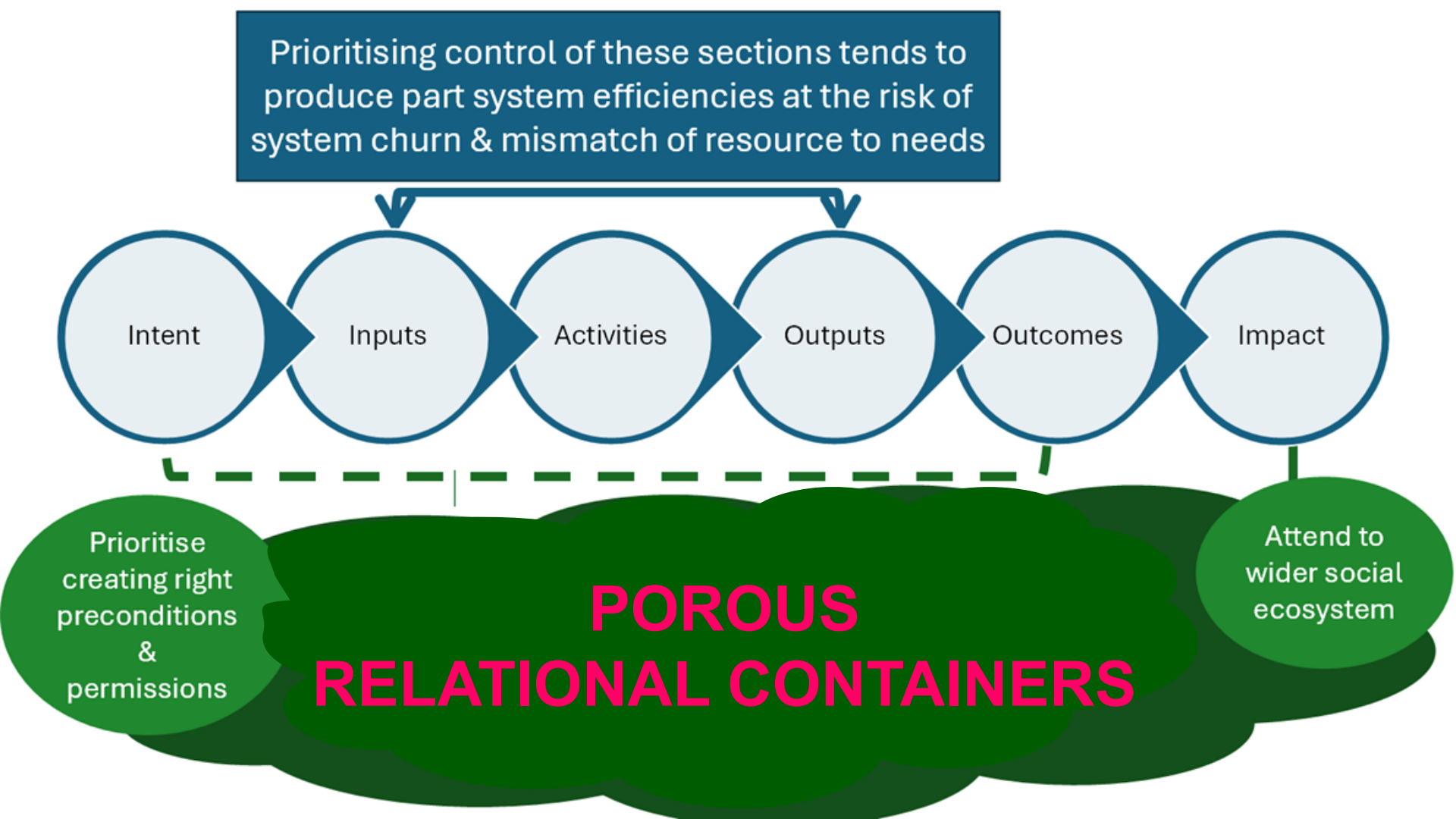
Canberra

SYSTEMATIC ATTENDING TO STORIES

ThinkPlace

All indicators are pointing towards...

- Rebalancing approaches to risk: working with who/what you can
- Prioritise meeting needs over criterion-led services
- Embedded embodied experience-based work
- Bringing together “victims” and perpetrators”, multiple perspectives – seeking understanding not consensus
- Not when but how relationship & relationality can be throughout systems
- Some big things to do but also small changes can make a big difference
- Starting with shared clarity and transparency for all
- Duty of care in balance with dignity of risk


Prioritising control of these sections tends to produce part system efficiencies at the risk of system churn & mismatch of resource to needs
Intent
Inputs
Activities
Outputs
Outcomes
Impact
Prioritise creating right preconditions & permissions
POROUS RELATIONAL CONTAINERS
Attend to wider social ecosystem

"What would happen if institutions held back by a culture of transactional prediction learned to think relationally and were financially rewarded for doing so?" (Jay, 2024)

Focus on relationality: *"the capacity of a given environment of information exchange to create relationship… weaving with intention, evolving, what to recreate and what to reimagine from the past…"* *(Jay, 2024)*

Madeline Li & Daniel Shalev

Reflections on practical successes and transferable learning

Getting involved:

- Join a movement for change
- Partner in practice-based local project
- Support inclusive research to grow the evidence base

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Discussion: three strands to support change

In your role/situation

- Could you be part of a movement to influence policy and decision-makers? How? What would help?
- Do you have ideas for actioning practice-based changes locally?
- What sorts of inclusive research to grow an evidence-based approach are needed to help you?

Salmon life cycle game

Power Smart for Schools

START

You start as a salmon egg.

Extra turn! You're safe in a fish hatchery.

You're almost ready to hatch.

Swim back 1 You're eaten by a bird.

Miss a turn You're covered in silt.

You hatch and eat tiny insects.

Miss a turn The river dried up.

Extra turn! Swim down river to the ocean.

Eat a small fish.

Swim back 1 An eagle caught you.

Miss a turn You got stuck in a fish net.

Keep swimming.

Eat more fish.

Swim back 2 You're eaten by an orca.

Begin swimming up river.

Swim back 1 A bear ate you.

Miss a turn Strong currents slow you down.

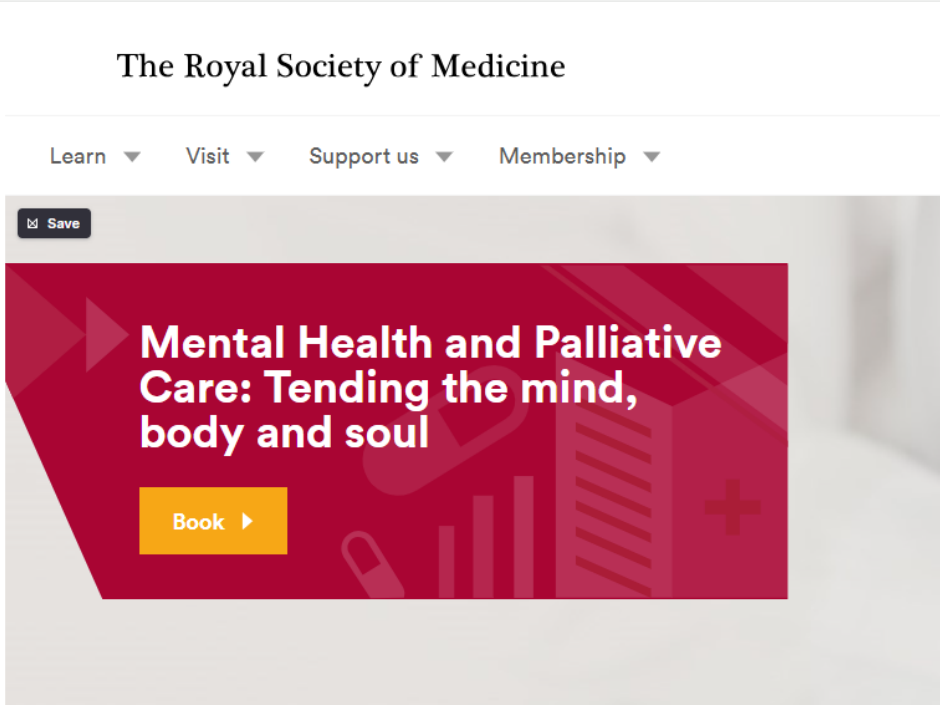
Extra turn! Use a fish ladder to get past a dam.

Make it up river and lay eggs in freshwater gravel.

Salmon life cycle complete.

Finish

19th November 2025, London



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