



Faculty of Design

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The reflection room: Shifting from death-avoiding to death-discussing

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Saint Elizabeth
Well beyond health care

The Reflection Room

Shifting from death-avoiding
to death-discussing

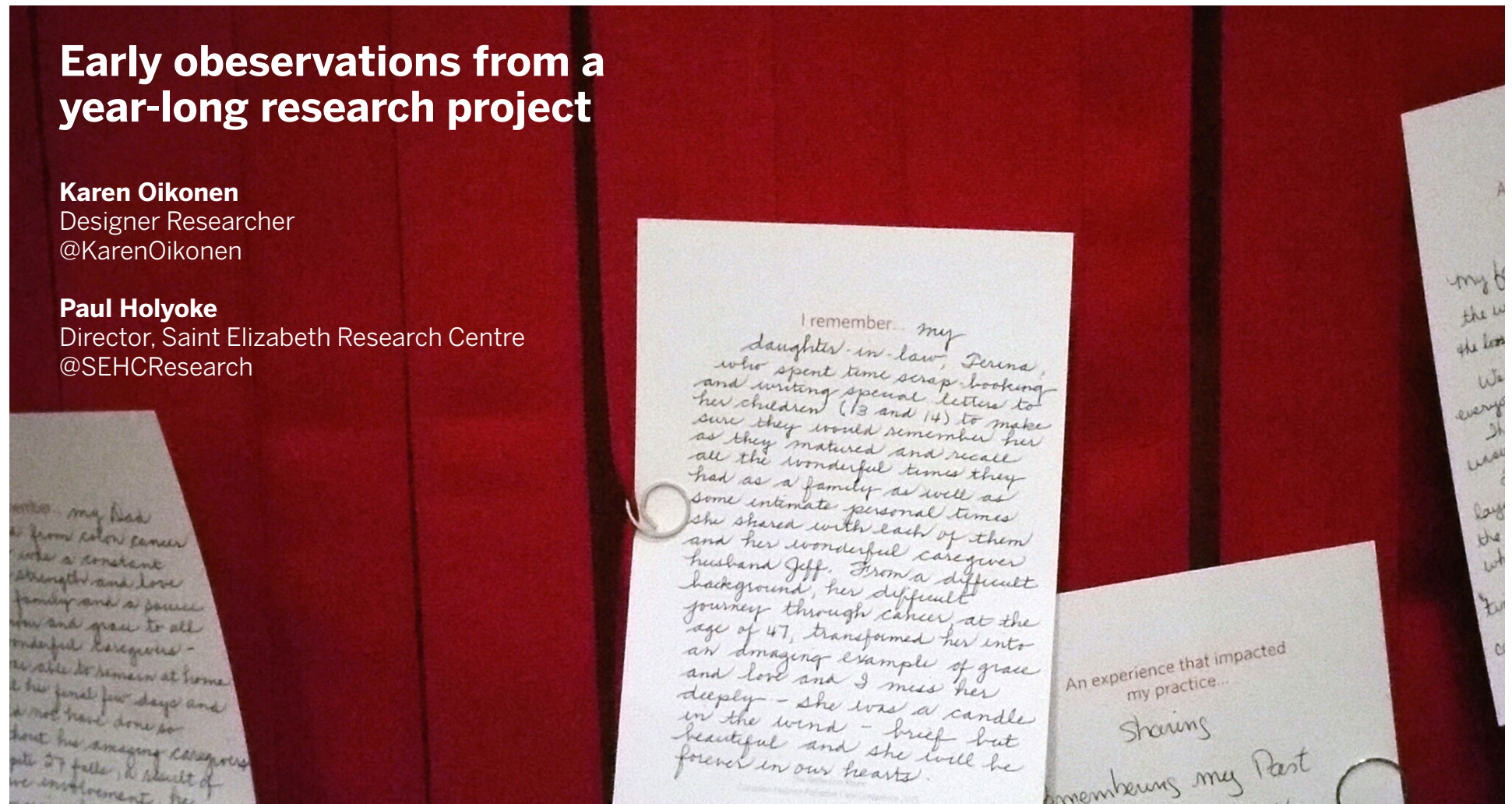
Early observations from a year-long research project

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It's very difficult to make end of life decisions in a time of crisis

There's nothing
more we can do...



What are our
options?



Only 25% of Canadians over age 30
have completed plans for end of life



70% of people die in hospital when over 50% want to die at home



Choice at end of life depends on our ability
to talk about death and dying

Canadians don't talk about
death and dying

Fear and denial are very real aspects of how Canadians relate to dying and death

**Death
denying**

**Death
discussing**

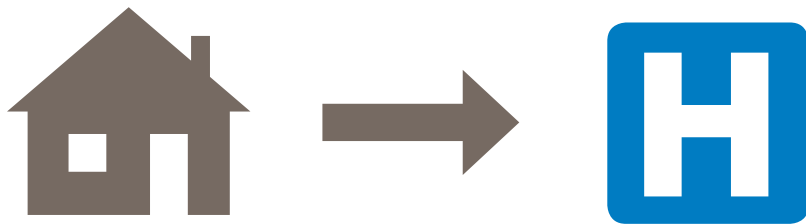
**Death
accepting**



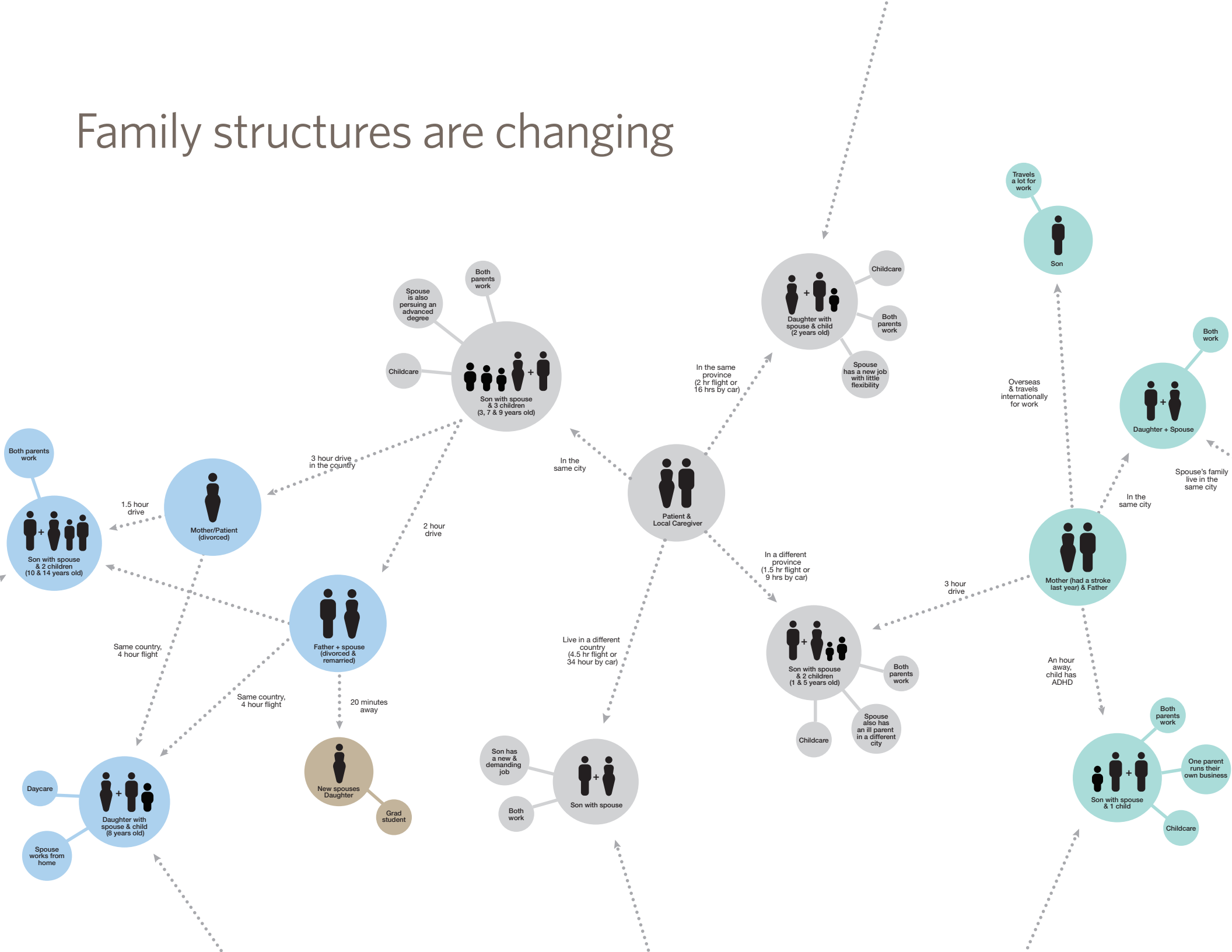
“Medicalization of death”

Created an institutional preference to be sick and curable rather than dying and incurable

Limited exposure to death and the dying process



Family structures are changing



Research suggests that people who are exposed to dying are more open to discussing it.

**Death
denying**

**Death
discussing**

**Death
accepting**



New approaches to support discussion and planning



GYST



the conversation project

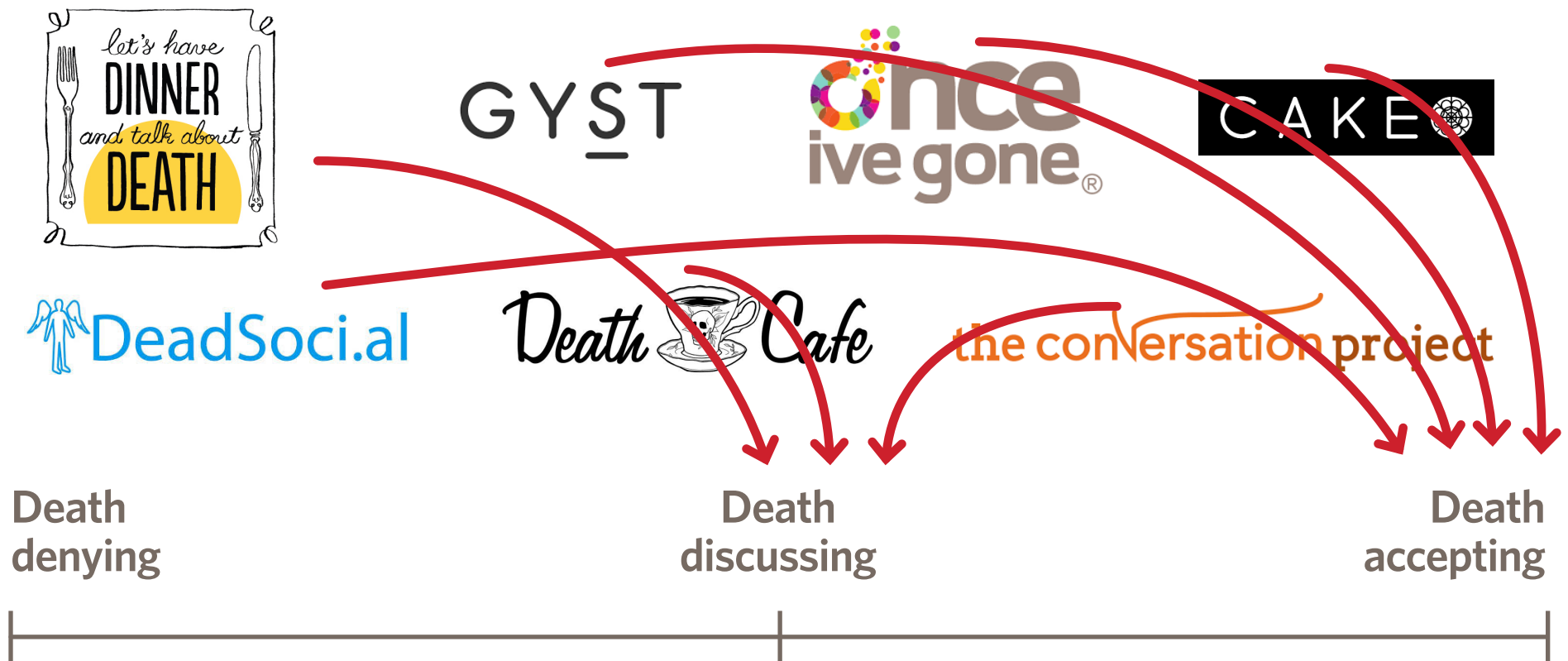
Death
denying

Death
discussing

Death
accepting

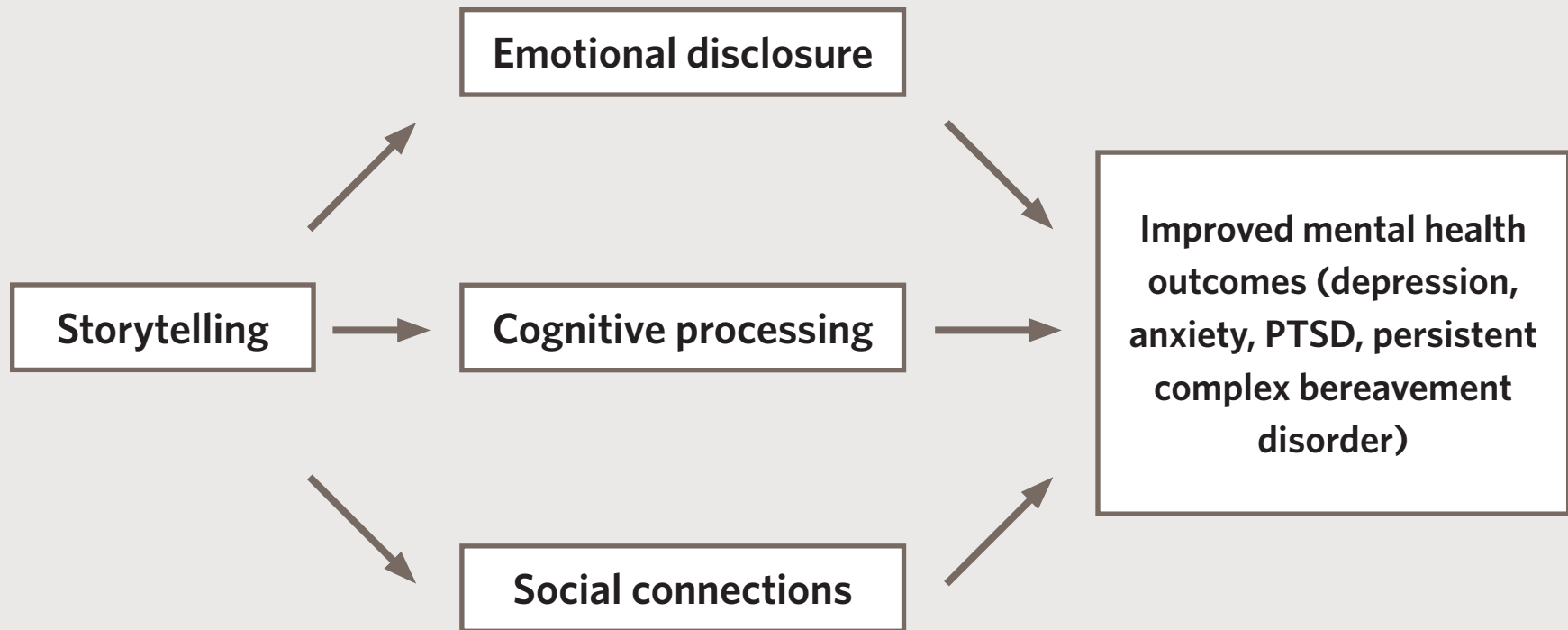


New approaches to support discussion and planning



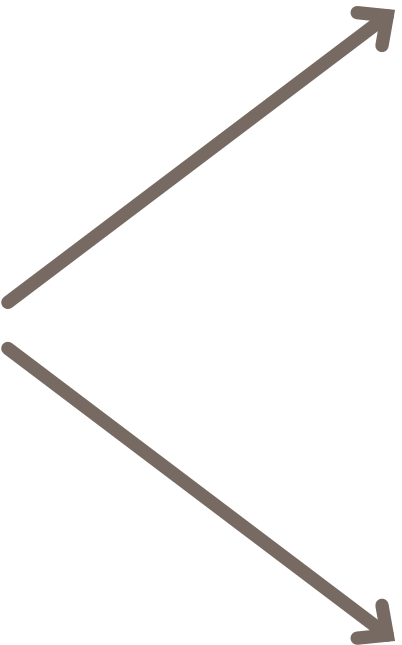
Human beings are storytellers

Storytelling effects



Schenker Y, Dew MA, Reynolds CF, Arnold RM, Tiver GA, Barnato AE: **Development of a post-intensive care unit storytelling intervention for surrogates involved in decisions to limit life-sustaining treatment.** *Palliative and Supportive Care* 2015, **13**(03):451-463

**Stories can be
a catalyst to
discussion about
end of life.**



It is more likely that people will discuss dying and death if they are exposed to the reality of death and dying through experience.

Hearing or reading true stories about serious medical conditions can increase the familiarity that appears to be a significant catalyst to discussions about end of life.

Spirituality Research + Participatory Art



How might we use human-centred design and qualitative research to go from being a death-denying society to a death-discussing society?

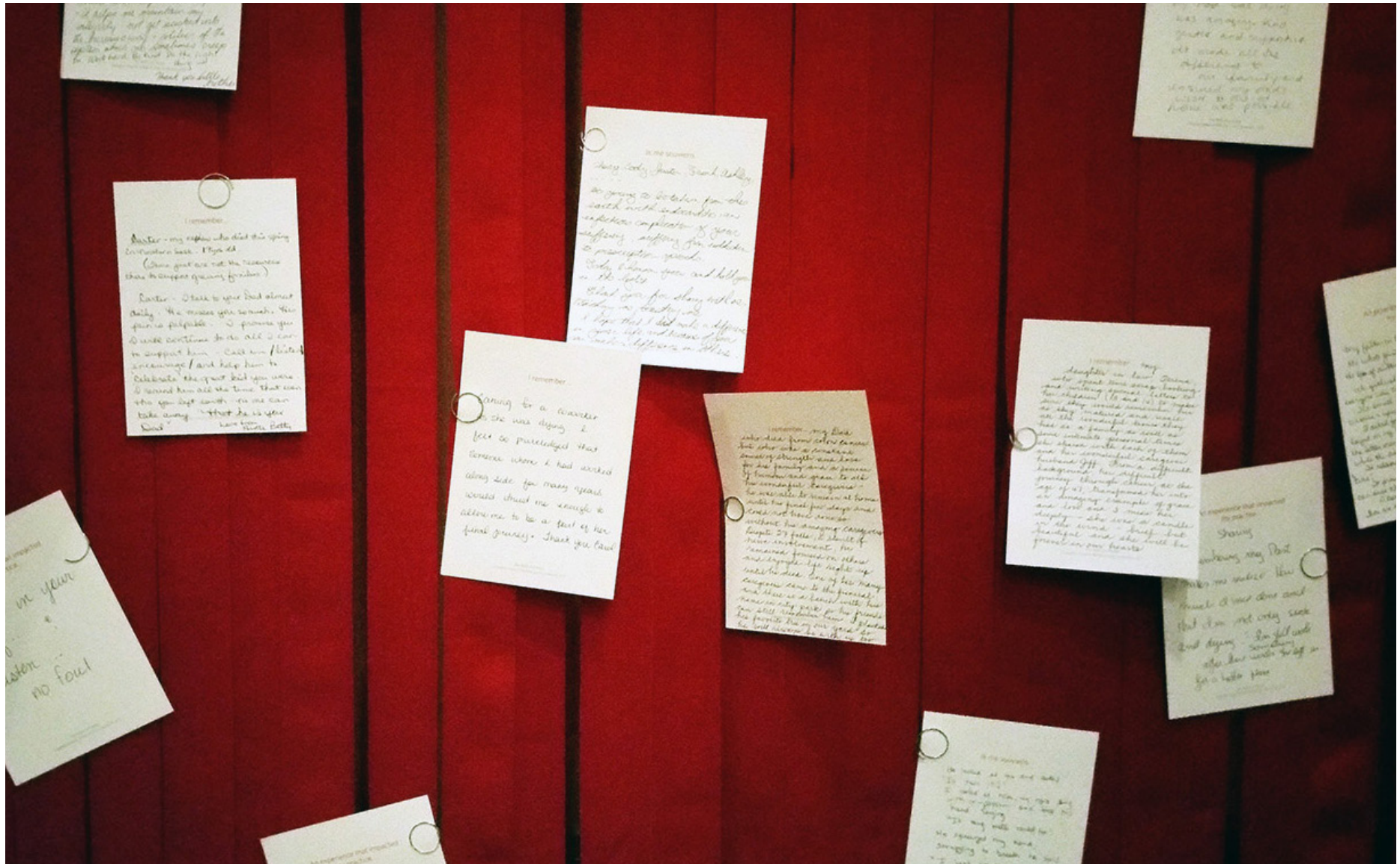
Canadian Hospice Palliative Care Conference



The invitation to share a story



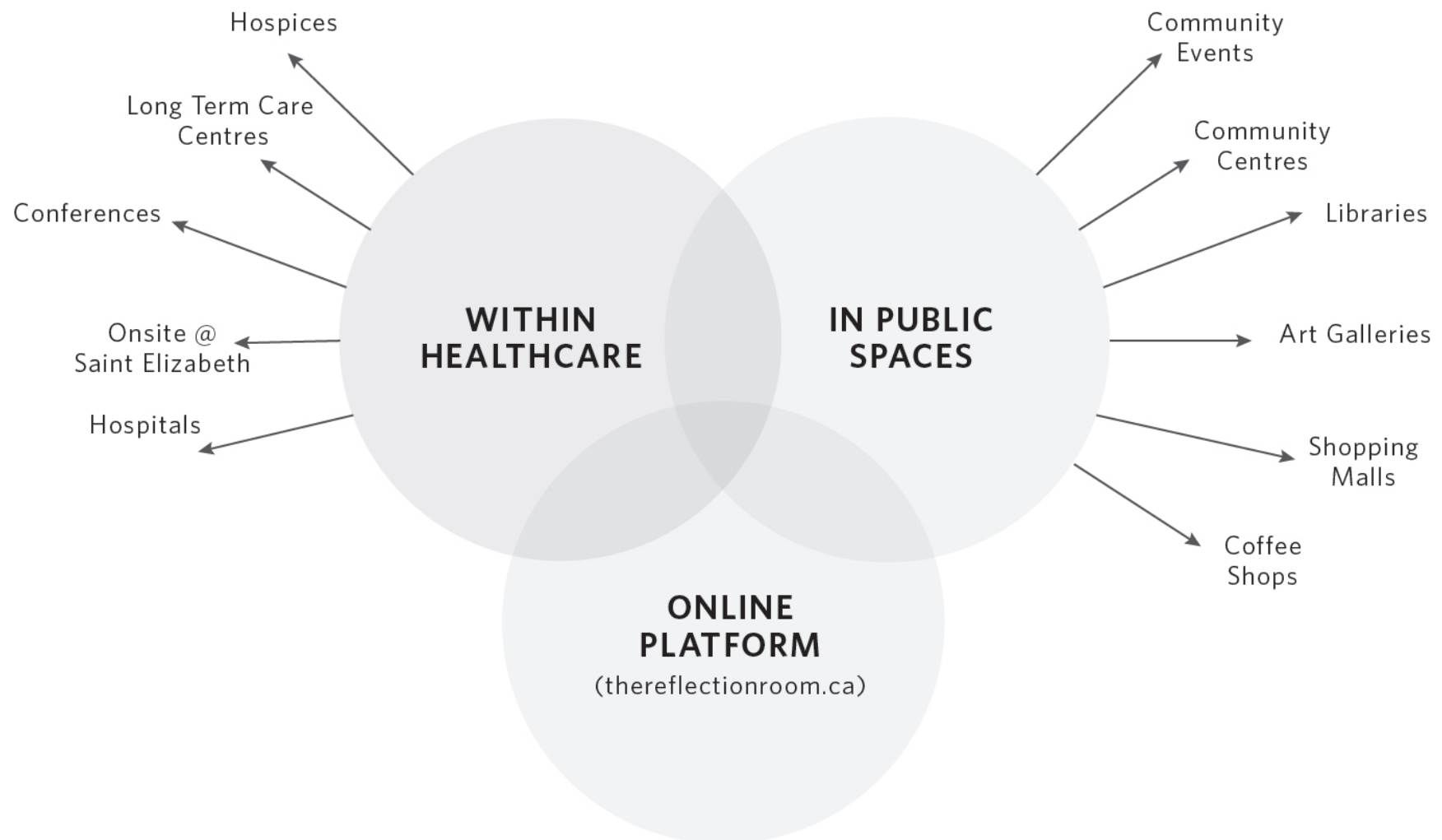
The Reflection Wall



Every hospital
should have
a room like
this

Expanding the project

Planning points of intervention



Within Healthcare



Hospice Palliative Care
Ontario Conference



Heart House Hospice, Mississauga

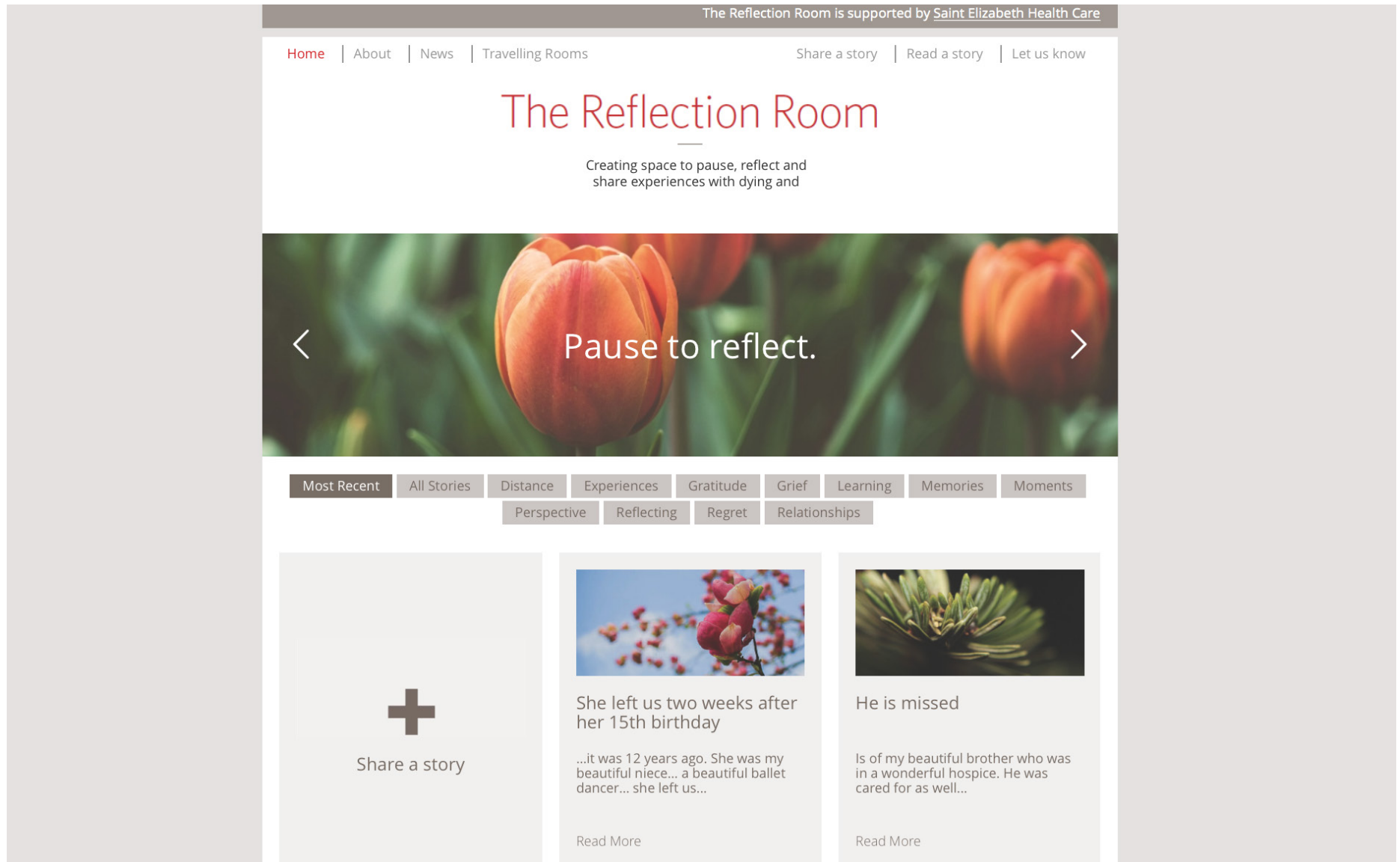


St. Paul's Hospital, Saskatoon

Public Spaces



Online @ thereflectionroom.ca



200 shared stories

1,100 visitors to the website

What have we learned so far?

Relationships are at the
centre of the stories

My reflection

Hey Mom Thank you
For the experience I
had with you at the
end of your life.
For all the things I
could have done that
I did not do ~~and~~ to
help the end of your
journey I am sorry
I hope I can have an
impact in other ways.
I love you forever

Experiences remain
in our hearts

Human experiences and
“moments in time”

My reflection

"Hi Uncle Pete, it's me, Clare..."

"Oh, Clare, it's so good to just
hear your voice!"

across many miles, last conversation by telephone,
between a young niece
and her dying young uncle

Expressions of gratitude & regret

Promises to do better

Sharing learnings

My reflection

My one regret is that I was so busy looking after your physical comfort that I didn't talk to you about what you would want for me and the family - or to talk more about how you felt & saw things.

To others facing the loss of their spouse - talk about the things that really matter....

Death is about life

My reflection

My wife's death was the single most defining moment in my life. I was with her in the hospital at the moment she passed away and it has changed how I look at living, and dying.

Appreciation for the
invitation to reflect

My reflection

Being here, now, and feeling a felt shift because I came here to be still and reflect. Thank you for opening this physical space and the space in me today.

People have complex lives

Embedded in complex social networks

Healthcare professionals work
within a complex system

Society that is struggling with
how, when and with whom we talk
about dying and death

Where are the leverage points?

90%

Read some of the reflections
in the Reflection Room

I found reading the other pages on the wall put me more at ease about some of my own reflections that I have in my head. It allowed me to see that most of my reflections were not way out there.

**Death
denying**

**Death
discussing**

**Death
accepting**



74%

Said the experience made them a bit, or a lot, more comfortable thinking about dying and death

78%

Said the experience made them a bit, or a lot, more likely to talk to family and/or friends about dying and death

Death
denying

Death
discussing

Death
accepting



Of people that did not read reflections or did not write a reflection, **'not enough time, maybe later'** was indicated as the primary reason.



Physical space can open emotional space.

Time = 'space'

People often visited more than once.



There are times and places where
the leap is too great.

It's easy to not accept the invitation.



Two leverage points are emerging

The creation of 'space'

The sharing of the human experience

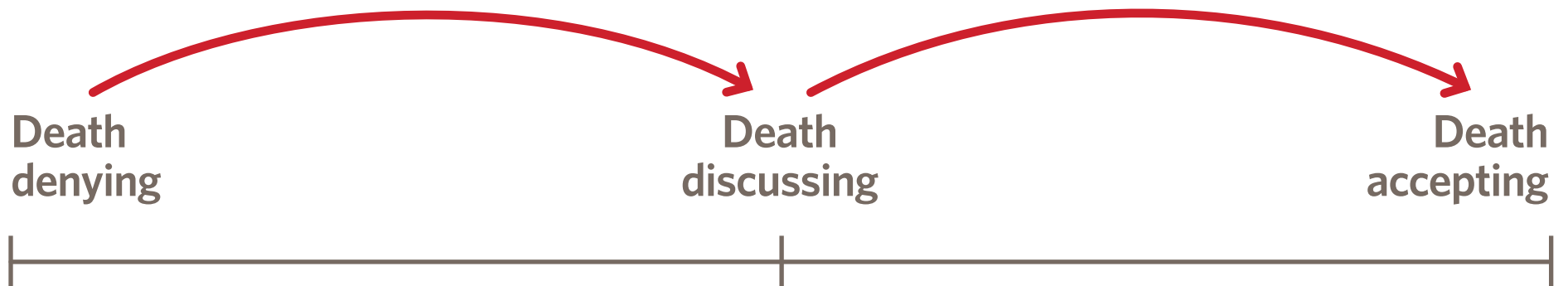


Further look at 'time' and 'space'

What do we need to know about creating space within our complex lives that acknowledges the complexity, and commonality, of individual experiences?

Our next steps

20 installations between now
and June 2017



Better chance of dying where we want, how we want and with whom we want



Thank you.

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We invite you to take a moment
to reflect on your own experiences
with dying and death.

thereflectionroom.ca

The Reflection Room is supported by
Saint Elizabeth Health Care

saintelizabeth.com