

Elevating lived experience: Safety, power & consumer stories in quality improvement

BMJ Workshop session

October 2023



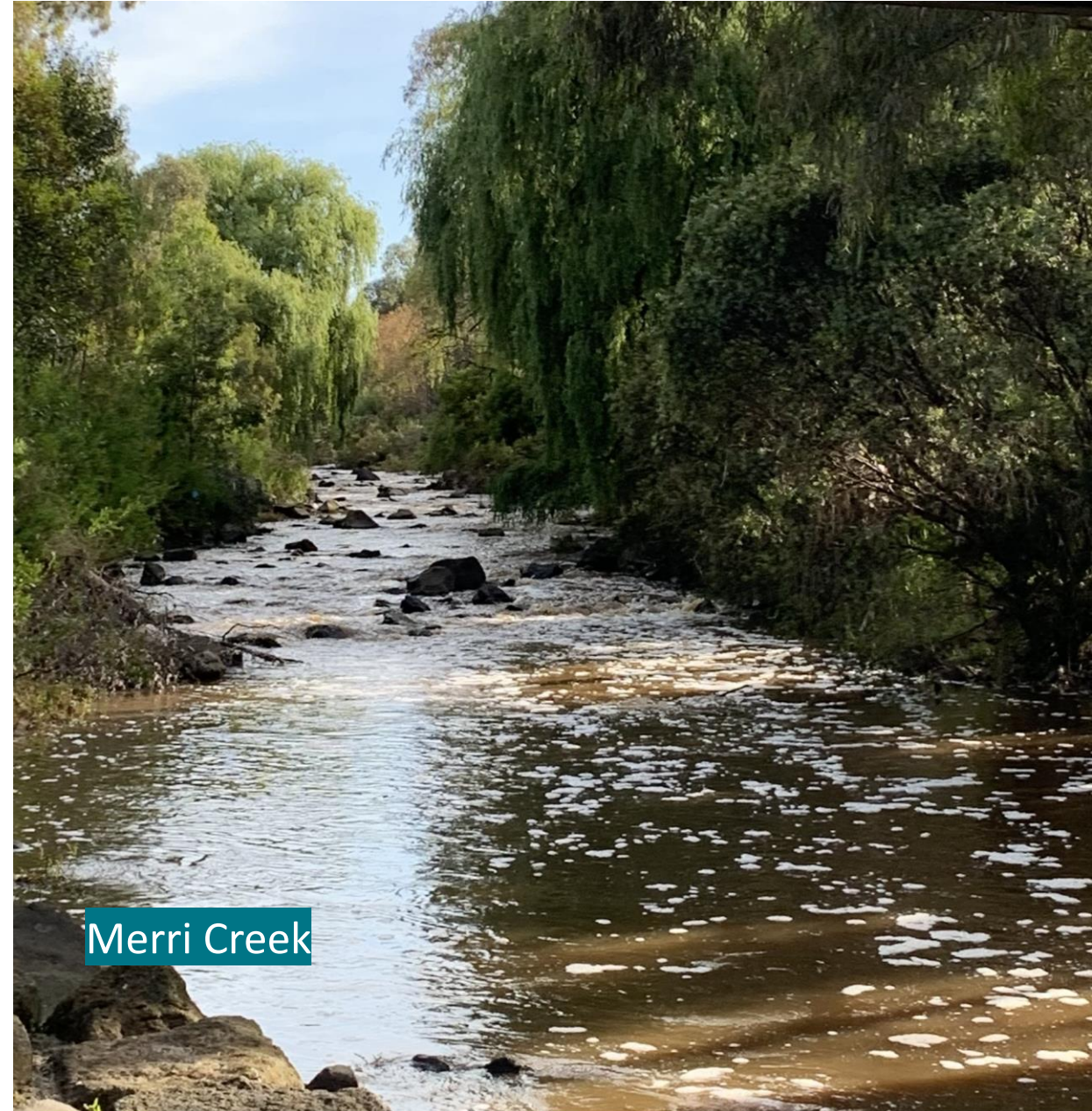
Safer Care
Victoria



Acknowledgement of Country

I acknowledge the Traditional Custodians who have lived and loved this country through the vastness of time.

I pay my respects to their Elders past and present. I extend that respect to Aboriginal and Torres Strait Islander people here today.



Merri Creek



Being different together

In this space, we're not the same and that's our greatest strength.

We draw on our differences in:

- who we are
- what we've experienced
- and how we think.

Who we are...

Today's story owners, collaborators and co-creators



Kristiina Siiankoski

Consumer Lead
Culture & Capability, SCV



Nami Nelson

Manager
Culture & Capability, SCV



Simon Waring

Consumer Lead
Centre of Clinical
Excellence,
SCV



Kaz Redmond

Senior Project Officer
Improvement Branch, SCV



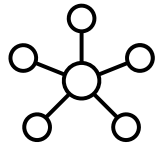
Alana Donaldson and Kay
Consumer
representatives,
SCV



Belinda MacLeod-Smith

Partnering and Co-design
Capability Lead
Culture & Capability, SCV

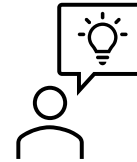
We are here today to...



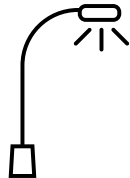
Share principles, mindsets and approaches



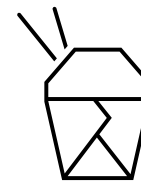
Reinforce the role of consumer stories in QI work



Highlight the reciprocal power of storytelling



Shine a light on the story telling experience



Provide practical **take-aways** about harnessing the power of consumer stories

You can't really change the heart without telling a story"

Martha Nussbaum

"This work is difficult because we repeatedly delve back into our experiences to help educate others. We're tasked with running back into the fires we've escaped"

Emilie Cuinn, as quoted by Morgan Lee Cataldo, CoDesign and Power at Social Design Sydney in 2020.

"Even when well-intentioned, the story's power tempts us to use them for our own gain"

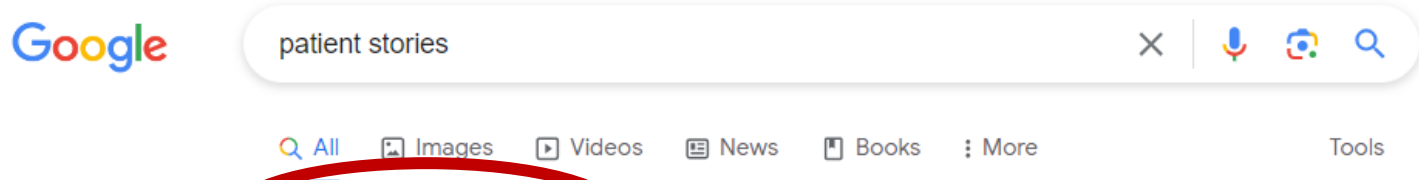
Wieland, L. 2021. Story Telling Ethics. <https://blogs.bmj.com/medical-humanities/2021/07/07/storytelling-ethics/>




Stories from experience

SCV Post-Partum Haemorrhage (PPH)
Collaborative, 100,000 Lives Program

CONSUMER STORY FORMATS



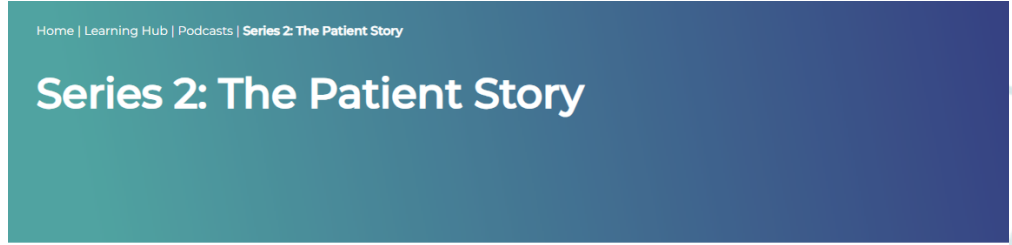
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 Australian Commission on Safety and Quality in Health
<https://www.safetyandquality.gov.au> › migrated

Patient Stories: A toolkit for collecting and using ...

Patient Stories involves interviewing patients directly to gather their insights on the service they have received either as part of a particular service ...

30 pages



In Series 2 of the Spot on Podcast, we are excited to have renowned Australian journalist **Deborah Knight** as our special host. In this series we are focusing more on the human side of a diagnosis. We would like to introduce Australians who have received a difficult diagnosis of skin cancer to discuss their journey, along with a member of their treating team.



“ Virtually nobody in my family, social, or professional sphere had a clue about what I was experiencing. I often felt isolated and alone. ”

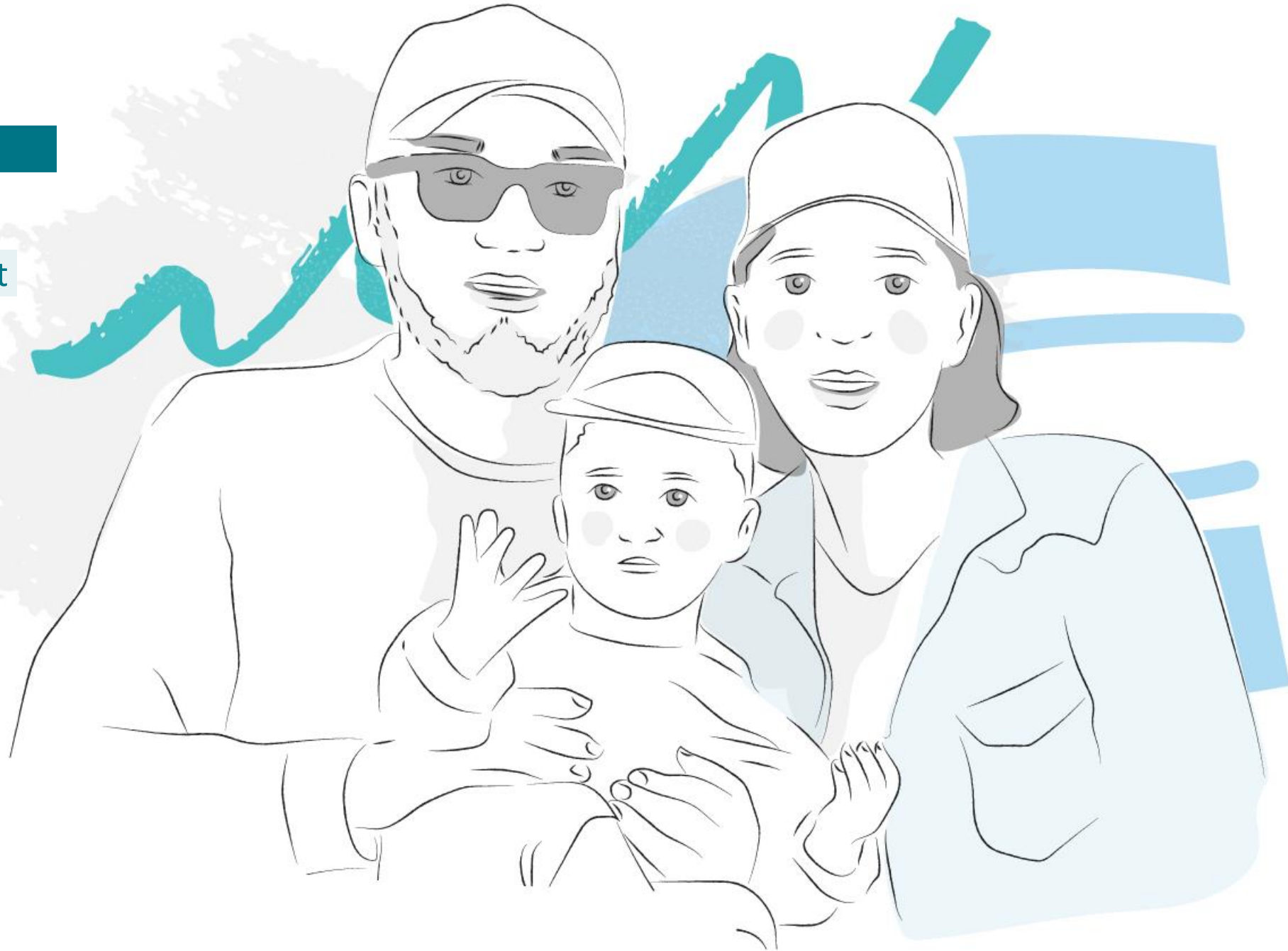


—John,
spinal CSF leak patient

Meet Anna

LIVED EXPERIENCE STORY

“we may not be perfect, but we still have the chance to make things better...”





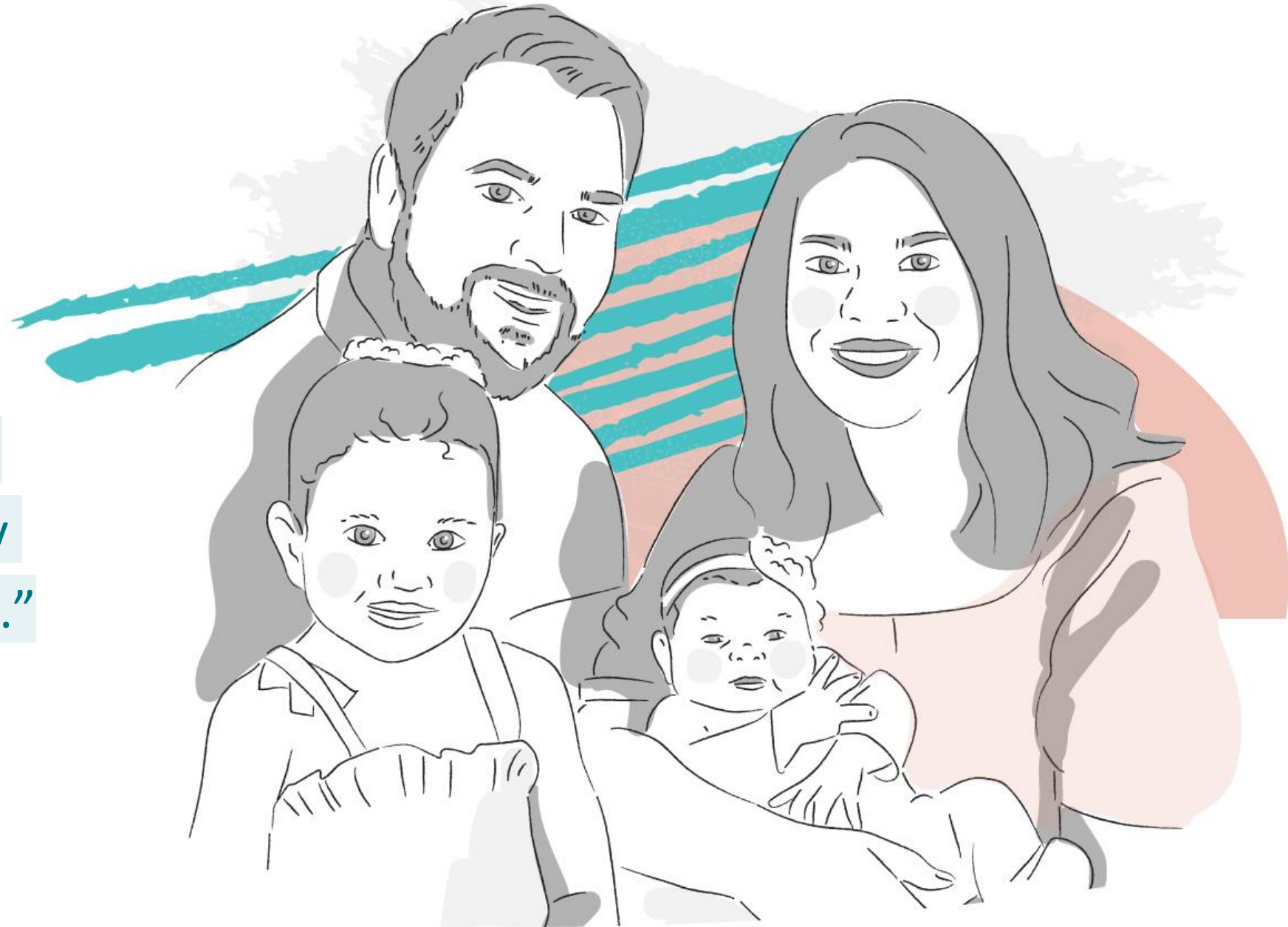
“I couldn’t do anything,
I couldn’t be there...”



Meet Kay

LIVED EXPERIENCE STORY

“having a healthy mum
and baby is not the only
thing that is important...”



“Patient experience is more than just having a good outcome..”



How did stories influence the Collaborative?



Enhanced project aim



Built will to improve



Generated change ideas

PPH Collaborative : Partnering evaluation

'I think those [consumer audio stories] are a really creative idea and good because you know, sometimes you can still get emotional talking about things sometimes when you are on a stage'

'I felt really safe and really respected'

'I felt like something I said, I felt like it did actually have a change'

Lessons learned

Using a trauma informed approach

Prioritising relationships

Share results



Plan to facilitate attendance

Agency over content

Lived experience stories and Quality Improvement work

Humanises the problem being addressed and its impact

Motivating story for change:
Helps frame "What matters"

Can provide context for other project data

Traumatic lived experience shared publicly
often repeatedly

Will sharing the story lead to action?
How will the story owner know?

Is this the only story being shared for
everyone affected by this situation?

What language considerations are made?

Will the people who were involved in my experience be in the audience?

Shared purpose

Stories that demonstrate impact

Passionate advocates

How public does the story owner want to
be with their experience?

What happens when others retell the
story?

Who decides when and where the
story is used?

Support needed pre and post sharing

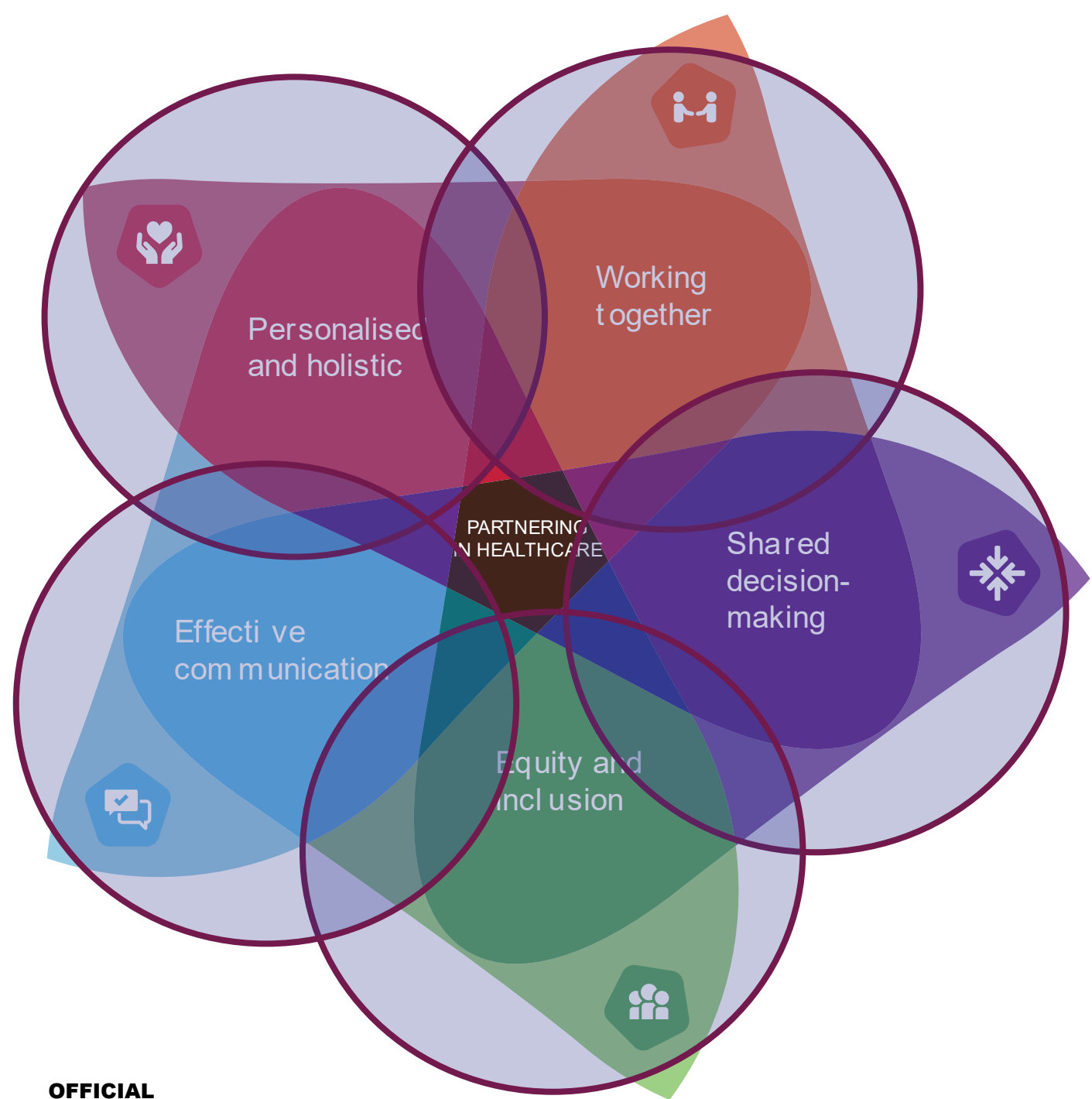
My experience is not all of who I am

How is the story and story owner valued?



Consumer stories as opportunities to partner

SCV's Partnering in healthcare framework, 2019



Consumer Panel



Kristiina Siiankoski

Consumer Lead – Culture and
Capability, SCV



Simon Waring

Consumer Lead – Centre for
Clinical Excellence, SCV



Practice Principle:

We acknowledge what it takes for people with lived experience to draw from intimate parts of their lives in a professional context. We understand the courage it takes.

Morgan Lee Cataldo, CoDesign and Power, Social Design Sydney 2020.



Putting principles into practice....

© 2010
University of
California

From principle to action: identifying the change we can make

Question 1: Yellow – What actions and reflections do you have about how you have partnered to share consumer stories in the past?

Question 2: Orange – What actions and reflections do you have about what you want to improve, or do differently to share consumer stories in your QI work moving forward?



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Table activity: from principle to action, identifying the changes we can make



Scan to read SCV's Partnering in Healthcare Framework



	Before	During	After
Current practice: How have you partnered to share consumer stories?			
Future practice: What do you want to improve, or do differently to share consumer stories in your QI work?			



Bringing it together

BRUNNEN
AG

Resources for more information and reflection

SCV, 2019. Partnering in healthcare framework.

Patient Advisors Network. No date. Making Stories Matter: 5 Tips for requesting stories from patients and caregivers

[5-tips-for-requesting-stories.pdf \(hic.org.au\)](https://www.hic.org.au/5-tips-for-requesting-stories.pdf)

Wieland,L. 2021. Story-telling Ethics (Blog)

<https://blogs.bmj.com/medical-humanities/2021/07/07/storytelling-ethics/>

Health Issues Centre, 2014. Getting involved: a dozen tips for telling your story for quality improvement. [HIC-Tips-for-consumer-storytelling.pdf](https://www.hic.org.au/HIC-Tips-for-consumer-storytelling.pdf)

What will you
do
differently?



Thank you!

For more information about SCV's work partnering with consumers and building capability for partnering and quality improvement please contact:

culture.capability@safercare.vic.gov.au

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Victoria

