

Conversations for Kindness

Whose story is it anyhow? Creating safe spaces for
patient storytellers

18 May 2023

Contents

Context	3
Joining the conversation	4
Who did we hear from?	5
Insights from Sue Robins	6
Group discussion	12
From the chat	15
Further resources	17

Context - Conversations for Kindness

About the movement

Conversations for Kindness is a monthly virtual meeting that was set up in the summer of 2020 by eight colleagues and friends working in healthcare across Sweden, the UK and the USA: Bob Klaber, Dominique Allwood, Maureen Bisognano, Goran Henriks, Suzie Bailey, Anette Nilsson, Gabby Matthews and James Mountford. The purpose of the meeting was to have some time together to continue some initial conversations around kindness, and its role at the 'business end' of healthcare, and to plan interactive workshops on this topic.

Conversations for Kindness

- Monthly Zoom call on the third Thursday of every month (6-7pm GMT)
- A focus on listening, learning, thinking differently and mobilising for action
- An open culture of sharing of resources, energy and ideas

If you would like to join the conversation for kindness, please complete [this contact form](#)

Joining the Conversation from across the world

More than **60** Kindness in Healthcare community members came together from all over the world for this Conversation for Kindness. Once again, we had new faces join us for the first time!

A few of the hellos from around the world...



AH Anne Marie Hadley (Ministry of Health) 18:04
Good morning 3am in beautiful Sydney
❤️ 3 🙋 1

BA Benjamin Anderson 18:03
Benjamin Anderson from Colorado.

VO Viviane Alves de Oliveira 18:05
Hello from London 🌞

SA Ahmad, Sumera R., M.B.B.S. 18:04
greetings! from Rochester, Minnesota

CS Claire Snyman (Guest) 18:04
Good morning from Vancouver everyone. Lovely to see everyone, this is always one of my favorite meetings.

SP Samit Purkayastha (Guest) 18:04
Hello Iam samit from Pembrokeshire, wales

Who did we hear from?

Our speaker today was **Sue Robins**, a gifted author and patient advocate, who helped us to explore storytelling in healthcare. Sue has been doing this work for the past 20 years. She has been widely published and written several [books](#), has spoken at dozens of national and international health conferences and owns a health communications company.

Today, Sue shared with us her own story of how she started advocating for families after her son was born with Down Syndrome and, more recently, having been diagnosed with breast cancer, how she became a patient storyteller as well. Following her treatment, Sue has continued her patient and family advocacy work.

In her time with us, Sue led the conversation about ‘creating safe spaces for patient storytellers’, exploring how sharing stories in the healthcare world helps to make it a kinder place.

This insights pack summarises the session, but you can also [watch the event on YouTube](#)



*Kindness in
healthcare*

What did we hear? Insights from Sue Robins

Everybody has a story

Sue reminded us that *“we feel through stories, we don’t feel through data”* and she planted two seeds of thought for us to consider:

- 1) **Patients need safe spaces to share their stories**
- 2) **Consider co-presenting or co-authoring with patients so they can share their own stories**

Sue shared how patients hold invaluable healthcare wisdom and insight having had lived experience. She asked us to consider ways to give patients the opportunity to share their own stories (whether with healthcare professionals or on their own).

She also highlighted the privilege health professionals have when they themselves are patients, having insider knowledge as a physician-patient.

Insights from Sue Robins

Sue talked us through how we can support patients to share their stories:

1. Sharing the microphone

Sue shared a piece of reading from her book *Bird's Eye View*, talking of the power of presenting a dialogue between clinician and patient at a conference or meeting in a co-presenting model. She spoke of how being a lay person (non-clinical) with lived experience should be enough, but often it's not. Presenting with a clinician to a group of clinicians helps the patient to feel credibility but also helps the clinician to share their own story of helping. Sometimes it is easier for clinicians to empathise with 'their own' than those whom they view as lay people.



2. Are you using patients for their stories?

Sue shared insight into tokenistic, tick-box sharing and the negative experience it is. As a patient, showing vulnerability and bravery in sharing a story with clinicians who may also be strangers to them, it feels awful to be shuffled into a room for 5 minutes to talk, then shuffled back into the hallway with the door shut behind you once more when you've done your sharing. "Patients can tell stories wherever you are telling stories" – we don't need to try to keep them separate or 'away' from other business.



Insights from Sue Robins

3. Creating safe spaces for patients to tell their stories

Spaces for Patient Storytellers

Education

Health
Conferences

Academic
Journals

Creative

Sue encouraged us to consider the creative ways patient stories could be shared. She shared an example of a patient who created a video describing how it felt like to be under the CT scan - for her, it felt like drowning. But what saved her from 'drowning' was the kindness of healthcare staff.

Insights from Sue Robins

4. Co-presenting

Sue asked us to consider: do you respect patients enough to stand up on stage with them? She shared examples of experiences co-presenting and what made for a positive experience.



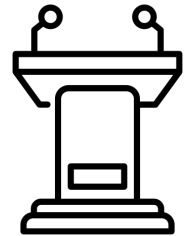
5. Co-authoring

Do you respect patients enough to share a byline with them? Sue also noted that this can sometimes be easier for patients as not everyone is a public speaker.



6. Beyond the podium

Beyond the podium – e.g. patient-friendly journals – where patients can tell their story through the means that they want to share e.g. poetry, art, long-form prose, diagrams, photography. There is no one way for patients to share their stories. Sue talked of her experience sharing a photo essay in the Journal of Medical Imaging and Radiation Sciences and shared a number of examples of other patients sharing their stories.



Insights from Sue Robins

Sue provided practical guidance to support patient storytelling in a safe and meaningful way.

Practical Take-Aways To Support Storytellers

Before –
prep

During -
support

After –
follow-up

Virtual

Insights from Sue Robins

To close, Sue reminded us how brave patients are to share their stories to make healthcare a better place. She said that being brave doesn't mean not being scared, it often means being scared and doing it anyway.

She also reminded us that patients sharing their stories with us is a gift, and that including patients in storytelling efforts might just move the needle on kindness.

Sue also shared her contact information if anyone wanted to get in touch.

Sue Robins



suerobins.com



suerobinsbooks



Sue Robins



Group discussion

Our group discussion question today was:

How have you created safe spaces for patient storytellers?

An insight into what participants shared...

Gabby: Talked of her tension between the patient advocacy work she has been doing since she was a teenager, and her work now as a doctor, which she has been doing for 10 months. At a recent conference, she felt challenged that she had 'won' a patient spot that should not have been given to a clinician, but this was difficult for her as she still sees herself as a patient first. She reflected on finding ways to challenge power structures to change the spaces we are making decisions in, to include patients more meaningfully.

Mastorah: Talked about the journey to understand patients' journeys. This includes why they engage or not, and what may have happened previously that now influences their engagement with us as clinicians. Also highlighted the tension between how different care professions may view the same patient or family, based on their particular discipline, skill set or world view.

Group discussion

Fred: Loves that journals are becoming more accepting of patient stories – we need to keep working at getting the patient and the professional comfortable speaking together, and some of that is getting our professionals more comfortable with speaking – if we are able to become more comfortable with being vulnerable with our patients, then maybe they may become more comfortable being vulnerable with us.

Sue: Talked about how some patient storytellers have more privilege than others, if you are one of those, then finding ways of using your privilege to ensure other voices are heard. Also challenging people to find a more diverse patient storyteller, if you know there are others out there who could share in a better or different way. Engaging patients who are different to you does mean you sometimes have to take extra measures to ensure the success of their engagement.

Benjamin asked how we enable people with special needs to be able to speak their stories?
Support groups for people with disabilities often have info for how to advocate, these are a great way to help find people with diverse stories, you need to think outside the box.

Closing the Conversation

Sue left us with some final advice – **give it a go, try it, start by acting small** e.g. at a student education session, you don't need to start with a grand conference. She asked for our help, **to be allies with our patients** – and to **make space from inside the system** for your patients to be able to share their voice and stories.

Sue also shared two references via email following the discussion, as valuable places to start reading:

- <https://hospitalnews.com/stollery-childrens-hospitals-family-talks-program/> - this is about a formal hospital programme that coaches patient speakers and provides liaison work between the speakers and the organisers.
- <https://www.thepermanentejournal.org/doi/full/10.7812/TPP/17-119> - article about the emotional toll of patient storytelling

From the chat...

While Sue was sharing, members of the Kindness in Healthcare community shared their thoughts and reflections in the chat. A selection of these have been captured below:

“I love the idea of sharing stories and presenting together. I have learned loads this winter by visiting a couple of warm hubs and just sitting around a table knitting and listening. The stories have been illuminating- and using the ideas to eg. change the times that carers with jobs can ring to access appointments, change the words we use in leaflets, think when we ‘tell’ people not to or to do things”

“There a fear in the medical profession to ‘let folk in’; it can hurt us more if something happens. Also the guilt of not providing the care we would want in a limited resource system”

“Moving to hear Sue talking about her breast cancer experience. And I **love her work** and all-round contribution!”

“As a patient who shares my story often, and also works with health care organisations on patient experience, there is a fear and reluctance to hear ‘all’ patient stories. **Every story is a gift. An opportunity. To learn and share together.** I hope through talks like Sue’s we can overcome this fear and move towards listening and opening up space”.

From the chat...

“**An idea:** Kindness is a foundation and route into all sorts of good things – belonging, equity, personalisation, meaning...Stories are a good route into kindness. is that helpful?”

“A team shared with me how they feel like they are failing patients. But when a patient said ‘this service is failing me’ it was met with a really defensive reaction and the patient seen as ‘difficult’ (even though the team knows it’s true). **As if it was intolerable for the team to have this mirror held up to it.** I wonder if co-producing stories could get around the defensive reaction?”

“**When people get chance to tell their story it can be very healing** but in a 10 minute GP consultation it can be so difficult to provide time for this. This is why I run an hour late in surgery often (and I have 15 minute appts).”

“**Making space for stories is a parallel idea to allyship** - because it’s helping not-natural-storytellers to communicate - and making a bridge between them and the audience - without changing the story.”

Further resources to check out

A number of recommended readings and resources were shared in the chat during the Conversation. These have been collated below:

- An article about work with voices of lived experience and GPs around primary care transformation: <https://www.cope-scotland.org/wellbeing-tips/entry/finding-common-priorities-matter>
- A video demonstrating how storytelling can be beneficial for us as patients but also for staff <https://www.youtube.com/watch?v=v04-DqyQPIs>
- An article from Healthcare Excellence Canada on how to support patients sharing stories at the board level <https://pxjournal.org/cgi/viewcontent.cgi?article=1742&context=journal>
- An article exploring from tokenism to empowerment: progressing patient and public involvement in healthcare improvement <https://qualitysafety.bmj.com/content/25/8/626>

Further resources to check out

- A blog about spaces for listening: <https://brigidrussell43.medium.com/spaces-for-listening-8c597c1f52a2>
- An article about learning to listen to patient stories:
<https://www.nytimes.com/2021/02/25/well/live/narrative-medicine.html>
- An organisation's website that helps people see and understand their interrelatedness:
<https://atlasofcaregiving.com/>
- A poem: Small Kindness by Danusha Laméris
<https://www.nytimes.com/2019/09/19/magazine/poem-small-kindnesses.html>
- Sue Robins' books including 'Bird's Eye View' written for health professionals, each chapter offers insight into how it feels to be vulnerable
<https://www.suerobins.com/books>

Acknowledgements

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For all enquiries please contact us [via the Kindness in Healthcare website.](#)

Thank you for joining, thank you for reading.

We'll see you next month!