



Storytelling for Impact: Creating a storytelling program for patient partners in research

Teresa Atkinson & Leah Getchell

International Patient & Public Involvement (PPI)
Network Webinar

November 26, 2024

Welcome & Land Acknowledgement

Members of the Can-SOLVE CKD Network office conduct their work from the traditional, unceded territories of the Coast Salish and home of x^wməθk^wəy'əm (Musqueam), S^kwx^wú7mesh (Squamish), and Səllwətał (Tsleil-Waututh) Nations.



Learning Objectives

1. Understand the importance of storytelling in the context of health care
2. Gain insights into how an educational module was co-developed and delivered with patient partners
3. Review resources and how they can be used

Have you shared your story?



Strategy for Patient-Oriented Research (SPOR)



- **Funded by Canadian Institutes of Health Research**
- **Partnership between researchers, those with lived experience, healthcare providers, policy-makers**
- **Committed to building a collaborative research environment centred around patients and health system decision makers**

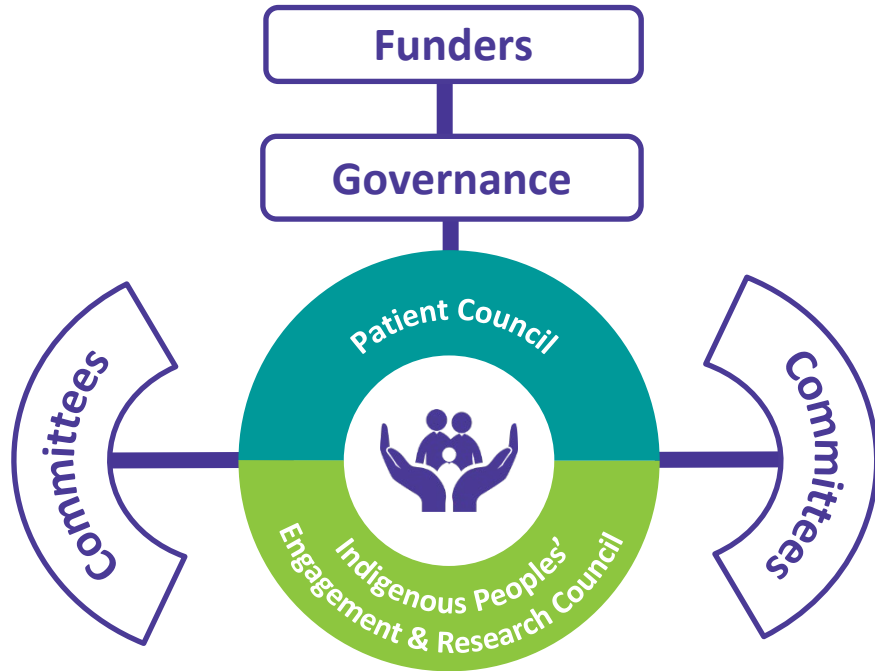
Can-SOLVE CKD Network

(Canadian Seeking Solutions and Innovations to Overcome Chronic Kidney Disease)



(www.cansolvekd.ca)

Patient engagement



A wobbly start



Not reinventing the wheel...

Lisa Hawthornthwaite
Senior Patient Experience Consultant
Fellow, Associated Medical Services

Rachelle Wood, Patient Experience
Specialist

June 2, 2015

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Sciences Centre

[Three Sides to Every Story
Beyond Catharthis](#)



London Health Sciences Centre

Quality, Patient Safety and Patient Experience

Patient and Family Advisors:

Storyteller Toolkit



Narrative Medicine:
a way for healthcare
practitioners to deeply
understand the experience
of illness and care through
patient stories

Online Pilot

WHAT'S YOUR STORY?

CAN-SOLVE CKD STORYTELLING PILOT



3 GROUP ONLINE MEETINGS

- Orientation Meeting
- Draft Story Presentations
- Final Story Presentations

3 INDIVIDUAL COACHING CALLS

Facilitators coached each participant on key elements within a story & provided feedback on written drafts



PROGRAM CREATORS

Lisa Hawthornthwaite, Lauren Lee & Mim O'Dowda, London Health Sciences Centre, London ON

PATIENT PARTNERS

Gwen Herrington - BC
Chantel Large - AB
Marian Reich - ON

STORY COACHES IN-TRAINING

Selina Allu - AB
Leah Getchell - ON



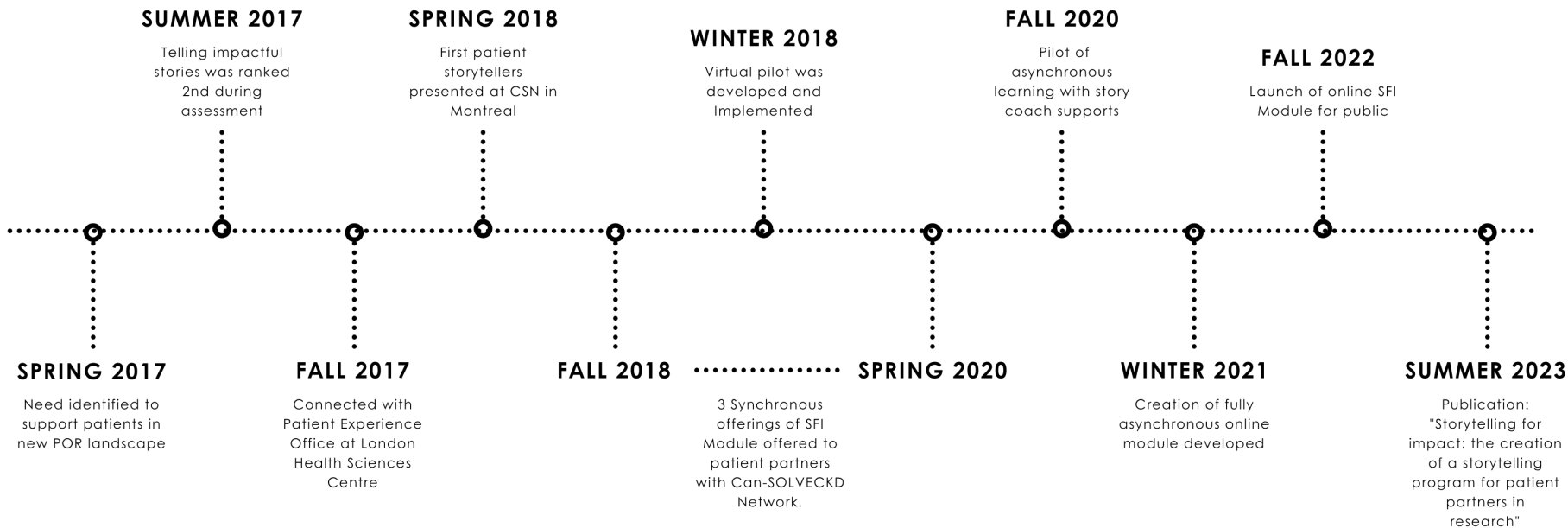
**Stories shared @ 2018
Canadian Association of
Nephrology Administrators
Summit
Montreal , QC**



"Inspiring! A great reality check, always great to hear from the patients' perspective to know if we are doing a good job..."

"Incredible! Passionate! [They] added a lot of values and perspective to the conference. Thank you for this session."

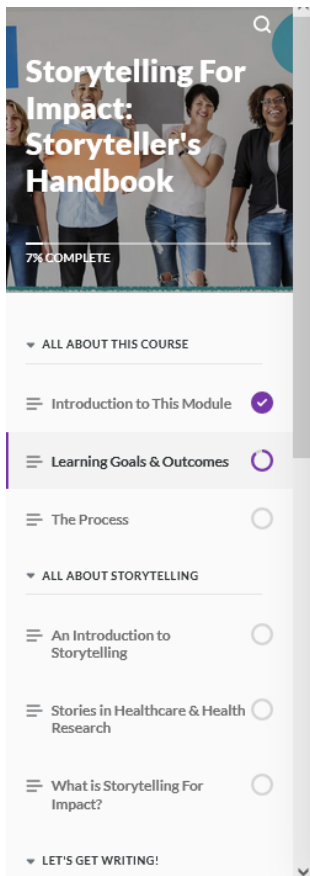
Timeline



Teresa's Story



Module development – interactive, asynchronous, online



Storytelling For Impact: Storyteller's Handbook

7% COMPLETE

▼ ALL ABOUT THIS COURSE

- ☰ Introduction to This Module ✓
- ☰ Learning Goals & Outcomes ○
- ☰ The Process ○

▼ ALL ABOUT STORYTELLING

- ☰ An Introduction to Storytelling ○
- ☰ Stories in Healthcare & Health Research ○
- ☰ What is Storytelling For Impact? ○

▼ LET'S GET WRITING!

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<https://cansolvekd.ca/storytelling/#/>

The Learning Outcomes:

The **LEARNING OUTCOMES** of this course are:

- 1 Have a written and practiced oral story of your health care experience to share with a live audience; impacting healthcare research & practice
- 2 Have the tools to adapt your story & message according to the focus of the speaking opportunity
- 3 Receive constructive and motivating feedback from story coaches and story alumni to enhance your story and build confidence as a storyteller
- 4 Join a growing community of Story Alumni who can support/train others in future offerings

CONTINUE

Patients sharing their stories



World Patient Safety Day
17 September 2024

Stories shared in Buenos Aires, Argentina; San Diego, CA; Cairns, Australia, and more!



Can-SOLVE CKD Network - Le réseau Can-S@ansolt · Nov 30, 2023 ...

Cathy Woods and Arlene Desjarlais presented their team's work, "Ensuring Indigenous Co-Leadership in Kidney Research: A Can-SOLVE CKD Case Example," at the 11th Annual Indigenous Health Research Symposium at @umanitoba this week 🌟

Read the full paper: bit.ly/3QSkEmh



University of Manitoba and 2 others



Strategy for Patient-Oriented Research
SPOR
Putting Patients First

Sharing our story

Getchell et al.
Research Involvement and Engagement (2023) 9:57
<https://doi.org/10.1186/s40900-023-00471-0>

Research Involvement
and Engagement

COMMENT

Open Access

Storytelling for impact: the creation of a storytelling program for patient partners in research



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Abstract

Storytelling is a powerful means to evoke empathy and understanding among people. When patient partners, which include patients, family members, caregivers and organ donors, share their stories with health professionals, this can prompt listeners to reflect on their practice and consider new ways of driving change in the healthcare system. However, a growing number of patient partners are asked to 'share their story' within health care and research settings without adequate support to do so. This may ultimately widen, rather than close, the gap between healthcare practitioners and people affected by chronic disease in this new era of patient and public involvement in research. To better support patient partners with storytelling in the context of a patient-oriented research network, Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) Network adapted an existing in-person storytelling workshop for patient educators within a hospital setting. The result is a 6-week virtual program called *Storytelling for impact*, which guides patients, family members, caregivers and organ donors in developing impactful stories and sharing them at health care and research events, e.g., conferences. The online series of synchronous workshops is co-facilitated by story coaches, who are program alumni and Can-SOLVE CKD staff with trained storytelling experience. Each story follows a structure that includes a call to action, which aims to positively impact the priority-setting and delivery of care and research in Canada. The program has been a transformational process for many who have completed it, and numerous other health organizations have expressed interest in sharing this tool with their own patient partners. As a result, we have also created an asynchronous online program that can be used by other interested parties outside our network. Patient partners who share their stories can be powerful mediators for inspiring changes in the health care and research landscape, with adequate structured support. We describe two novel programs to support patient partners in impactful storytelling, which are applicable across all health research disciplines. Additional resources are required for sustainability and scale up of training, by having alumni train future storytellers.

Keywords Patient partnerships, Patient and public involvement, Patient engagement, Storytelling, Health research, Patient-oriented research, Kidney, Kidney transplant, Organ donation, Living organ donation

"By telling your stories you may have acquainted many doctors, nurses, students, etc. with the importance of just plain listening to patients and relatives..." (email from a retired physician)



Lisa Hawthornthwaite @hawthorl · Jul 28, 2023

...

Kudos for co-creating a virtual workshop and publishing with patient partners. Love the emphasis on supporting the emotional impact of returning to difficult events in the illness/healthcare experience. The role of partnering with the story coach is key. #patientvoices



Evaluation and next steps



Can-SOLVE CKD Network - Le réseau ... @can... · May 3, 2019 ...

Listening to the [#patientstories](#) of Kevin Settee, Arlene Desjarlais, and Cathy Woods (facilitated by [@SelinaAllu](#) and [@WorkshopDiva](#)). Thank you all for your contribution! Merci à tous pour vos contribution ! [#canSOLVE19](#)



STORYTELLER'S HANDBOOK

Storytelling for Impact



Resources to enhance POR - Learning Tree



- [6 training programs to enhance POR skills and knowledge](#)
- Based on survey findings of greatest training needs in POR
- Co-built by patient partners

Collaborators & Storytellers

Patient Collaborators & Storytellers

Marian Reich – Patient Partner, Story Coach, SFI Special Project Assistant
Cathy Woods – Patient Partner, Storyteller
Mary Beaucage – Patient Partner & Storyteller
Dwight Sparks – Patient Partner & Storyteller
Chantal Large - Patient Partner & Storyteller
Gwen Herrington - Patient Partner & Storyteller
Mike McCormick - Patient Partner & Storyteller
Arlene Desjarlais - Patient Partner & Storyteller
Helen Robinson Sette – Patient Partner, Training & Mentorship Committee
Teresa Atkinson – Patient Partner & Storyteller

Collaborators

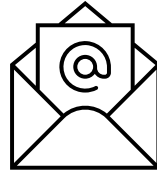
Chantal Boucher – Kidney Foundation of Canada
Liz Fowler – Kidney Foundation of Canada
Craig Settee – Can-SOLVE CKD IPERC Coordinator, Patient Partner & Storyteller
Leah Getchell – Can-SOLVE CKD Patient Partnerships & Training Lead, Story Coach
Selina Allu – Can-SOLVE CKD Knowledge Translation Broker, Story Coach
Leanne Stalker – Stakeholder, Kidney Foundation of Canada National Office
Catherine Turner – Can-SOLVE CKD Indigenous Liaison Manager
Audrey L'Esperance – Centre of Excellence for Partnership with Patients and the Public (CEPPP)
Kevin Burns – Nephrologist
Meghan Elliott – Nephrologist
Norm Rosenblum – Nephrologist
Ruth Sapir-Pichadze – Nephrologist
Helen Chiu – BC Renal
Eva Bernstein – SFI Special Projects Assistant
Simone Dew – SFI Special Projects Assistant
Linnea Franson – Can-SOLVE CKD Communications Specialist



Q&A (and how to stay in touch)



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Connect with us!

Subscribe to learn more about what we do, why it matters, and how you can get involved!

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Storytelling for Impact Online Module

<https://cansolveckd.ca/storytelling/#/>

