



Patient Leaders:

An introduction

Presented by

Alies Maybee
For Sholom Glouberman

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Make your
experience
count



What is a "patient"?

We use the word "patient" as an all encompassing term to include:

- Patients
- Other people with health conditions
- Those close to them as caregivers and family members

Why we use the term

- We believe "patient" is ok to use once we understand it in this all-inclusive way.
- We think struggling over the term separates those concerned with the place of patients in healthcare from each other.



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What is a patient leader?

Patients who are:

- **Thought leaders** -- knowledgeable about the issues and the system and can bring the patient perspective at the highest levels
- **Advisors** -- experienced in bringing the collective patient p.o.v. to work collaboratively within the system



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Why do we need patient leaders?

People's health needs have changed over time:

- 90% of deaths due to chronic conditions (WHO Atlas)

Our health system is struggling to deal with this phenomenon

People with chronic conditions:

- 80%+ are not well prepared to care for themselves
- Spend 5 -10 hrs/year with their doctors
- Spend 6000 hrs/year together with their family caregivers on their care

Partnerships with patients are now necessary



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What kinds of partnerships?

Patient leaders bring the patient perspective to:

- Service redesign
- Research in health and health policy
- Policy development
- Education -- in the humanities curriculum in health sciences
- Strengthen partnerships in patient care



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Patients Canada developing patient leaders

- **KPT Workshops:** We have a group of patients and caregivers who come together regularly to learn from experiences of others and develop targets
- **Conferences:** We participate in conferences to learn about the issues facing providers, administrators and policy makers – and to share our understanding of the patient perspective
- **Workgroups:** We collaborate in workgroups learning how best to work with colleagues in healthcare



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Pathway from experience to impact

Partnering with patients to improve healthcare



Design by Pivot Design Group



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Six targets for hospitals developed by our leaders

1. **Hospital gowns** are not obligatory and do not erode people's dignity
2. **Parking fees** are significantly reduced for patients, frequent visitors and family members
3. There is a **third chair** in the triage position in Emergency
4. There is an open **visiting policy** that recognizes the important contribution that visitors make to the health of older people
5. A **care plan** for older people is devised together with them and their family members and is available to them at all times
6. **Hospital food** policy is known to family members and encourages them to bring in healthy food the patient likes



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Where our leaders are making a difference

- Health Quality Ontario - Primary Care Measurement Group
- Accreditation Canada Advisory Panel
- CIHI -- on measurement issues
- CIHR SPOR grant to Ontario (OSSU) member
- PATH project -- patient advisers
- TVN Research Management Committee
- and more

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Patient leaders are healthcare leaders

web patientscanada.ca
 email communications@patientscanada.ca
 facebook Patients Canada
 twitter @PatientsCanada

