PATIENT ENGAGEMENT IN SETTING RESEARCH PRIORITIES

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ICDC
interdisciplinary chronic disease collaboration

Objectives

☐ To understand the importance of engaging patients in research priorities

☐ To describe our experience with a research priority setting process developed by the James Lind Alliance (in dialysis)

How do we traditionally determine research priorities?

- Importance / Novelty

- Unanswered question

- Extends your current line of research

- Feasible

- YOU are interested in it

Why involve patients in setting research priorities?

What we were concerned about?

☐ Low on-line Kt/V

☐ Blood flow through the dialysis line is low

☐ Hemoglobin is 96 g/l, and phosphate is 2.3mmol/l

What she was concerned about?

☐ I hate the fact that there is a different doctor every week

☐ All you tell me is to drink less water

☐ Why am I so itchy, and what can you do?

☐ Why do I feel terrible after dialysis?

☐ Do I really have to do four hours of dialysis?

Patients are at the centre of what we do

What Alberta Health (provincial gov't) and Alberta Health Services (deliver health-care for the province) talk about:

"Patient-centered care"

"Patient engagement"

"Patient self-management"

Patient-oriented research initiatives in Canada

"Strategy for Patient-Oriented Research" (**SPOR**) – CIHR

Patient-oriented research initiatives in the United States

"Conducting research to help patients make more informed decisions"

"Interests of patients will be central to decision-making"

Patient-Centered Outcomes

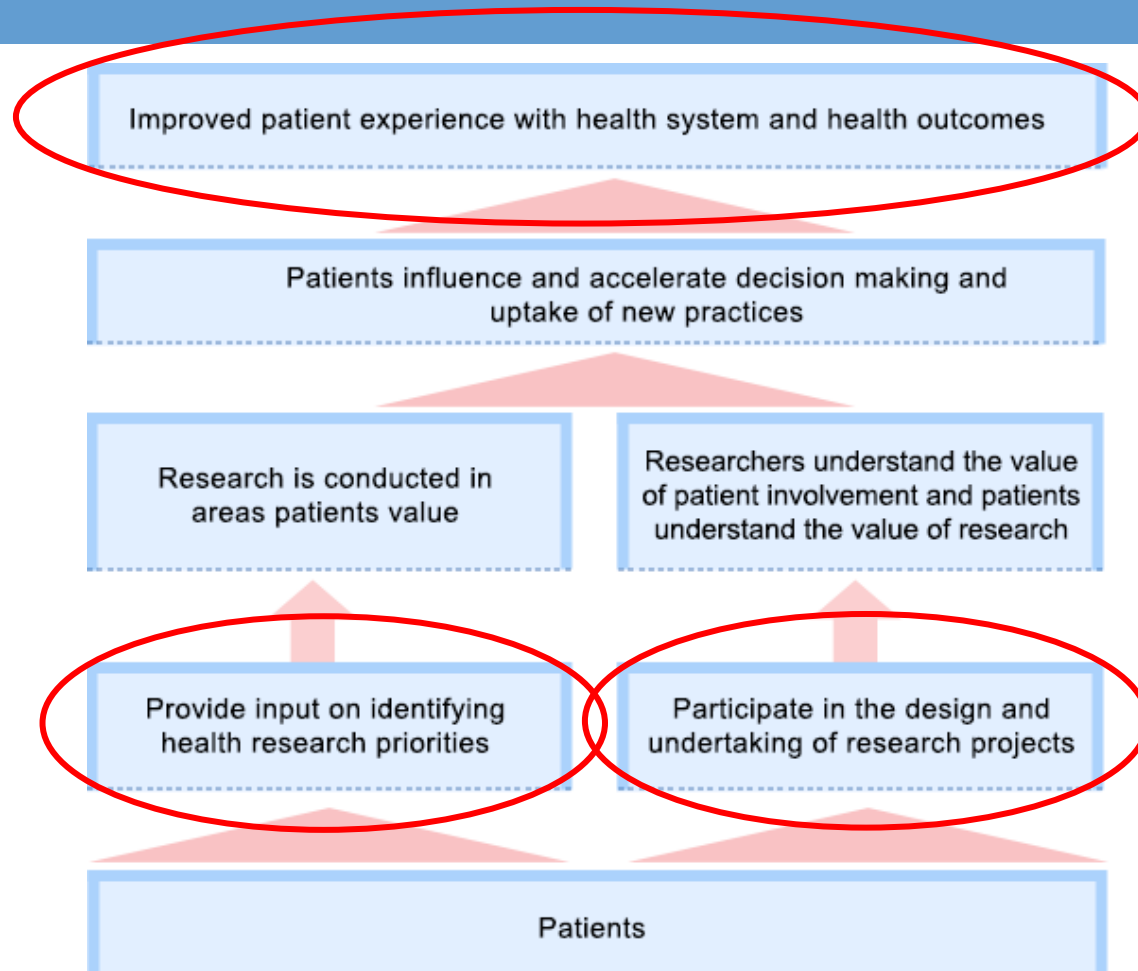Research Institute (**PCORI**) - US

What is Patient-Oriented Research?

- A continuum of research:

  - Initial studies in humans

  - Comparative effectiveness and outcomes research

- Integration of this research into clinical practice

CIHR SPOR 2011

Patient engagement (CIHR)

Improved patient experience with health system and health outcomes

Patients influence and accelerate decision making and uptake of new practices

Research is conducted in areas patients value

Researchers understand the value of patient involvement and patients understand the value of research

Provide input on identifying health research priorities

Participate in the design and undertaking of research projects

Patients

# Why involve patients in research priority setting?

- They live with the disease
- They will sometimes identify research priorities that are different from researchers
- They have insights into the importance of outcome measures that may differ from researchers
- Justice/fairness
- It may increase their support for research

How do you identify patient research priorities?

"Setting Research Priorities for Patients on or nearing Dialysis"
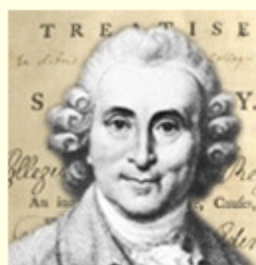
The James Lind Alliance

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Welcome to the James Lind Alliance website

The James Lind Alliance (JLA) is a non-profit making initiative which was established in 2004. It brings **patients**, **carers** and **clinicians** together to identify and prioritise the **top 10** **uncertainties**, or 'unanswered questions', about the effects of treatments that they agree are most important.

This information will help ensure that those who fund health research are aware of what matters to both patients and clinicians.

The JLA is part of the James Lind Initiative and is principally funded by the **National Institute for Health Research**.

Input to the JLA comes from a mix of lay people, healthcare and clinical research professionals and experts in patient and public involvement. Its activities are overseen by a **Strategy and Development Group.**

This website contains information for those interested in finding out more about the JLA, and those who wish to become involved.

Click **here** to hear about what the JLA does, and click **here** to watch a video describing the JLA's approach to stakeholder involvement in research priority setting.
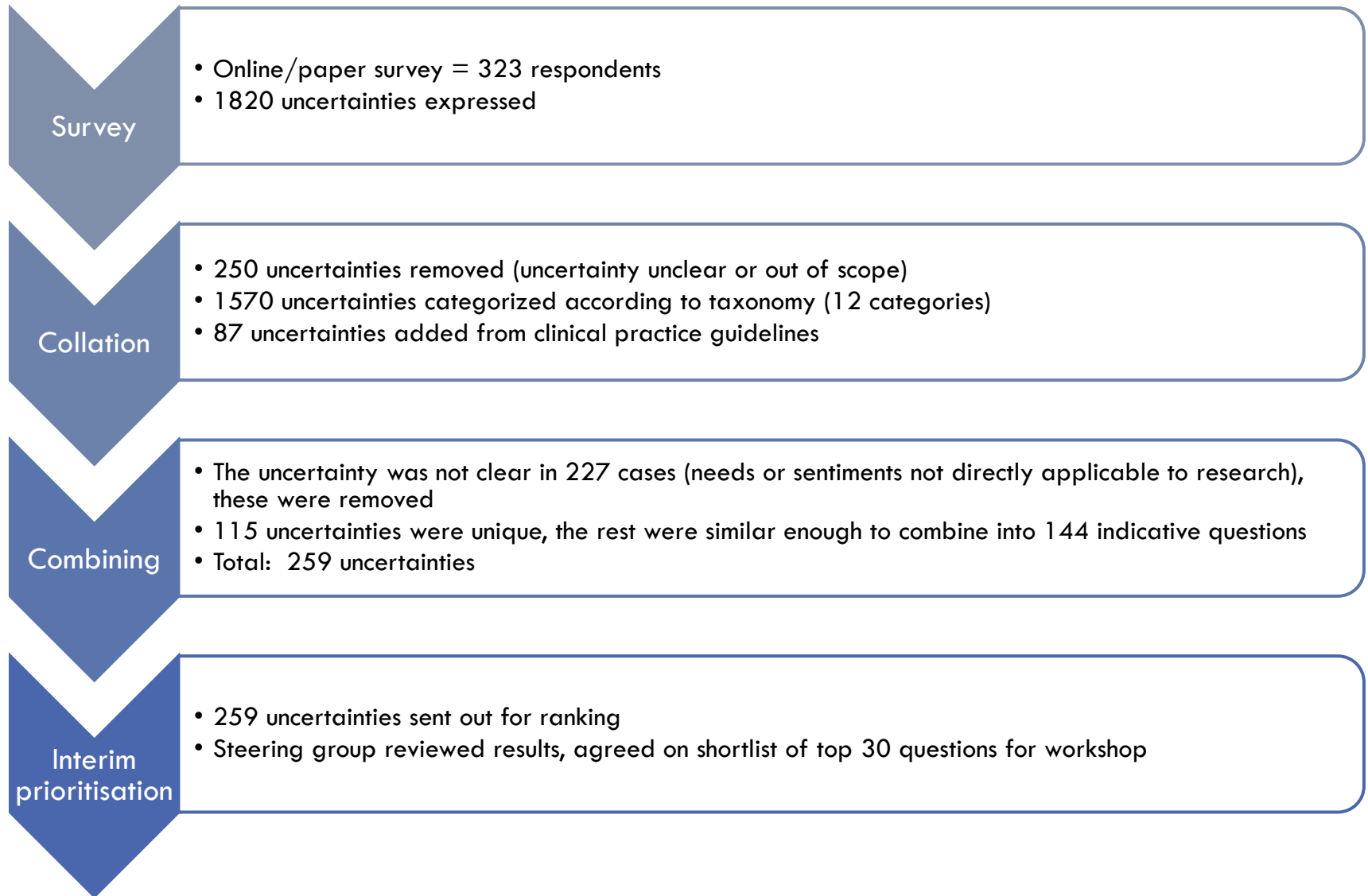
What we did – an overview

- Established a Steering Group

- Identified and invited potential partners

- Collected potential research questions through a national survey, local surveys and review of CPGs

- Steering group prioritized and refined the questions to a shortlist of 30

- Held a workshop of patients, carers and clinicians to identify the top 10 questions.

Steering Committee for Dialysis Research Priority Setting Project
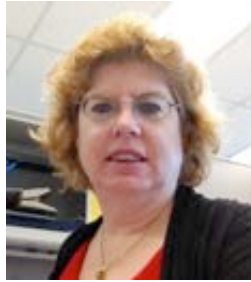
From left to right (starting at top): Sally Crowe, Annette Cyr, Michael Gladish, Brenda Hemmelgarn, Claire Large, Andreas Laupacis, Erin Lillie, Braden Manns, Howard Silverman, Brenda Toth, Wim Wolfs

Figure 1. Process for identifying top research uncertainties

Survey
- Online/paper survey = 323 respondents
- 1820 uncertainties expressed

Collation
- 250 uncertainties removed (uncertainty unclear or out of scope)
- 1570 uncertainties categorized according to taxonomy (12 categories)
- 87 uncertainties added from clinical practice guidelines

Combining
- The uncertainty was not clear in 227 cases (needs or sentiments not directly applicable to research), these were removed
- 115 uncertainties were unique, the rest were similar enough to combine into 144 indicative questions
- Total: 259 uncertainties

Interim prioritisation
- 259 uncertainties sent out for ranking
- Steering group reviewed results, agreed on shortlist of top 30 questions for workshop

Table 1. Profile of survey respondents

	n (%) Total n=323
Type of Respondent	
Patient	
Patient on in-centre hemodialysis	92 (28.5)
Patient on home hemodialysis	32 (9.9)
Patient on peritoneal dialysis	22 (6.8)
Patient, within a year of starting dialysis	9 (2.8)
Health care professional	
Physician	25 (7.7)
Nurse	38 (11.8)
Dietician	6 (1.9)
Social worker	6 (1.9)
Other health professional	24 (7.4)
Caregivers	36 (11.1)
Member of an organization	5 (1.5)
Other	28 (8.7)

Workshop participants

- 11 people with kidney disease
- 5 carers
- 14 clinicians
- 4 allied health professionals
- 4 facilitators

Workshop format – 1

- Each participant ranked the top 30 independently before the meeting

- Orientation to the goal and process

- Met in small groups in the morning, and ranked the 30 by the end of the morning

- Facilitated by a series of cards

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s patient

What are the causes and effective treatment(s) of, and ways to prevent, cramping in dialysis patients?

X

For people with kidney failure across Canada (and between urban and rural areas), how much variation is there in access to care (including access to the various dialysis modalities), patient supports and financial costs borne by patients; what is the impact of these variations, and how can they be reduced?

R

2/25

Vascular access

What can be done to increase the longevity of a fistula, including:

2/25/29

Vascular access

What are the causes and effective treatment(s) of sexual dysfunction in patients on dialysis?

Symptoms

F

What is the frequency, cause and treatment of restless leg syndrome in people with kidney failure?

Would greater access to allied health care practitioners (e.g. psychologists, nurse practitioners, pharmacists, dietitians) improve health and quality of life of people with kidney failure?

H

What is the best way to needle fistulas to reduce pain and local complications, including aneurysms?

Symptoms

Z

T

What is the effect of exercise on a dialysis patient's health?

Other

Access

In the Canadian health care system, how can the desire of dialysis patients to travel be accommodated in an efficient manner?

Other

Q

What is the best strategy for managing calcium and phosphate balance in people with kidney failure on dialysis (considering the impact on quality of life, and other important outcomes)?

A

How can hemodialysis be tailored to a patient [in terms of: length, frequency, location and schedule (e.g. day/nighttime)] to enhance effectiveness and quality of life?

Hemodialysis

Chronic complications

N

What is the best type of access for people on...

AA

Workshop format – 2

- 4 new groups considered the average rankings from the morning, discussed them, and re-ranked them

- The "almost final" rankings were presented to the whole group, and agreement on the final ten was reached

The top ten – (1)

1. What is the best way to **enhance communication** between health care professionals and patients and to maximize patient participation in decision-making with regards to different forms of dialysis, and access to test results to facilitate self-management?

2. How do different **dialysis modalities** compare in terms of their impact on quality of life, mortality and patient acceptability, and are there specific patient factors that make one modality better for some patients?

3. What are the causes and effective treatment(s) of, and **ways to prevent itching** in dialysis patients?

The top ten – (2)

4. What is the **best strategy to increase kidney transplantation**; including access to transplantation, efficiency of the recipient workup, and availability of donor kidneys?

5. What is the **psychological and social impact** of kidney failure on patients, their family, and other caregivers, and can this be reduced?

6. What are the best **ways to promote heart health** in dialysis patients, including management of blood pressure?

The top ten – (3)

7. For people with kidney failure, what is the **impact of each of the dietary restrictions** (sodium, potassium, phosphate) separately, and when taken in combination, **on important outcomes including quality of life**?

8. What are the **best ways to manage symptoms** in people on or nearing dialysis including poor energy, nausea, cramping, and restless legs?

9. What are the **causes and effective treatment(s) of depression** in dialysis patients?

10. What is the **best vascular access** (among both new and existing types) for people on hemodialysis?

Reflections on the process

- The different backgrounds of people complemented each other well

- Process generally respectful

- This is not an exact science – another workshop would likely come up with a slightly different top ten

- Despite concerted efforts, only 323 people responded (but they had lots to say!)

- Sometimes hard to sort out if a submission was a research question or a health care delivery issue

- Older, frail and Aboriginal people under-represented

Criticisms of this approach

- Time consuming and complex

- May lead us down unfruitful paths

- Will decrease "basic" or "discovery" research

- The type of research that will be done will change – therefore some scientists will be losers

Next steps

- Share results with funders and professional societies

- Publish

- Compare priorities with research that is being funded and papers that are being published

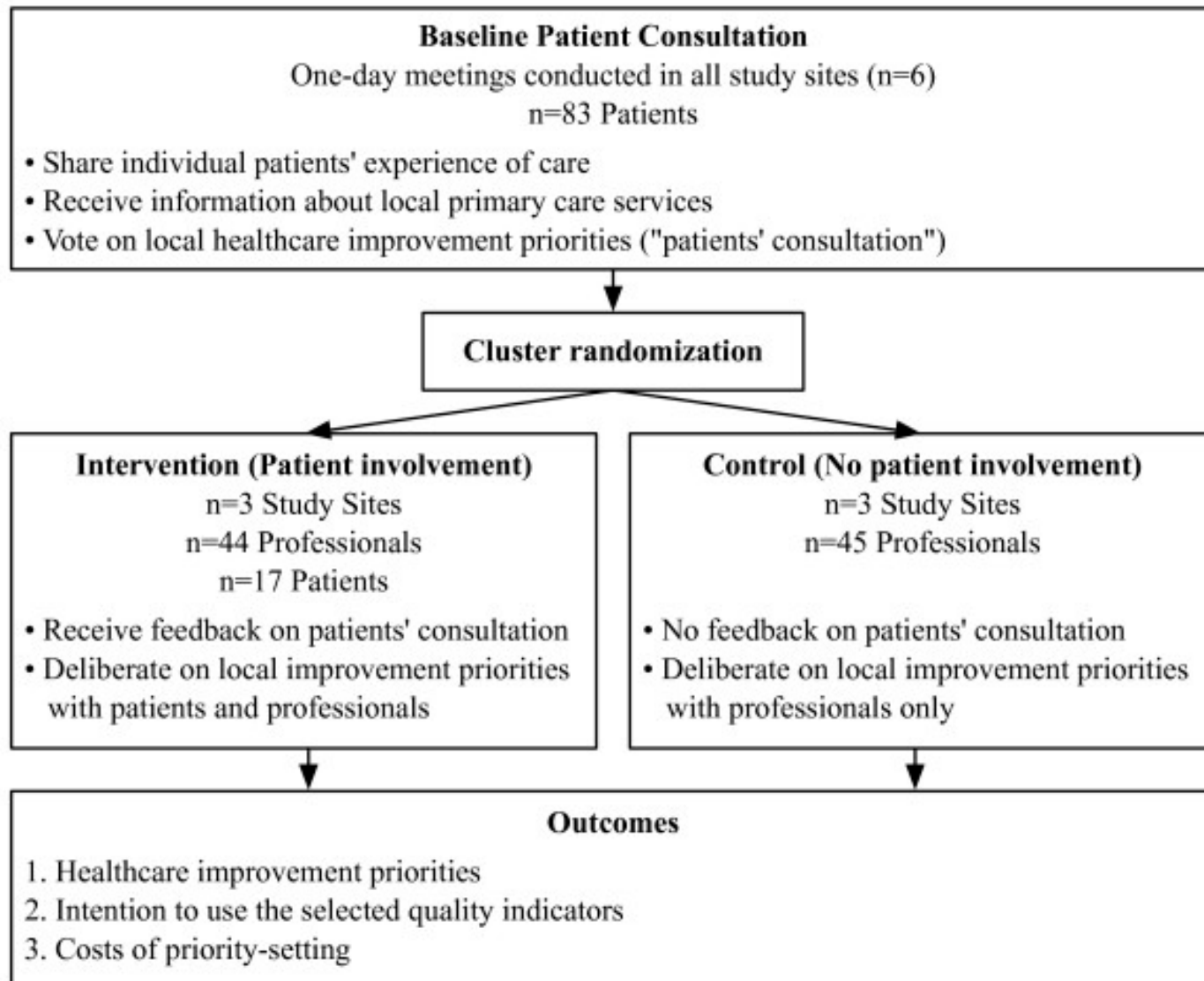- Consider doing this for other disorders and clinical situations

Bring on the evidence

It is time to probe whether the trend for patient and public involvement in medical research is beneficial, say **Sophie Petit-Zeman** and **Louise Locock**.
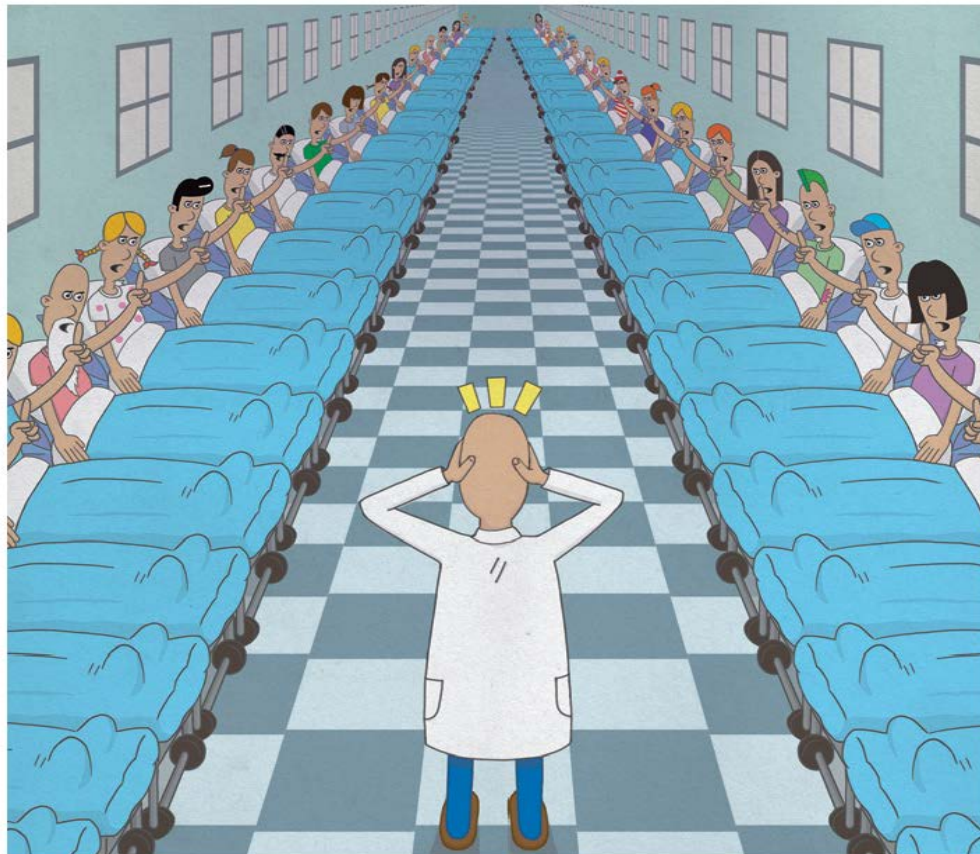
A recent cluster RCT

□ Involving patients in setting priorities for healthcare improvement: a cluster randomized trial

□ Boivin *et al. Implementation Science* 2014, **9**:24   doi:10.1186/1748-5908-9-24.

Baseline Patient Consultation

One-day meetings conducted in all study sites (n=6)

n=83 Patients

- Share individual patients' experience of care
- Receive information about local primary care services
- Vote on local healthcare improvement priorities ("patients' consultation")

Cluster randomization

Intervention (Patient involvement)

n=3 Study Sites

n=44 Professionals

n=17 Patients

- Receive feedback on patients' consultation
- Deliberate on local improvement priorities with patients and professionals

Control (No patient involvement)

n=3 Study Sites

n=45 Professionals

- No feedback on patients' consultation
- Deliberate on local improvement priorities with professionals only

Outcomes

1. Healthcare improvement priorities
2. Intention to use the selected quality indicators
3. Costs of priority-setting

Conclusion:

- Hard to say we are providing patient-centred care if we don't ask patients what is important to them

- Priorities for research can be elicited from patients (and with the right study, they can be answered)

- Asking patients for their input may help improve patient care and experience

RESEARCH

Open Access

Views of Canadian patients on or nearing dialysis and their caregivers: a thematic analysis

Lianne Barnieh[1,2], Kathryn King-Shier[3,5], Brenda Hemmelgarn[1,2,3,4], Andreas Laupacis[6,7], Liam Manns[1,2]
and Braden Manns[1,2,3,4,8*]