PATIENT ENGAGEMENT IN SETTING RESEARCH PRIORITIES

Brenda Hemmelgarn MD, PhD  University of Calgary
Michael Gladish, Whitehorse Yukon
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?
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
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
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”
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

<table>
<thead>
<tr>
<th>Type of Respondent</th>
<th>n (%)</th>
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<tbody>
<tr>
<td><strong>Patient</strong></td>
<td></td>
</tr>
<tr>
<td>Patient on in-centre hemodialysis</td>
<td>92 (28.5)</td>
</tr>
<tr>
<td>Patient on home hemodialysis</td>
<td>32 (9.9)</td>
</tr>
<tr>
<td>Patient on peritoneal dialysis</td>
<td>22 (6.8)</td>
</tr>
<tr>
<td>Patient, within a year of starting dialysis</td>
<td>9 (2.8)</td>
</tr>
<tr>
<td><strong>Health care professional</strong></td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>25 (7.7)</td>
</tr>
<tr>
<td>Nurse</td>
<td>38 (11.8)</td>
</tr>
<tr>
<td>Dietician</td>
<td>6 (1.9)</td>
</tr>
<tr>
<td>Social worker</td>
<td>6 (1.9)</td>
</tr>
<tr>
<td>Other health professional</td>
<td>24 (7.4)</td>
</tr>
<tr>
<td><strong>Caregivers</strong></td>
<td>36 (11.1)</td>
</tr>
<tr>
<td><strong>Member of an organization</strong></td>
<td>5 (1.5)</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>28 (8.7)</td>
</tr>
</tbody>
</table>
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
What are the causes and effective treatment(s) of, and ways to prevent, cramping in dialysis patients?

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?

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

Vascular access
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.
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?
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?
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

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

Lianne Barnieh, Kathryn King-Shier, Brenda Hemmelgarn, Andreas Laupacis, Liam Manns, and Braden Manns