Involving patients in research priority setting (using dialysis as an example)

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James Lind Alliance

Priority Setting Partnerships

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

The aim of this is to help ensure that those who fund health research are aware of what matters to both patients and clinicians.

Top 10s

See the top priorities for future research, agreed by patients, carers and health professionals working with Priority Setting Partnerships.

▶ More

The PSPs

Find out more about the areas in which Priority Setting Partnerships have been identifying the uncertainties which really matter.

▶ More

The JLA Guidebook

Read a step-by-step guide to the processes involved in a Priority Setting Partnership. Essential for achieving a useful outcome.

▶ More

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Important things to know about JLA

- Has been going since 2004
- A priority setting exercise that involves patients, carers and clinicians (equal representation throughout)
- Process takes about 8-18 months to complete
- Important players include JLA advisor, Steering group, partners and the wider community
- Goal is to identify top 10 management uncertainties

Main stages of a JLA PSP

- Choose a Steering Committee
- Develop a questionnaire that asks patients, carers and clinicians about management uncertainties
- Combine the responses into a manageable number and choose the top 20-30 to be considered at a workshop
- At the workshop choose the top 10

Steering Committee for Canadian 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
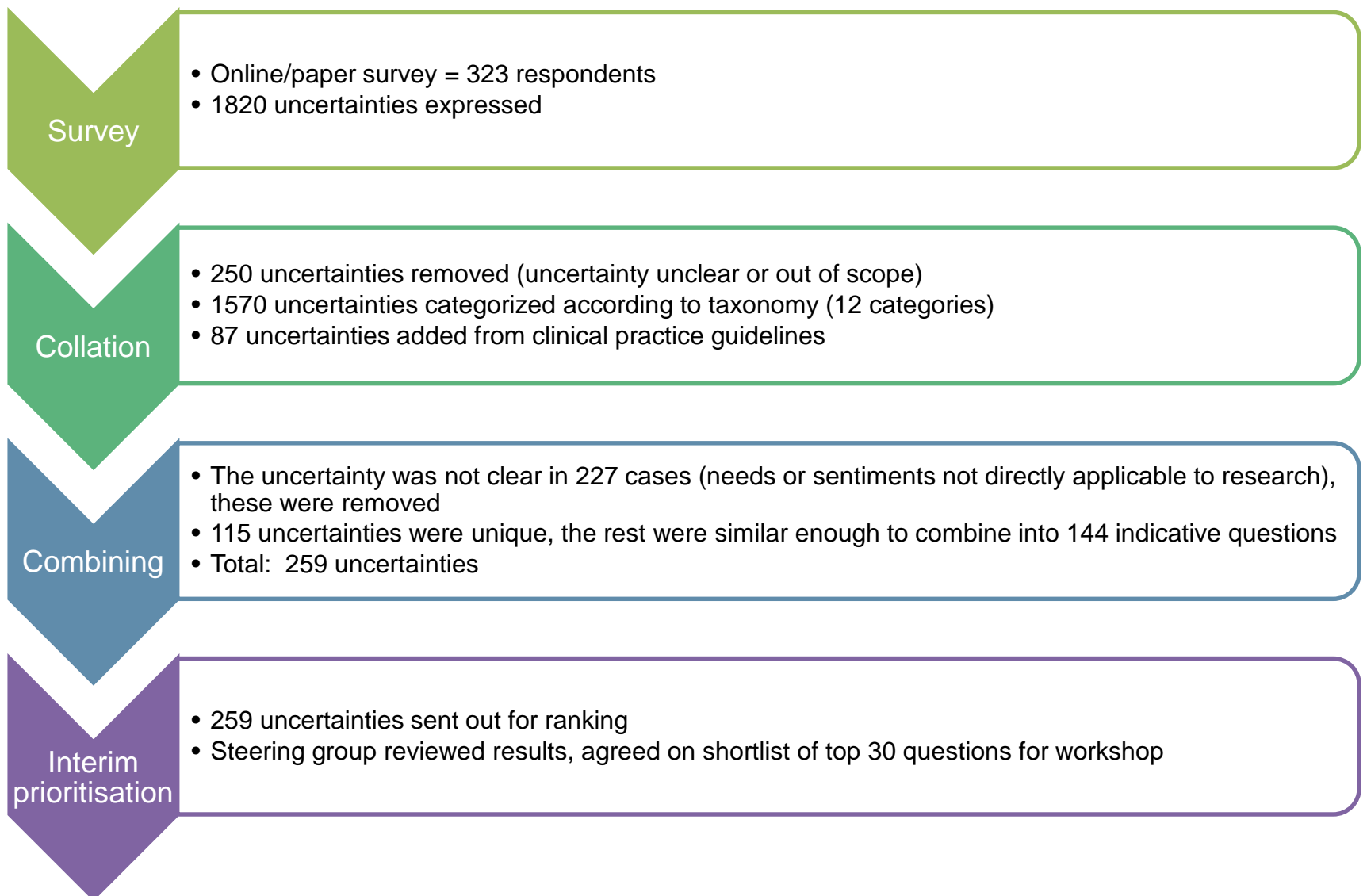
Questions

- Who would you invite as partners?
- How would you collect potential research questions?
- How would you advertise existence of the PSP?

Figure 1. Overall process for establishing 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

Workshop

- Who to invite?

Workshop participants

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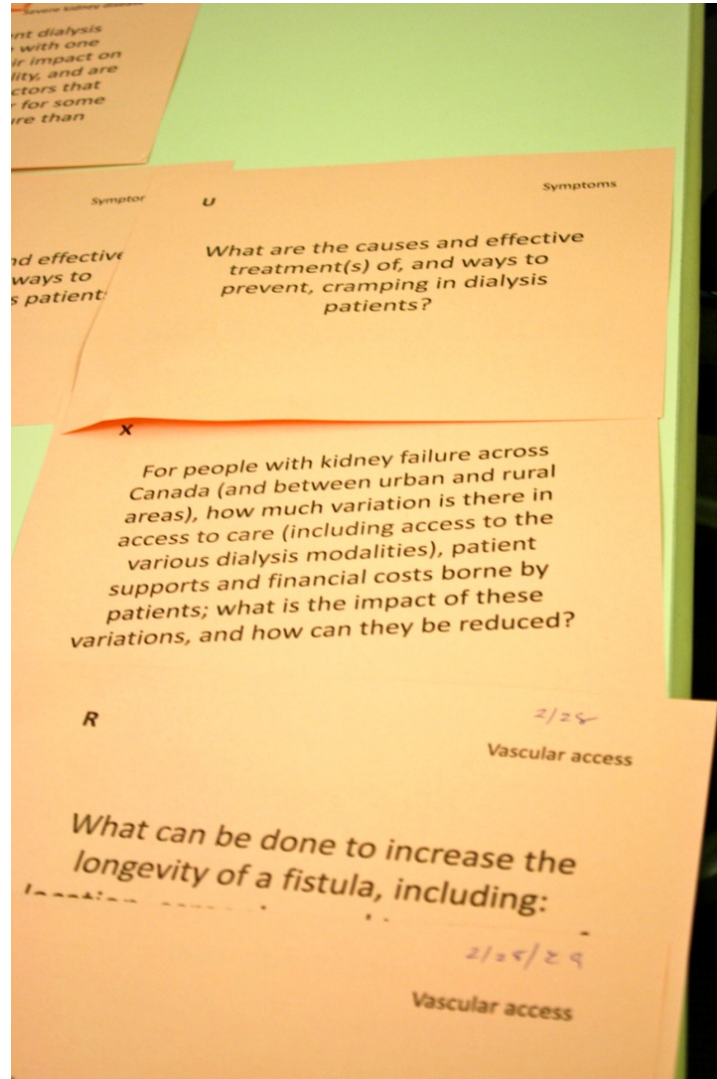- 14 clinicians
- 4 allied health professionals
- 4 facilitators

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
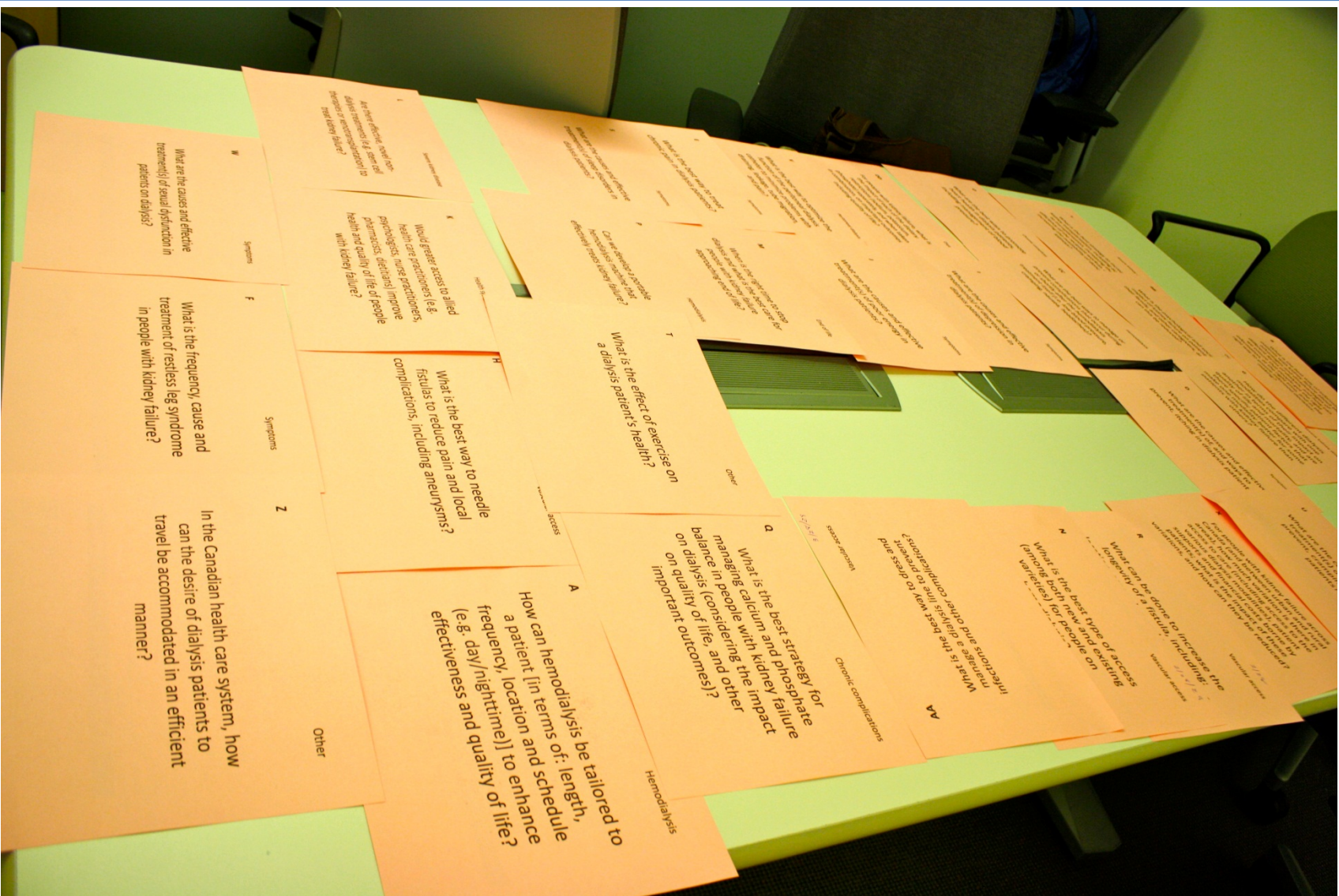
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Workshop format – 2

- 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 respectful
- This is not an exact science – another workshop would likely have 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