Patient involvement in health care and health services research

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St. Michael's
Inspired Care. Inspiring Science.

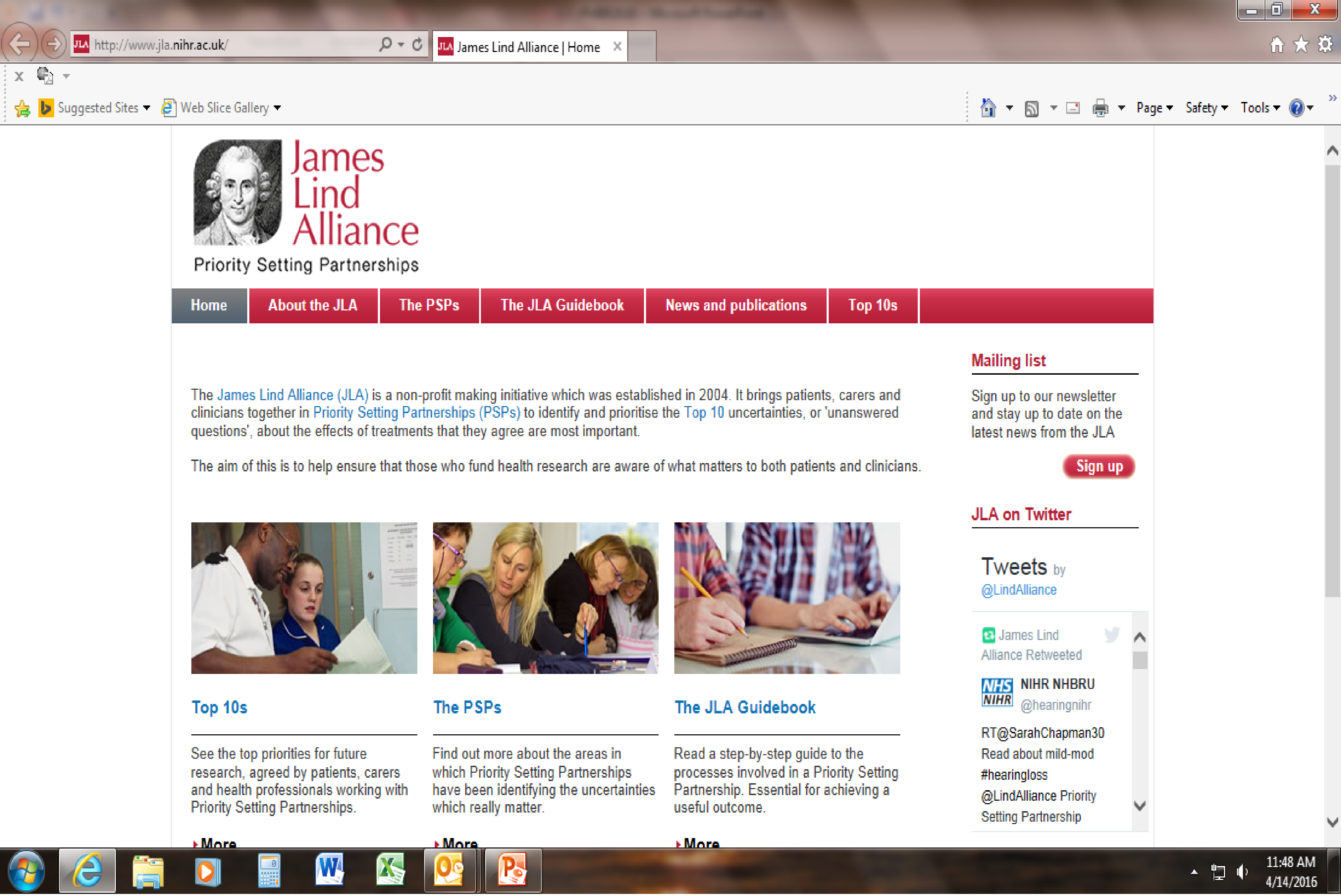
Organization of this talk

- An example of patient partnership in research priority setting
- Four brief patient/caregiver “stories” (from www.facesofhealthcare.ca)
- Some hopeful slides about the future of patient partnership in health care from Vincent Dumez (Centre of Excellence on Partnership with Patients and the Public – U Montreal)
- Some things to think about as you move forward
- A final patient voice

Mike Katz

Why Involve patients in research priority setting?

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



James Lind Alliance

Priority Setting Partnerships

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

Mailing list

Sign up to our newsletter and stay up to date on the latest news from the JLA

JLA on Twitter

Tweets by @LindAlliance

James Lind Alliance Retweeted

NIHR NHBRU @hearingnihr

RT@SarahChapman30 Read about mild-mod #hearingloss @LindAlliance Priority Setting Partnership

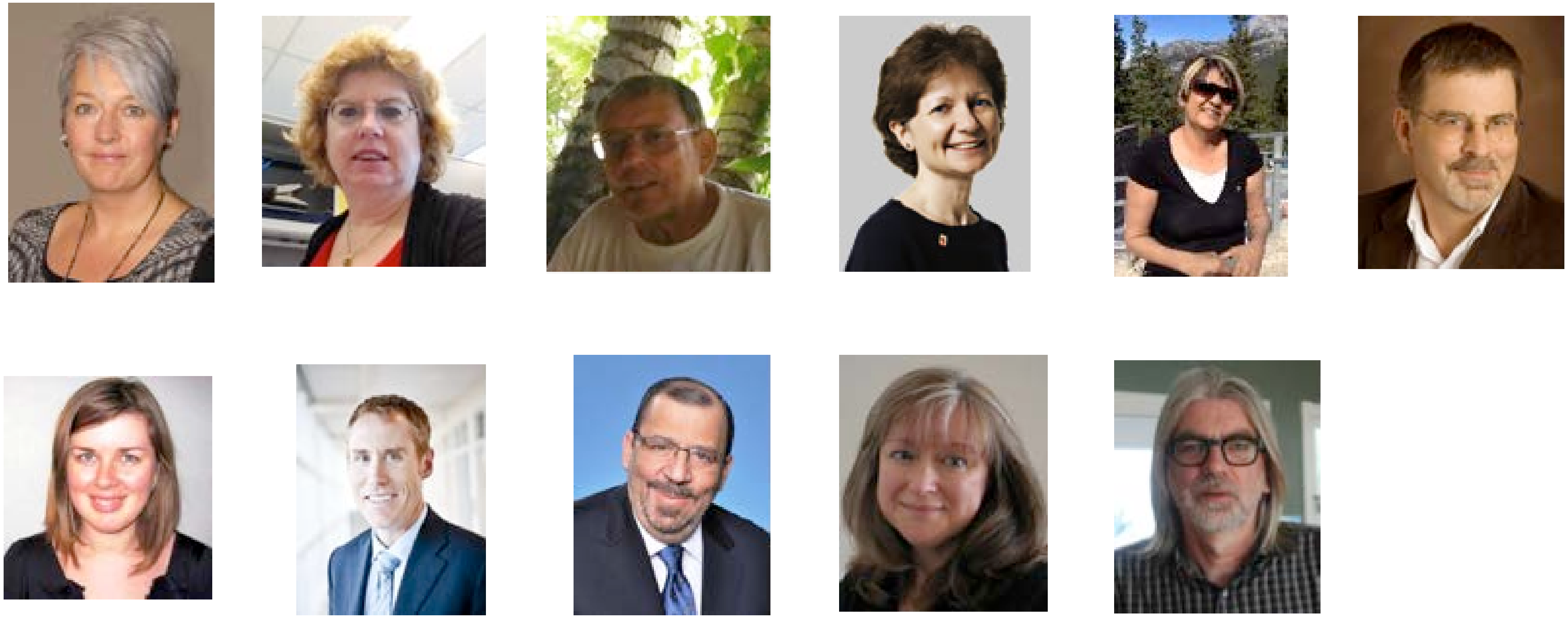
Important things to know about JLA

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

Main stages of a JLA PSP

- Choose a Steering Committee and identify partners
- 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

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

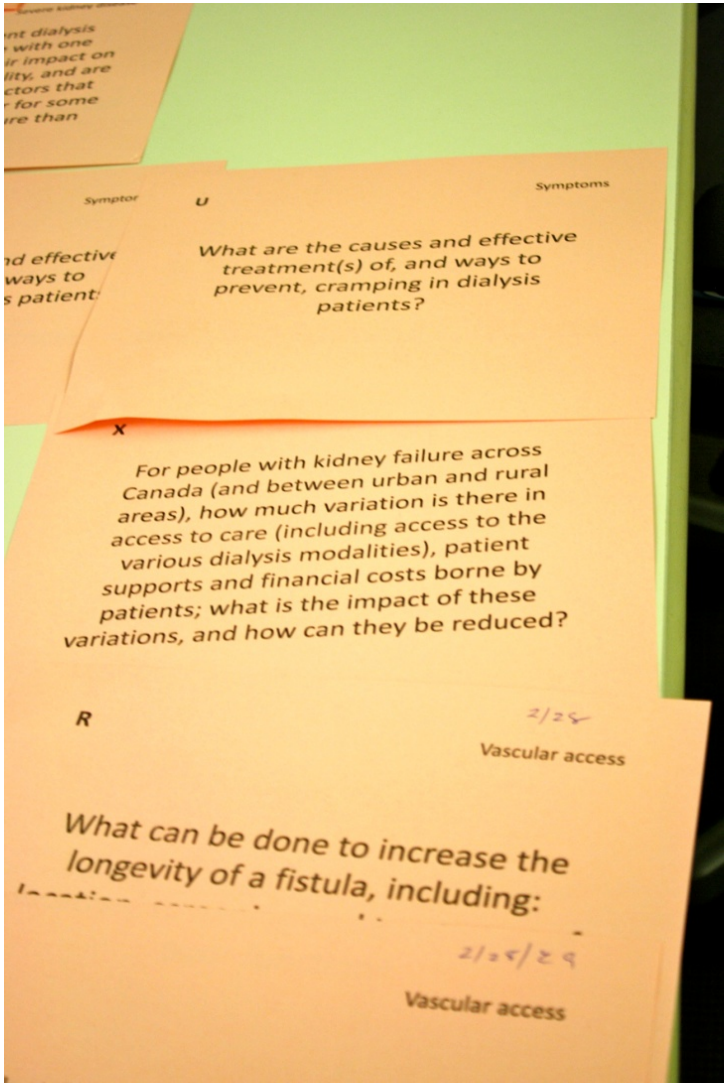
- 259 uncertainties sent out for ranking
- Steering group reviewed results, agreed on shortlist of top 30 questions for workshop

Workshop participants

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

Workshop format

- Each participant ranked the top 30 independently before the meeting
- Using a nominal group technique, meet in 3 small groups sessions and one final large group session to rank the 30, facilitated by a series of cards



U

Symptoms

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

2/28

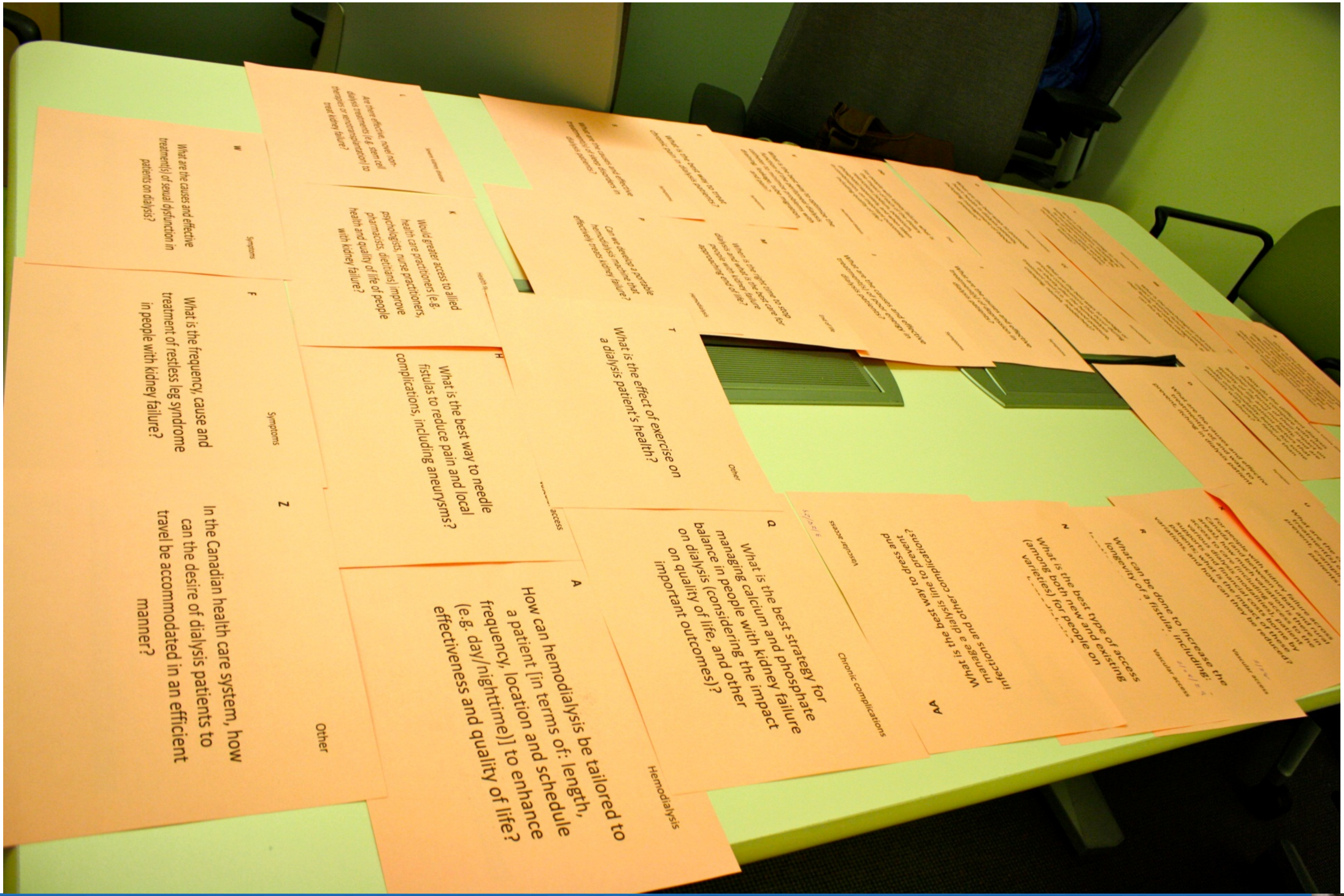
Vascular access

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

2/28/29

Vascular access


What is the best way to optimize the function of the peritoneal dialysis catheter to minimize problems with draining, leakage, tube migration.
What are the causes and effective treatment(s) of poor energy in dialysis patients?
Symptoms
Peritoneal dialysis



W

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

Symptoms

L

Are there effective, novel non-dialysis treatments (e.g. stem cell therapies or xenotransplantation) to treat kidney failure?

F

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

Symptoms

K

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?

What are the causes and effective treatment(s) of sleep disorders in dialysis patients?

What is the best way to treat chronic pain in dialysis patients?

P

Can we develop a portable hemodialysis machine that effectively treats kidney failure?

Hemodialysis

M

When is the right time to stop dialysis and what is the best care for people with kidney failure approaching end of life?

H

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

T

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

Other

Z

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

Other

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

Q

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

Chronic complications

AA

What is the best way to prevent and manage a dialysis line complications? infections

Vascular access

N

What is the best type of access (among both new and existing varieties) for people on

R

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

Vascular access

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?

Vascular access

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

- There are important differences between these priorities and research currently being done
- The different backgrounds of people complemented each other well
- Process respectful (participants carefully chosen)
- It was a lot of work and took time
- It was a good balance of spontaneity and structure
- Older, frail and aboriginal people under-represented

www.facesofhealthcare.ca

"I was so hooked on opiates! My doctor didn't know how to deal with me so he kept prescribing and prescribing. He started giving me Demorol shots every 48 hours. And I was on a Fentanyl patch and swallowing hydromorphs at the same time. The nurses at the hospital started saying 'This isn't right.' So he stopped giving me those injections. But there was no going back. It was like something flipped in my brain. If it wasn't going into my arm I was not happy. I would freak. I would go to the hospital and stomp my feet and they would give me Ativan and all that. Over the years it was a learned behaviour – if I stomped my feet I would get what I wanted. This went on for ten solid years."

"I got all those drugs from the same doctor. He cared about me a lot, but he didn't know how to deal with me. I truly believe that he wanted to help me and just didn't know how. I've been struggling for a long time with anger towards him, but I have let it go. I have accepted that I played a big role in my addiction." …

http://healthydebate.ca/faces-health-care/prescription-opioid-addiction-recovery

"There's a huge range in the quality of hospital care. Here's a suggestion for quality improvement questionnaires. Don't ask about how care was overall. I rated everything as medium. But it wasn't really medium. I had fantastic people for whom this was obviously their life vocation, and other people who I don't know what they were doing there. My nursing care was fantastic and it was crappy. Some of the residents were unbelievably compassionate and careful, and others were just totally oblivious."

"The surgical residents and fellows – oh my gosh! I went back and forth between wanting to give them a slap in the side of the head and feeling sorry for them because they were so busy. My first post-surgical visit with the residents and the fellows – they came whipping in. There were about five of them. I was trying to have a pee. I had the bottle and when they came in I pulled the sheet up. They asked, 'How it's going?' I said, 'Well, I am having a little trouble peeing.'…

http://healthydebate.ca/faces-health-care/cancer-religion-philosophy

"I think the ALS clinic has all the right puzzle pieces in place, but it needs some organization. Every time we would go there it was 'Okay, you'll see this person for 15 minutes.' Then we'd wait an hour and a half and we'd see another person for 10 minutes. Then we'd wait… I have all the patience in the world but if I have ALS - no way. Mom literally had to not drink all day because no one could change her diaper at the hospital, which is a long drive away. That was really tough."

"WHAT I STRUGGLED WITH IS WHY THEY KEPT CALLING US BACK FOR APPOINTMENTS, BECAUSE ALL THAT WAS BEING SAID IS 'YES, THE DISEASE IS PROGRESSING.'"

"The doctor at the clinic was very interested in trials and that's what seemed to come up more often than anything. I think they felt kind of defeated and they wanted to get a new medical trial going, so there was a lot of pressure about trials. It would come up all the time and pretty much sometimes be the focus of the appointment. And I am thinking 'I didn't come all the way here to be asked this question. I get that trials are an important part of medicine, but…'"

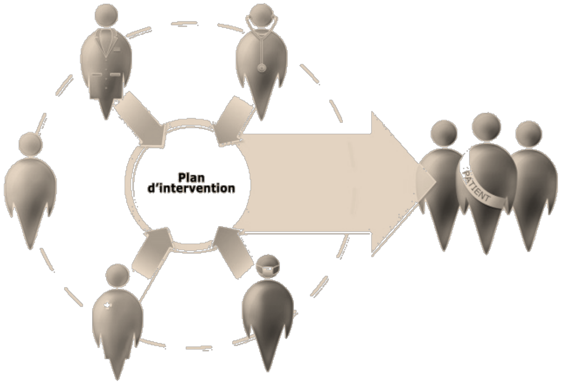
NINA ON HER MOTHER'S ALS CARE

“WHENEVER SHE CAME OVER, THE NURSE SEEMED JUST AS CONCERNED ABOUT ME AND MY DAUGHTER AS ABOUT MY MOM."

"One day she came out of my mom’s bedroom and we were sitting at my dining room table. She took 5 bottles of nail polish out of her bag and lined them up in front of me and said 'Choose a colour.' I kind of looked at her quizzically and she said 'I am going to do your nails for you. You need to take care of yourself so you can be there for your mom.' And she gave me a manicure and painted my nails. It was just phenomenal - I just couldn’t believe that.”

PAT ON BRINGING HER MOTHER HOME TO DIE

THE NEED TO BUILD "WITH" NOT ONLY "FOR" PATIENTS



FREE AND INFORMED DECISION MAKING

RECOGNITION & MOBILISATION OF EXPERIENTIAL-BASED KNOWLEDGE

DEVELOPMENT OF SELF-CARE COMPETENCIES

MEMBER OF HIS/HER OWN CARE TEAM

MOBILIZATION OF ONE'S OWN LIFE PROJECT

PATERNALISM — *CENTERED APPROACH* — *PATIENT PARTNERSHIP*

PROFESSIONAL: INFORM → CONSULT → STIMULATE → CONSTRUCT TOGETHER → SHARED LEADERSHIP

PATIENT: READ → QUESTION → REACT → CONSTRUCT TOGETHER → SHARED LEADERSHIP

ADVOCACY →

ceppp.ca

THE CHANGING FUTURE OF HEALTHCARE

- Challenges to humanizing the future

The patient of today is:

- Overloaded with health information
- Lacking support to understand their choices
- Challenging healthcare professionals with new information/questions
- Unaware of how new healthcare technologies are/will impact their health
- Not involved in the development of healthcare's future

- **The patient of tomorrow is:**

- Recognized as a full actor of care
- Owns their medical information
- Connected (self-monitoring)
- Better informed (social media + online diagnosis)
- Understands the value of evidence-based medicine
- Better decision maker
- Helping to inform a healthcare environment that is ethically and socially responsible

THE CHANGING FUTURE OF HEALTHCARE

- Challenges to humanizing the future

Healthcare professionals of today are:

- Struggling to keep up with evidence-based information
- Lacking support to be better partners with their patients
- Challenged with new questions from their patients
- Being replaced by new diagnostic tools
- Not fully aware of the ethical and social challenges that new technologies may bring.

- **Healthcare professionals of tomorrow are:**
  - Enabled by technology to ‘humanize’ the way they provide care
  - Working in partnership with their patients
  - Returning to the ‘art’ of medicine (not only the technology)
  - Working in ‘communities’ of health
  - Helping to inform a healthcare environment that is ethically and socially responsible

ceppp.ca

- *Together,*

I am better.

CEPPP

Stages of patient partnership

- **Foundations of expertise**: Becoming care partners
- **Mobilizing expertise**: Transmitting experiences to partners
- **Maturity of expertise**: Assuming transformational leadership

From MASS LBP – How we see patients/public

- Polarized, volatile, emotional, uniformed (**Risk management**)

- Caring, reasonable, purposeful, curious (**Resource**)

- Unconvincing reasons not to partner with patients

- Patients are advocates for their particular hobby horse
- Patients can’t be representative of the perspectives of all patients
- We haven’t studied the impact of patient partnership sufficiently

Some other thoughts going forward

- Personality and fit is important
- Patients must realize that “their story” is important, but it isn’t the only thing –perhaps more important is, together, to improve the quality of care going forward
- Some patient stories can cause harm
- Don’t ask patients to represent anyone other than themselves
- Training is needed for clinicians, managers and patients
- Think about the voices that often aren’t heard
- Deliberately try to make yourself a little (but not too) uncomfortable
- Just do it! If everyone is in this for the right reason, together you’ll figure out what is and what isn’t working, and improve as you go

What happens when we are ill is sometimes so unbelievably beautiful. The tenderness that happens within families at that moment of suffering. That awareness of our humanity and our mortality that we keep at a distance most of the time. The kind of intimate, beautiful, sacred conversations that happen in those moments that we would never ever be open to at other times."

"When I was recovering from surgery one of the guys in the bed next to me grew up in a poor part of Toronto. A poor black kid. He'd become very successful in theatre and film and at the time he was working on a Hollywood action movie. Just before he left the hospital, he said he couldn't leave until he had prayed with me. So I thought, 'Okay, he wants me to pray for him.' But he came around, took my hand, took my wife's hand and then he said the most beautiful prayer. He was grateful to God that he had met my wife and I. It wasn't so much the words, but the tactile connection of holding the hands of essentially, a stranger, and both of us having a sense of great connection through our shared vulnerability. Then he said, 'It's been really great to meet you,' and off he went."

http://healthydebate.ca/faces-health-care/cancer-religion-philosophy

“I know this sounds weird, but I am very lucky to be on dialysis, because if I decide that I have had enough, end of life care is really settled. We know how to stop dialysis and we know exactly how to keep somebody comfortable and for them to pass. It’s not considered committing suicide, it’s just considered discontinuing treatment. That’s something that I have held onto this whole time, knowing that if things just get too much, that I have an out.”

“I’ve had some friends who were like you know, ‘F that! What, what are you talking about?’ But most people understand. They know that I’ve really worked hard. This has not been an easy ride. I’ve come home in a walker in my 30s. I think it’s really important to understand that some of the things that we have the capability to do in medicine, we shouldn’t be doing. Just because we can doesn’t mean we should. For example, the doctors are worried the cancer will come back and they're talking about me having a heart transplant. I am going to consider it, but just because you can give me a heart transplant doesn’t mean that it’s right for me.”

KAREN ON LIVING WITH KIDNEY DISEASE

http://healthydebate.ca/faces-health-care/patient-advocacy-karen-nicole