

Supplementary Material - **Setting research priorities for patients on or nearing dialysis**

Appendix 1: Detailed Methods:

The research uncertainties relevant to patients on or nearing dialysis were identified using four key steps¹: identification and invitation of potential partners; collection of research uncertainties through a national survey; refinement and prioritization of uncertainties to assemble a shortlist of the top 30 uncertainties, and a workshop to determine the top 10 research uncertainties. Ethics approval was obtained from the sites that administered the survey in person including St. Michael's Hospital, Toronto, the Conjoint Health Research and Ethics Board, University of Calgary and Capital Health, Halifax, Nova Scotia.

Identification and invitation of potential partners

The priority setting process was initiated in July 2012, with the formation of an 11 person Steering Group including patients, a caregiver, clinicians, an employee of the Kidney Foundation of Canada and a person with experience with the James Lind Alliance (JLA) approach (see www.CANN-NET.ca for a list of members). Potential partner organizations were identified through consultation of peer and Steering Group members' networks. We worked with not-for-profit and research organizations including the Kidney Foundation of Canada, the Interdisciplinary Chronic Disease Collaboration (www.ICDC.ca), and the Canadian Kidney Knowledge Translation and Generation Network (www.CANN-NET.ca). We also notified the Canadian Society of Nephrology, Canadian Association of Nephrology Nurses and Technologists, Renal Pharmacist Network, and the Canadian Association of Nephrology Administrators (the professional societies for Canadian Nephrologists, Nephrology nurses, Nephrology pharmacists, and Nephrology administrators respectively) about the survey, and asked them to encourage

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their members to participate. The Steering Group held bi-weekly conference calls from July 2012 to June 2013 to oversee the process.

Identifying Uncertainties

Survey development and dissemination

A taxonomy of dialysis issues was created by the Steering Group to guide the development and scope of the survey used to identify uncertainties, and to categorize the survey responses (as noted in Table 2). The survey consisted of broad questions about the overall management of severe kidney failure and dialysis including diagnosis, prognosis and treatment issues (See Appendix 2).

Patients, caregivers and clinicians were invited to complete the online survey through communications from the partner organizations (e.g.. the Kidney Foundation of Canada website), social media (Twitter, Kidney Foundation of Canada Facebook page), advertising in newsletters of partner organization(s), and emails to Canadian Society of Nephrology and Canadian Association of Nephrology Nurses and Technologists members. The online survey was open from October 2012 to mid-January, 2013. Because patients on dialysis who are older and of poorer health might be less likely to respond to an electronic survey, 10 Canadian hemodialysis centers, as well as 3 clinics that care for people with severe chronic kidney disease (not yet on dialysis) and those on peritoneal dialysis distributed paper-based surveys.

Uncertainties from clinical practice guidelines

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We also searched the most recent guidelines relevant to the care of patients on dialysis from the most relevant clinical practice guideline developers (Kidney Disease Improving Global Outcomes, National Kidney Foundation/Kidney Disease Outcomes Quality Initiative, and Canadian Society of Nephrology,) to identify guidelines with limited evidence to support the recommendations (i.e. additional research uncertainties), and to identify research recommendations suggested by the guideline developers.

Collation of uncertainties

The uncertainties identified by respondents to the surveys (web and paper-based) and from guidelines were combined. We eliminated uncertainties that were deemed not relevant to adult patients on dialysis (e.g. prevention of kidney failure, management of a patient with a kidney transplant, issues exclusive to pediatric patients), and where the uncertainty was not clear. The remaining uncertainties were then assigned by three Steering Group members to one of the 12 categories within the taxonomy (Appendix 1).

Interim priority setting

Combining uncertainties

For each of the 12 categories in the taxonomy, Steering Group members worked in pairs (a clinician paired with a patient or caregiver) to assign uncertainties from the survey and clinical practice guidelines into similar groups, with the goal of identifying a summary question for each group (for instance, questions about the causes and treatment of itching were combined into a summary question “What is the cause and treatment of itching in dialysis patients?”). Unique questions that could not be grouped were kept separate.

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Ranking exercise

A summary document was then prepared with the summary and unique questions assigned to each of the 12 categories. This document included the frequency each uncertainty was identified in the initial survey, and information about the respondent type (i.e. the number of times the uncertainty was identified by patients, caregivers, and clinicians, and whether it was identified from a clinical practice guideline). The document was then circulated to Steering Group members to facilitate an interim ranking exercise where each member was asked to rank their top 30 uncertainties independently.

Identifying the top 30 uncertainties

The scores from the Steering Group members were combined to rank the 259 uncertainties identified from the process described above. Over the course of 4 Steering Group conference calls, the relative importance and wording of the uncertainties that were most highly ranked were discussed. Participants considered whether there were uncertainties that overlapped and might therefore be grouped further. When combining and/or rewording, care was taken to consider the original submissions to ensure that intent of the source uncertainties was being honoured. Finally, participants considered whether any of the uncertainties had been answered by recent high-quality research, in which case they were excluded. The end product was a shortlist of 30 uncertainties to be considered at the workshop (Appendix 2).

Final priority setting workshop

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Thirty-four people from across Canada participated in the 1-day workshop, including 11 patients, 5 caregivers, 8 physicians, 6 nurses and one social worker, pharmacist, physiotherapist and dietician (see Appendix 3 for a full list of participants). The workshop was facilitated by four individuals (two with extensive experience with the James Lind Alliance approach), and involved a nominal group technique approach and a combination of small and large group exercises¹. The intent was to ensure an informed, structured, purposeful and respectful discussion amongst participants. A consensus approach (with voting when needed) was used to identify the top 10 uncertainties.

Appendix 2: Research Questionnaire

What are the Research Priorities of People on Dialysis, their Care Providers and Clinicians?

You are being invited to share your ideas about the research you think is needed to help improve the treatment and quality of life of people on dialysis. Your responses will be used to identify the top research priorities of patients, care providers and clinicians. The final list will be available for you to see at: <http://www.cann-net.ca>, and will be presented to researchers and organisations that fund research.

This research project focuses on people who are on dialysis, or who will be starting dialysis in the next year. We are also interested in the opinions of care providers (e.g. relatives and friends) and clinicians or health care workers who care for people on dialysis – nurses, social workers, physicians, pharmacists, dialysis technicians and others. If you are not a member of any of these groups, we welcome your interest, but would ask you not to complete this questionnaire.

We hope that you will share your opinions with us by completing this short survey. Your responses will be anonymous because we are not collecting any information that will identify you, such as your name or date of birth. This survey will need to be completed by December 31st, 2012. Data will be kept at the University of Calgary for 10 years, after which it will be destroyed. Participation in this study is voluntary.

The study is funded by the Canadian Institutes of Health Research and supported by The Kidney Foundation of Canada. It is being led by a steering committee of 4 patients, 1 care provider, 2 nephrologists, 2 researchers, a staff member from The Kidney Foundation of Canada and a collaborator from the James Lind Alliance. If you have any questions concerning your rights as a possible participant in this research, please contact: Dr. Andreas Laupacis, Li Ka Shing Knowledge Institute of St. Michael's Hospital, 30 Bond Street, Toronto, Ontario, Canada. M5B 1W8; Phone: 416-864-5780; laupacisa@smh.ca.

Kidney failure and dialysis can affect people's lives in many ways. Please think about your experiences with dialysis, from when you first were told you would need dialysis until now, and the questions you think should be considered for research.

1. What question(s) about the overall management of your kidney failure and dialysis [including questions about diagnosis, prognosis (prediction of how things may develop in your disease), treatment, and anything else] would you like to see answered by research? You can submit as many questions as you like.

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It is easy to overlook or forget about some research questions that are important to you. Therefore, in the next part of this questionnaire, we have provided some prompts to help you think about possible research questions. Please do not repeat any of your previous responses.

2. Are there questions about decisions regarding the way in which kidney failure can be treated (e.g. preparing for transplantation, when or how to initiate dialysis, peritoneal versus hemodialysis, home versus hospital/clinic dialysis) that you would like to see answered by research? You can submit as many as you like.

3. Are there questions about dialysis access options (e.g. dialysis line, fistula, peritoneal dialysis catheter) that you would like to see answered by research? You can submit as many as you like.

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4. Are there questions about treatment (e.g. length of dialysis, medications, and supplements) that you would like to see answered by research? You can submit as many as you like.

5. Are there questions about diet (e.g. fluid intake, dietary restrictions) that you would like to see answered by research? You can submit as many as you like.

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6. Are there questions about symptoms which affect your quality of life (e.g. restless legs, difficulty sleeping, itching, nausea, poor energy, pain, depression, changes in mood, or symptoms during or after hemodialysis) that you would like to see answered by research? You can submit as many as you like.

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7. Are there questions about lifestyle and/or personal issues (e.g. interactions with family and friends, sexuality, ability to travel, work, or

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exercise) that you would like to see answered by research? You can submit as many as you like.

Thanks for answering those questions. We will end with some questions about you.

Which of these best describes you? (check one)

- I am a person with kidney failure on dialysis.
- I am a person with kidney disease who is likely to start dialysis in the next year.
- I am a person with kidney disease, but am not on dialysis and am not likely to start dialysis within the next year. (Note – this questionnaire focuses on dialysis or those who are likely to start dialysis soon.)
- I am a care provider or relative of a person with kidney failure.
- I am a health professional.
- I am a member of an organisation representing people with kidney failure on dialysis. Please name:
- Other – please describe.

If you are a health professional, are you a: (please circle one)

Physician Nurse Social worker Dietician
Pharmacist

Other (please specify):

If you are a patient on dialysis, are you on: (please circle one)

Peritoneal dialysis Hemodialysis

If you are on hemodialysis, are you receiving hemodialysis: (please circle one)

At home In a hospital setting in a satellite / clinic setting

What is your age? (please circle one)

18-29 30-39 40-49 50-59 60-69 70-79
80 +

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What is your gender? (please circle one)

Female Male

What is your ethnic group? (please circle one)

Aboriginal Asian Black Mixed White Other
Prefer not to say

Which part of Canada do you live in? (please circle one)

Atlantic Quebec Ontario Prairies British Columbia
Territories

Thank you for completing this survey!

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Appendix 3: Top Thirty Uncertainties (in random order) identified by the interim priority setting process which were brought to the priority setting workshop (Questions ranked 11 to 15 at the workshop are denoted in brackets)*

1. What are the causes and effective treatment(s) of poor energy in dialysis patients?
2. What are the causes and effective treatment(s) of, and ways to prevent, itching in dialysis patients?
3. 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?
4. What are the causes and effective treatment(s) of depression in dialysis patients?
5. What are the causes and effective treatment(s) of sleep disorders in dialysis patients?
6. How do the different dialysis modalities compare with one another in terms of their impact on quality of life and mortality, and are there specific patient factors that make one modality better for some patients with kidney failure than others?
7. 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)? **(Ranked #13)**
8. What is the best type of access (among both new and existing varieties) for people on hemodialysis?
9. What is the best way of informing patients with kidney failure about the advantages and disadvantages of different forms of dialysis; and how can we ensure that people get the right information, at the right time, and in the right way to ensure informed decision-making?
10. What is the frequency, cause and treatment of restless leg syndrome in people with kidney failure?
11. Can we develop a portable hemodialysis machine that effectively treats kidney failure?

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12. How can communication between patients with kidney failure and health care providers be improved, and does enhanced communication (including providing test results) increase patients' ability to participate in the management of their condition?
13. In the Canadian health care system, how can the desire of dialysis patients to travel be accommodated in an efficient manner?
14. What are the causes and effective treatment(s) of, and ways to prevent, cramping in dialysis patients?
15. 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?
16. What is the effect of exercise on a dialysis patient's health?
17. Are there effective, novel non-dialysis treatments (e.g. stem cell therapies or xenotransplantation) to treat kidney failure?
18. What are the causes and effective treatment(s) of sexual dysfunction in patients on dialysis?
19. What are the best ways to manage or prevent complications that occur during or shortly after the hemodialysis treatment itself (i.e. low blood pressure, cramping, nausea, headaches)?
20. What is the best strategy to increase kidney transplantation; including access to transplantation, increasing the efficiency of the recipient workup, and increasing the availability of donor kidneys?
21. What is the best way to dress and manage a dialysis line to prevent infections and other complications?
22. What is the best way to optimize the function of the peritoneal dialysis catheter to minimize problems with draining, leakage, tube migration, and pain?
23. What is the best way to needle fistulas to reduce pain and local complications, including aneurysms?
24. What can be done to increase the longevity of a fistula, including: location, screening and treatment of poor function? **(Ranked #15)**

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25. When is the right time to stop dialysis, and what is the best care for people with kidney failure approaching end of life?
26. What is the best way to treat chronic pain in dialysis patients? **(Ranked #12)**
27. What are the best ways to promote heart health in dialysis patients, including management of blood pressure?
28. 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? **(Ranked #14)**
29. 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? **(Ranked #11)**
30. What is the psychological and social impact of kidney failure on patients, their family, and other caregivers, and can this be reduced?

* patients, caregivers and clinicians on the steering committee worked together to develop wording for each question that reflected the original uncertainty but was posed in a format that was clear and addressable by researchers

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Appendix 4: Workshop participants:

Participant list:

- Allan Grill, Toronto ON
- Annette Cyr, Halifax, NS
- Beverley Rhodd, Courtice ON
- Bill Putzer, Halton Hills ON
- Braden Manns, Calgary AB
- Brenda Hemmelgarn, Calgary AB
- Brenda Toth, Saskatoon SK
- Chantel Large, Calgary AB
- Charmaine Lok, Toronto ON
- Claire Large, Calgary AB
- Cynthia Bhola, Toronto ON
- David Brooks, Sundridge ON
- Denise Sullivan, St. John's, NL
- Dennis Ricketts, Mississauga ON
- Erika Gabinet, Ajax ON
- Helen Godfrey, Toronto ON
- Huey Ng, Vancouver BC
- Ilan Lenga, Oshawa ON
- John Putzer, Halton Hills ON
- June Martin, Kitchener ON
- Karl Rhodd, Courtice ON
- Kien Dang, Toronto ON
- Lilac Chow, Toronto ON
- Marcel Godfrey, Toronto ON
- Marisa Battistella, Toronto ON
- Mark Benarolia, Kitchener ON
- Mark Cassius Ferguson, Toronto ON
- Mary D'Andrea, Toronto ON
- Michael Gladish, Whitehorse YK
- Michelle Jensen, Halifax NS
- Neesh Pannu, Edmonton AB
- Sarah Thomas, Richmond BC
- Trisha Parsons, Kingston ON
- Valerie Earles St. John's, NL
- Wendy Kerr, Halifax NS

Facilitators:

- Karen Born, Toronto ON
- Katherine Cowan, East Sussex UK
- Sally Crowe, Oxford UK
- Andreas Laupacis, Toronto ON

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References:

1. JLA Method. 2013. (Accessed August 2013, at http://www.lindalliance.org/JLA_Method.asp.)