

SURVEY: Priorities for improving INFORMATION, INTERACTION & INDIVIDUALIZATION for patients on hemodialysis

Thank you for taking the time to complete this survey. Can-SOLVE Triple I is a large, Canadian research study working with patients on hemodialysis (HD) and healthcare providers to find ways to improve the overall care experience for HD patients. Over the past year, we conducted focus groups in multiple cities across Canada to identify patients', caregivers' and healthcare professionals' concerns and possible solutions to improve *information* transfer, *interaction* and communication with the healthcare team and *individualization* of HD care (providing care to best suit your own needs). Our next step is to reach more Canadians and hear from patients, caregivers and healthcare professionals who have experience in HD like you!

On the next few pages, topics and concerns mentioned in our focus groups and interviews are listed. Please rank these by identifying the top 5 priorities in each section that are the most important to improve. At the end of each section, there are open-ended questions where you may write your solutions and ideas to improve HD care.

This survey is anonymous, which means that we will not be able to identify who completed the survey once you have handed it in. Finishing and handing in the survey indicates your willingness to participate in the project.

If you choose to participate, please place the completed survey in the envelope provided and return it to your HD nurse or mail it in the self-addressed stamped envelope provided with the survey.

For your convenience, this survey may also be completed on line at: <http://betterkidneycare.ca>
(Participants' IP addresses cannot be tracked or identified if survey is completed online)

If you have a family member or caregiver that is interested in completing the survey, he/she can complete the survey online at the address above. You can also ask your HD nurse for a paper copy of the survey to take home for him/her to complete.

This study has been approved by the University of Manitoba Health Research Ethics Board.

If you have any questions, please contact:

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INFORMATION:

Read the entire list below. Based on your hemodialysis (HD) experience, **choose up to 5 topics** that you would like to see **improve FOR PATIENTS** in getting **information** in HD. **Rank your choices from 1 to 5** in the boxes on the Right. Please use **only one ranking number for each of your top 5 topics**.

1= Most important, 2, 3, 4, 5= Least Important
(HD = Hemodialysis)

<i>Priority</i>	<i>Rank</i>
Better information (<i>more frequent, clearer, better timing</i>) about the pros and cons of different dialysis modalities (Peritoneal Dialysis, Home HD, In-Centre HD)	
Better information (<i>more frequent, clearer, better timing</i>) about the pros and cons of different HD access types (Central Line, Fistula, Graft)	
<i>More detailed</i> information on how to care for my HD access	
Better information (<i>more detailed/more frequent</i>) about transplant status	
<i>More</i> information about what to expect on the first day of HD	
<i>More</i> information about health risks and other conditions associated with HD	
<i>More</i> information about what can go “wrong” during HD	
<i>More</i> information about the HD machine	
<i>More</i> information about how to manage HD symptoms	
Better information (<i>more and better timing</i>) about nutrition and diet	
<i>More</i> information on the role of exercise in HD and exercise programs	
<i>More</i> information about medications and their side effects from prescribers in HD	
<i>More</i> information on social programs for people on HD	
<i>More</i> information about traveling while on HD	
<i>More</i> information about financial support and managing financial issues	
<i>Different format</i> or way of receiving any information in HD	
Timing, frequency and amount of information being received should be <i>individualized</i> (specific to each patient)	
<i>More</i> information on research and advances in kidney health	

1. Please comment on any additional ideas you have regarding INFORMATION in HD that was not mentioned on the previous page:

2. For your top 3 priorities with INFORMATION in HD that you ranked on the previous page, please tell us what you think could improve each:

Priority #1 from previous page _____

Priority #2 from previous page _____

Priority #3 from previous page _____

INTERACTION

Read the entire list below. Based on your hemodialysis (HD) experience, choose **up to 5** priorities that you would like to see improve **FOR PATIENTS** in **interacting with healthcare providers** in HD. **Rank your choices from 1 to 5** in the boxes on the Right. Please use **only one ranking number for each of your top 5 topics**.

1= Most important, 2, 3, 4, 5= Least Important
(HD = Hemodialysis)

<i>Priority</i>	<i>Rank</i>
Patients have enough time with or the ability to access the rounding nephrologist when needed <i>(rounding nephrologist is the kidney doctor who visits you while you are on HD)</i>	
HD nurses have specialized experience/training	
Patients have enough time with or the ability to access nursing/allied health staff when needed <i>(ex. dietitian, pharmacist, physiotherapist, social worker)</i>	
Improve continuity of care by having same staff for patients during each HD session	
Have HD nurses who are familiar with patients' health details and history	
Fewer differences in HD healthcare providers' opinions for patient care plans	
Improved communication between patient and/or healthcare providers <i>(within HD unit, but also with specialists, transplant and family physicians)</i>	
It's frustrating for patients when they are told to see a family physician about health concerns they bring up in HD	
Understanding which physician is most appropriate to see to deal with patient concerns	
Sometimes it seems that no one working in HD cares or is interested in patients' issues	
Physicians have access to all the information they need to take care of patients in the HD unit	
Information about a patient's care is complete and available in the HDs chart	
Patients have access to HD unit managers and the managers seem connected to the unit	
Allied health staff <i>(ex. dietitian, pharmacist, physiotherapist, social worker)</i> have specialized experience/training in HD	
The way the HD unit is organized and run helps patients and healthcare providers get the information they need to optimize care	
Sometimes patients may not want to actively participate in their care	

1. Please comment on any additional ideas you have regarding INTERACTION with healthcare providers in HD that were not mentioned on the previous page:

2. For your top 3 priorities with INTERACTION in HD that you ranked on the previous page, please tell us what you think could improve each:

Priority #1 from previous page _____

Priority #2 from previous page _____

Priority #3 from previous page _____

INDIVIDUALIZATION

Read the entire list below. Based on your hemodialysis (HD) experience, choose **up to 5 priorities** that you would like to see improve **FOR PATIENTS** in their **individualization of care** (providing care to best suit each individual) in HD. **Rank your choices from 1 to 5** in the boxes on the Right. Please use **only one ranking number for each of your top 5 topics**.

1 = most important, 2, 3, 4, 5= least important

(HD= Hemodialysis)

<i>Priority</i>	<i>Rank</i>
HD machine and chair/bed set-up and positioning should be individualized <i>(ex. change the side of machine depending on the side that fistula or line is on)</i>	
Availability of several HD chair/bed options in each unit	
Availability of flexible, reliable and affordable transportation to/from HD	
Access to exercise/biking programs specifically designed for HD	
Access to social programs for people on HD	
Access to employment aid and resources for people on HD	
Patients' care plan considers finances and there is access to resources for people with low income	
Privacy in the HD unit to allow for comfortable discussions of sensitive or private issues	
More notice when HD schedule is changed	
More flexibility to change HD spots/schedule	
More information about self-care and opportunities to do self-care in HD <i>(ex. learn to self-needle fistula if patient is interested)</i>	

1. Please comment on any additional ideas you have regarding INDIVIDUALIZATION of HD care that were not mentioned on the previous page:

2. For your top 3 priorities with INDIVIDUALIZATION in HD that you ranked on the previous page, please tell us what you think could improve each:

Priority #1 from previous page _____

Priority #2 from previous page _____

Priority #3 from previous page _____

Any other comments about HD care? (Use back space for additional comments)

Thank you for providing your opinions and ideas. We will end with some questions about you. Please mark the box beside the best answer for each question:

1. Which of these best describes you?

- I am a person with kidney disease
- I am a care provider or family member of a person with kidney disease
- I am a healthcare professional:
 - Physician
 - Nurse
 - Social worker
 - Dietician
 - Pharmacist
 - Other (please specify) _____

2. How long have you been on hemodialysis?

- Less than 3 months
- 3-6 months
- 6 months – 1 year
- 1 year - 3 years
- 3 years - 5 years
- More than 5 years
- Don't know
- Not applicable

3. What is your age?

- 18-34
- 35-49
- 50-64
- 65-79
- 80 +
- Prefer not to answer

4. What is your gender?

- Woman
- Man
- Gender fluid, non-binary and/or Two-Spirit
- Prefer not to answer

5. What is your ethnic group?

- White
- Indigenous (First Nations, Inuit, Métis)
- East Asian
- South Asian
- African-Canadian/Caribbean Canadian
- Other
- Prefer not to answer

6. Which part of Canada do you live in?

- Atlantic
- Quebec
- Ontario
- Prairies (Alberta, Saskatchewan, Manitoba)
- British Columbia
- Territories

7. I frequently (at least daily) use the Internet and technologies such as cell phones, tablets etc.

- Yes
- No
- Not Sure
- Prefer not to say

8. I use social media sites (e.g. Twitter, Facebook, Instagram, Snapchat)

- Daily
- 1-3 times per week
- 1-3 times per month
- Rarely (< 1 time per month)
- Never
- Prefer not to say
- Not Sure

