



# The Burden of Out-of-Pocket Costs for Canadians with **Kidney Failure**

2018 REPORT

# The Issue

Canadians living with kidney failure face significant financial challenges as a result of dialysis treatment. Starting dialysis often results in a decrease of income at the same time that out-of-pocket costs increase, such as those for transportation to treatment and medication. Government coverage and financial support for people on dialysis varies, resulting in inequalities across jurisdictions.

The Kidney Foundation of Canada (KFOC) and the Canadian Association of Nephrology Social Workers (CANSW) partnered to administer a survey of Canadians on dialysis and found that:

- **Many Canadians report a drop in household income as a result of starting dialysis.**

Nearly 50% of respondents indicated that their annual household income decreased since starting dialysis. Of those who said their income decreased, two-thirds said it had decreased by 40% or more.

- **The proportion of patients on dialysis who are below Canada's Low Income Cut-Off (LICO)<sup>1</sup> is much higher than the general population.**

Of all respondents, 41% are below the Canadian Low Income Cut-Off (LICO), compared to 8-14% of the general Canadian population.

- **Out-of-pocket costs related to dialysis treatment are a significant burden.**

The reported annual average out-of-pocket costs related to dialysis treatment ranged from \$1,400 to \$2,500 (depending on treatment modality).<sup>2</sup> This is significant when you consider that:

- 55% of respondents reported an annual household income of less than \$35,000; and
- 23% of respondents reported an annual household income of less than \$20,000.

The average out-of-pocket costs represent a considerable portion of total annual household income (up to 12.5% for those reporting an annual household income of \$20,000). The burden of these out-of-pocket costs is substantial. Of all respondents, 21% reported going without food or basic necessities in the last six months due to the financial burden of dialysis treatment (see the annex for more details).

There is no cure for kidney disease. Not all Canadians on dialysis are eligible for a transplant. Of the people on dialysis, only 16% are on the waiting list for a transplant<sup>i</sup>. People not eligible for a transplant will bear the burden of the costs associated with dialysis for the rest of their lives.

<sup>1</sup> Statistics Canada defines Low Income Cut-Offs (LICO) as income thresholds below which a family will likely devote a larger share of its income on the necessities of food, shelter and clothing than the average family. The approach is essentially to estimate an income threshold at which families are expected to spend 20 percentage points more than the average family on food, shelter and clothing.

<sup>2</sup> Non-response was interpreted as having a \$0 value for many of the sections, and therefore it is likely that the results here systematically underestimate true costs, especially monthly out-of-pocket costs.

# Recommendations

The significant financial hardships associated with dialysis are evident. The Kidney Foundation of Canada and the Canadian Association of Nephrology Social Workers make the following recommendations to all levels of government to address the financial burden of kidney failure.

## TRANSPORTATION

### 1 Subsidize transportation costs and expand access to travel grants, particularly for people in rural areas.

The latest figures show that 75% of patients on dialysis receive treatment in-centre (at hospitals or community satellites units).<sup>ii</sup> Respondents on in-centre hemodialysis reported an average monthly out-of-pocket cost of \$155 (\$1,858 per year), \$57 of which is spent on travel and parking each month (\$684 per year).<sup>3</sup>

It is important to recognize that these are average values, and a certain percentage of respondents indicated costs far above the average. Approximately 25% of respondents on in-centre hemodialysis have monthly costs that are greater than \$250 (\$3,000 per year). This variability is also demonstrated when data for monthly dialysis costs for people on in-centre hemodialysis is analyzed by time spent travelling to and from their hemodialysis unit. Those travelling one to two hours had an average cost of \$200 per month (\$2,400 per year) and those travelling for longer than three hours had monthly out-of-pockets costs of \$272 (\$3,264 per year).

## MEDICATION

### 2 Minimize disparities in accessing medications for people with kidney disease and develop mechanisms to offset costs equitably across jurisdictions.

The cost of medication is a barrier to optimal health. Nineteen percent of respondents said they have missed purchasing medication in the last six months due to a financial barrier. This proportion increased to 27% when looking only at respondents who fall below LICO. The average reported cost of prescription drugs was \$756 annually and increased to \$1,083 with the inclusion of non-prescription medications.

Saskatchewan provides complete drug coverage to people on dialysis through its Saskatchewan Aids to Independent Living (SAIL) program. We call on other provinces to follow this example, recognizing that those living with kidney failure tend to be part of a low-income and high-cost population.

<sup>3</sup> Non-response was interpreted as having a \$0 value for many of the sections, and therefore it is likely that the results here systematically underestimate true costs, especially monthly out-of-pocket costs.

## ADEQUATE SUPPORT FOR HOME DIALYSIS

### **3 Provide adequate support for home dialysis through reimbursement of utility costs and consideration of the financial and health literacy of patients when operationalizing “home first” policies.**

#### **Reimburse utility costs of home dialysis**

There is an increasing trend of provincial renal programs promoting “home first” policies that aim to maximize the proportion of people on home dialysis therapies. Home therapies have been shown to be of similar efficacy and safety as in-centre dialysis for people who are eligible for both modalities; however the cost to the health care system for home therapies is significantly less. The cost-shifting associated with home hemodialysis means that it is the most costly treatment in terms of out-of-pocket patient costs. Respondents on home hemodialysis indicated that their average out-of-pocket cost for electricity and water for their home hemodialysis machine is \$1,152 annually.

In August 2015, Manitoba became the first province in Canada to offer a Home Hemodialysis Utility Reimbursement Program. Ontario introduced a similar program this year. We recommend that all other provinces follow these examples and expand on them to reimburse all travel and accommodation costs associated with the extensive training required for home-based therapies. Upfront coverage of the out-of-pocket costs associated with training and periodic utility reimbursement for home-based therapies will still result in net savings for the health care system.

#### **Consider financial and health literacy to increase access to home-based therapies**

Twenty-two per cent of patients on home hemodialysis are below the LICO, compared with 47% and 41% on in-centre hemodialysis and peritoneal dialysis, respectively. Income is often a surrogate marker for health literacy, and it is possible that those with a greater income have greater health literacy and are more confident in choosing an independent dialysis treatment. It is also possible that only those with higher socioeconomic status have the financial and social support to embark on the longer training time required for home hemodialysis, have a stable home environment that is suitable for home hemodialysis, and are not dissuaded by the higher utility costs that some patients must bear. The financial and health literacy status of patients should be considered when operationalizing policies such as “home first” that aim to maximize the proportion of patients on home dialysis therapies.

Those undergoing in-centre hemodialysis had the highest proportion of respondents below the LICO (47%). This is also the group with the highest out-of-pocket costs (if utilities associated with home hemodialysis are reimbursed). There is an obvious need here for greater financial support to allow lower-income individuals to access home-based therapies, thus reducing the burden of transportation costs to treatment.

# Putting it into Perspective

During the past 10 years, the number of Canadians living with end stage kidney disease increased by 36%. While the preferred treatment is kidney transplantation, the majority of patients are treated with dialysis therapy, due to both the stagnant supply of organs as well as co-existing medical conditions contraindicating transplantation for a large portion of patients. The escalation in the number of Canadians with kidney failure treated with dialysis therapy has significant public health implications given the excess morbidity and striking reduction in quality of life, mortality of nearly 20% annually,<sup>iii</sup> and the high cost of therapy to the health care system of \$30,000-100,000 per patient per year.<sup>iv</sup>

## Other Considerations - Transplant

Transplantation is considered the optimal treatment modality for most patients with end-stage renal disease. While financial barriers slowed or stopped the transplant work up process in a small proportion of patients, it remains an issue as approximately 40% of patients stated that financial barriers were a significant burden to their workup. Further research is needed to determine if the financial impact of the transplant work-up process limits access to transplantation.

## Conclusion

Canadians with kidney failure and their families face significant out-of-pocket costs. This burden is further compounded by the loss of income that is often associated with starting dialysis. It is important to note that poverty is a determinant of health. This means that patients and their families that live in poverty may not be able to achieve optimal management of their medical issues. There are gaps and inconsistencies in support for people on dialysis across the country. For these reasons, The Kidney Foundation of Canada is calling on governments to act on the above recommendations to address the financial burden of kidney failure experienced by Canadians and their families.

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### Sources

i CORR Annual Statistics 2017 and Statistics on Organ Replacement in Canada: Dialysis, Transplantation and Donation, 2007 to 2016, <https://www.cihi.ca/en/corr-annual-statistics-2007-to-2016>.

ii CORR Annual Statistics 2017 and Statistics on Organ Replacement in Canada: Dialysis, Transplantation and Donation, 2007 to 2016, <https://www.cihi.ca/en/corr-annual-statistics-2007-to-2016>.

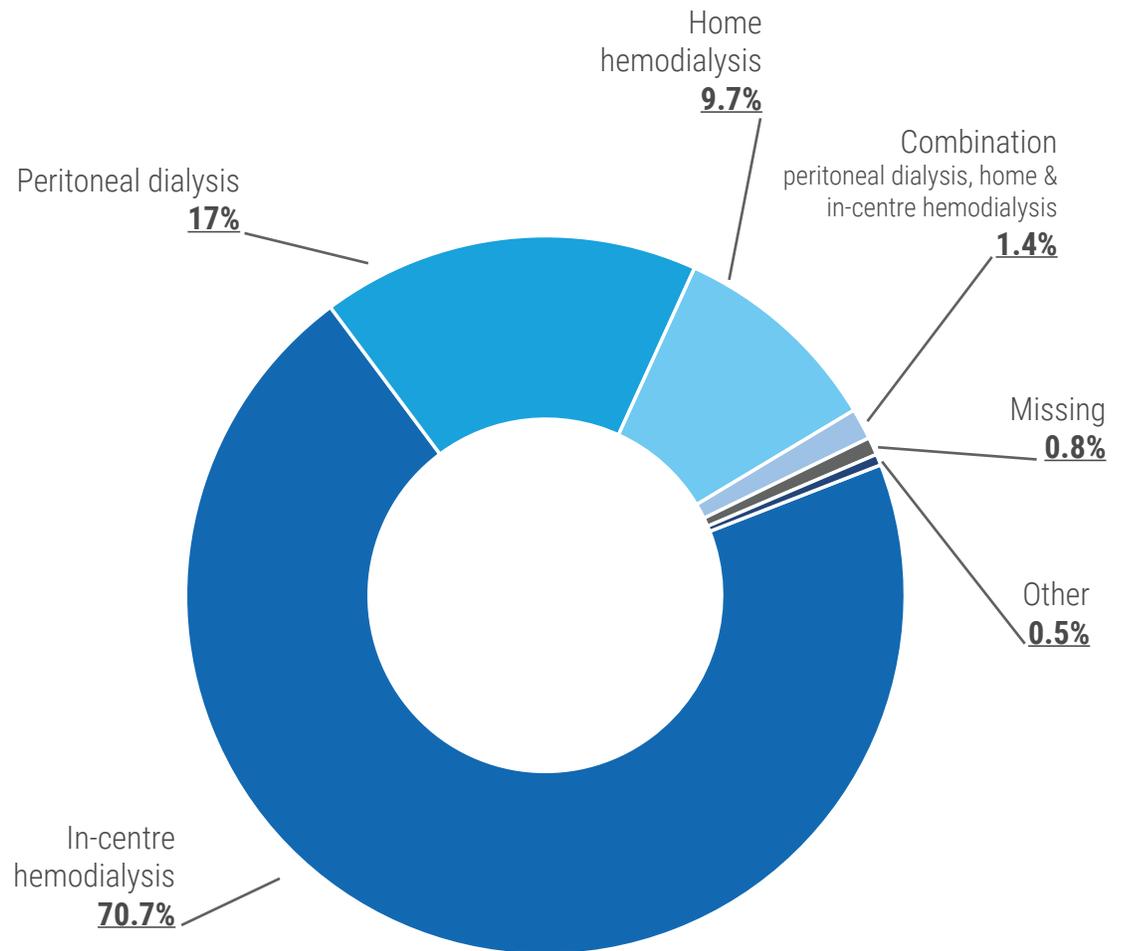
iii CORR Annual Statistics 2017 and Statistics on Organ Replacement in Canada: Dialysis, Transplantation and Donation, 2007 to 2016, <https://www.cihi.ca/en/corr-annual-statistics-2007-to-2016>.

iv Klarenbach, S. W. et al. *Nat. Rev. Nephrol.* advance online publication 26 August 2014; doi:10.1038/nrneph.2014.145, <https://www.nature.com/articles/nrneph.2014.145>, March 15, 2018

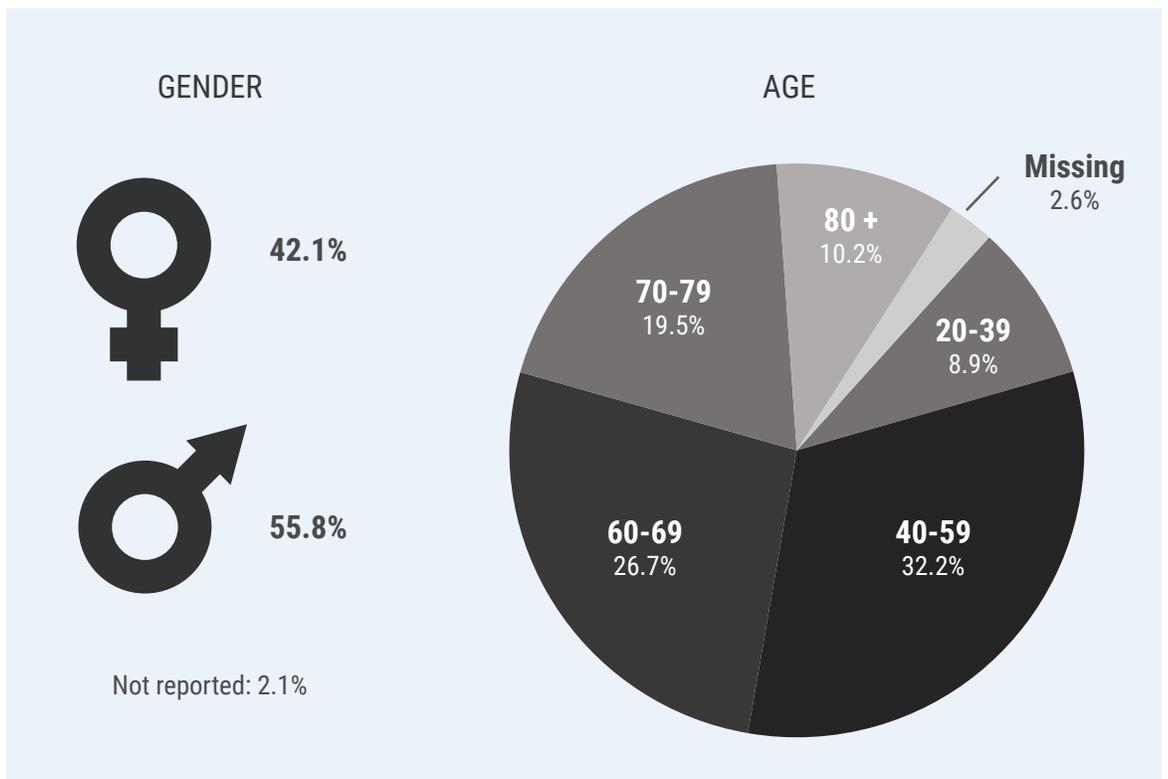
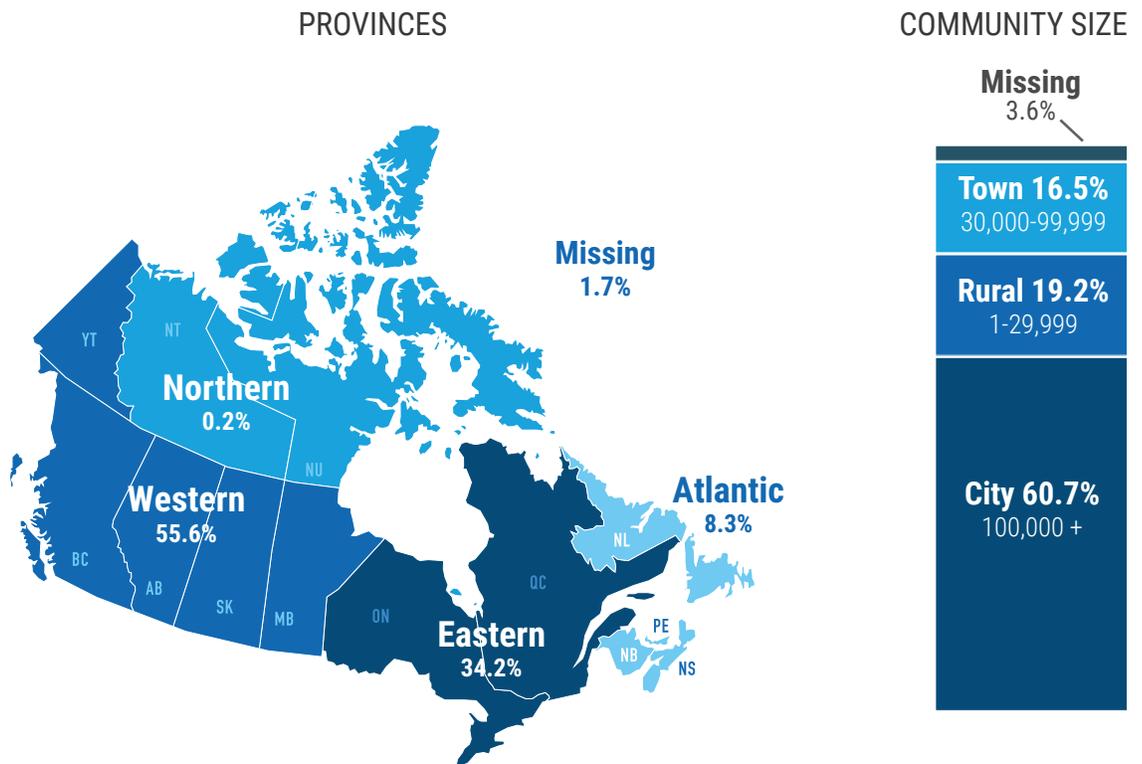
## Annex

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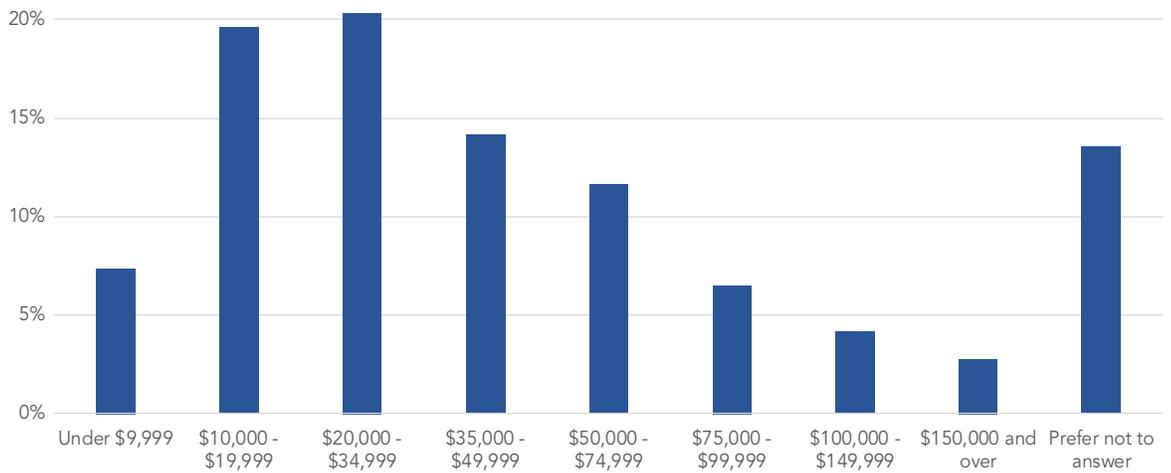
### 1. Current dialysis treatment of respondents



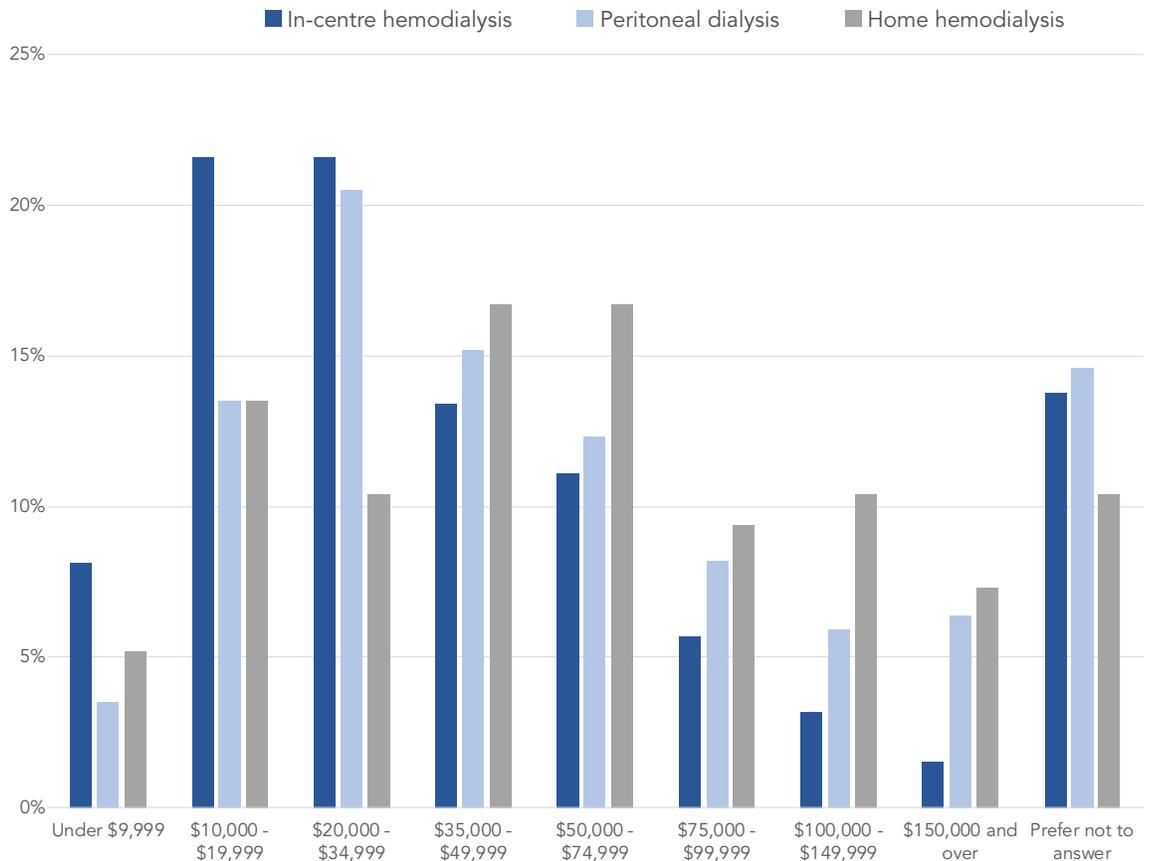
## 2. Socio-demographics of respondents



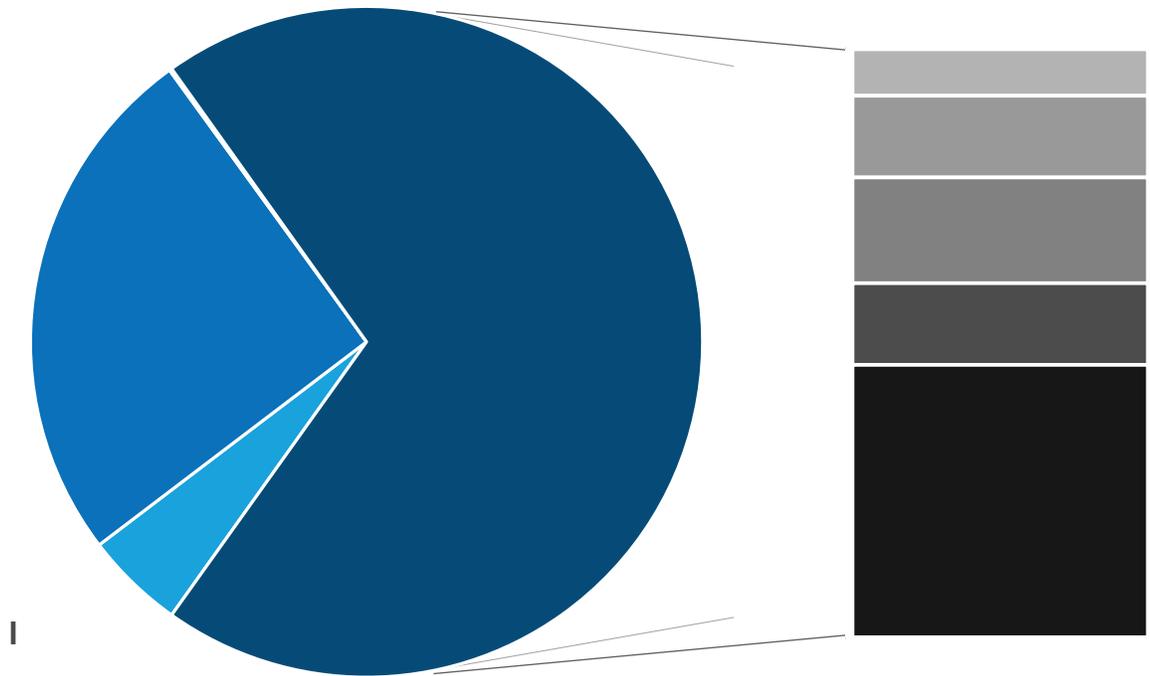
### 3. Annual household income for respondents



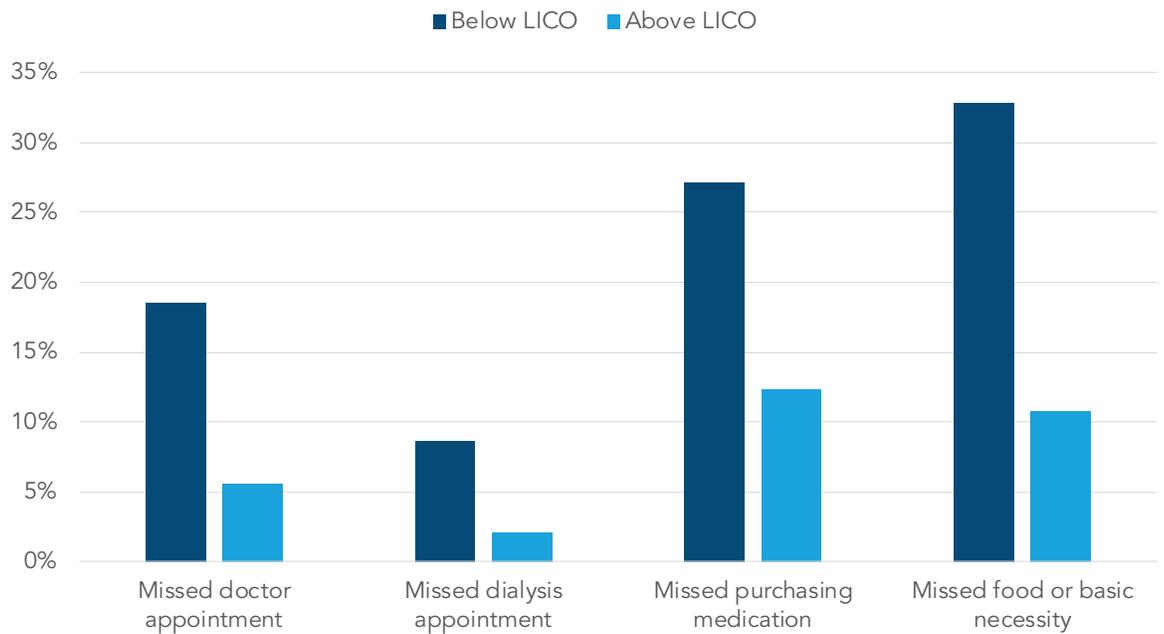
### 4. Comparison of annual household income for respondents for in-centre hemodialysis, peritoneal dialysis and home hemodialysis



## 5. Annual household income change since starting dialysis



## 6. Proportion of respondents who missed the following in the last six months due to financial barrier



## **Acknowledgments**

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