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The Nanos Survey on Drug Affordability is Flawed. Here's Why.

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Background

Last month, with colleagues we published the largest study to date on problems of prescription drug affordability reported by Canadians.[1] The study estimated that 8.2% of Canadians who received one or more prescriptions—or around 1.69 million people across the country—could not afford one or more of their prescriptions over the past 12 months. Further, we estimated that nearly 1 million Canadians reported trading off drug expenditures with other household necessities, including food, heat, and housing.

In the wake of our release, we have received many questions from researchers and journalists about the difference between our findings and the results of a survey published by Nanos Research late last year. This survey was commissioned by two industry trade groups: the Canadian Life and Health Insurance Association, which represents private for-profit insurance companies, and Innovative Medicines Canada, which represents the manufacturers of patented medicines. The key result of the Nanos survey is captured in their lead release headline: "Fewer than one per cent of Canadians who received a prescription in the past six months say cost is a contributor to non-adherence to prescription medicines".[2]

The difference between 8.2% and <1% is clearly worth investigating and has important implications for the policy initiatives one might think are worth undertaking. To start, it is worth pointing out that these two pieces do not exist in a vacuum. A number of previous studies conducted by various organizations have been done on issues of drug affordability in Canada in recent years, including Statistics Canada and the Commonwealth Fund.[3–6] These prior results range between 5.1% and 9.6%. So even taking it at face value, the rate of <1% from the Nanos survey is out of line with similar studies.

To understand why these differences arose, we need to explore the manner in which the surveys were conducted and the ways in which the questions were developed and asked. Below we detail the differences in the approach taken by the two surveys.

Conduct of the surveys

The underlying data source for a survey is important to understanding its potential strengths and weaknesses. What matters is whether or not the people who answer—the sample—are representative of the overall Canadian population. The three most important components of this are (1) how people were included, (2) how many people participated, and (3) who responded when they were contacted.

How people were included

Both surveys contacted people using reasonably similar methods. Our results came from a module of the Canadian Community Health Survey (CCHS), which is conducted every year by Statistics Canada. Both the CCHS and the Nanos survey rely on a telephone survey of Canadians, conducted in both English and French. The results in both are then weighted by various charac-

teristics, such as age, sex, and province, to try and make them better match the known demographics of the Canadian population from the census. While Statistics Canada included individuals 12 years of age and older, Nanos focused on those aged 18 and above.

How many people participated

The sample size of a survey matters a great deal: the larger the number of people contacted, the more precise the estimates are going to be. Comparatively, our sample size was significantly larger than the Nanos survey: we based our results on 28,091 respondents, whereas Nanos contacted 4,445. This means our sample size was more than 6 times larger.

What percentage responded to the survey

When one looks at who responded, there is also a dramatic difference in the response rates between the two surveys. For ours, 62% of the roughly 45,000 people who were contacted agreed to answer the questions. In contrast, the response rate to the Nanos survey was 8%—meaning only 1 in every 12 of the roughly 55,000 people they contacted agreed to answer. For the most part, a study with an 8% response rate would not be publishable in the academic world. This is because readers should be concerned that these individuals differed in a systematic way from those who did not respond, which could skew the estimates of important variables.

Summary of survey conduct

Taken together, how many people participated and the response rates are key differences between the two surveys, with the Nanos survey having far fewer respondents and a far lower response rate. Where this becomes critical is in how many people actually form the basis of the drug affordability estimates in both surveys. Our estimate of 8.2% is based on responses from approximately 1,500 Canadians. The Nanos result is based on just 14 individuals who reported that a drug was too expensive for them to afford. There is no way to

tell if this would have changed, and by how much, had their response rate been higher, but we feel that it merits serious concern.

The way the questions were developed

When designing a survey, it is vital to know that your questions are being interpreted correctly by your respondents, otherwise you might not be measuring what you intend to measure. Our team worked closely with experts at Statistics Canada to select and pilot test each of our questions. The main structure of the questions was determined by drawing on extensive prior research that has been done on this topic both in Canada and internationally to ensure we used strong questions. We then engaged in in-depth pilot interviews with participants in both English and in French to ensure the questions were clear and respondents understood the questions the way we intended. We revised the survey in response to all the issues that arose during qualitative testing to ensure the responses reflected what we intended to study.

In contrast, the questions used in the Nanos survey were developed specifically for this particular survey. They were tested by collecting 100 standard responses, following which no changes were made to the survey questions. Further, the questions were not tested through an in-depth process with respondents, which will lead to concerns below when we discuss how the questions were asked.

The way in which questions were asked

How the questions are asked and how respondents make their way through the survey is critically important to the estimates one derives. To start, it is worth comparing how respondents flowed through the two surveys:

Questions on the Canadian Community Health Survey

In the survey we used, every individual was given the following questions to respond to:

> *During the last 12 months, was there a time when you did not fill or collect a prescription for your medicine, or you skipped doses of your medicine because of the cost?*

> *In the last 12 months, was there a time when you reduced the dosage of your medication or delayed filling your prescription, because of the cost?*

If a respondent indicated for the first question that they did not receive a prescription in the past year—identifying themselves as people for whom prescription affordability problems were not possible—they skipped Question 2. Otherwise, each person was asked both questions, specifically asking whether they had experienced one or more of the generally accepted forms of drug affordability problems.

The Nanos survey question flow

In contrast to our questions that were presented to all individuals, the Nanos survey required individuals to answer several questions before being able to report problems with drug affordability. As a consequence, the vast majority of respondents did not get to answer the question about affordability problems. To understand why this was the case, it is helpful to work through their survey question-by-question, starting with the first question:

Nanos question 1

> *In the past six months, has anyone in your household, including children, been given a prescription, either new or for a refill for a medication?*

Individuals only proceed in the survey if they answered 'Yes' to this question. This is reasonable, and as described above, something that we also did in

our survey flow to reduce asking people unnecessary questions.

However, there are two important issues with the wording of this question:

1. First, the timeframe asked about is only half the length of the timeframe in our study (6 months versus 12 months). Our question above asks about a one-year timeframe, which is the standard in surveys regarding prescription use. Researchers use one year as a timeframe for a very specific reason: a good portion of drug use is seasonal in nature – think fall allergy season, asthma, and some mental health conditions. By shortening the timeframe, the Nanos question wording would likely have excluded some people with affordability problems that our survey wording would have captured.

2. Second, given the wording, individuals might have been confused between being given a prescription by a physician and actually filling a prescription in a pharmacy. If some individuals interpreted it as the latter, then this wording would exclude those who received a prescription from a physician that they didn't fill because of the cost. We know that this is potentially a big factor as over 31% of prescriptions given by doctors are never filled, and we also know this is more common for more expensive medications.[7] Given the lack of information on pilot testing, we do not know whether people were responding as the Nanos researchers expected.

Nanos question 2

If respondents answered 'Yes' to the question above, they were asked this second question:

> *Have you been given a prescription in the past six months?*

This question is narrowing the responses for the questions that follow to the individual on the phone, which is completely reasonable.

Nanos question 3

Respondents who answered 'Yes' to the above question were then asked this third question:

> *You personally took all prescriptions without exception as prescribed?*

While asking about whether all prescriptions were taken as prescribed might seem reasonable, we feel there is the substantial potential for what researchers call social desirability bias to influence how people answered. This bias comes up in surveys when participants feel that they should answer in a particular way that is more "socially desirable". For example, people might report they drink less alcohol or smoke less in order to appear like better people. The socially desirable answer to the above question is that you, of course, followed your doctor's advice and took what you were prescribed as instructed, "without exception". Further, the question is also unclear about whether the respondent should report not taking prescriptions they filled once and never refilled, such as a long-term treatment for a heart condition.

The Nanos survey found that 93% of people reported taking all their prescriptions "without exception as prescribed" (emphasis added). We believe that this number is implausibly high given what we know from the extensive academic literature on whether people take their drugs as prescribed. For example, as noted above, we know that over 31% of prescriptions people are given are never filled.[7] This includes patients not filling things we would expect them to, such as heart medicines intended for long-term use. Further, we know that a substantial number of patients do not continue effective therapies they would be instructed to take over the long term. For example, Canadian studies have shown that among patients discharged for coronary angiography, more than 20% had stopped taking guideline-recommended therapies within 6 months of their hospital discharge.[8] This is exactly the type of population where one might expect adherence to be high—but it is not.

The problem this presents is that Nanos excludes everyone who answers 'Yes' from completing the rest survey. Given the unreliability of the responses to this question, this is a major, and in our opinion completely inappropriate, way to exclude respondents from talking about whether they can afford their prescription drugs.

Nanos question 4

After all of the exclusions outlined above, we get to the question where people who reported 'No' to the above question are asked the following:

> *What was the one reason for not filling/stopping early/taking a smaller dose of your personal prescription on any occasion?*

This question was open-ended, meaning that respondents were asked to name a single reason for why they may have not filled, stopped taking, or took a smaller dose of a prescription on any occasion in the past 6 months. They were not asked specifically about cost, but rather were only counted as having cost problems if they chose to mention it. The issue with this approach is two-fold: many people take more than one prescription, and people might have more than one reason for why they stop taking any particular medicine. The average Canadian receives 16 prescriptions per year in a community pharmacy.[9] Further, we know that individuals engage in very complex decision-making processes as to what drugs they take, and how they trade-off between various medications, their effectiveness, their side effects, and their different costs.[10]

Given this complexity, the structure of this question is highly problematic. An individual would have had to determine which drug they were going to base their answer upon, and then choose a single reason, among many possible interrelated reasons, to name. A more useful version of this question could have asked respondents to identify all the reasons for not taking their medication as prescribed. Instead, the net impact is that this question will understate the number of prescriptions foregone due to cost, as people might choose

other drugs to report on that were not foregone due to cost or might choose to answer different reasons other than cost when cost was in fact part of a more complex decision-making process involving several factors.

Summary of the way in which questions were asked

The differences between our survey and the Nanos survey in terms of the way in which the questions were asked is substantial. We asked two questions of the entire population to specifically quantify problems of prescription drug affordability. In contrast, the Nanos results only allowed someone to report cost as a concern if the respondent made it through the screening questions and then chose cost over all the other possible reasons in their last question. This way of asking questions is almost certainly going to have the net impact of excluding respondents who truly had issues with drug affordability at each step, and thus lead to artificially lower estimates than truly exist in the Canadian population.

Conclusion

In our opinion, the Nanos survey on drug affordability has serious flaws both in the conduct of the overall survey and in the design of the question flow. As outlined above, we believe the net effect would be to significantly lower the estimated extent of drug affordability problems within the Canadian population than truly exist. Given the number and severity of these flaws, in our view these results should not be considered accurate, and should not be used to guide policy decisions.

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