## COMMENTARY

# The Nanos Survey on Drug Affordability is Flawed: Rejoinder

Michael Law (michael.law@ubc.ca) and Ashra Kolhatkar May 3, 2018

Following the publication of our <u>criticism of the Nanos</u> <u>Survey</u>, Nik Nanos, the Chairman of Nanos and senior researcher on the study, published a <u>response to our arguments</u>.

The most telling aspect of his response is what he chose not to address. Most notably, the core fault identified in our critique is related to the question flow of the Nanos survey, and Mr. Nanos said nothing about this in his response. Further, even on the more minor points he does address, Mr. Nanos is far from correct. Below we discuss each of his specific points (his text in italics):

1. Law's comment on the number of survey participants comparing their own published study and the Nanos study. The number of interviews conducted is not relevant to the reliability of research. Larger data sets do allow for greater flexibility in the analysis of sub samples and target populations but should not be conflated with reliability. Both large and smaller surveys can be accurate or flawed, for a number of reasons, but the sample size is not a primary driver of reliability. In my experience over the past 30 years, question wording is among the greatest contributors to research reliability.

Mr. Nanos has misunderstood our criticism. We stated in our commentary that having a larger sample size makes estimates "more precise", not "more reliable". It is entirely possible that, were Mr. Nanos to run his survey again, it would produce the same result and thus be reliable. It is also entirely possible for a survey to produce reliably incorrect results. However, reliability says nothing about the precision of the resulting estimates one produces.

Further, we fully agree with Mr. Nanos that question wording is a very important aspect of survey design. Therefore, it is notable that his response ignores the concerns we raised about his question wording, most notably the points we made about taking a medication "as directed". We will return to another point about issues with the Nanos survey question wording in Point 4, below.

2. Law's comment on response rates. The latest research completed by the independent Pew Trust suggests that both higher and lower response rates in studies can provide accurate data. To cite the response rate of a survey as the basis for the reliability of one study over another is misplaced.

Certainly, while surveys with low response rates *can* produce accurate results, that doesn't mean they actually *do*. Surveys with low response rates are much more likely to provide misleading results than those with higher response rates, a phenomenon known as nonresponse bias. The <u>Pew Trust report</u> cited by Mr. Nanos acknowledges this: they assert that in surveys with response rates above 60% (like ours) the "risk of nonresponse bias is generally thought to be lower". Any further doubt about this point should be allayed by the fact that the original Nanos survey stated their response

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rate was "consistent with industry norms". We think the fact that they felt the need to defend their very low response rate is telling.

3. Law's questioning the Nanos pilot process. The fact that the questionnaire was designed by Nanos and not changed from pilot to implementation speaks to the quality of the questionnaire. Because the Nanos questionnaire used an open-ended question to allow Canadians to articulate reasons for behavior, there was less of a likelihood for questionnaire design issues because there was no priming of respondents with content. If Law in his study redesigned his questions on a number of occasions, as he claims, it puts a spotlight in terms reporting what changes he made, why they were made, and what different types of information was presented to respondents.

Mr. Nanos appears to not understand how our process worked. Following the initial drafting phase of our survey, we engaged in in-depth qualitative pilot testing with a group of participants before finalizing the content of the survey. After implementing several changes arising from this process to ensure participants would understand our questions as intended, we finalized the survey for delivery. All of the changes to our questions were made during the pilot testing, after which they remained the same for the entirety of our data collection.

It is frankly absurd to suggest that making no changes to a survey following pilot testing "speaks to the quality of the questionnaire". The qualitative pilot testing process we used is the standard used by Statistics Canada and other agencies that are experts in survey design. It is very rare to get question wording right the first time out, even with decades of experience. This is particularly true when one works on a particular subject matter for the first time, which is to our knowledge the case for Mr. Nanos and drug affordability. In personal correspondence with Mr. Nanos, he informed us that his survey was piloted by delivering it to 100

respondents prior to rollout, no changes were made as a result of this testing, and no qualitative pilot testing was performed. The fact of the matter is that it is very likely Mr. Nanos has no idea whether or not participants were understanding his questions as he intended because he never rigorously tested his questions to find out.

## 4. Comparing the Law and Nanos questions.

### Law Questions:

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?

### Nanos Question

What was the one reason for not filling/stopping early/taking a smaller dose of your personal prescription on any occasion? [OPEN-ENDED]

Readers should note that the Law question is flawed in terms of not being balanced. First, a binary yes/no answer should be a flag as a potentially leading question. The question should have posed "was cost a factor or not a factor in not filling a prescription...". The lack of balance could be interpreted as leading respondents. More importantly, it can be argued that the introduction of cost in the question as the only response element could noticeably lead respondents.

Conversely, the Nanos question is open-ended allowing Canadians to express why they did not fill a prescription in their own words, without priming them on cost or any other factors and without introducing any additional information.

As an example, Law's approach can be compared to a health practitioner with an interest in sore elbows to ask a patient only, "Does your

elbow hurt?" which could prime some patients to respond, "Come to think of it, I have a pain in my elbow." This approach is in contrast with Nanos' approach which can be compared to a health practitioner asking, "Where is the pain", which would allow the patient to articulate where the pain is as opposed to answering about the pain in their elbow as directed (like Law) by the health practitioner. To put this into context from a measurement perspective, if Law's leading question influenced at least one in 20 respondents that could yield a minimum over-reporting of five percentage points in his estimate on the influence of cost.

Ironically, this example is actually the perfect way to demonstrate why the Nanos question is flawed. If patients were asked, "Where is the pain?" some patients may cite their elbow, whereas others may describe a different body part. However, if a patient were to say they had pain in their knee, that doesn't preclude the presence of pain in their elbow. In fact, the only thing one can conclude from a question worded in this manner is the location of one source of pain for the patient. To use another example, this would be like asking people, "What is one item you plan to buy at the grocery store?", then concluding that their first answer was the only thing they were planning to buy.

Nanos' survey made this same mistake. It asked, "What was the one reason" for non-adherence to prescription medication and then asked respondents to name only a *single* reason. They take something for which there are many possible responses, ask for only a single response, then incorrectly characterize patients' responses as representing the *only* reason for non-adherence. As we pointed out in our original critique, there are numerous reasons people do not take their prescriptions. As a result, the headline finding of the Nanos survey is not a justifiable claim.

5. The connection between estimates and reality. It is fair for any researcher to examine the estimates of a study. In an ideal world, the estimates would align with real behavior. When a research organization conducts a poll during an election, it produces an estimate and then once the election occurs, the estimate is proven to be reliable or not. Research conducted by Nanos on the day before voting day for independent news organizations during federal elections have proven to be reliable, without exception (reliability being defined as within the margin of error of the survey). Nanos estimates, such as the 2006 Federal Election, have been dead accurate.

Citing the accuracy of previous work by the same company on a completely unrelated topic has absolutely no bearing on the findings of this survey. The concerns we highlighted in our commentary refer to problems with the conduct, development, and structure of this specific survey. The defensibility, or lack thereof, of other work done by Nanos is irrelevant to this assessment.

The Law estimate using the question which some could consider leading and could have primed respondents to report cost as a factor, estimates that 1.69 million people across Canada could not afford one or more of their prescriptions over the past 12 months. To put this into context, there are 338 Federal Ridings in Canada. Using the Law estimate of 1.69 million would suggest that there could be 5,000 Canadians unable to afford medicines in each riding. The phone lines of Members of Parliament should be deluged with calls from Canadians needing help, so they can take the medicines they need.

This is nonsense. Mr. Nanos presents no evidence that suggests if people are not phoning their Members of Parliament about a particular issue, it means that the issue is not either affecting or of importance to Canadians. Our result is consistent both with other surveys,

and with numerous analyses that have been done using insurance claims data showing that patient charges are leading many Canadians to forego their prescriptions.

*Likewise*, the estimated 1.69 million Canadians would also effectively represent a crisis in emergency rooms and healthcare outcomes of epidemic proportions. According to Health Canada, and their trend analysis of the health of Canadians from a healthy living and chronic disease perspective "In general, Canada is a healthy nation. Over the past several decades the overall mortality rate and life expectancy have improved considerably." In considering estimates of Canadians not taking medicines, one should reconcile estimates with the actual health outcomes of Canadians as measured by Health Canada. The Law estimate suggests a health crisis driven by Canadians unable to afford medicines they are prescribed. The Nanos estimates suggest that cost is one factor but not as prevalent as Law suggests.

This argument demonstrates another example of the spurious reasoning Mr. Nanos is using in his response. Medicines are just one of many factors that determine health in Canadian society (and a comparatively minor one at that). In general, Canada *is* a healthy nation, but that does not preclude the fact that an estimated 1.69 million Canadians have difficulty affording their prescription medicines. The health of Canadians has improved over the past several decades because Canadians are wealthier, better educated, have improved access to immunizations, better non-drug medical care, and so on. Medicines are important for many Canadians, but they are not the primary reason why they are healthy or not. The true crisis that should concern us is that a very significant number of Canadians

cannot afford medicines deemed by their health care providers to be medically necessary. While this may not be causing the "epidemic" Mr. Nanos envisions, it is leading to ill health and premature mortality.

The key question to ask is what is the better question to reliably estimate why prescriptions are not filled and to see how important or unimportant cost is: Telling people cost is a factor in not filling a prescription and asking to people to answer as Law did in his research OR the Nanos method which was plainly just asking why they did not fill a prescription and allow Canadians to answer as they wished?

We did not *tell* people that cost was a factor, we *asked* them if it was. Any responsible survey should do that before reporting population-level figures on the occurrence of some behaviour. To do otherwise is to potentially mislead readers regarding the true scale of a problem. Further, this is not the key question. The broader context regarding the development, content, and conduct of the survey are all equally relevant to the reliability and validity of the results. On these key considerations, the Nanos survey has fundamental shortcomings.

Mr. Nanos is missing the forest for the trees in his response and is asking his readers to do so too. He unsuccessfully challenges a small selection of minor points about our critique, and completely ignores the much more important fundamental challenges that we put forward. On a problem of this importance, Canadian policymakers and the Canadian public deserve the highest quality information and estimates that are available. We maintain that the Nanos survey does not provide them.