Motivators and barriers to participation in government-led participatory research/citizen science

Executive Summary

Prepared for Health Canada

Supplier Name: Nanos Research
Contract Number: CW2269369
Contract Value: $119,560.67 (including HST)
Award Date: 2022-12-15
Delivery Date: 2023-08-11

Registration Number: POR 117-22

For more information on this report, please contact Health Canada at: HC.cpab.por-rop.dgcap.SC@canada.ca.

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Prepared for Health Canada by Nanos Research

August 2023

Health Canada commissioned Nanos Research to conduct a public opinion survey to support the use of citizen science to address government and departmental science and research priorities, as well as Open Science initiatives. A total of 4,702 Canadians were surveyed using an online panel to reflect the Canadian population. The online survey was conducted between March 16th and March 30th, 2023. Four focus groups were also conducted on March 21st and 23rd, 2023. This publication reports the findings of this research.

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Catalogue Number: H14-448/2023E-PDF
International Standard Book Number (ISBN): 978-0-660-67506-0

Aussi disponible en français sous le titre *Motivations et obstacles à la participation à la recherche participative/science citoyenne menée par le gouvernement.*

Numéro de catalogue : H14-448/2023F-PDF
Numéro international normalisé du livre (ISBN) : 978-0-660-67507-7

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Executive Summary

Background and objectives

Health Canada has a mandate to help Canadians maintain and improve their health, supported by science and research. There is increasing interest in better engaging the public in these research initiatives; public volunteers who may or may not have any background in science. These volunteers might be involved in data collection (e.g., collecting or contributing samples, recording observations, installing environmental sensors on their property or home), supporting the analysis of data, or sharing their expertise or lived experience to help with the research project design or with the interpretation of the results. This collaborative approach to research between the general public and federal scientists is called participatory research or citizen science.

Researchers with Health Canada investigate and study complex issues, which often requires a large amount of timely data to address the issues adequately. This is often logistically challenging and costly to attain due to Canada's immense size and diversity in environments and people. However, there is evidence to suggest that participatory research/citizen science could prove the ideal solution to these challenges for the government. Participatory Research/citizen science can not only help meet Health Canada's data needs, but also support Open Science objectives by directly involving the public, improving scientific literacy and garnering buy-in and trust from the public. This multitude of benefits has led governments and organizations around the world to find great success in adopting participatory research/citizen science. However, Health Canada is lagging behind with relatively few formal participatory research/citizen science projects having been undertaken, and those that have, being conducted without formal guidance, consistency or infrastructure.

The success of participatory research/citizen science in the context of Health Canada will rely on participation from a wide and diverse range of Canadians to ensure that the data that is collected and the resulting decisions or policies, reflect the diversity of the Canadian population. However, international research has shown that, typically, participation in citizen science/participatory research projects does not reflect the demographics of the population. Other forms of public engagement have also seen challenges related to reaching Canadians, especially those in groups that are traditionally underrepresented in research (including rural Canadians, visible minorities and low-income Canadians). This results in data and research outcomes that may not be relevant especially within the context of health, to those not reflected among the participants.

To that end, Health Canada was interested in conducting public opinion research to understand if, how, and why Canadians would be willing to participate in government-led citizen science/participatory research projects. Understanding the motivators and barriers to reaching and engaging traditionally underrepresented groups (and Canadians as a whole) will enable Health Canada to increase participation from a more diverse sample of the population and create a formal strategy and structure to engage these individuals in participatory research/participatory research projects. Specifically, Health Canada was looking to explore what is needed to increase adoption of the participatory research/citizen science approach and to help develop the required guidance and infrastructure to better ensure diverse representation among participants.

Purpose and objectives

The research will inform efforts to support the use of citizen science to address government and departmental science and research priorities, as well as Open Science initiatives. The findings will also be used to support a number of future initiatives to include and collaborate with different communities, and to actively seek out and incorporate the views of Canadians, including helping Health Canada researchers to recruit and attract collaborators and respondents from the public.

Methodology

Qualitative phase

Nanos conducted four online focus groups among 36 Canadians, 18 years of age and older, randomly recruited, who self-identified as low-income (household income of less than $40K), a visible minority and/or from a rural community as defined by Health Canada. The groups were conducted on March 21st and 23rd, 2023. Three (3) focus groups were conducted in English (with participants from British Columbia, Ontario, and the Prairies) and one (1) in French (with participants from Quebec).

Readers should note that focus group research is qualitative and directional in nature and must not be used to estimate the numeric proportion or number of individuals in the population who hold a particular opinion. The focus group research allowed Health Canada to gauge the views and gather in-depth insights from their specific communities and profiles of interest.

Quantitative phase

The survey is comprised of 4,703 Canadians, 18 years of age and older, including sub-populations of low-income individuals (household income of less than $40K), individuals residing in rural areas and visible minority populations. The survey was conducted across Canada in each province and territory between March 16th and 30th, 2023. The results were weighted by province, age and gender, using 2021 Census data.

The survey sample was drawn from two sources:

1) The Nanos Probability Panel, which contains about 50,000 Canadians who were randomly recruited to join the panel by land- and cell-lines with live agents.
2) Random recruitment by land-and cell-lines and administered the survey online.

The resulting sample contains Canadians who were all randomly recruited by telephone; thus it is a probability sample and allows a margin of error to be associated with the research. The margin of error for a random survey of 4,703 Canadians is plus or minus 1.4 percentage points, nineteen times out of twenty (a confidence interval of 95 per cent). All respondents self-administered the survey online.

Key findings

Awareness, familiarity and experience of Canadians with regards to participatory research/citizen science

Familiarity and awareness of participatory research or citizen science among Canadians is low. Few survey respondents have heard of the terms on their own (18% unprompted). When the methodology is explained, a small percentage more are familiar (22%), but the majority are unfamiliar (54%). Participation experience is similarly low (11%) even when prompted with examples illustrating what these projects may entail.

Highly engaged community members (defined as those who did four or more community/civic engagement activities in the past year) are more likely to report being aware of participatory research/citizen science prior (30%) than low/moderately engaged Canadians (1-3 community/civic engagement activities in the past year)(16%) or non-engaged Canadians (did not do any of the listed community/civic engagement activities in the past year)(7%).

Focus group participants felt the terms 'participatory research' and 'citizen science' accurately describe the concept, and a majority preferred the term 'citizen science' over 'participatory research', noting it was clearer what the term represents and that they felt the term was more inclusive.

Specific project examples seem to be more familiar to focus group participants than the general category of this research methodology alone. There may be a need to provide substantial detail about what the projects entail and the level of participation expected in order to garner interest.

There is also a need to promote participatory research to the public, especially to those who are not as engaged in their communities, who for the most part is not familiar with this type of research. It will be key to demonstrate examples of what this methodology entails, as well as how they can get involved.

Willingness to participate in participatory research/citizen science projects

A majority of surveyed Canadians are at least moderately interested in participating in a future government-led participatory research or citizen science project (81%). When asked why they indicated they were interested in participating:

- Those who are interested in participating (score of 7-10) most often mentioned that they want to make a difference and help their community (17%), and that science is important, and they want to support and advance science (11%).
- Those moderately interested (score of 4-6) most often said they were too busy and did not have time (21%) and that it would depend on whether the subject interested them (17%).
- Those not interested (score of 0-3) most often mentioned being too busy and not having time (23%), that they do not trust the government and believe it would be biased (15%), that they are just not interested and/or no topics interest them (14%) and that they do not have the physical capabilities to volunteer currently (10%).

When asked what kinds of topics they would be interested in, surveyed Canadians most often mentioned wanting to participate in anything where they can learn or contribute their perspective (16%), biology/ecology (12%), climate change (8%), and environmental health (6%). Among health-related topics, respondents are most interested in projects related to well-being (64%), the healthcare system (62%), food and nutrition (58%), environmental health (56%) and climate change (52%). In the focus groups, topics of interest frequently mentioned were the environment, health, education, public services, quality of life, financial literacy, and sports.

Respondents with an interest in science (those who agree that they would like to know more about science) are more likely to be at least moderately interested in participating in a future government-led participatory research/citizen science project (83% score 4-10) than those who would not like to learn more about science (54%). The same observation can be noted for survey respondents who are comfortable with science (those who agree that they are reasonably confident they could contribute to science research) (88%; 70% of those who are not reasonably confident in their ability to contribute) and those who agree that they generally understand science concepts when they are explained to the general public (82%; 64% of those who do not generally understand science concepts).

It appears as though there is a high degree of interest in government-led participatory research/citizen science projects on health-related topics, but participation may be limited to those most interested in the specific subject-area of the study or those who have some interest in or comfort level with science in general.

Motivator and barriers to participation in participatory research/citizen science

The biggest unprompted motivators for surveyed Canadians to participate in government-led participatory research or citizen science project were being able to contribute, help society, science and their community (22%), an interesting subject or an interest in the outcome (17%) and a reward or financial incentive (gift card, honorarium, etc)(14%). After prompting with a list of potential motivators, survey respondents were most likely to be encouraged to participate by contributing to a topic of importance or interest to them (70%), having the ability to gain insights or learn more about their health, and receiving follow up communications on the results of the project (55% each). Close to four in ten say receiving a monetary incentive (42%) or learning more about the topic (38%) would very much encourage them to participate. Advertising and promoting the projects and the provision of incentives were top suggestions to encourage others to participate.

In terms of motivators, non-engaged surveyed Canadians are more likely to mention a reward or incentive unprompted (19%; 10% of highly engaged Canadians). When prompted with a list of potential motivators, Canadians who are highly civically engaged are more likely to say that contributing to a topic of interest or importance to them would very much motivate them (80%) than those with no engagement (59%). They are also more likely to be very motivated by connecting with other participants (33%; non-engaged: 20%), providing support to the organization leading the project (32%; non-engaged 22%), learning more about the project topic (45%; non-engaged: 28%), a hands-on workshop (38%; non-engaged: 28%), having an opportunity to connect with science experts (40%; non-engaged: 30%) and follow-up communications about the results of the project (64%; non-engaged: 45%).

Survey respondents who are reasonably confident they could contribute to science research are more likely to be motivated to participate by the opportunity to provide support to the organization leading the organisation (30%) and the opportunity to connect with science experts (40%), than those who are not confident (20% and 21% respectively).

Learning more about the project topic (39%), having an opportunity to connect with science experts (35%), the ability to gain insights and learn more about their own health (57%), follow-up communications on the results of the project (57%), and regular support from the project organizers (31%) were key motivators for surveyed Canadians who are interested in knowing more about science. Those not interested in learning more about science were less motivated to participate across most measures but were more interested in gaining insights and learning about their own health (33%) and receiving follow-up communications (34%) than learning about a topic (19%), getting support from project organizers (16%) or connecting with science experts (12%).

Asked what the biggest motivators for them would be to participate in a participatory research or citizen science project, focus group participants often mentioned their level of interest in the topic or purpose of the project, whether there is a financial incentive, and the social aspect, such as the potential to participate with their family.

Having the project focus on a topic of interest is a big motivator for the majority of Canadians. Among civically minded Canadians, the altruistic contribution to their community or science was noted. Financial incentives seemed to also be important especially for certain demographic groups. These findings also indicate that those already engaged civically are more likely to participate and be interested in participating in citizen science projects. While less motivated, those un-engaged may be motivated by a subject matter of interest to them or an opportunity to receive the results.

Those who are interested in science are more motivated to participate overall than those uninterested in science. Among the interested group, the opportunity to learn and connect with others is much more important and they are willing to put more effort into the projects. Those less interested in science or less

confident with science concepts and participation are more likely to be motivated by getting insights or learning about their own health.

In terms of unprompted barriers to participation, Canadians most frequently mentioned: the time commitment and their availability (53%); accessibility issues including mobility issues or age (9%); distance, transportation needs and location of the project (8%); and if the project was not enjoyable or too difficult (8%). Once prompted with a list of potential barriers, not having enough detail about what is expected from participants at the start of a project (41%), not having enough detail about how the results will be used (36%), privacy concerns (33%) and a lack of spare time (32%) were most often rated as very much preventing them from participating in a future project.

Regarding barriers to participation, substantial reading of training being required is seen as a bigger barrier to participation by non-civically engaged surveyed Canadians (28%) than those who are highly engaged (18%), as well as having to interact with other participants and/or science experts (12%; highly engaged: 2%). Surveyed Canadians who disagree that they would like to know more about science are more likely to say substantial reading or training required for participation would be very much a barrier to them (40%) than those who agree (23%), as well as having to interact with other participants and/or science experts (16%; 6%). Canadians who generally do not understand science concepts when they are explained to the general public (25%) are more likely than those who do understand (9%) to say that having to learn to use new instruments, tools and /or technology would very much prevent them from participating.

In the focus groups, barriers to participating in a participatory research or citizen science project were noted as time and availability, including the time commitment required for a project, the location of the project and if transportation was needed, as well as required access to or knowledge using any required technology. The level of difficulty related to participating, their own perceptions of science and their qualifications, and privacy concerns or concerns related to their anonymity were also noted as barriers.

Prompted specifically on what their concerns would be related to a participatory research or citizen science project, focus group participants most often mentioned privacy and anonymity concerns, including knowing how their information will be used, who will have access to it and how it may be analyzed or shared. Other concerns mentioned were the integrity of the data and ensuring the project is legitimate, as well as meeting the time commitments.

All focus group participants agreed that anonymity is important, especially for potentially sensitive topics such as mental health. They noted that if their anonymity could be assured and the purpose of the project was important, then generally they would feel comfortable sharing almost anything, with the exception of a few participants who said they would still not feel comfortable sharing information related to their finances or their personal medical information.

Providing flexibility for when, how frequently, and/or how long a participant must commit to a project, may lessen the barrier for many potential participants. However, while the biggest barriers for most topics might be the time availability of participants, the project details, knowing what information will be collected and privacy considerations appear to be equally important. As aforementioned, this information, with adequate detail, should be provided in the project invitation and promotion. Those less interested in science or less confident with science concepts and participation are more likely to be dissuaded from participating if it had substantial requirements either in training and reading or in using new technologies.

The type of participatory research or citizen science project may also influence interest in participation. Survey respondents were most interested in participating in a project where they respond to a survey or enter data in one-time only (80% were interested; score of 7-10 out of 10). Interest was lower for projects that required

longer time commitments or more involvement from participants, such as leaving their home to collect and share samples at a regular interval (45%), logging into an online platform to add data daily over the course of a few weeks (48%) or logging something they encounter into an online app over several months or years (47%). Just over four in ten were interested in participating in a project involving passive data collection where information is collected via an app with their consent for a set period of time (41%).

Overall, survey respondents who are highly engaged in their communities have a higher level of interest in participating overall (70% vs 56% for those who are moderately engaged and 47% of those who are not engaged), as well as in participating in specific types of projects, including projects where they will be asked to log into an online platform daily to add data in order to track a change over time for a few weeks (57%; non-engaged: 39%), where they encounter something an log into an online app over a period of months of years (56%; non-engaged: 39%), or a project where they help provide context about what data already collected might mean to their community (71%; non-engaged: 42%).

In the focus groups, participants were prompted with various examples of potential projects. They were generally interested and saw little to no barriers to participating in a project that requires passive participation, such as installing an air quality sensor in their home, or one that would require more involvement such as submitting a photo of their cleaning products. A majority of participants were also interested in projects that would support the interpretation of data or results with their own experiences or local knowledge, but some added that it would depend on the topic or time commitment required. There was less interest in a project with more regular or ongoing involvement. Those who were not interested or said that it would depend, mentioned the project sounded invasive, privacy was a concern, or they would need to know more about the duration, methodology and end use of their data.

Focus group participants stressed the importance of clarity and honesty when the government communicates with the public about participatory research/citizen science, including being clear on the purpose and expectations, and for the target demographic/participant group. They also suggested highlighting the importance of the project and why their participation is key, and to target their messaging so it is relevant to the demographic(s) they are targeting.

Low commitment projects were preferred to those with longer time commitments or more in-depth effort on the part of the participant, which aligns with earlier findings that a large time commitment may be a barrier to participation unless the topic is of interest or importance to participants. Passive participation had a mixed response, and it may require more documentation and precise messaging to engage participants in this type of participatory research or citizen science project.

Engaging traditionally underrepresented demographics

A key component of the research was to examine ways to engage with, as well as motivators and barriers to participation for traditionally hard to reach and underrepresented audiences.

These audiences include:

- Visible minorities;
- Indigenous peoples;
- Low-income individuals; and,
- Rural-residing individuals

Overall, there is no significant gap in awareness or familiarity between these underrepresented audiences and the rest of Canadians, with over four in ten having at least moderate familiarity with the methodology (45%).

This means that to reach them and engage them, while there is a need to increase awareness, a lack of awareness is likely not a significant driver of their lack of participation in these projects.

Barriers

Of note, for low-income individuals the time commitment and their availability were less of a barrier than for high-income individuals, but it was still the main barrier to their participation. It will also be key to consider the activity required from participants, as potential accessibility or mobility issues are seen as a barrier to those with a low household income.

For rural individuals where internet broadband connection is a barrier to participation, it will be key to detail to participants whether this is necessary for their participation or to consider providing them with all alternative methods of sharing their results that do not require the same level of access to the internet. Of note, although they were more likely to identify this as a barrier, nearly all surveyed rural residents do report that they have access to high-speed internet at least some of the time (93%) or access to some form of technology (either a computer, tablet or smart phone) (100%). Technology in general is not a significant barrier to these audiences; while there are slight differences in the level of comfort they feel, a majority feel at least moderately comfortable using a tablet or smartphone, downloading or using apps, communicating via email, using a computer, using social media or navigating the internet.

A lack of spare time was especially key as a barrier to visible minorities, so ensuring participation can be short-term or relatively unobtrusive to their lives may be key to engage these individuals. However, focus group participants said that while they are less interested in a project with ongoing or regular involvement, those who did express interest said they would participate due to their interest in the sample topic mentioned (mental health).

Focus group participants also said that the more interested in the topic they were, the more involved they would want to be, even up to a few hours per week. This demonstrates that an interest in or personal importance given to the topic and results could overcome perceived barriers related to time commitment.

Motivators and engagement

Similar to Canadians overall, these underrepresented audiences are motivated by being able to contribute and make a difference in their community, but there is a larger than average proportion who would be motivated by a reward of financial incentive (especially in the case of visible minorities, low-income individuals and Indigenous individuals). However, as noted earlier, just as important a consideration as a reward would be the impact of the research on their community and whether the topic is of interest or importance to them.

In terms of engaging these audiences in specific project types, the most interest is observed for projects with less of a time commitment (one time data entry or providing context to already collected data), but across nearly all potential types of projects respondents are more likely to be interested rather than not interested (with the exception of passive data collection through an app or device). Focus group participants did note that a passive commitment is easier for them, so this could be an effective method to engage these individuals as long as there is transparency around how the app or device would work and what data was collected as they did note concerns around this.

It will be key to provide a lot of detail about the project to potential participants if they wish to reach these underrepresented audiences and engage them in the research, especially since not having enough detail on what is expected of them or how the results will be used were the top-rated barriers. Providing this information from the outset can help assuage some of the key barriers to participation for these audiences, including outlining clear expectations for participants and their role, any requirements (reading, training or technical

knowledge), the time commitment expected from them, privacy concerns (by being transparent about what data or information is collected and what it will be used for), how the results will help their community or society, and if accommodations can be made in the case of a slower internet connection or a physical disability.

Project communications should also be very clear about the level of knowledge required for participants, so they are not self-selecting themselves out of consideration because of assumptions that they do not have the required knowledge or skills.

When engaging these individuals, projects with less of a time commitment (either in frequency of contribution or overall length of project) will potentially be more successful in engaging all Canadians, including these key audiences. However, as projects will inevitably range in terms of the commitment required, it will be important to clearly communicate what is required of participants, how results will be used and how the project will help society and/or their community.

Reaching underrepresented audiences

In order to reach these audiences, consideration should be given to increasing advertising of these opportunities on social media, as well as locations such as public libraries, medical centres, community centres, religious centers and newspapers to reach a wider range of Canadians. Since they are already underrepresented in participatory research, they are unlikely to be tuned into more active methods of recruiting such as an email newsletter or posts on a webpage.

As visible minorities are more likely to be motivated to participate if they know someone else who participated, consideration should be given to recruiting by referral or snowball sample, where participants are asked to refer other individuals to participate and could be provided with a reward for each person, they refer who then participates in a project. Some individuals in the focus groups also mentioned being able to participate with their family and friends, so this could enable them to recruit their family members and/or friends to participate as well. This could be a key opportunity to utilize word of mouth among these audiences, especially among visible minority communities, and help sow trust in the project and its organizers and thereby lead to repeat participation from these audiences.

Messaging should be tailored to these audiences and address their motivators and barriers at the outset in addition the project specific information being communicated, for example targeting rural audiences through more offline methods such as advertising in public libraries, medical centres, community centres, religious centers and newspapers and clearly stating requirements related to technology or needing to travel to a larger city. For visible minorities, low-income Canadians and Indigenous individuals, messaging should be sure to clearly state what incentive or reward is being offered.

Communicating about participatory research/citizen science projects

Whether being notified of opportunities to participate in upcoming projects or updates or reminders related to projects they were already involved in, survey respondents most often say their preferred notification method is by email (87% for upcoming; 90% for ongoing). This method was of communication followed in preference by smart phone notifications and texts (32% upcoming; 39% ongoing), a newsletter (28% upcoming; 26% ongoing), updates on a web page (28% upcoming; 26% ongoing), social media (20% upcoming; 12% ongoing) and community meetings (11% upcoming; 9% ongoing).

Surveyed Canadians say they are most comfortable (score of 7-10) communicating by email (93%), using a desktop or laptop computer and navigating the internet (89% each), as well as using a tablet or smart phone (84%). About three in four say they would be comfortable downloading and using a mobile application (76%) and under six in ten would be comfortable using social media (59%). Differences are noted by age, with individuals between 18 and 44 years of age generally being more comfortable using technology than the

national average and individuals 55 and older generally less comfortable, especially in terms of using social media.

Technology access does not pose a significant barrier to Canadians with nearly all of those surveyed reporting having some access to technology, whether via a smartphone, laptop, tablet or desktop computer. The same is true for internet access, with more than nine in ten Canadians surveyed reporting they have access to stable high-speed internet all or most of the time (93%), while six per cent report having it some of the time and one per cent report not having access to stable high-speed internet.

During the focus groups a potential platform to support these projects was discussed and participants were asked to provide recommendations for their design. Participants emphasized that if created, privacy of participant data is essential and should be top of mind in the design and implementation of such a platform, as well as the ease of use of the platform. A forum or chat function to connect participants and to ensure the platform is accessible was also suggested.

A mobile application may be well positioned to maintain communication with future participatory research/citizen science participants given comfort and preference of smart phone notifications for communication.

Comfort and interest in science

In terms of statements meant to gauge their comfort and interest in science, surveyed Canadians have the strongest intensity of agreement that they like to thoroughly research their options when making a decision (97% strongly or somewhat agree) and that they generally understand science concepts when they are explained to the public (96% strongly or somewhat agree).

Misinformation and the spread of inaccurate scientific information is a concern for surveyed Canadians with more than nine in ten who strongly or somewhat agree that they are concerned with the spread of inaccurate scientific information (94%) and over eight in ten strongly or somewhat agree they are interested in taking action against inaccurate scientific information (82%). A majority also strongly or somewhat agree that they are confident in their own ability to assess the accuracy of scientific information shared in the media (88%). A strong majority strongly or somewhat agree that they would like to know more about science and how it affects our world (93%) and just over six in ten Canadians strongly or somewhat agree that they are reasonably confident they could contribute to science research (63%).

The contract value was $119,560.67 (including HST)

Supplier name: Nanos Research
PWGSC contract number: CW2269369
Original contract date: 2022-12-15
For more information, contact Department at HC.cpab.por-rop.dgcap.SC@canada.ca.

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