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The Use of Antivirals for Prophylaxis: Deliberative Dialogue Process

FINAL FINDINGS REPORT

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EXECUTIVE SUMMARY

In February 2004, the Government of Canada and provincial and territorial jurisdictions developed the Canadian Pandemic Influenza Plan for the Health Sector. The Plan outlines a strategy to deal with the impact and implications of a potential influenza pandemic. A national policy recommendation is being developed on the prophylactic (preventative) use of antivirals during a pandemic. The Council of the Public Health Network (PHN), through the Public Health Agency of Canada, has commissioned the current public consultation to help to inform their recommendations. Specifically, the purpose of the consultation is to foster a dialogue among randomly-selected citizens to develop and prioritize potential decision options on the use of antivirals for prophylaxis. The dialogue process offers a way to gain insight into citizens' values and the "common ground" developed on the use of antivirals for prevention when given the opportunity to learn about the issues and reflect on and discuss them. In addition to the dialogue results, the Public Health Network Council reviewed other considerations, including separate reviews of legal, scientific, economic and ethical issues related to the use of antivirals for prevention; the technical feasibility and logistics associated with timely distribution of antivirals; and, a review of international experience with this issue.

This report presents the results of eleven dialogues: seven dialogues conducted with citizens; two with stakeholders; and two with those in occupations that may be targeted for antivirals for prophylaxis, to explore the values and principles that Canadians believe should guide decisions about providing publicly-funded antivirals for prevention during an influenza pandemic. Across the sessions, there was a high level of satisfaction with the dialogue process expressed informally and during participants' closing comments, as well as on the evaluation forms. Participants indicated that they had learned a lot, enjoyed the discussion and appreciated the opportunity to participate. By their questions and comments, participants demonstrated a reasonable grasp of the technical material and of the dilemmas at hand. Their comments overall were insightful and thoughtful.

In essence the dialogue sessions were designed to seek views and considerations from citizens, stakeholders and target groups on three key questions: should governments provide publicly-funded antivirals for prevention during an influenza pandemic and, if yes, under what conditions, and specifically to whom, should antivirals be provided. The dialogue used a number of tools to elicit these views and to determine the underlying values and principles by which citizens resolved the dilemmas and trade-offs inherent in these decisions. An information session and the ongoing input of medical experts during the sessions proved invaluable to ensure that participants had the best information available to inform their choices.

In examining the discussions across the seven dialogue sessions, shared goals and values are visible, often articulated in the "common ground" that was presented and tested with participants. Other goals and values emerged in the latter parts of the day.

The qualitative discussions from the deliberative dialogue process, as well as the accompanying quantitative survey data, provide a sound design for obtaining citizens' input on the provision of publicly-funded antivirals for prevention. The survey administered at the recruitment stage shows few differences between the general population in the dialogue centres and dialogue participants. While the dialogue sessions (and also the quantitative results) are clustered (i.e., drawn from seven centres), the consistency of results across the sessions is encouraging and suggests that the findings are likely a good approximation of the views of most Canadians when they have the opportunity to work through the issues.

Results

Participants generally favoured governments proceeding with a program to provide antivirals for prevention, in support of three goals which emerged as important for them: to ensure that normal societal operations are maintained; to minimize public fear and panic; and, (in part through the accomplishment of these first two) to reduce serious illness and death during a pandemic. This support was stronger in the citizen sessions (Vancouver being more mixed) and weaker among target group and stakeholder participants (who were more divided). Among those supportive there was an expectation that, if the means are available to achieve these ends, governments should undertake to use them to protect citizens.

While there was considerable discussion and divided views about priority recipients, the clear choice (and easier for participants to make) was for health care workers with close patient contact, as the group that would be most needed in the defence against a pandemic and the most exposed to the virus by virtue of their occupation. Whether or not their families should be extended the same consideration was a topic of considerable debate, as was the extension of antivirals to health care workers without close patient contact. In the case of the former, those most in favour argued the same considerations: the need for health care workers to be available and at their best when needed; and that the same responsibility to protect those on the front line should also extend to the families that they would expose by virtue of their work. With regard to health care workers without close patient contact, those in favour argued that they would also be exposed in their work setting and that the interdependence of functions in a hospital (and other health care settings) argued for the protection of all individuals doing those jobs.

There was also considerable discussion about the need for antivirals for those in emergency services. Many argued that people in these functions should be protected in order to keep society functioning, while others argued that this may not be required given the rate of absenteeism and time interval of maximum expected risk before a vaccine would be available. Even among those in favour there was often discussion of limiting the application of antivirals to only those individuals that could not be replaced, and only for those functions that would be most critical. There was even greater divide with regard to essential services, with some arguing the need and others suggesting that again, the rate of absenteeism was not so steep as to make prevention critical, given that antivirals would be available for treatment and vaccines would be available within a period of time. It should also be noted that the distinction between emergency and essential services was often unclear throughout a number of the sessions.

The most vulnerable, including children, those in institutions, the chronically ill and elderly were often argued as the third most prominent and likely candidates for protection, however, there was considerable diversity and divergence of opinion on this segment of society and the need for this method of prevention, as well as the practical considerations of identifying these individuals and getting the drugs to them in a timely and efficient manner (which were not deemed to be significant considerations for the other groups).

Central to all discussions about priority groups was the delicate balancing of considerations for the depth of illness and disruption in the lives of Canadians (individually and at a societal level), the difficulty in determining who was most vulnerable and who was most valuable, and the efficacy, cost and side effects. In most sessions, and for many of the priority groups discussed, there was argument made for limiting the use of antivirals for prevention to the fewest individuals required to safeguard society the most from the illness and disruption. In a few sessions (although far from all) there was additional discussion of planning for the use of antivirals for prevention for the smallest and most strategic period of time (i.e., as a bridge from the start of a pandemic until the availability of a vaccine or even shorter).

As became evident in the dialogues, pandemic planning and its execution are areas where government leadership is expected and where public expectations of government are high. Governments are seen to be well-placed to communicate information about a pandemic to the public and to guide individual action. Governments were clearly preferred to oversee a stockpile of antivirals for prevention, both because governments are able to secure advantageous pricing due to economies of scale (an efficiency-related argument) and individuals simply indicated greater confidence that governments would undertake a fair and sensible distribution process (as opposed to a less regulated or individual/private sector-based approach).

On the other hand, in all the dialogue sessions, participants raised concerns about the decision-making process itself with respect to distribution. If there are to be priority recipients, who will decide who they are? Participants themselves struggled enormously to identify and prioritize groups. They wondered how decision-makers would ultimately decide the "value" of different groups of citizens and the risks for governments when they do. Participants were very attuned to the ethical complexities of the issue and a few wondered whether the benefits of antivirals outweighed the potential quagmire that could result. One central theme that was discussed in most sessions was the need for consistency. People wanted the decisions to be the same across the country, (e.g. if it was HCWs as priority recipients, it should be HCWs everywhere). The only nuance to this was that in some cases the people providing the service may be different, (e.g. since there are few family doctors in Iqaluit, nurse practitioners or others would provide prescriptions and therefore some tailoring of priority groups may be required to ensure consistency of service and protection related to the pandemic).

Consistent and Central Emphasis on Public Education and Need for More Research

At the end of the day, the provision of publicly-funded antivirals for prevention and the accompanying designation of priority groups must inspire the trust and approval of Canadians overall. The

frame of reference for decision-making that emerged during the course of the citizen dialogues emphasized the following values: practicality/efficiency/pragmatism; fairness and equity; compassion; public engagement/awareness; role of government (with minimal government involvement not being a viable option on its own).

With respect to the value of public engagement/awareness, each of the sessions included a number of themes underscoring the fact that public understanding, acceptance and support is predicated on good communications of the issues. Citizens across all regions indicated the importance of Canadians staying informed; a message emerged during the dialogue discussions and was also often reiterated in participants' closing comments. Public education itself was raised in a number and variety of contexts. Participants saw the need for public education even prior to the occurrence of an influenza pandemic about pandemic planning, preventative or general public health measures and individual emergency preparedness.

In addition, citizens talked about public education during an influenza pandemic. Many participants highlighted the need for public education to minimize public panic during a pandemic, using information and awareness as a way to avoid societal disruptions during a period of uncertainty and fear.

Public education was further raised in the context of ensuring that the public is able to understand and support the decision to stockpile antivirals for prevention and their selective distribution to priority recipient groups – that is, "selling" the strategy for the distribution of antivirals. The goals and values that emerged in the dialogue provide good guidance as to the rationales that citizens find convincing in pursuing a course of action in this area – e.g., provision of publicly funded antivirals guided by efficiency, fairness and compassion. The results of the dialogue sessions emphasized the theme of consistency – whereas there was support for, for example, HCWs as priority recipients, it was considered important that this criterion be the same across regions (with some flexibility in rural/remote areas or in an outbreak-based strategy). Similarly, participants generally objected to inequities based on income. The dialogue also indicates areas where citizens' concerns must be reasonably addressed (e.g., efficacy and safety).

A final implication of the dialogue sessions has to do with the safety and effectiveness of antivirals themselves. During the course of the dialogue session, many participants asked questions about antivirals that, at this time, simply cannot be answered definitively. The research base is quite limited and, of course, prior experience with the use of antivirals under pandemic conditions non-existent. In their closing comments, many participants urged that significant progress be made on the safety and efficacy of antivirals to improve the confidence of decision-makers and the general public in the appropriate use of antivirals for prevention.

Strong Role for Government

Across the different sessions an underlying theme was the strong role for governments to play in planning, coordinating, educating the public, researching and working with others to be prepared for a pandemic. Throughout the results described in this report the reader will find, more implicit than explicit, the

argument made by citizens, stakeholders and target group members alike the important role for government in leading and being seen to be leading the efforts in pandemic preparedness (with regard to the use of antivirals for prophylaxis as well as in broader planning for a pandemic).

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SOMMAIRE

En février 2004, le gouvernement du Canada ainsi que les autorités provinciales et territoriales ont mis au point le Plan canadien de lutte contre la pandémie d'influenza pour le secteur de la santé. Le Plan énonce une stratégie pour affronter les effets et conséquences d'une éventuelle pandémie d'influenza. Une recommandation de politique nationale touchant l'utilisation prophylactique (c'est-à-dire préventive) d'antiviraux en cas de pandémie est en voie d'élaboration. Le Conseil du Réseau de santé publique (RSP) a, par l'intermédiaire de l'Agence de santé publique du Canada, commandé la présente consultation publique en vue des recommandations qu'il doit faire. Plus précisément, la consultation veut favoriser le dialogue entre des citoyens choisis au hasard, de manière à concevoir diverses options en vue des décisions à prendre touchant l'utilisation prophylactique des antiviraux, et à donner à ces options un ordre de priorité. Le dialogue est une démarche qui permet d'approfondir une question, en l'occurrence les valeurs et points de convergence des citoyens concernant l'utilisation préventive des antiviraux, lorsque l'occasion leur est offerte de réfléchir à la question et d'en débattre. En plus des résultats des séances de dialogue, les membres du Conseil du Réseau pancanadien de santé publique ont examiné d'autres éléments, y compris des examens distincts de questions juridiques, scientifiques, économiques et éthiques touchant l'utilisation d'antiviraux à des fins de prévention, la faisabilité technique et la logistique associées à la distribution d'antiviraux en temps opportun, ainsi qu'un examen de l'expérience internationale dans ce domaine.

Le rapport présente les résultats de onze dialogues, dont sept qui ont réuni des citoyens, deux qui se sont tenus avec des intervenants et deux autres, avec des personnes susceptibles en raison de leurs fonctions d'être choisies pour recevoir des antiviraux à des fins prophylactiques; ces dialogues portaient sur les valeurs et les principes qui devraient, de l'avis des Canadiens, orienter les décisions touchant la fourniture à des fins préventives d'antiviraux payés à même les fonds publics advenant une pandémie d'influenza. Il est ressorti de toutes les séances un fort taux de satisfaction au sujet de la démarche, exprimée sans formalité et lors des mots de la fin provenant des participants, de même que dans les formulaires d'évaluation. Les participants ont affirmé qu'ils avaient beaucoup appris, que la discussion les a intéressés et qu'ils se réjouissaient d'avoir pu y prendre part. D'après leurs questions et commentaires, les participants ont fait preuve d'une assez bonne compréhension de la documentation technique et des enjeux. Dans l'ensemble, leurs observations étaient judicieuses et réfléchies.

Les séances de dialogue visaient essentiellement à obtenir les points de vue des citoyens, des intervenants et des groupes cibles sur trois questions clés : les gouvernements devraient-ils fournir à des fins préventives des antiviraux payés à même les fonds publics advenant une pandémie d'influenza et, dans l'affirmative, dans quelles conditions et, en particulier, à qui devraient-ils fournir ces antiviraux. La démarche comportait divers instruments en vue d'obtenir ces points de vue et d'établir quels sont les valeurs et les principes sous-jacents qui permettent aux citoyens de résoudre les dilemmes et d'atteindre les compromis inhérents aux décisions de cette nature. La séance d'information du début et les

interventions de spécialistes de la médecine tout au long du dialogue ont été fort précieuses pour ce qui est de munir les participants des renseignements les plus à jour afin d'éclairer leurs choix.

L'examen des échanges qui ont eu lieu au cours des sept séances de dialogue avec les citoyens fait ressortir des objectifs et des valeurs partagés qui ont souvent été formulés comme points de convergence sur lesquels les participants ont été appelés à se prononcer. D'autres objectifs et valeurs se sont également dégagés vers la fin de la séance.

Les discussions qualitatives qui émanent du dialogue délibératoire ainsi que les données quantitatives provenant des sondages connexes constituent un solide moyen d'obtenir l'opinion des citoyens touchant la fourniture à des fins préventives d'antiviraux payés à même les fonds publics. Le sondage effectué lors du recrutement montre peu de différences entre la population des régions où se sont tenus les dialogues, d'une part, et les participants aux séances de dialogue, d'autre part. Bien que les résultats des séances de dialogue (ainsi que les résultats quantitatifs) apparaissent par grappes (puisqu'ils proviennent de sept centres), ils font voir une cohérence encourageante et qui permet de penser que les observations correspondent sans doute assez bien aux points de vue de la majorité des Canadiens quand l'occasion leur est donnée de réfléchir à ces questions.

Résultats

De façon générale, les participants ont jugé bon que les gouvernements entreprennent de fournir des antiviraux à des fins préventives, en vue d'atteindre trois objectifs qui leur ont paru importants : assurer le fonctionnement des services essentiels, réduire au minimum la peur et la panique parmi la population et (en partie grâce à l'atteinte des deux premiers) réduire les maladies graves et les décès lors d'une pandémie. Le soutien à cet égard provient surtout des séances avec des citoyens (le groupe de Vancouver y a donné un appui plus mitigé), et il s'avère le plus faible parmi les participants qui représentaient les groupes cibles et les intervenants (dont l'appui était plus variable). Les personnes en faveur d'un programme semblable étaient d'avis que si les gouvernements avaient les moyens d'atteindre ces objectifs, ils devraient les prendre afin de protéger les citoyens.

Si la question des personnes devant bénéficier en priorité des antiviraux a été vivement débattue, le choix qui s'est imposé (et qui a été le plus facile à prendre pour les participants) a été celui des travailleurs de la santé qui sont en contact étroit avec les malades, en tant que groupe qui aurait le plus besoin de défense en cas de pandémie et qui serait le plus exposé au virus à cause des professions exercées. La nécessité d'accorder ou non aux membres de leur famille la même protection a aussi été fortement débattue, de même que celle de fournir des antiviraux aux travailleurs de la santé qui ne sont pas en contact étroit avec les malades. Pour ce qui est des membres de la famille, les plus en faveur ont fait valoir les mêmes considérations, c'est-à-dire la nécessité que les travailleurs de la santé soient disponibles et en forme lorsqu'on aura besoin d'eux, si bien que le devoir de protéger les travailleurs de première ligne doit donc s'étendre aussi aux membres de leur famille qu'ils exposeraient au danger à cause de leur travail. En ce qui concerne les travailleurs de la santé qui ne sont pas en contact étroit avec les malades, les participants en faveur de les protéger ont fait valoir que ces personnes seraient exposées dans leur milieu

de travail et que, compte tenu de l'interdépendance des tâches dans les hôpitaux (et tout établissement de santé), il faudrait protéger toutes les personnes exerçant ces professions.

La nécessité de procurer des antiviraux aux travailleurs des services essentiels a aussi suscité la discussion. Beaucoup de participants ont soutenu que les gens qui exercent ces fonctions doivent être protégés si l'on veut que la société continue à fonctionner, tandis que d'autres ont fait valoir que la chose ne serait peut-être pas nécessaire étant donné le taux d'absentéisme et l'intervalle du risque maximum attendu avant qu'un vaccin ne soit disponible. Même parmi les personnes en faveur, il a été souvent question de limiter la fourniture d'antiviraux aux seuls travailleurs ne pouvant être remplacés, et uniquement pour les fonctions qui seraient les plus cruciales. La divergence était encore plus marquée en ce qui a trait aux services essentiels, certains parlant de nécessité alors que d'autres étant d'avis, ici encore, que le taux d'absentéisme n'est pas assez grave pour que la prévention devienne cruciale, étant donné qu'il y aurait des antiviraux de disponibles pour soigner les gens et que des vaccins seraient disponibles après un certain temps. Il y a lieu de souligner que la distinction entre situation d'urgence et services essentiels ne ressortait pas toujours dans un certain nombre de séances.

Les plus vulnérables, notamment les enfants, les pensionnaires des établissements, les malades chroniques et les personnes âgées ont souvent été cités comme membres du troisième groupe le plus susceptible d'être protégé, mais la question de ces candidats potentiels a suscité divers arguments et des divergences d'opinion quant à la nécessité pour eux de cette méthode de prévention et quant aux considérations pratiques entourant l'identification de ces personnes et la possibilité de leur fournir les médicaments de façon efficace et en temps opportun (considérations qui n'ont pas été jugées importantes pour les autres groupes).

À propos des groupes prioritaires, toutes les discussions ont eu pour point central l'équilibre délicat à atteindre entre les considérations touchant la gravité de la maladie et le chambardement provoqué dans la vie des Canadiens (sur les plans individuel et social), la difficulté d'établir qui sont les plus vulnérables et les personnes les plus précieuses, ainsi que l'efficacité, le coût et les effets secondaires des médicaments. Dans la plupart des séances et en ce qui concerne bon nombre des groupes prioritaires étudiés, certains ont fait valoir qu'il fallait restreindre l'utilisation des antiviraux à des fins préventives au plus petit nombre de personnes nécessaire pour protéger le mieux possible la société contre la maladie et les bouleversements. Dans quelques séances (mais non toutes, loin de là) la discussion a aussi porté sur la nécessité de prévoir l'utilisation d'antiviraux à des fins préventives pour la période de temps la plus courte et la plus stratégique (i.e., qui ferait le pont entre le début d'une pandémie et le moment où un vaccin deviendrait disponible, voire moins longtemps encore).

Ainsi qu'il est devenu évident au cours des dialogues, la planification en cas de pandémie et la mise à exécution d'un plan sont des domaines où l'on s'attend à ce que le gouvernement fasse preuve de leadership et où le public a de fortes attentes à l'égard du gouvernement. Le public estime que les gouvernements sont bien placés pour lui communiquer de l'information au sujet d'une pandémie et pour orienter les individus. On préfère de beaucoup confier aux gouvernements le soin de surveiller les réserves d'antiviraux à des fins préventives, tant parce qu'ils sont en mesure d'obtenir des prix avantageux en raison

des économies d'échelle (argument lié à la question d'efficacité) que parce qu'on a davantage confiance en eux, ainsi que certains l'ont simplement affirmé, pour ce qui est d'assurer une répartition équitable et judicieuse (par opposition à un processus moins bien réglementé et assumé par des particuliers ou le secteur privé).

Par contre, dans toutes les séances de dialogue, des participants se sont dits inquiets du processus de prise de décisions en matière de distribution. S'il doit y avoir des bénéficiaires prioritaires, qui décidera de qui il doit s'agir? Les participants ont eu eux-mêmes énormément de difficulté à définir les bénéficiaires et à établir un ordre de priorité. Ils se sont demandé comment feraient en fin de compte les responsables pour décider de la « valeur » de divers groupes de citoyens, de même que des risques pour les gouvernements au moment de prendre ces décisions. Les participants étaient très sensibles aux enjeux éthiques de la question et certains se sont demandé si les bienfaits des antiviraux pourraient faire contrepoids au bourbier qui pourrait en résulter. Le besoin de cohérence a été un thème central dans la plupart des séances. Les gens insistent pour que les décisions soient les mêmes partout au Canada, (p. ex., si les travailleurs de la santé doivent avoir la priorité, que ce soit partout la même chose). À cet égard, la seule nuance tient à la possibilité que les fournisseurs de services puissent être différents d'un endroit à l'autre (p. ex., comme il n'y a pas beaucoup de médecins de famille à Iqaluit, ce sont les infirmières praticiennes qui rédigeraient les ordonnances, de sorte qu'il faudra peut-être un peu de souplesse pour établir quels seront les membres des groupes prioritaires, en vue d'assurer un service et une protection uniformes lors d'une pandémie).

Insistance constante et de premier ordre sur l'éducation du public et la nécessité de poursuivre la recherche

En bout de ligne, il faut que la fourniture à des fins préventives d'antiviraux payés à même les fonds publics et que la désignation des groupes qui les recevront en priorité suscitent la confiance et l'approbation de l'ensemble des Canadiens. Le cadre de référence pour la prise de décisions, issu des dialogues avec les citoyens, met l'accent sur les valeurs suivantes : faisabilité/efficacité/pragmatisme; justice et équité; compassion; sollicitation/sensibilisation du public; rôle du gouvernement (l'option d'un rôle réduit au minimum n'étant pas viable en l'occurrence).

En ce qui concerne la sollicitation et la sensibilisation du public, chacune des séances a abordé certains thèmes qui montrent à quel point la compréhension, l'acceptation et le soutien de la population dépendent d'une bonne communication à propos des enjeux. Les citoyens de toutes les régions s'entendent sur l'importance de tenir les Canadiens au courant de la situation, message qui a été formulé dans le vif des discussions et sur lequel les participants sont revenus dans leurs mots de la fin. La question de l'éducation du public a quant à elle été soulevée dans des contextes nombreux et variés. Les participants jugent nécessaire, avant même que survienne une pandémie d'influenza, de faire de l'éducation touchant la planification, les mesures préventives ou de santé publique en général et la préparation individuelle à une situation d'urgence.

Les citoyens ont également parlé de l'éducation du public durant une pandémie d'influenza. Beaucoup de participants ont insisté sur la nécessité de faire de l'éducation afin de calmer les esprits lors d'une pandémie, le recours à l'information et à la sensibilisation du public devant servir de moyen pour éviter les bouleversements sociaux en période de crainte et d'incertitude.

L'éducation du public est aussi apparue comme moyen de s'assurer que la population comprend et appuie la décision de faire des réserves d'antiviraux qui seront distribués à des fins préventives à certains groupes prioritaires – c'est-à-dire comme moyen de faire accepter la stratégie de distribution des antiviraux. Les objectifs et les valeurs qui ressortent du dialogue donnent une bonne idée des justifications d'un plan d'action capables de convaincre les citoyens dans ce domaine – p. ex., la fourniture d'antiviraux payés à même les fonds publics, inspirée par un souci d'efficacité, d'équité et de compassion. Les résultats des séances de dialogue révèlent une insistance sur le thème de la cohérence – si l'on s'entend, par exemple, sur la priorité à accorder aux travailleurs de la santé en tant que premiers bénéficiaires, on estime important de retenir le même critère dans toutes les régions (tout en accordant un peu de souplesse aux régions rurales ou éloignées ou dans le cas d'une stratégie pour cause d'épidémie). De même, les participants s'opposent de façon générale aux inégalités fondées sur le revenu. Le dialogue indique également des domaines où il convient de tenir compte raisonnablement des préoccupations des citoyens (comme l'efficacité et la sécurité).

Une dernière incidence se dégage des séances de dialogue, soit celle de la sécurité et de l'efficacité des antiviraux. Au fil de la discussion, bien des participants ont posé au sujet des antiviraux des questions pour lesquelles il n'existe pas, pour l'instant, de réponses définitives. La recherche à ce sujet est encore très rare et l'expérience touchant l'utilisation d'antiviraux lors d'une pandémie est, bien entendu, inexistante. Dans leurs propos de la fin, beaucoup de participants ont exhorté les chercheurs à réaliser des progrès significatifs en matière de sécurité et d'efficacité des antiviraux afin de renforcer la confiance des décideurs et de la population en général dans le caractère adéquat des antiviraux à titre préventif.

Rôle important du gouvernement

Dans toutes les séances, l'un des thèmes sous-jacents a été le rôle important que les gouvernements doivent jouer afin de planifier, de coordonner, d'éduquer le public, de faire de la recherche et de collaborer avec d'autres intervenants pour pouvoir affronter une pandémie. Au fur et à mesure de la description des résultats, le lecteur du présent rapport va constater, exprimé de façon plus implicite qu'explicite et émis aussi bien par les citoyens, les intervenants et les membres des groupes cibles, l'argument selon lequel il est important pour le gouvernement d'exercer le leadership, et de montrer qu'il l'exerce, en matière de préparation en vue d'une éventuelle pandémie (tant en ce qui concerne l'utilisation prophylactique d'antiviraux que la planification générale en cas de pandémie).

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1. INTRODUCTION

1.1 RESEARCH CONTEXT

In February 2004, the Government of Canada and provincial and territorial jurisdictions developed the Canadian Pandemic Influenza Plan for the Health Sector. The Plan outlines a strategy to deal with the impact and implications of a potential influenza pandemic. The goal of pandemic preparedness, as outlined in the Plan is, first, to minimize serious illness and overall deaths, and second to minimize societal disruption among Canadians as a result of an influenza pandemic. Canada's Pandemic Influenza Plan is comprehensive, including many strategies to prepare for a pandemic such as basic prevention measures (e.g., handwashing and cough etiquette), early detection and monitoring, other public health measures, and vaccines. The use of antivirals for *treatment* in a pandemic is an important component of Canada's pandemic planning. Currently, the country's National Antiviral Stockpile is sufficient for treatment of the number of influenza cases expected during a moderate to severe pandemic (55 million doses). At this time, a national policy recommendation is being developed on the *prophylactic (preventative)* use of antivirals during a pandemic.

The use of antivirals for prevention is quite new and is still the subject of considerable debate. Experience with the use of antivirals for prevention is limited, though the available evidence shows that antivirals may be used effectively for prevention and thus to minimize occurrences of the illness and to curb outbreaks. There are, however, possible risks in the use of antivirals for prevention (e.g., safety, side effects) and there are implications for social and economic costs as well.

The development of a national policy recommendation on antivirals for prevention is the responsibility of the Public Health Network (PHN). The PHN is a pan-Canadian mechanism that facilitates collaboration on public health issues across provincial, territorial and federal jurisdictions. The process to arrive at recommendations and options for a national policy on antivirals for prevention includes national consultations with citizens, as well as other components such as information from scientific, legal, economic and ethical experts.

The Council of the PHN, through the Public Health Agency of Canada, has commissioned the current public consultation to help to inform their recommendations. Specifically, the purpose of the consultation is to foster a dialogue among randomly-selected citizens to develop and prioritize potential decision options on the use of antivirals for prophylaxis. The dialogue process offers a way to gain insight into citizens' values and the "common ground" developed on the use of antivirals for prevention when given the opportunity to learn about the issues and reflect on and discuss them. These common views, values and priorities regarding the use of antivirals will provide a reference framework that all governments can use to develop a national policy recommendation in this area.

1.2 DIALOGUE PROCESS

The dialogue process is significantly different from more traditional qualitative research designs in that it focuses on having Canadians from different walks of life learn and then work through, with each other, the pros, cons and trade-offs associated with different courses of action. In the current context, dialogue participants were assembled to provide direction on the specific issue of the use of antivirals for prevention during an influenza pandemic. During the dialogue session, participants were not asked to provide views related to technical subject matter, but to discuss and develop common ground about the values, principles and conditions that could guide decision-makers in making a national policy recommendation in this area.

It is important to ensure that a wide diversity of people are recruited for these dialogues that take place across the country. The premise is that these sessions should provide people living in different regions and different types of places (i.e., rural versus urban), with different socioeconomic backgrounds, an opportunity to come together and talk about the issue at hand. Since people from different places are likely to have different experiences, this coming together challenges them to think of solutions that address their different experiences.

Participants were sent an information package in advance of the dialogue to provide background and help frame the discussion. Each session took place over the course of a Friday evening (information session) and a full Saturday (the dialogue). An overview of the broad agenda of the two days is as follows:

- Day 1 Evening (6:30 pm - 9pm)
  - Welcome and Opening
  - Participant Introductions
  - Pre-dialogue Questionnaire
  - Presentations: Learning About Pandemics and the Use of Antivirals (made by a provincial Medical Officer of Health)
  - Discussion and Questions
- Day 2 (9am - 4:30pm)
  - Overview of the Process
  - Discussion: Personal Experiences of a Public Emergency
  - Dialogue Using Three Approaches: On what basis should publicly funded antivirals for prevention be provided during an influenza pandemic?[1]

[1] Participants were instructed to think of the approaches as tools for dialogue (not mutually exclusive policy options).

APPROACH # 1: MINIMIZE SERIOUS ILLNESS AND DEATH
Minimize serious illness and death by providing antivirals for prevention to take care of the most vulnerable

APPROACH # 2: KEEP SOCIETY FUNCTIONING
Maintain basic health, social and economic functions by providing antivirals for prevention to essential workers

APPROACH # 3: MINIMIZE GOVERNMENTS' ROLE
Trust institutions and individuals to make their own decisions about whether or not to stockpile for prevention

* For all approaches, the following assumptions apply: Publicly funded antivirals for treatment will be available for anyone who requires them; it will take at least six months to produce sufficient vaccine and immunize all Canadians because production of vaccine can only begin after the particular influenza virus is known; it would not be feasible to give antiviral drugs for preventive use to all 33 million people in Canada; and the pandemic will be of moderate severity.

- Lunch
- Elaboration of "Common Ground" (shared values and views that could guide decision-making)
- Identification of Priority Recipients for Antivirals for Prevention
- End of Dialogue Questionnaire
- Final Considerations: Should the government be funding antivirals for prevention in a pandemic? If so, should the government be stockpiling now? What else do governments need to consider in making a decision about whether or not to provide publicly funded antivirals for prevention?
- End of Day Questionnaire
- Closing Comments – Participants
- Closing Comments – Facilitators and Hosts
- Evaluation Form

A copy of the information workbook sent to participants in advance of the dialogue can be found in Appendix A. It should be noted that the advance copy of the workbook did not include a description of the approaches, which was provided, in a fuller version of the same workbook, at the education portion of the dialogue. A copy of the facilitator's script used for the sessions can be found in Appendix B.

The target group and stakeholder sessions followed a very similar process. Because of larger numbers of participants, however, the actual dialogue was conducted in two concurrent and parallel sessions. Participants attended a common presentation and were all given the same opportunity to pose questions and hear answers and explanations. Participants were then assigned to one of two dialogue sessions, each with a facilitator, note-taker, and resource person to respond to questions. A participant delegate was then asked to present a synopsis of the dialogue results back in the plenary session as a last tie up to the exercise. Effort was made to ensure that there was a reasonable balance of health care and non-health care representatives in each dialogue.

This splitting out of dialogue sessions afforded an interesting opportunity to see how groups of similar composition could independently arrive at similar or different conclusions, depending on the course that the discussion took, emphasis placed on certain considerations and so on.

1.3 Description of Citizen Participants

Citizen dialogue sessions took place in Halifax, Toronto, Winnipeg and Vancouver in November/December 2006. There was also a session in Edmonton (First Nations people on-reserve) and one in Iqaluit in January 2007, followed by one in Montreal in February, for a total of seven sessions. Halifax was used as the pilot, which was attended by the three facilitators who led the seven sessions, a representative from EKOS Research Associates, as well as representatives from the Public Health Agency of Canada (who would also observe most of the sessions) and provincial representatives. The pilot session was used to examine the process and potential need for changes prior to conducting the remaining six sessions. Some small changes were made as a result of this initial testing and implemented in the other six dialogues.

A total of 160 citizens participated in the citizen dialogues. Each session was attended by roughly 20 to 25 participants, randomly recruited to be representative of the region, according to gender, age, income and education level. While most participants came from within commuting distance of their respective centres, some were drawn from other parts of the province, and adjacent provinces and territories. Following is a table of where participants were drawn from for each session.

Table 1.1: Regional Distribution for Recruitment by Session

Halifax Nov. 17-18/2006	Winnipeg Nov. 24-25/2006	Toronto Nov. 24-25/2006	Vancouver Dec. 01-02/2006
23 participants attended	24 participants attended	21 participants attended	20 participants attended
CITY BREAKDOWN	**CITY BREAKDOWN**	**CITY BREAKDOWN**	**CITY BREAKDOWN**
Halifax, NS	Winnipeg, MB	Hamilton, ON	Surrey, BC
Dartmouth, NS	East Selkirk, MB	Waterloo, ON	Langley, BC
New Minas, NS	St. Andrews, MB	Oshawa, ON	Vancouver, BC
Kings County, NS	St. Clement, MB	Sarnia, ON	Victoria, BC
Maitland, NS	St. Paul, MB	Toronto, ON	Prince Rupert, BC
Walton Hamts County, NS	Portage La Prairie	Bolton, ON	Coquitlam, BC
Eastern Passage, NS	Lorette, MB	Orangeville, ON	Richmond, BC
Fredericton, NB	Brandon, MB	Etobicoke, ON	Burnaby, BC
Riverview, NB	Thompson, MB	Acton, ON	Edmonton, AB
Charlottetown, PEI		Scarborough, ON	Calgary, AB
St. John's, NF		Mississauga, ON	Whitehorse, YK
		Barrie, ON	
		Maple, ON	
		Holland Landing, ON	
		East York, ON	

Edmonton Jan. 12-13/2007	Iqaluit Jan. 26-27/2007	Montreal Feb. 16-17/2007
25 participants attended	22 participants attended	25 participants attended
CITY BREAKDOWN	**CITY BREAKDOWN**	**CITY BREAKDOWN**
Morley, AB	Iqaluit, NT	Montreal, QC
Calgary, AB	Kimmirut, NT	St. Leonard, QC
Morinville, AB		Anjou, QC
Hythe, AB		Sherbrooke, QC
Hobbema, AB		Gatineau, QC
West Vancouver, BC		Quebec City, QC
North Vancouver, BC		St. Lazare, QC
Vancouver, BC		Pierre-Fond, QC
Delta, BC		Chicoutimi, QC
Fort Qu'Appelle, SK		Longueil, QC
Paskwa, SK		Rimouski, QC
Balcarres, SK		Vaudreuil, QC
Edenwolb, SK		
Beaver Creek, YK		
Teslin, YK		

Two dialogue sessions were also held with each of stakeholders and target group participants in January. As noted earlier each set of two included a common presentation and question and answer period, as well as an opportunity to report the results of the dialogue back to the larger group, however, the actual dialogues were conducted independently. With regard to the target group sessions, a total of 60 individuals working in a range of occupations that could potentially be targeted for antivirals were recruited. Roughly half came from the health sector and half came from a range of emergency or essential service categories. Of those recruited, 48 attended. A full listing of the target group occupations, along with the number of individuals recruited and who attended can be found in Appendix G. Individuals working in target group occupations were asked to attend the dialogue representing their own point of view, as an individual working in a particular occupation, not as a representative of a particular organization.

Among stakeholders, 60 representatives of a range of organizations were asked to participate, of which 28 stakeholder organizations participated in the dialogue. A full listing of attendees can be found in Appendix F. Of the 28 participants roughly two-thirds were from the health sector.

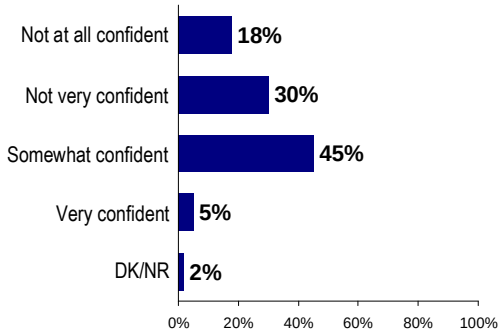
1.4 Survey Results – General Public (Recruitment Phase)

During the recruitment for the citizen sessions, all individuals invited to participate in a dialogue session were asked a series of questions including a few demographic items and a handful of attitudinal measures. Another 100 or so randomly selected residents from each centre were also asked these questions in order to establish the representativeness of those invited in comparison to a wider group of citizens. While participant responses showed a reasonable reflection of the wider group of citizens in terms of basic demographic measures, there were noted differences between those who were recruited and the general public in terms of attitudes described throughout this section. Detailed results are provided in Appendix D.

Overall, as captured in the recruitment stage, the views of citizens' in regional centres on government preparedness for a public health emergency are mixed. While few are very confident (five per cent), 45 per cent say they are somewhat confident in government emergency preparedness plans. The remainder are not very confident (30 per cent) or not at all confident (18 per cent). There are only slight and not statistically significant differences between dialogue participants and non-participants (in the order of four percentage points).

Confidence in Government

"In general, how confident are you that governments are well-prepared for a public health emergency?"



EKOS Research Associates Inc.

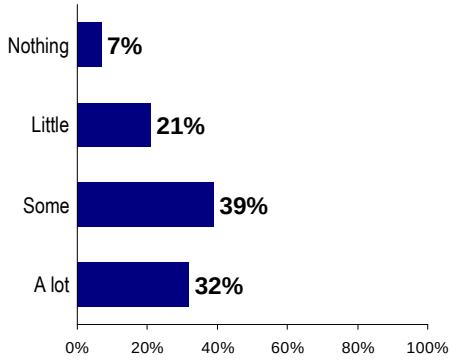
n=939

Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

Most regional centre citizens indicate at least some exposure to information about an influenza pandemic. About one in three (32 per cent) have seen, heard or read a lot about the subject and another 39 per cent indicate they have heard something. One in five (21 per cent) have heard little and only seven per cent say they have heard nothing. Again, differences between participants and non-participants with respect to these ratings are minimal (though dialogue participants are slightly more apt to indicate having heard "little" about an influenza pandemic).

Exposure to Information About Pandemic

"How much have you seen, heard or read about an influenza pandemic; that is, an influenza virus that quickly spreads worldwide, causing illness among many people at once? Would you say...?"



EKOS Research Associates Inc.

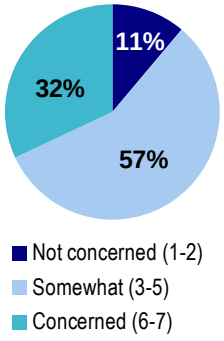
n=939

Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

Regional centre citizens most often indicate being somewhat concerned about the issue of an influenza pandemic (57 per cent responded 3, 4 or 5 on a 7-point scale). However, one in three (32 per cent) say they are quite concerned (6 or 7 on a 7-point scale), while only one in ten are not concerned (responded 1 or 2 on a 7-point scale). Dialogue participants are slightly more likely to indicate being quite concerned (39 per cent compared to 30 per cent of non-participants).

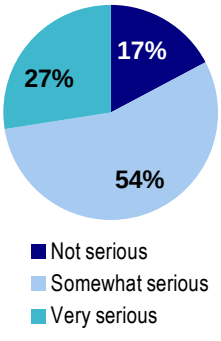
Perceived Risk of Pandemic (I)

"How concerned would you say that you are about the issue of an influenza pandemic?"



Not concerned (1-2)
Somewhat (3-5)
Concerned (6-7)

"How serious of a health risk do you think that an influenza pandemic is for Canadians today? Would you say...?"



Not serious
Somewhat serious
Very serious

EKOS Research Associates Inc.

n=939

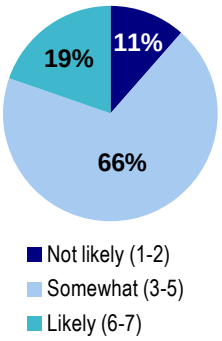
Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

In terms of the seriousness of the health risk of an influenza pandemic for Canadians today, 27 per cent of regional centre citizens think the risk is very serious and 54 per cent say somewhat serious. A smaller proportion (17 per cent) say this risk is not very or not at all serious. Results for dialogue participants are no different than they are for non-participants.

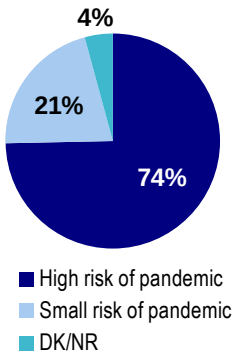
One in five regional centre citizens (19 per cent) think it is quite likely that Canada will be affected by an influenza pandemic in the next five years (responded 6 or 7 on a 7-point scale). Two-thirds (66 per cent) believe a pandemic is somewhat likely in the next five years (responded 3, 4 or 5), while one in ten say it is not likely (responded 1 or 2 on a 7-point scale). Results are essentially the same for participants and non-participants.

Perceived Risk of Pandemic (II)

"How likely do you think that it is that Canada will be affected by an influenza pandemic in the next five years?"



"I am going to read two statements and ask you to tell me which one most closely reflects your own point of view…?"



EKOS Research Associates Inc.

n=882

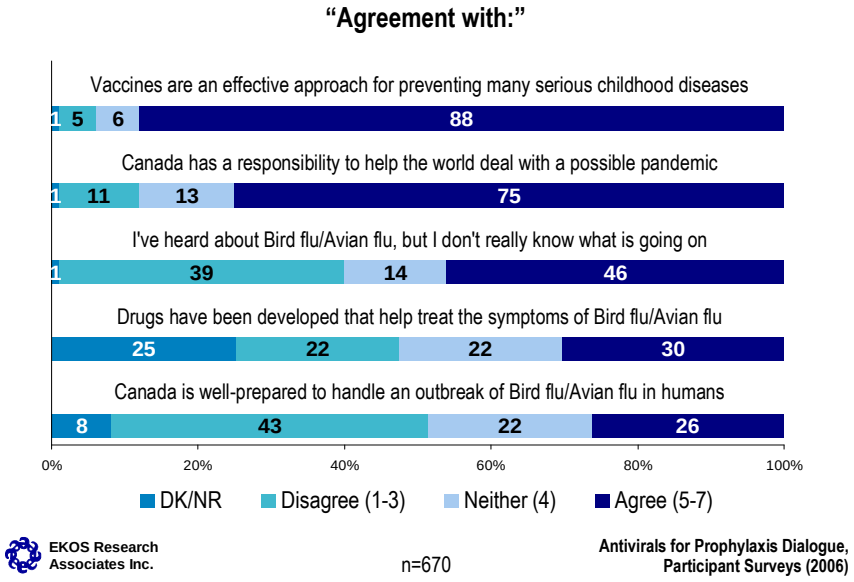
Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

In terms of priority of the issue for government, respondents were read two statements and asked to choose which one more closely reflects their own views: "I believe the risks to Canadians of an influenza pandemic are quite serious and a national program to deal with a pandemic should be a high priority for governments" or "I believe the risks to Canadians of an influenza pandemic are quite small and a national program to deal with a pandemic is not very important". The majority of regional centre citizens (74 per cent) indicate that the former statement more closely reflects their own point of view compared to 21 per cent who chose the latter statement. On this item, the response of dialogue participants and non-participants is virtually the same.

The recruitment survey included a battery of agree/disagree statements that further examined regional centre citizens' knowledge levels and views about an influenza. Briefly:

- Self-assessed knowledge levels about Bird flu/Avian flu are mixed, with 46 per cent of respondents agreeing that "I've heard about Bird flu/Avian flu, but I don't really know what is going on", while 39 per cent disagreed with the statement. Results for participants and non-participants are the same.
- Knowledge levels about the availability of drugs to treat the symptoms of Bird flu/Avian flu are limited: 30 per cent agree that such drugs have been developed, 22 per cent disagree, 22 per cent indicated they were neutral and 25 per cent said they don't know. Results for participants and non-participants are the same.
- Many respondents expressed doubts about Canada's public health emergency preparedness: 43 per cent disagree that "Canada is well-prepared to handle an outbreak of Bird flu/Avian flu in humans". One in four agreed with the statement and 22 per cent were neutral. Dialogue participants are somewhat more likely to be neutral on this issue compared to non-participants (not statistically significant, however).
- The majority of citizens (75 per cent) in the centres where the dialogues were held agree that "Canada has a responsibility to help the world deal with a possible pandemic". A minority (13 per cent) was neutral and 11 per cent disagreed with the statement. No differences exist between the two groups.
- A strong majority of regional centre citizens (88 per cent) agree that "vaccines are an effective approach for preventing many serious childhood diseases". Again, results are the same for participants and non-participants alike.

Perceptions of Bird Flu



So, while citizens have some sense of a looming emergency with regard to Avian flu, they don't really feel well informed about how well prepared Canada is to deal with Avian flu (with drugs or otherwise). They do, however, believe that Canada has a strong role to play, even on the international stage with regard to combating the disease. They are also generally sold on the efficacy of vaccines for a range of illnesses.

In terms of engagement indicators and socio-demographic variables, dialogue participants are very similar to other residents of their community who were contacted but declined to participate. Rated levels of personal interest in public policy and government affairs are virtually the same, and participants and non-participants were about equally likely to agree that "we could probably solve most of our big problems in Canada if ordinary people had more say in decisions". Dialogue participants do, however, indicate a somewhat higher degree of involvement in their community than non-participants (considering community-based groups, schools or religious institutions).

Considering socio-demographic indicators, dialogue participants are somewhat more likely to be women and are less apt than non-participants to have less than a high school education. Older individuals (65 years and over) are somewhat underrepresented among dialogue participants, as are persons with a disability.

About half of regional centre citizens indicate that they typically get a seasonal flu shot (a virtually equivalent proportion of dialogue participants and non-participants). Four in ten regional centre citizens (42 per cent) have been directly affected for a period of time by a public emergency such as the Ice Storm, forest fire or flood.

1.5 Citizens' Initial Thoughts About Pandemic Influenza

In their opening comments (prior to the presentation by a provincial resource person, who was typically the Chief Medical Officer of Health for the hosting province or territory) participants were invited to introduce themselves and share an interest or concern they have on the topic of pandemics or antivirals. Many participants did not indicate any specific concerns, simply stating that they were pleased to be a participant in the dialogue, were eager to learn more and expressed a hope that they would be of assistance. The following table presents more specific themes raised in opening comments by participants across the sessions, and illustrates each theme with selected quotes. The themes are arranged in the table in order of the frequency, beginning with most frequent, that were cited across the seven sessions.

Theme Raised	Illustrative Quotes
Adequacy of current preparedness. Some participants expressed concerns and questions about Canada's current level of preparedness and whether our current health infrastructure has the capacity to meet additional demands during a pandemic.	"How are all levels of government going to manage to make policy decisions about closing down the schools and so on and how could we coordinate that fast enough to ensure we are as safe as possible?" (Winnipeg) "I would like to have an understanding of how much of a plan we have for today and how much we have a plan for tomorrow." (Winnipeg) "If a pandemic were to occur there wouldn't be any health care infrastructure to help cope with anything." (Vancouver) "One of the major issues is in terms of infrastructure. Everybody is saying: are we prepared and are we ready?" (Vancouver) "What sort of strategy in Canada do you have in place now? I know you tell patients they can come to hospitals. Do we have that in place for this?" (Toronto) "I would like to have more information to know how the people that are making the decisions for us are preparing in a proactive way for this epidemic or pandemic so that again it's not reactive and that we're ready for it and so that our society, our communities and our lives can be as easy as possible faced with the difficulties that are about to come about regardless if we agree about it or not." (Iqaluit) "My interest and concern with respect to virus and the pandemics that occur around the globe is that I think the federal government doesn't really look at it from a community level whereas in a community level you look at things from a community point of view when any disaster is a community

Theme Raised	Illustrative Quotes
	responsibility, meaning emergency preparedness, how well is Health Canada involved in emergency preparedness because if a pandemic ever occurs how well coordinated would that be if any pandemic arises? That's a question we should be asking, how prepared are we in that regard. Yes, if a pandemic occurs and we have the big majority of population affected and if the worst scenario happens and the victims are dead, beyond that how prepared are we?" (Iqaluit)
Distribution of antivirals/vaccines. A number of participants wondered whether the current stockpile of antivirals/access to the vaccine during a pandemic will be sufficient for all Canadians, and if not, who will be selected as priority groups and who will decide.	"My concern is the ethical dimensions on this question. The impact of who does and who doesn't get the vaccine." (Winnipeg) "What I would be mostly worried about is just if there would be enough for everybody if there was a national pandemic." (Vancouver) "My main concern is mainly timeframe and how long it is going to take and if there is enough for everybody." (First Nations) "My main concern is this antiviral medication or serum going to be developed fast enough to disperse to whomever and who gets first choice. Not only that but will First Nations be a priority. I guess that is the main concern I have." (First Nations) "Maybe some people won't get the stockpile of the drugs. If they are low income family will the government provide any financial support for them?" (Toronto) "Does Canada have enough antiviral drugs for everybody or who needs them?" (Vancouver)
Vulnerable populations. In their opening comments, several participants spoke about the need to protect vulnerable populations, for example, children and the elderly.	"Because I am a mother and a grandmother and I work for the school board, I am concerned about how this would affect students and the school system if anything like this happened." (Halifax) "There are so many young people today and the elderly. Who will get it first really? You kind of ask yourself and then how is it going to affect first nation's people. Are we going to be one of the first people to get the flu shot or are we going to be at the bottom of the list?" (First Nations) "I am described as an elderly, I am concerned with the triage concept, who decides and what do they do with people like me?" (Toronto)

Theme Raised	Illustrative Quotes
	"My big concern is for young children in that age range who might be affected by this whose entire lives lay before them." (Toronto) "How effective would this be, at what cost to the public, would this be mandatory to everyone, from what age to the time a child was born or to the elderly, and who would be the major decision maker, who decides who gets it and who doesn't?" (Toronto) "Mostly I'm concerned about children and we should focus more on the elders too. I think there is a lack of caring of our elders, that's my concern." (Iqaluit) "We are in an isolated area and when healthcare care is in trouble, its families and communities who suffer first, not healthcare providers and professionals." (Iqaluit)
Safety and efficacy. A number of participants raised their concerns about the safety of antivirals, to what extent they could be expected to work and the potential for development of drug-resistant viruses.	"The one issue about the use of antivirals would be…. could the cure be worse than the illness. Will we be fostering different strains of viruses?" (Vancouver) "Could we be dealing with mutations very quickly?" (Toronto) "My concern about the antiviral: what will be the side effects of using this medication? We don't know very much about how the medication reacts and there are some reports that people have even died from using this medication so that is what I would like to address." (Vancouver) "My concern is if there is an antiviral is it going to be effective because we are not sure what the strain of what kind of germ we are going to be fighting." (First Nations) "What is the consensus in the medical community and the scientific community about the development of resistance in the viruses?" (Halifax)

No similar initial introductory comments were made by stakeholders or target group participants in the four national sessions.

2. What Participants Told Us

In this chapter are a number of sections presenting the results from the dialogues and from the survey questionnaires. Results are divided into four sections following the flow of the dialogues: discussions of the three approaches, common ground, priority recipients and overall views about whether the government should provide publicly funded antivirals for prophylaxis or not. For each of these, results are presented first from the seven citizen sessions, and second, from target groups and stakeholders. In order to minimize repetition, results from target groups and stakeholders are presented in terms of overall similarities, as well as differences from the results of the citizen sessions (and are therefore more succinct.)

2.1 Dialogue Using Three Approaches

a) Citizen Session Results

The initial dialogue question posed to participants in the citizen sessions was: *"On what basis should publicly-funded antivirals for prevention be provided during an influenza pandemic?".* As indicated in the previous chapter, an important tool for the dialogue was for participants to review and discuss three different approaches to the provision of antivirals for prevention. Again, participants were advised that the approaches are not mutually exclusive and elements of different approaches may be combined. For each approach, citizens explored what they did and did not like, and considerations, dilemmas or trade offs within or among the approaches. A summary of comments across the dialogue sessions is presented below.

Table 2.1: Summary Reactions to Approaches from Citizen Sessions

Approach 1 - MINIMIZE SERIOUS ILLNESS AND DEATH	
Likes	A caring, values-based approach (compassionate, respectful). Oriented around people, not positions Pragmatic/proactive - helps contain spread and is easy to administer in institutional settings Efficient - addresses in prevention those who would otherwise need treatment. Also reduced burden to already stressed health care system ('an once of prevention is worth a pound of cure') Precludes private sector abuse of situation Government assumes its responsibility to care for the vulnerable (1 session)
Dislikes	Exclusive – leaves some people out (prefer universality) and potential for backlash among those left out Expensive if vulnerable are wide segment of population – big undertaking Shelf life consideration - possible waste of money Concerns for compliance and resistance Concerns for lack of information re: side-effects and long-term use Lack of information about who vulnerable groups are (won't know until pandemic and could be moving target) Concern for moral choices and who will make them Concern for narrow focus on drugs and symptoms – preference for more holistic and natural approach Impractical to administer to vulnerable populations outside institutions, e.g. children, elderly living at home, remote communities
Considerations	Flexibility as information becomes available Cannot diffuse focus on public education Side-effects, resistance Who makes decisions and potential for abuse/consistency of application (equality & fairness) Absolute cost is not a factor, but opportunity cost is Distrust government to hand it out efficiently. Preference for holding locally in communities (note that this was a general consideration – not particularly linked to a single approach)
Groups considered vulnerable	Front line health care workers Children Elderly Chronically ill Economically vulnerable/homeless Some mention of isolated, institutionalized, and day care workers/teachers Family members of HCW (1 session)

Approach 2 -- KEEP SOCIETY FUNCTIONING	
Likes	Efficient – front lines there for everyone else who gets sick (especially since health care system fragile) Protects social infrastructure – keeps things going Controls panic and fear – there's a plan Greatest expected compliance and least likelihood of resistance build up Protects those in the line of fire – those serving the public Easier to administer – employer (possible existing procedures in place for flu shot) Less costly – fewer people in this group
Dislikes	Difficulties in identifying who the "essential" are/list overly narrow for some Creates inequities (and room and motivation for abuse) – argument for more universal application Creates pressures on workers (e.g., families don't have it) and in society (creates classes of people) Will create fear and panic – some have and some don't Excludes vulnerable (e.g., elderly) and children Front line workers may already have it (through employer)
Considerations	Efficacy – will it work? Cost should not be a consideration More emphasis on public education Must define people/positions that are essential narrowly (consider positions not people) Setting a consideration for some (small and remote communities have little flexibility with small pool of HCWs) Possible extension to include family members Concerns regarding conditions (e.g., mandatory), but clear that HCWs, etc. would be expected to work if they are getting antivirals (principle of reciprocity – we'll protect you so you are there to serve us) Must communicate with public about who is getting antivirals and why
Groups considered	HCW, emergency and essential Teachers/daycare workers (1 group) Media (1 group)

Approach 3 - MINIMIZE GOVERNMENTS' ROLE	
Likes	Individual freedom to decide – personal control and willingness to take risk as safety of drug for long-term use is not certain Lack of government involvement – dictating decisions. 1 group argued for community control (keep antivirals in community and make independent/community-based decisions) Frees up government fund for other things-opportunity cost and doesn't subsidize private ventures, e.g. Utility companies
Dislikes	Strain on health care system-physicians Access an issue (cannot get in to see a doctor/some don't have doctors even before pandemic) Creates economic classes in society (concerns about fairness and equity) Makes it difficult to plan – results in inconsistencies Room for companies to abuse/profit (also some discussion about black market) Government needs to be seen to be playing a role – taking leadership No cost savings (cost per dose) More apt to result in chaos
Considerations	Need for more emphasis on education Make it available without a prescription Shelf life an issue More research is needed (e.g., side effects, efficacy, long term use) Lack of confidence in government ability to handle quickly and efficiently, and to provide quality supplies.

While the table summary reflects comments across the seven sessions, it is nonetheless useful to get a sense of the regional variation from session to session. The following is a high level synthesis of overall views about the approaches.

- *Halifax* – expressed appreciation for positive elements of all three approaches. Found Approach 1 very compelling and placed considerable value on the protection of the vulnerable and those less able to help themselves. Those with limited incomes were included as being economically vulnerable. In Approach 2 they focused on the pragmatic nature of keeping society functioning, particularly in the health care environment, given its fragile nature and the exposure that HCWs could face (and the duty to protect workers "in the line of fire". Approach 3 seemed to resonate somewhat less with most of the group, however, many agreed that (over and above the targeted publicly-funded antivirals) individuals and business should be able to make their own choices for their workers and that government cannot do everything.

- *Toronto* –Approach 3 did not resonate well with this group, that concerned itself with the creation of a two-tiered system of have's and have not's. They felt that government should take a lead in this area and saw the philosophies of both Approaches 1 and 2 as compelling. Although they expressed a strong appreciation for the value in protecting the vulnerable in Approach 1 (as well as the pragmatic argument that it would save on treatment and burden to the health care system later),

they did express concern for making tough moral choices about who is vulnerable and who is not and how and where to draw the line. In fact, this was one of the few groups to argue for a universal application of antivirals for prevention. The protection of workers in Approach 2 (particularly HCWs) seemed a reasonable and obvious course of action.

- *Winnipeg* – the three approaches each had merits for this group. Approach 1 and 2 were seen as compassionate, but also pragmatic and sensible ways of looking at priority recipients. For both approaches, participants argued that they should be expanded to include HCW and ESW (for Approach 1) and the most vulnerable (Approach 2). While they expressed appreciation for the merits of individual decision in Approach 3, they were concerned for the pressure that this would place on physicians (and the resulting access issue that it would create).

- *Vancouver* –participants in this group leaned toward Approach 2 as making the most practical sense to them, with the fewest concerns (although they did wonder about defining who is essential). They expressed appreciation for the compassionate and pragmatic elements of Approach 1, however, they also worried about costs, and compliance, as well as safety. Approach 3 seem to resonate best for this group when considered in conjunction with either Approach 1 or 2, but with concern for the potential to create have's and have not's with this approach.

- *First Nations* –tended to be more supportive of Approach 3 as the option that offered the most freedom to choose (which is a value that resonated well with them). In fact, they argued strongly that governments should make antivirals available at the community level so that local decisions could be made about dissemination and use. The also expressed appreciation for the value of protecting the vulnerable in Approach 1. While the practicalities of Approach 2 were seen as reasonable, the group focused on the difficulties that this would create in having some people/workers eligible for something that others were not, thereby creating inequities and social tensions.

- *Iqaluit* – participants indicated a strong positive response to the first approach which seemed to strike a chord with cultural values of treating the most vulnerable of society with care and respect and as reflecting Canadian values of compassion. Children were identified as a particularly important target group, given this region's young population. There was also broad approval for Approach 2 which was viewed as complementary to the first approach and, in fact, health care and emergency workers (and their families) were identified as an important vulnerable group within Approach 1 given the isolation, size and fragile nature of Nunavut communities. The expansive territory and remote locations also raised concerns for some about the logistics of moving medications. Approach 3 was viewed as reasonable only once target groups in Approaches 1 and 2 were covered, and within a context where economics would not dictate access.

- *Montreal* – Approach 1 resonated well in terms of being compassionate and caring for vulnerable members of the population, but was seen as costly and impractical to administer. Participants were uncertain whether there was sufficient evidence to support investment of public funds in this approach, with participants expressing concern that government would be acting in a manner that "looks good" but is not the most efficient or cost-effective. The second approach was seen to be more practical and easier to accomplish, and important in ensuring the continued functioning of the health care system in a pandemic situation. While participants felt strongly that HCW with direct patient access should have access to antivirals (and many felt that their families should also), they felt that identifying other groups to receive antivirals would be perceived as discriminatory and compromise public confidence in government, and that "essential" workers must be very narrowly defined (e.g., police could be replaced by army). The third approach did not resonate well with the values of participants, who felt that government would be abandoning its responsibility to its citizens (particularly those most in need), and who also believed that this approach would create chaos (such as in New Orleans in the aftermath of Katrina).

b) Stakeholder and Target Group Results

There is a remarkable degree of overlap between the reactions of citizens to each of the three approaches and those of stakeholders and target groups. The likes, dislikes and considerations raised by target groups and stakeholders are very similar to those raised by Canadian citizens. Like citizens, target groups and stakeholders express concerns regarding the ethics and moral dilemmas in decisions surrounding who will and will not receive antivirals within the first two approaches, while they appreciate the "compassion" and "pragmatism" evident in these two approaches that will help to limit the impact and burden of the pandemic. Like citizens, they also focus on the importance of public education and research regardless of the approach taken, underscoring the importance of prevention through hygiene, social distancing, etc. Target groups and stakeholders (like citizens) express concern with the potential for disparity and consistency under Approach 3, as well as disagreeing strongly with the responsibility placed on family physicians under this approach.

Target groups and stakeholders, however, focus more closely on issues surrounding the protection of health care workers. Target Group participants and some stakeholders would fall into the categories of health care workers, emergency workers or essential workers. They expressed very pragmatic concerns with respect to the protection of these groups within the approaches, to minimize the burden on the health care system and to maintain the functioning of society. At the same time, they identified concerns regarding the potential compliance with antivirals for prevention within these groups, noting that compliance with the annual flu shot is less than optimal. The value of stockpiling antivirals is brought into question if priority groups would be

unwilling to take them. Furthermore, under potential considerations they raise the need for some policies regarding those who refuse to take antivirals (e.g., limiting their exposure to patients) and those who do (e.g., commitment to continue working).

Target group members and stakeholders also brought up the issue of protecting the supply of antivirals under any approach which limits access to specific segments of the population. They also comment positively on the fact that Approach 3 ensures that the costs of antivirals for protection are shared by governments and the private sector (doesn't subsidize private industry).

A summary of the likes, dislikes, and considerations identified in target group and stakeholder sessions is provided in Table 2.2.

Table 2.2: Summary Reactions to Approaches from Stakeholder and Target Group Sessions

Approach 1 - MINIMIZE SERIOUS ILLNESS AND DEATH	
Likes	Very "Canadian", compassionate approach Targeted approach, efficient Focused on minimizing death and illness Focus on vulnerable will help reduce the demand they place on the health care system
Dislikes	Limited to vulnerable populations Limited approach may leave "have-not" segments of society at risk Decisions regarding who to target are difficult to make, may be influenced by social biases Logistics of distribution Does not necessarily protect health care workers
Considerations	Specific needs, vulnerable groups may vary by jurisdiction/context Impossible to determine who vulnerable groups will be in advance Important to protect security of supply if antivirals are limited to specific groups There is a concern that people may rely on antivirals for protection and become lax about other measures (e.g. handwashing) Must include focus on public education Potential compliance of different groups not known
Vulnerable Groups	Seniors – greatest users of health care system Health care workers – on front lines, have no choice regarding exposure – need to limit absenteeism Children - also recognized as being key spreaders of the virus Economically vulnerable

Approach 2 - KEEP SOCIETY FUNCTIONING	
Likes	Good disaster planning Focused on maintaining essential services Recognizes interdependence across sectors Protects those most needed in pandemic situation Will help to limit burden on health care system
Dislikes	Essential workers don't live in a vacuum – may need to care for ill family members Still limits availability of antivirals – ethics surrounding decision-making of who is to receive and not Social impacts/consequences of limiting availability
Considerations	Definition of essential services will be key. Should focus on essential needs and sectors/roles where a 25% absenteeism rate would make it impossible to deliver services How to ensure compliance with antivirals, and policies for those who refuse Need to combine with public education
Groups Considered	Health care workers Emergency workers Food distribution Essential workers linked to utilities Those working with children
Approach 3 - MINIMIZE GOVERNMENTS' ROLE	
Likes	Provides greater freedom to the individual Includes public research and education component Costs are shared by governments, private sector, insurance companies
Dislikes	Will lead to inconsistency, disparity American, not Canadian in nature Places physicians in gatekeeper role: they will be overwhelmed Potential that disadvantaged members of society (those without medical coverage, without GP) are at risk
Considerations	Not convinced that private sector will invest where government does not May lead to increased cost for antivirals (price not negotiated in bulk) Uncertain whether private organizations can be trusted to stockpile and use properly Inconsistency will make it harder to plan for emergency – may be more apt to lead to panic, fear, chaos

c) Survey Results

Prior to and following the dialogue, participants completed questionnaires asking them to rate their support for each of the three approaches. Both prior to and following the dialogues for all sessions (citizen, target group and stakeholder sessions), participants' rated support is highest for the second approach ("maintain basic health, social and economic function by providing antivirals for prevention to essential workers), which is consistent with discussions in

the dialogue sessions. Somewhat lower, but still strong support was obtained from citizens in the questionnaires for the first approach ("minimize serious illness and death by providing antivirals for prevention to take care of the most vulnerable") and quite muted for the third approach ("Trust institutions and individuals to make their own decisions about whether or not to stockpile for prevention"). The exceptions were First Nations and Quebec where support was higher for minimizing illness and death than it was for maintaining societal functioning. In fact, in the Quebec session, participants provided considerably lower ratings of support for maintaining basic functioning after the dialogue and considerably higher ratings of support for minimizing illness and death by the end of the discussion.

Support for the first approach is far lower among target groups and stakeholders, and support for the third approach is minimal among these groups. These results also reflect the tone and sentiment of the discussions. It is noteworthy, however, that First Nations were quite positive about the third approach in their discussions. They also rated the third approach somewhat more positively than citizens in other sessions did (although even among First Nations, support for this approach was modest).

Citizens' ratings of their support for the first and second approaches are quite similar pre- and post-dialogue (i.e., within seven percentage points for each response category, not statistically significant given the relatively small number of cases). Over the course of the day, however, already tepid support for the third approach at the outset of the dialogue waned even further (with a portion of responses shifting from moderately supportive to not supportive) by the end of the discussion. In fact, this approach lost ground in the level of support that it received in the post-dialogue questionnaire, even with First Nations participants (who were more supportive of this approach than other citizens). Results were also higher for this approach at the start of the Quebec session, but dropped considerably by the end of the discussion.

Similarly, support for all approaches is quite similar both pre- and post-dialogue among target groups and stakeholders, although the first approach did lose some ground among stakeholders between the pre- and post-dialogue surveys. This is also reflective of the discussions, in which stakeholders were more apt to vote against the use of antivirals for prevention at the end of the day.

Table 2.3: Level of Support for Three Approaches Pre- and Post-Dialogue

	CITIZENS			STAKEHOLDERS			TARGET GROUPS		
	Low/Modest	Medium	High	Low/Modest	Medium	High	Low/Modest	Medium	High
Approach #1: Minimize serous illness and death by providing antivirals for prevention to take care of the most vulnerable									
Pre-dialogue	23	30	44	43	21	21	31	38	24
Post-dialogue	22	28	41	53	21	11	37	31	27
Approach #2: Maintain basic health, social and economic functions by providing antivirals for prevention to essential workers									
Pre-dialogue	12	23	61	15	21	50	15	18	62
Post-dialogue	21	21	48	21	21	43	11	20	64
Approach #3: Trust institutions and individuals to make their own decisions about whether or not to stockpile antivirals for prevention									
Pre-dialogue	58	17	20	64	14	7	83	9	2
Post-dialogue	55	5	18	79	0	7	78	13	4

Following the main question of level of support for each approach participants were asked to indicate any considerations that they felt should be taken into account. Among citizens, for the approach related to minimizing serious illness and death most participants based their support on a requirement to contain the outbreak and prevent further spread of infection, while at the same time saving those most at risk by the pandemic. Many said that the application of antivirals should be concentrated in the hospitals (saving the weak and minimizing death), in particular among health care workers and staff, along with other front line workers, since they would be required to take care of the ill population along with those most vulnerable. Children and nursing homes were also cited, but with less frequency. As with other citizens, residents of Quebec focused on front line HCW, although there was a slightly greater emphasis on children and the elderly. As with other citizens (but perhaps even more so) Quebecers also emphasized the importance of further determining the efficacy and safety (long-term effects) of the antivirals.

Among citizens, support for maintaining basic health, social and economic functions was largely based on the rationale that health care workers would be needed to care for the ill, and secondly, that such essential service workers as police and firefighters would be required to keep society under control. Their continued need to work effectively when they were needed was cited as a primary reason, along with a responsibility to protect those who were most exposed to the virus (particularly given that the exposure would be "in the line of duty"). Full compliance with the required antiviral regiment was also noted by some as a consideration. Perhaps more than other citizens Quebec participants wished to see the distribution of antivirals narrowly contained to those in direct contact with the ill and felt that there was limited justification to extend this to other essential workers.

In terms of trusting institutions and individuals to make their own decision to stockpile or not, many of the citizens who were supportive said that people and/or institutions were responsible for their own health care. A number said that they were supportive of this approach because it would give people a sense of control and that it is better to be prepared if such an event were to occur. Some noted that education would be a primary condition if citizens would be asked to make their own decision. Some participants who were supportive of this approach, in Quebec for example, believed that this approach would spread the responsibility and costs for prevention across both the public and private sectors.

Of those citizens who were not supportive of this more independent approach, the reason most often given was the lack of fairness and general unequal access to the drugs that would result in some citizens (particularly those with less income) being left out, and a sense that this approach could lead to public chaos.

Among stakeholders and target groups who supported the first approach (minimizing serious illness and death by targeting vulnerable), the most important reason was to avoid strain on the health care infrastructure. Many in the target groups felt that efforts should be focused on vulnerable groups within institutions, and some in both the stakeholder and target groups noted

that a strong likelihood of patient survival should be a consideration. Other considerations included that potential groups (e.g., elderly, children, chronically ill) indeed prove to be vulnerable during the pandemic and that antivirals are found to be effective with these groups.

Support for the second approach – maintaining basic societal functions – was based on the need for HCWs and emergency workers to treat cases of influenza and to uphold normal health and societal operations during this period. A number of comments were directed toward the question of identifying priority or essential services or workers. Many in the stakeholder group held to the guideline of identifying sectors where a 25 per cent absenteeism rate over a six to eight week period could not be tolerated. Others noted that priority groups must be based on public consensus and include workers beyond primary care deliverers.

While the third approach received significantly less overall support from stakeholders and target groups, it was viewed as possibly complementary to the first two approaches and likely to occur to some extent whatever course of action the government chooses. Notably, several in the target and stakeholder groups noted the importance of educating individuals and physicians to make effective decisions about taking antivirals. Those who did not support the third approach raised their concerns about the potential for gross inadequacies and inequities in access to antivirals, with some predicting black market potential (low supply coupled with high cost). Others noted the potential for burden/pressure on physicians, lack of compliance monitoring and possible inappropriate usage of the drug. For some, the third approach was viewed as an approach lacking systematic and coordinated planning and therefore an ineffective response to the problem.

In a rank ordering exercise on the pre- and post-dialogue questionnaires, participants' ranking of the three approaches similarly gives greatest support to the second approach, followed by the first approach. Again, support for the third approach is lowest in the pre-dialogue ranking and falls further in the post-dialogue questionnaire (with 77 per cent ranking this a third choice).

Table 2.4: Ranking of Three Approaches Pre- and Post-Dialogue (All sessions)

Approach	Pre-Dialogue			Post-Dialogue		
	% ranking 1st choice	% ranking 2nd choice	% ranking 3rd choice	% ranking 1st choice	% ranking 2nd choice	% ranking 3rd choice
Minimize serious illness and death by providing antivirals for prevention to take care of the most vulnerable to reduce the number of Canadians who need to be hospitalized and decrease the risk of overload to the health care system	37	54	9	33	61	6
Maintain basic health, social and economic functions by providing antivirals for prevention to essential workers to reduce social and economic disruption in an emergency	54	36	10	57	36	6
Trust institutions and individuals to make their own decisions about whether or not to stockpile for prevention	9	25	66	7	16	77

n=160
Source: Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

Results reflect the input from citizens, stakeholders and target groups. Generally these results were similar across the three different types of participants. Citizens were generally more apt to rank minimizing illness as first or second order of preference, compared with stakeholders and target groups following the discussions. Target group participants were more apt than other participants to rank maintaining societal functions as a first order of preference, both before and after the dialogue. Target group participants were the least positive about approach three (minimizing government role) after the dialogue, compared with other participants.

2.2 Common Ground

a) Citizen Session Results

As citizen participants discussed the strengths and weaknesses of the three approaches, and worked through the dilemmas and trade offs among the approaches, common ground or shared values/principles emerged. Facilitators noted and presented the perceived areas of common ground on a flipchart and then tested the common ground with participants. Participants could modify, refine and prioritize their common ground as a group. The following table summarizes the common ground agreed to in each of the dialogue sessions.

Table 2.5: Dialogue Session Common Ground by Citizen Session

Dialogue Session	Common Ground
Halifax	1. Compassionate concern of vulnerable 2. Fairness/access 3. Practicalities/flexible/efficient 4. Public education (voted by group as top priority) 5. Effectiveness/economies of scale 6. Consistency of systematic approach
Toronto	1. Concern for both vulnerable and valuable (i.e. those providing a valuable service) 2. Fairness and equity 3. Agency (priority for government role) 4. Universal versus selective 5. Prevention as an insurance policy 6. Private sector-free enterprise will inevitably have a role in acquiring and distributing antivirals for prevention
Winnipeg	1. Moral obligation to the vulnerable – compassion 2. Priorize HCW and first responders (keep health care system functioning during pandemic and to continue to provide care to non-pandemic illness and injury) 3. Minimize fear and panic 4. Equity and fairness – access, affordability (including consistency in approach across the country) 5. Use of antivirals in outbreaks/institution-based approach (containment of the virus and practicality) 6. Priority on public education and information (connection made: public education as a vehicle to achieving #3 minimizing fear and panic)
Vancouver	1. Controlling panic and fear 2. Equity and equal access 3. Education – public (what are antivirals, why are some groups prioritized to receive prophylactic antivirals) 4. Antivirals for HCWs (to fulfil their duty of care) and to EW (to maintain a sense of normalcy) 5. Practical approach to vulnerable – possibly institution-based as a place to start as this is an extension of what we already do 6. Flexibility in settings (e.g., giving consideration to the setting – example comparing the role of HCWs in a small community where there are few of them with a larger centre where the human and infrastructure resources are more extensive) 7. Need for more research

Dialogue Session	Common Ground
Edmonton (First Nations)	1. Caring about others both in communities and across Canada 2. Maintain society's priorities of fairness, equity and equal access 3. Support prevention of illnesses 4. Emphasize priority populations such as children, vulnerable groups, health care workers and others 5. Education and awareness of the pandemic flu, antivirals and the need to begin planning for an outbreak 6. Distrust that the system will work for First Nations 7. Need for a First Nations perspective 8. Costs should not be a key consideration if government has the funds available
Iqaluit	1. Strong value about taking care of the vulnerable 2. Strategy should slow the spread and help with containment and also promote other preventative measures 3. There should be reciprocity – therefore protect Health Care Workers (HCWs) and Emergency Workers (EWs) because we need to rely on them 4. Another strong value - Protect Caregivers 5. Should be a proactive approach not just reactive– 3 approaches are inter-related 6. Take psychological and social dimensions into consideration – Short Term and Long Term 7. Children are a #1 priority 8. Tailor approach to Nunavut and the communities
Montreal	1. Universal, timely access to health care is the most important principle which should guide the government in the management of the health care system, and cannot be compromised 2. Governments are responsible for vulnerable members of society 3. Public education programs are vital to explain how and why antivirals will be used and to increase knowledge of other prevention tactics (e.g., handwashing) 4. Public education must go beyond media campaigns to engage Canadians in communication through schools, workplaces, meeting places 5. Public funds must be invested based on the most effective and efficient manner possible, and not based on public opinion or popular demand. This principal (effectiveness) is not contrary to values of equity and social justice 6. Any plan should be flexible and adaptive to change (necessitating cooperation between government, private sector and society) 7. We cannot ask HCW with direct access to patients to place themselves at risk without providing them with access to protection from antivirals 8. Young children are a priority for ethical (they are vulnerable) and practical (a key source of transmission) reasons 9. The private sector has a role to play in prevention, although the primary responsibility and leadership must reside with the public sector

b) Target group and Stakeholder Results

Target group and stakeholder participants tended to place even more emphasis than citizens did (although all citizen sessions did) on pragmatic elements, focusing on the continued functioning of society in a pandemic situation. There are some common elements between the common ground identified by citizens and target group members/stakeholders. These include:

- The importance of public education, information and research: Participants across all types of sessions (citizens, target groups and stakeholders) agree on the importance of an emphasis on public education as part of their common ground. Public education is seen as an essential element in preparation for a pandemic.
  - *"Broad and vigorous public education program on this particular risk. It seems the magnitude of some investment in particular needs to go into the education system. The school system should almost have a national day of awareness or something to really elevate everyone's awareness and health understanding of what we are dealing with here. The more individuals - particularly the adults - understand what they can do and what they can do to help others and so forth the better in reducing the incidence and also the cost… An effort to raise that awareness is really critical of some investment. From that strategy I think it needs to go into that direction." (Stakeholder)*
  - *"A possible pandemic is really central and I think that she was maybe implying that the government maybe needs to make strong connection to community groups to involve them in the basket of solutions. Part of that is more focus on public education in terms of investment in the level of awareness and making sure it really permeates society the seriousness of the threat and the relatively simple things that can be done to combat it. The low tech approach can go really far in addressing a possible pandemic." (Stakeholder)*
  - *"The communication to make sure all the information is out there and it is just going to be rumours on rumours that are just going to go around. There is going to be scares. Tactics and all kinds of misinformation out there. People are going to panic in the streets. It is going to be to try to have some information plan." (Target Group)*
- The importance of government leadership: Participants in most groups agree on the importance of some type of national plan as well as leadership on the issue, to ensure that there is some consistency across the country and some national plan to protect priority groups.
  - *"I think in a crisis situation you are going to be faced with panic. You are going to need some leadership and perception that someone out there is going to have to do something. If someone out there in the planet is doing something on this and Canada just is really not, in our interest doing something, then there is going to be a heavy toll on those decision makers." (Stakeholder)*
  - *"The world doesn't stop while the government tries to determine what it is that they are going to do. I think that there certainly is a great deal of benefit to showing leadership by governments." (Stakeholder)*

- *"First and foremost, who is going to be at risk? Second ensuring that we are reducing morbidity as public protection. Minimizing social disruption in keeping society functioning ensuring that the approach is equitable that it is based upon trust. That we protect those in society that are most vulnerable and that the approach ensures reciprocity." (Stakeholder)*
- *"Speaking a little bit to government's role on this besides looking at what those groups are and what is important to us and looking at the fact that there is any interruption in the services and government would take action. It is important for government to plan and protect those services by having something like this in place." (Target Group)*

Other key elements coming out of the common ground in target group and stakeholder sessions include:

- The importance of keeping society functioning during a pandemic situation, including ongoing health care services (which are already taxed and will be further burdened by the pandemic). As well, groups note that the identification of essential workers should be made carefully, and restricted to only those roles, positions or sectors that cannot absorb a 25 per cent absenteeism rate.
  - *"As a health care employer I need the work. If my son can't go to school and I can't come to work. If we are taking about people at risk then that is one risk. The second component is the essential services component and that is really about can you function with 25 per cent absenteeism." (Stakeholder)*
  - *"Are you valued as protecting those who are most vulnerable or the values of those with the most social worth? Which in this case would be those who can keep the society going." (Stakeholder)*
  - *"I think it is important that we protect the essential service sector of our communities but I think that it is very important that upfront these essential services are clearly delineated because in most people's minds their job is essential and so it has to be clearly defined who these people are…there is going to be huge line ups for these antivirals because everybody is going to deem themselves essential." (Target Group)*
- The importance of taking opportunity cost into consideration in the decision; acknowledging that there is an opportunity cost of spending limited health dollars on other issues, and ensuring that the decision is based on the best scientific evidence available.
  - *"I like the goals that minimize the society disruption and I like the goal minimizing mortality and morbidity. My fundamental question is something that we talked briefly about last night. Is this the most efficient estimate of our health care dollars in order to accomplish these goals? If I was to take a billion dollars or five billion dollars a year and keep reinvesting that in other types of activities would I have a greater impact in achieving those goals." (Stakeholder)*
  - *"It was raised yesterday that is was something that we should even be putting our resources in terms of if we have limited resources. Money doesn't grow on trees, but the idea of is this the best usage of the funds that we have. Could we allocate this to get some better bank?' …I think there is a consideration that even outside of this with the*

assumption that money should be saved in the money field might be a lot smarter." (Stakeholder)

- *"If the pandemic doesn't come for 10 years then maybe there is another antiviral or vaccine or derivative that would be much more effective. You need to be able to work with these people to give them some sense of where is the money best spent and the current market where health care is in a bit of a crisis and organizations are struggling. Is this the best use of those dollars?" (Target Group)*

- The importance of protecting workers (health care, emergency and essential service workers) who have no choice but to put themselves at risk of contagion through the fulfilment of their work duties. As well, participants note that while these individuals can be protected by antivirals, they do not live in a vacuum and their availability may be affected by the illness of family members.

  - *"One thing I like about this proposal is that is does recognize that there is some obligation society has to those who we are asking to put themselves at risk for their benefit whether it is a health care worker or somebody that is going to keep the water supply going. If we are asking them to put themselves at risk then there is an obligation that we have to do to keep them safe." (Stakeholder)*

  - *"I guess where we got with unlimited consensus is the value that people need to be protected on a level if they are taking a risk." (Stakeholder)*

  - *"Everybody has a responsibility to protect those workers who are at great risk and are at greater risk because they are doing service to society as a whole." (Stakeholder)*

  - *"I like this idea that we have to look after our frontline workers in order to care for the sick when they do become ill. Regardless of how we have to do it." (Target Group)*

- Acknowledging that vulnerable or priority groups cannot be identified with any certainty prior to a pandemic; that any response must be flexible in nature. As well, the targeted vulnerable, essential and priority groups may be interlinked and changing.

  - *"I just hope that a decision is made and that this can be sort of documented to change. Right now they made the decision based on the information that they already have "decrease and increase the effectiveness on the whole population" but it doesn't have to be the absolute final decision that it can be fluid and change and which dynamic groups are in and out of it and who is going to get it if something changes over time." (Stakeholder)*

  - *"Trying to narrow the top of the pyramid. The big number one was anybody to do with health care and essential services. So basically bullets 4,5,6 and 7. We identified that as the priority eight groups of the pyramid. The next group is around the chronically ill and those with immune system problems. Then comes the children and elderly depending on what the target of the bug is." (Stakeholder)*

  - *"We do not know and won't know in advance what populations will be affected by the possible pandemic and who will be the group that is most impacted or more vulnerable." (Stakeholder)*

- *"Why wouldn't you want to help the most vulnerable? It is the Canadian thing to do. I guess the big question is we are not going to know who the most vulnerable is. Pauline says it is probably going to be the very old. Well it may not be the very old, it might be the very young. I think that is the million dollar question here. The answer to the big question to me is yeah let's look after the vulnerable because that is what we do. You can't come up with the answer until you know the question and who the most vulnerable is going to be." (Target Group)*
- *"Until you know the strain of virus you are not going to know the vulnerable group." (Target Group)*

- There are serious concerns with Approach 3 and a sense that this approach is not viable on its own. This approach is thought to reduce the ability to plan an effective response, lead to disparity, place "have-not" Canadians at risk, burden physicians, and potentially lead to inconsistencies in approach.
  - *"My organization does a lot of work with health literacy and people may feel panic stricken of this type of thing and not be making the right decisions because they don't have the understanding they need. They may not be storing it properly. They may not take it properly. There are all of these concerns." (Stakeholder)*
  - *"These institutions are already worried about funding and resources and I think that federal funding across the province and the jurisdiction, I think that it falls back on a blended plan and perhaps you start with the essential workers and already have a plan in place for the vulnerable and I think the data must already be out there to calculate the numbers. If we look at a blended plan and go from there you get your numbers to manage your resources. The government can manage their resources on a whim or on a plan. I think that if the government had a plan the federal would be good." (Target Group)*

- Any decision should take into consideration a range of other issues such as efficacy, compliance, side-effects, improper use, etc.
  - *"We want to try to find somewhere the way we are protecting what we call the high risk category. The vulnerable and maybe those that we want to consider the high essential, but main point of this is that we are not saying it is mandatory that they have to do it." (Stakeholder)*
  - *"The adequacy of the science is a very important consideration from our perspective." (Stakeholder)*

- Thought should be given to the security of the supply of antivirals if their distribution is limited.
  - *"From my industry perspective – from a pharmacy perspective we have to start considering what security measures are going to be put in place for securing the supply. It raises the whole issue of theft diversion and black market. I just shudder to think of the implications of this type of approach." (Stakeholder)*
  - *"We use antivirals in long-term care facilities to minimize the rate of deaths and severe illness but in the well and younger population very rarely do we use community antiviral distribution. One of the concerns is compliance and the opportunity for resistance will occur. My concern would be that you would be able to use this in a long-term facility*

because you have a captive audience. Pandemic is a community spread disease. It is not a facility spread disease. How do you ensure compliance with these people and concern for the development of resistance. It is paramount." (Target Group)

- *"(Seniors)..a lot of them as they get older and debilitated refuse to comply with medication and don't even want people in their homes. To be honest, I am concerned that they are going to be ill and not be found until they are gone and are they just going to be a breeding ground for the ones who have to bring them out? They may not recognise that they are ill and people like Meals on Wheels who they are relying on, they will be spreading it to." (Target Group)*

Table 2.6: Dialogue Session Common Ground for Target Group and Stakeholder Sessions

Dialogue Session	Common Ground
Stakeholders 1	1. Difficult decisions - requires ethical framework, common values, and best information available 2. Values/considerations to apply: a. Identifying who will be at risk b. limiting morbidity c. public safety and protection (important to ensure ongoing health services) d. minimize social disruption, keep society functioning e. equity f. trust g. protecting those most vulnerable 3. Responsibility to protect workers at greater risk 4. Opportunity costs - consideration for efficiency, effectiveness 5. Define emergency and essential services narrowly (most critical to ensure functioning of society, and ability to absorb 25% absenteeism) 6. Interconnected nature of sectors (good functioning of society relies on a number of sectors) 7. Emphasis on publicly-funded research and public education 8. Need to ensure the security of the supply of antivirals 9. Approach #3 - difficult to plan response and greater burden on physicians
Stakeholders 2	1. Absolute cost not an issue, although opportunity costs are (given efficacy, etc) 2. Agreement with minimizing illness and social disruption (Approaches 1 and 2) 3. The vulnerable, valuable and essential are likely interlinked, and possibly moving target 4. Consideration for ripple effects of decisions (social fall out) 5. Essential groups and roles should be specific and narrowly focused 6. The decision/plan must fit into broader preparedness and based on good public education and information 7. Key considerations: a. Cost, shelf life, efficacy b. Compliance; resistance c. Side-effects and long-term use d. Cannot trump other measures of prevention 8. Government take lead responsibility (provide leadership to private sector) 9. Approach #3 is not viable on its own

Dialogue Session	Common Ground
Target Groups 1	1. Protecting most vulnerable in society – Canadian values, compassionate, right thing to do 2. Limit additional burden placed on already stressed health care system 3. Ensure society continues to function - protect health care workers and other essential services (at risk, ensure they continue to work) 4. Careful distinction/identification of who essential workers are 5. Workers' families may need protection to ensure workers available 6. Identification of most vulnerable difficult (and may be moving target). Protect elderly (even if not vulnerable) to reduce the burden on health care and adult children 7. Public education (and emphasis on individual responsibilities) is important 8. Plan/prepare for public security and protection of the supply of antivirals 9. Opportunity costs (money be better spent on building stronger, healthier communities 10. Approach #3 would place an unreasonable burden on physicians, create inequities and place burden on public education/provision of information
Target Groups 2	1. Keeping society functioning is generally the best premise on which to base decisions around publicly funded antivirals for prevention 2. That the approach should help prevent further crisis in a pandemic 3. That any approach consider practical implications and be logistically feasible to implement 4. That there should be consistency across the country 5. That those who have a responsibility/duty of care be protected so that they are unencumbered to help others 6. That while approach 3 couldn't work on its own, no company or individual should be prevented from obtaining/taking antivirals on their own 7. That a strong priority be placed on public education and information (broad range of prevention and public health issues). These cannot be seen as secondary or take a back seat to antivirals)

c) Overall Values Framework

Examining the common ground agreements reached by the groups across the seven dialogue sessions provides the basis for an understanding of widely-shared values and principles. In this case, practical/efficient approaches, compassion/caring for the vulnerable, fairness/access, the priority placed on public education, and the role of government in inspiring trust and confidence are visible values across the groups. Drawing on this values framework across the dialogue sessions, as well as discussions that occurred in other parts of the day, the values, principles and considerations that citizens, stakeholders and target groups feel should guide governments in developing policies on prophylactic antivirals may be summarized as follows:

Table 2.7: Values from Common Ground

Practicality/efficiency/ pragmatism	› minimize illness and death › protection of HCW/EW to uphold normalcy and to be able to serve society › outbreak based, institution-based possible distribution strategies › safety concerns about resistance, side effects, long term effects
Fairness and equity	› troubled by possible inequities of access on basis of income and access to doctors › across country
Compassion	› protection of vulnerable (broadly defined)
Public engagement/ awareness	› public must be kept informed of planning, prevention measures › minimize fear and panic, avoid secondary disruptions due to irrationality › discussions/planning/efforts related to antivirals should not diffuse efforts at public education as primary method of prevention
Role of Government/ Trust and confidence	› government to lead and be seen to lead › responsibility to protect the vulnerable and workers who are exposed through their jobs › research to ensure confidence in use of antivirals › involvement to ensure confidence in pricing and quality › selection of priority recipients must be defensible › issues with regard to government making moral/difficult priority decisions
Minimal government involvement (Approach 3) not a viable option on its own	› Although most agreed that independent action should not be precluded, on its own, not seen as reasonable: ¤ Burden on physicians ¤ Requirement for very informed public ¤ Introduces inequalities ¤ Creates inconsistencies

Once established, the values and principles shared and supported by participants then became the basis for considering the remaining questions in the dialogues: "given the common ground identified, who should be the priority recipients to receive antivirals for prevention?" and "should government provide publicly-funded antivirals for prevention of the common ground (and other considerations such as safety, cost, priority recipients and so on) and priority recipients discussed".

In a survey question put to participants, roughly two in three citizens and three in four or more stakeholders and target group participants said that they personally agreed with the common ground point of view established by the group on the approach to antivirals for prevention in a pandemic. This agreement was reasonably consistent across the sessions, although it seemed marginally higher in Toronto and Vancouver (where nine in ten agreed) and lower in the First Nations and Iqaluit sessions where two in three agreed.

Perhaps related to this finding, roughly half of participants said that they believe that their point of view had shifted from the opinion they had come to the dialogue with. Another one in four reported that their opinion had not changed over the course of the discussion (although this

was one in three in the Quebec session) and one in ten said that they had become even more sure of their original point of view as the dialogue progressed. (Ten per cent were unsure.)

2.3 IDENTIFICATION OF PRIORITY RECIPIENTS

a) Citizen Session Results

Based on common ground values and principles, citizens were asked to determine priority recipients of antivirals for prevention. Across the dialogue sessions, the question on priority recipients generated tremendous discussion and presented great difficulties for some participants. To guide the discussion, participants were provided with a listing of various possible priority recipient groups – children, elderly, health care workers, media and so on. In small groups, participants chose and, if possible, ranked the three most important priority recipient groups. The results of these discussions are summarized in the following table. Across the groups, there was most convergence on the first priority group, with most of the small groups in each dialogue choosing health care workers with close patient contact. The second choice and third choice show somewhat greater variation, both within the sessions and across them, though emergency workers and vulnerable groups (with varying definitions) appear most often.

Table 2.8: Ranking of Priority Recipients: Small Groups - Citizens

	1st choice (number of mentions)	2nd choice (number of mentions)	3rd choice (number of mentions)
Halifax (seven groups in total)	HCW close patient contact (3) Children (1)	Chronically ill (4)	EW (1) Elderly (1) Economically vulnerable (1)
Toronto (five groups in total – four completed exercise)	HCW close patient contact (7) EW (1)	EW/Essential (5) Children (3) Vulnerable (general (1)	EW/Essential (3) Vulnerable (general) (1) Public decision-makers (1)
Winnipeg (six groups in total)	HCW close patient contact (5) HCW w/o patient contact (2) Educators/public health educators (1)	EW (4) HCW close patient contact (1) Families of HCW (1) Children (1) HCW w/o patient contact (1)	Vulnerable (general) (3) Chronically ill[2] (1) Outbreak areas (1) EW (1)

[2] It should be noted that often in participant discussions those with weakened immune systems were combined under chronically ill. Also, in some discussions vulnerable children were also grouped under those with weakened immune systems (which some used as their rationale for not including children as a priority group).

	1st choice (number of mentions)	2nd choice (number of mentions)	3rd choice (number of mentions)
Vancouver (five groups in total)	HCW with patient contact (4) Children (1)	EW (2) Children/elderly (1) Elderly/chronically ill (1) Children (1)	EW (2) HCW close patient contact (1) HCW w/o patient contact (1) Children/chronically ill (1)
Edmonton (First Nations) (five groups in total)	HCW close patient contact (3) Children (1) Most vulnerable (1)	HCW close patient contact (2) HCW families (1) Children (1) EW (1)	EW (2) Other ESW (2) Children (1)
Iqaluit (five groups in total)	HCW close patient contact (3) Vulnerable (1) Government workers and decision-makers (1)	HCW close patient contact (2) HCW no close patient contact Elderly and children (1) Children (1)	EW (4) Children (4th choice: family members of HCWs (2), EW (1), Other ESW (1))
Montreal (five groups in total)	HCW close patient contact (5)	Children (4) Elderly (4)	Families of HCW (1) Chronically ill (2) EW (1)

* Note that "votes" do not always add to the number of groups, as some indicated "ties". It should be further noted that consensus was not reached in every group.

b) Target Group and Stakeholder Session Results

There was far less divergence in the identification of priority groups in target group and stakeholder sessions. Again, the focus of target group members and stakeholders is more pragmatic, focusing on protecting those at risk and those necessary to the continued functioning of society. In all target group and stakeholder sessions, participants identified health care workers with close patient contact as a priority group. In some groups, all health care workers (regardless of patient contact) were grouped together, with participants acknowledging that all types of health care workers are essential to the continued operation of the health care system (e.g., dieticians, orderlies, laundry workers are all needed for a hospital to run). Emergency workers and essential services workers were also identified unanimously as either a first or second priority in all groups.

While citizens tend to identify general population groups (e.g., chronically ill, children, the elderly) as a second tier in priority, these were most likely to be placed last (as a third order of priority) by target group and stakeholder participants. Only one stakeholder group identified the chronically ill and those with weakened immune systems as a second level priority. Others identified the chronically ill, children and other vulnerable populations as a third priority.

Table 2.9: Ranking of Priority Recipients by Stakeholders and Target Groups

	1st Choice (number of mentions)	2nd Choice	3rd Choice
Stakeholders 1	HCW in close patient contact (unanimous) Emergency workers (unanimous)	Essential services workers (unanimous)	Chronically ill and with weakened immune systems (3 of 14 participants)
Stakeholders 2	HCW in close patient contact Emergency workers Essential services workers	Chronically ill and with weakened immune systems (2 of 3 sub-groups)	Children (1 sub-group) Family members of 1st choice groups (1 sub-group) Those who cannot afford antivirals Government workers and media
Target Groups 1	HCW regardless of patient contact (unanimous)	Emergency workers (unanimous) Essential services workers (unanimous)	Vulnerable populations with an emphasis on children (unanimous)
Target Groups 2	HCW with close patient contact (unanimous) Other HCWs (3 Groups)	Emergency workers (unanimous) Essential services workers (unanimous)	Vulnerable populations (2 Groups)

c) Survey Results

To complement the qualitative results from the dialogue sessions, participants were asked to rate and then rank the importance of potential priority recipient groups on the surveys (before and then again after the dialogue session). The results of the qualitative discussion on priority recipients are generally confirmed in citizen participants' survey responses. Interestingly, health care workers with close patient contact received a high priority rating prior to the dialogue, but were virtually tied with the level of priority also assigned to children in the survey results prior to the dialogue. Over the course of the day, participants' opinions tended to converge, with health care workers emerging clearly as the highest priority recipients. The initial priority given to children, on the other hand, diminished over time (likely due to information during the course of the dialogue that the precise definition of "vulnerable" is unpredictable and may not follow the same patterns as other pandemics, as well as recognition of the difficulty of administering the drug to children). Emergency workers are also viewed as high priority recipients, although their priority rating also dropped over the course of the dialogue.

Survey responses from target group and stakeholder sessions also largely mirror the results of the qualitative discussion. Health care workers with close patient contact (who are acknowledged as having to face exposure to contagion as a result of their job) are identified as the first priority pre- and post-dialogue by target group and stakeholder participants. Emergency

workers emerge as the second clear priority, and the emphasis placed on this priority group grew noticeably from pre- to post-dialogue survey results in both stakeholder and target group sessions (likely due to the fact that they were identified as "essential workers" during the discussions). There were several other significant shifts in support for specific groups from pre- to post-dialogue survey results. In particular, the emphasis placed on children declined in both target group and stakeholder sessions (possibly due to the recognition that it will be difficult and costly to protect all vulnerable populations; the fact that these populations cannot be identified in advance; and the increasing pragmatic emphasis on protecting front line HCW and essential workers). The level of priority assigned to HCW without close patient contact increased among target group respondents (likely due to the emphasis in discussion among some participants that all types of HCW are needed to ensure the continued functioning of the health care system). Finally, in the stakeholder groups, the priority placed on other essential service personnel increased, likely as a result of the emphasis in the discussion that was placed on maintaining the functioning of key services.

Citizens' rank ordering of priority recipients in the pre- and post- dialogue questionnaires follows a similar pattern to the scaled ratings above: health care workers with close patient contact are ranked as the first priority most often. One in four also placed children at the top of the list prior to the dialogue, but this is no longer the case once the dialogue has taken place. Emergency workers are most often ranked within the top three priority recipients groups (the potential for being selected as first, second or third priority increasing over the course of the day). Children are third overall after the dialogue, with individuals who are chronically ill and the elderly following behind this.

Table 2.10: Level of Priority Assigned to Different Recipient Groups Pre- and Post-Dialogue

	CITIZENS			STAKEHOLDERS			TARGET GROUPS		
	Low/Modest	Medium	High	Low/Modest	Medium	High	Low/Modest	Medium	High
Health care workers with close patient contact (e.g., doctors, nurses, other technicians and staff in clinics and hospitals)									
Pre-dialogue	5	23	66	4	17	79	2	14	83
Post-dialogue	9	13	73	8	4	83	0	9	88
Emergency workers (police, fire fighters, food and water safety officials, other emergency response personnel)									
Pre-dialogue	17	23	55	8	38	54	12	21	67
Post-dialogue	25	27	42	12	21	67	0	9	88
Children (if vulnerable population)									
Pre-dialogue	8	23	64	34	33	33	7	33	60
Post-dialogue	18	27	51	33	33	17	33	16	47
Elderly (if vulnerable population)									
Pre-dialogue	28	29	38	63	25	13	36	50	14
Post-dialogue	34	23	34	58	17	8	42	28	23
Chronically ill and/or those with weakened immune system									
Pre-dialogue	32	27	32	67	25	8	33	38	26
Post-dialogue	35	27	32	58	17	8	45	33	19
Health care workers without close patient contact (e.g., laboratory technicians, central supply staff)									
Pre-dialogue	43	27	23	42	46	13	48	31	21
Post-dialogue	46	27	15	33	38	17	32	21	40
Other essential service personnel (e.g., postal services, financial services, food production and distribution, transportation, other basic public services)									
Pre-dialogue	51	19	21	46	50	4	48	36	12
Post-dialogue	60	17	11	8	42	42	51	28	12
Government officials and decision-makers									
Pre-dialogue	60	16	14	75	25	0	67	21	12
Post-dialogue	70	8	8	67	13	0	79	2	7
Other public health professionals and decision-makers (administrators, inspectors, non-patient care nurses)									
Pre-dialogue	52	25	15	71	21	8	60	33	7
Post-dialogue	63	16	7	58	17	13	82	9	2
Media									
Pre-dialogue	73	12	7	100	0	0	91	10	0
Post-dialogue	75	5	5	62	13	4	91	2	0

Table 2.11: Ranking of Recipient Groups: Pre- and Post-Dialogue – All Sessions

	Pre-Dialogue				Post-Dialogue			
Recipient Group	% 1st choice	% 2nd choice	% 3rd choice	% 1st, 2nd or 3rd	% 1st choice	% 2nd choice	% 3rd choice	% 1st, 2nd or 3rd
Health care workers with close patient contact	40	15	10	60	56	14	5	69
Children (if vulnerable population)	25	11	15	47	12	12	15	37
Emergency workers	5	26	14	43	6	31	22	55
Elderly (if vulnerable population)	3	13	6	20	2	5	4	10
Chronically ill and/or those with weakened immune system	4	4	13	20	4	7	9	18
Health care workers without close patient contact	0	5	9	14	0	6	5	10
Other public health professionals and decision-makers	0	1	0	2	0	1	2	3
Other essential service personnel	0	1	8	9	0	1	13	13
Government officials and decision-makers	1	1	0	3	0	0	1	1
Media	0	1	1	3	1	0	1	2
No response	20	21	24	23	19	22	23	20

n= 160
Source: Antivirals for Prophylaxis Dialogue, Participant Surveys (2006-2007)

Results were quite similar across participant types with a few exceptions. Citizens provided a higher rating for children and the elderly in the pre-dialogue questionnaire than target group or stakeholder participants. They also gave children a higher ranking than did other participants in the post-dialogue questionnaire. Target group participants rated emergency workers higher than citizens or stakeholders did after the dialogue.

A discussion of the results of the dialogue sessions for each of the priority recipient groups is presented below.

Health Care Workers

Reporting in a plenary format, small groups indicated their selections, with greatest consensus emerging across the small groups and across the dialogue sessions around the priority of health care workers (HCWs) with close patient contact (only in Winnipeg was there a very strong sense of including HCWs without close patient contact). Due to their integral contribution in assessing and treating patients – influenza-related and otherwise – HCWs were consistently identified as priority recipients in order to fulfil their duty of care to others during a pandemic. This was seemingly cast as a decision grounded in pragmatism for participants who characterized the preservation of the health care infrastructure and health human resources as critical given the expected increase in both the numbers of citizens who will fall ill.

Preserving the operation of the health care infrastructure will provide treatment for the seriously ill due to influenza, as well as continued care for other emergency or chronic conditions.

- *"Health care workers number one, with close contact. Emergency workers number two. Health care workers without close contact. Rationale was that without the core group functioning everything else will fall apart. That core group keeps society running." (Vancouver)*
- *"It would protect the patients as well. I was also thinking that it would keep our health care workers healthy to take care of the ones who do get sick. If all our doctors and nurses get sick then who is going to look after the ones in the community who get the flu and who need the antivirals for the treatment." (Winnipeg)*
- *"I feel that the health workers should be the first people to receive this antivirus because they are going to look after the rest of us. If they don't have it and a lot of us get sick at the same time who is going to look after us. When I say health workers I mean like doctors and people in the hospitals and anyone who is looking after people who are ill." (Toronto)*
- *"I find that those most at risk are those who will be directly treating the sick. Them, I would make a particular exception to give them antivirals to protect them, because I find that they are most at risk" (Montreal, translated)*

Again, target group and stakeholder participants (some of whom were health care workers) were also unanimous in identifying health care workers with direct patient contact as a priority group. They felt that there is a responsibility to protect these workers, who have no choice but to accept risk of infection as part of their job responsibilities. They also acknowledge that it will be essential to protect these workers to ensure the ongoing provision of health care services in a pandemic, particularly given that the health care system is already taxed.

In some sessions and some sub-groups, participants also argued (like citizens) that health care workers without direct patient contact should be included in the priority group, given that both categories of health care workers are essential to the continued functioning of the health care system (e.g., a hospital could not function without laundry, clean beds and labs).

- *"Taking 30 per cent of the people out of the system will cause the system to halt. Keeping in mind that the people will need the system moving and not just nurses, doctors and pharmacists, and taking it down to the kitchen staff, the janitorial staff and it is a very broad group of individuals that keep a hospital and associated info structure moving." (Stakeholder)*
- *"..we were not satisfied with your list so we did combine and make that one category because laboratory techs and essential staff. They are dealing with … So we decided to combine them with health care workers… It is not a matter of exposure. It is a matter of having the hospital running. If you don't have techs the hospital is not going to run. How can doctors and nurses function if they don't have any techs." (Target Group)*
- *"We certainly recognize that health care workers whether they are with close patient contact or not. It is such a close circuit that they rely on each other in order to keep the hospital running. If we don't have the laundry service in the facilities if we don't have the dietary staff. If your hospital can't function for any reason it really affects the whole production of the hospital. We clumped. We cheated a little bit. We clumped health care workers with close contact as well as health care workers without close patient contact. Simply because if you don't have the lab techs able to give you the results of blood work and what not you cannot choose appropriate treatment for the patients." (Target Group)*

In two citizen sessions it was noted that HCWs could assume different priority depending on the setting, having particular priority in smaller communities or remote locations:

- *"In the communities that are further north and which are smaller we have many more vulnerable people than we do essential workers, so maybe for this territory we need to take a two tiered approach where if we want to choose approach one or approach two or a combination of them, that would have to be looked at on a separate basis between the three bigger centres of the territories and in smaller communities and make it work for each different place." (Iqaluit)*
- *"We went with the Nunavut context. One of them is healthcare workers with close patient contact and we grouped that with healthcare workers without close patient contact only because in the Nunavut situation the Baffin Hospital is one building and janitors will be exposed as much as anyone else in that building with patients coming through, walking by them etcetera. In the south you might send samples to labs that are in other buildings, other situations but in Nunavut in the nursing centres and all that stuff it's one building. Anyone working in that building is a priority as far as we're concerned." (Iqaluit)*
- *"It's hard to differentiate the front line staff to the support staff in a hospital setting in Nunavut. They're working side by side." (Iqaluit)*
- *"We have ten vacant positions for nurses in Iqaluit alone. If the hospital were to work at 100 percent efficiency and capacity if those ten positions were filled, we're already 10 positions, so if we were to lose 20 to 25 percent more of our healthcare professional staff – a nurse is just one example. I know we're short lab techs, probably LPNs as well, there are a huge number of different positions at our hospital that are considered to be healthcare professionals – if we're already down so much in just nurses and lab techs alone, you can assume that we're down in the other healthcare professional jobs as well so to take 20 to 25 percent more of these people out of the workplace, we're in trouble or at least it sounds like we are" (Iqaluit).*

Conversely, according to participants, a health care system overwhelmed by seriously ill patients without sufficient human resources to assess and treat them, could lead to elevated levels of risk, cause secondary incidents of illness and death, and escalate fear and panic.

- *"Should the pandemic hit and it affect the health care people we wouldn't have any of the doctors or nurses to take care of us so people could get sicker and have nobody to take care of them – like a domino effect." (Toronto)*
- *"If we forgo the first approach in favour of the second approach would that not create more of a challenge for the healthcare workers or the facility, whatever facilities are in place? If too many of the vulnerable people get sick, wouldn't that create too much strain on the existing system even if the healthcare workers are healthy and have been provided with the antiviral, the amount of people that would be infected would be almost exaggerated to the point where it would impact their own health outside the viral infection?" (Iqaluit)*
- *"Those on the front lines have a direct impact on events to follow; that is to say if we lose half these groups that are waging war on the pandemic, the consequences will be large and very negative." (Montreal, translated)*

An important concern for participants across the sessions was that society continues to "work" during an influenza pandemic. This practical concern was cast both in terms of maintaining normal operations so that the pandemic itself could be dealt with effectively, but also to avoid ancillary crises that

could emerge if normal operations break down and citizens become gripped by fear and panic. Health care workers with close patient contact and, to a lesser extent, emergency workers were identified with a strong degree of consensus as priority recipients for antivirals for prevention on the grounds that this workforce must remain fully intact to care for the influenza-ill, but also those who fall sick for other reasons.

> *"It is akin to if you are flying and if there is a drop in pressure they always say you put on the oxygen mask on yourself first and then you help the small children around you. We need a back bone with the health. We need our health care workers and we need our emergency and first responders in place otherwise when things fall apart they really fall a part." (Winnipeg)*

> *"Actually we did have a sense of priority and that's when you're traveling on an airline and the oxygen mask pops out, it says take care of yourself first. We kind of used that as a principle, we need to take care of those who are taking care of everybody else and that was our priority kind of. If those people who are doing all the work and are the most exposed are taken care of, that would be our priority." (Iqaluit)*

In some groups, protecting HCWs was noted as being the "best bang for the buck" - having benefits for vulnerable groups as well as broader society.

> *"When you compare with approach one if you protect one elderly person you have potentially saved one life. If you protect a doctor in a small community that doctor might be able to save 20 elderly people just because he is able to work to help people from getting sick and potentially getting sick. So as a society it will be a more effective use of the resources."(Vancouver)*

Health care workers are also a group perceived to be worthy of priority owing to their greater (assumed) personal risk and level of exposure to the influenza virus as a result of patient contacts (e.g., being "in the line of fire", "in harm's way"). In some groups, HCW's greater exposure to the virus also raised the issue of containment: that is, that it would be pragmatic to provide HCWs with publicly-funded antivirals to contain the spread of the virus.[3]

> *"It protects people that society is expecting a whole lot of. From the exposure to the maintaining grids and all the sort kinds of stuff. I like that part of it. I think from what I know about SARS there were an awful number of people at work exposed because hospitals were not prepared. The mass did not fit and all that kind of stuff. People, they were put in harms way unfairly. I think that if this is what we are asking these particular people we owe them all the protection we can provide." (Halifax)*

> *"My interest is the protection of workers that would be most exposed. Health care workers and so forth. Not only their medical protection but their protection along financial and so forth if they were hurt by being in the line of fire." (Halifax)*

[3] Note that in other dialogue sessions (Winnipeg and Vancouver) the extent to which HCWs are exposed to or spread the virus in any significantly greater degree than other citizens was debated, with medical resources noting that unlike SARS, influenza is a community disease which spreads easily and rapidly among individuals at home and in public places.

Target group and stakeholder participants were more pragmatic, believing that the risk of spread would probably be greater in the community. Those arriving at a hospital for treatment are already ill and health care workers will know to take precautions. The need to protect health care workers was seen more as essential to ensuring the continued functioning of the health care system.

- *"The release of the antivirals should be focussed at places that can't function during a pandemic with more that 25 per cent absenteeism. Public health I am sure is going to be one of the groups that can't do that." (Stakeholder)*
- *"..on their best experiences and they said that the health care workers were estimating about 30 per cent health worker absenteeism where as the rest of the population is about 20 to 25 per cent. When you look to protect the most vulnerable you look at how that population ends up being you are going to end up going to those health care workers to do that either to administer the antiviral or to see whether they are hospitalized or whatever is necessary for their care. I would say that they become very high in the whole priority list in keeping the vulnerable protected properly and you want them there to be able to provide the services because I think it just covers all of the areas. In my mind I am having them properly protected." (Stakeholder)*
- *"..as a health care workers I don't have the option of isolating myself from the illness or preventing myself from close contact with the illness. It is inevitable that I will have 100 per cent chance on getting the virus and 70 per cent chance of getting sick. I guess the thought that is really emphasized here is that not only can I transport the virus to the people in the community and in the institution I think that I agree that individuals that have a 100 per cent chance of being in contact with the virus should be protected because they ultimately don't have the option of control in one isolation." (Target Group)*
- *"...your risk eventually becomes the same as your risk is just as high as your general population virus and become a risk that we have no way of isolating ourselves from the virus. It is not like I can choose not to go into the zone. That is where yes I can catch it at the superstore as easily as I can catch it at work. As a matter of fact there is some argument that I can get a decrease of catching it as an employee and a mass unit of medicinal measures but I don't have a choice of isolating myself completely from the virus." (Target Group)*
- *"My concern is also if nurses and doctors start getting sick we already have such a shortage of it. There is nobody to replace them." (Target Group)*

Finally, HCWs were also viewed by citizen participants as more likely to take antivirals as prescribed, thus alleviating some of their concerns about poor compliance leading to wasted doses or the development of drug-resistant strains. According to these participants, HCW's practical familiarity with prescription medications and greater awareness of the dangers on non-compliance inspired greater confidence that the lengthy six to eight week course of antivirals would be completed.

- *"I think this group would probably be the one that would take the medication properly to prevent it from becoming resistant to the virus...I don't want to generalize but a lot of parents are like 'oh he threw it up or he will take it tomorrow' and if a lot of that is happening maybe we can develop a resistance to it." (Winnipeg)*

Conversely, participants in the target group and stakeholder sessions were more inclined to believe that compliance would be poor within this group, as they are aware that health care workers are

likely less apt than others to take the annual flu vaccine. They felt that the level of compliance among health care workers could not be certain or would need to be ascertained through further research.

- *"Two comments on the health care providers, they are notoriously bad in terms of compliance.. that is assuming that the federal government hasn't invoked the order in good government so they impose good compliance. Which means here are your pills take them. Which could mean they could overcome the notorious complaints." (Stakeholder)*
- *"We talked about concerns around compliance and health care workers being the least compliant with all kinds of strategies with dealing with some aspects of some clients. We talked about concern for side effects and we talked about appropriate use. Again the need for more information and education for the sense that access to medication seems to trump other kinds of public health medications and preparedness..." (Stakeholder)*

Despite a general consensus on the importance of a fully functioning health care infrastructure during a pandemic, participants also raised some concerns about health care workers as priority recipients. An issue for some was the decision process itself – who will decide who is essential and who is not? (an issue discussed in more detail at the end of the section). A second concern raised in several sessions (and particularly in Winnipeg, Iqaluit and Montreal) was the potential emotional difficulty for health care workers themselves in being recipients of antivirals when their family members, friends and neighbours likely would not be. As mentioned above, this led participants in one of the small groups in Winnipeg, Iqaluit and Montreal to suggest that family members of health care workers could be priority recipients or possibly receive antivirals that were subsidized by government.

- *"As someone who works in health care I would be obliged as a condition of my employment to take an antiviral. I am not sure about the safety of the long term use and also if I take the antiviral that doesn't mean my family won't get sick and then the moral distress that might be created by wanting to serve my clients and my sick kids after." (Winnipeg)*
- *"Does a nurse stay home to protect her family or does she go to work and help the community where they can actually kill her children and it is when we start to get into these dilemmas that we can't resolve. We start to behave either selfishly or unwisely. I think you get the best cooperation when you have volunteers and good education. Not only is the moral obligation to reduce death in that vulnerable group but also for the effects of that group could have on the rationale of your community." (Winnipeg)*
- *"Do you ever think about when it does hit how everybody is going to live after that? Let's say all these workers get the pill and then let's say it works. What are their lives after that? How is this person going to live after that with the guilt knowing they got it instead of me? This child got it instead of me. This person is really crucial to their reserve or where they live. Do we go per community do we go to things we really need? How do we choose?" (First Nations)*
- *"Would it be helpful for essential workers family members to take the antiviral prevention medication to help keep the virus from spreading? Like there is already a threat for the essential workers to get sick on the job, but what if they have family members who are out in the public, children or whatever, they might bring the illness home. Would it be beneficial to extend the care to family members?" (Iqaluit)*
- *"You're looking at a family system here and you cannot have your primary healthcare workers or your emergency workers second guessing what's happening at home or having sick children or spouses and operating at an optimal level. It increases their stress, their anxiety and diminishes their own*

immune system's capacity to fight off any disease…We didn't think that our primary healthcare workers and our support emergency workers would be at their optimal best if they had to worry about their family." (Iqaluit)

- *"In terms of doctors, nurses who have direct contact, it makes a lot of sense that these people need to be in shape to be able to take care of others. On the other hand, I think morally, the doctor or nurse will have access to preventative drugs but their patients will not. That is hard to take! I think it will be hard for them too." (Montreal, translated)*

While this issue also came up in target group and stakeholder sessions, participants in these sessions were more pragmatic in their views. Several note that health care workers do not live in a vacuum, and although they can be protected by antivirals there is no guarantee that they will subsequently be absent from work when forced to care for an ill family member. Some sub-groups discussed the possibility of providing antivirals to the family members of these workers as a further method to reduce absenteeism, although this approach was largely discarded as unrealistic or impractical (would involve too many people).

- *"Things that came out in SARS was health professionals came out and asked what is my real professional duty. Is it to stay on the frontlines or is my duty to partly care for my family who is also sick. Who is going to look after them? One of the things that had become clear is that across the professions including paramedics and police and so on who have a very clearly stated social protection role. Whereas in health care it doesn't become more and more circumstantial there is a choice element that is to gradually come in there. The health professional might have some - we need to protect some degree of autonomy." (Stakeholder)*
- *"In the discussion of service providers is the idea of providing antivirals to those people and they are willing to accept that if their families don't have access to it as well. This is something that has come up in conversations in other areas as well where parents, mothers and fathers will say I will just not protect myself if I can't protect my family as well." (Stakeholder)*
- *"I think that a lot of it has to do with responsibility for their family and this idea of projecting forward of potential guilt. Maybe I will survive but my family won't." (Stakeholder)*
- *"We looked at the first issue which is containing the problem so we looked at the essential health care workers and the workers required to contain that and we grouped not just the health care workers but their family members because you don't want a health care worker going home spreading this to their children or vice versa. We said that a big part of their physical and mental health involves keeping their own families safe and so we had a discussion about putting those in with the health care workers." (Stakeholder)*
- *"We also included in number two the family members of the priority recipients for the same reason for the children because those essential services workers need to feel confident that they can come to work and not worry about their families." (Stakeholder)*
- *"We have already discussed who is essential and who is not. I think that anybody who is frontline in health we get 100 per cent exposure. So obviously I think I should be protected, just kidding. But I think the point that was made is that all of us, we don't live in a vacuum. We are surrounded by family members young or old who are going to be sick. I would actually like to see a sort of blending here in the possible actions." (Target Group)*
- *"As an ER nurse is my family going to be put on the priority list for receiving the antiviral? As a mom I know if my son becomes ill I know that my first priority is going to be him. Will he be put higher on the*

list than somebody's non-healthcare child that was discussed. For me to do my job properly and function well I have to know that my family is going to be protected." (Target Group)

- *"Number one was health care workers because basically we think there is people there that should be doing 100 per cent of their work. We clumped with that their family members because if they are at work and they are worried about their family back home it is pretty tough on them so we put them two together." (Target Group)*

Other citizens urged that the selective distribution of antivirals be accompanied by a public education strategy that enlightens (and convinces) citizens about the rationale for the distribution of the drugs.

Similarly, target group and stakeholder participants emphasized the importance of public education regardless of the strategy taken. Several groups expressed fear that people would rely on antivirals for protection and possibly be lax with other important preventative measures (e.g., handwashing, social distancing). They felt that prevention through education is a critical component of any approach or plan taken.

- *"..although we have prioritized health care workers to be the primary group for consideration of the antiviral for prevention I think that we also have to consider the structures of processes that we put into place so that we really educate, support, ensure that whoever is the priority group is going to have the knowledge that it is really critical for them to take it and follow through with it. In particular if it is our health care professionals… we really need to build capacity within the health care providers to be leaders and role models for the rest of the organizations – the rest of society because we will be in a chaotic state. Where there are haves and have nots. If the health care providers are not compliant with the registry then what is the point in spending all the money and giving it all to them as a priority." (Stakeholder)*
- *"I think it is going to depend on education, education, education. If you educate the people and population the way we should be educating then you will not have to force people into taking it. They will take it because they have been educated. I think there is an alternative to forcing it on and I think that reassigning and the employer has the right to reassign 99.9 per cent of the time. I would think that would be the better way to go then to be forcing people to take it. It is education number one. If you educate the person properly common sense will prevail. You won't have to push them." (Target Group)*
- *"I would have liked to see an approach where just for treatment where we do a good job and we get to all those hard to reach individuals. At the same time we do a huge education campaign and provide a cornerstone of prevention to everybody." (Target Group)*
- *"We were very clear on those two (priority groups) but number three was difficult and opened a whole can of worms and ethical decisions and who gets what. We felt as a group that the money would be better spent on education of all those other groups." (Target Group)*

Following the discussion on priority recipients, there was a component of the dialogue that focused on what conditions, if any, should be placed on the distribution of antivirals to priority recipients. The example provided to participants was, if health care workers are a priority group with access to publicly funded antivirals, would they then need to commit to coming to work. This example tended to dominate the discussions, with participants for the most part agreeing that if HCWs (and presumably, by extension,

emergency workers) are provided publicly-funded antivirals then they must fulfill their work obligations (the privilege of antivirals being accompanied by the responsibility to work). In some groups, a related condition was cast in reverse: in the interests of protecting patients, HCWs who elected to come to work, are obliged to take antivirals. On the other hand, most felt that it would not be reasonable to make anything "mandatory". Another condition suggested by participants was that no annual leave/vacation would be allowed for priority recipients during the period of the pandemic.

> *"If we are giving health care workers antiviral drugs especially during the time of a pandemic then we would like them not to be absent. They would be there. They would be working and fulfilling their work, their hours, and their duties. This a condition that we would want put on paper. This is a condition that it would be nice if they would actually be there if they were receiving antiviral treatment. Receiving it because people are putting them forward to be there." (Vancouver)*

Similarly, the issue of compliance was discussed by participants in many stakeholder and target groups. This group was not optimistic that compliance would be high, and suggested that there be some policy in place to obtain consent of those who agree to take antivirals (with the agreement that they take it properly and continue to work), and also a policy for those who refuse (possibly to limit their exposure to patients).

Emergency Workers

A second order priority group that emerged during the dialogue discussions (with the exception of Halifax) was emergency workers or first responders who support the health and safety infrastructure (e.g., ambulance, fire, police). The rationale underpinning the priority of this group was similar to that of HCWs – with less emphasis on compassion and more on efficiency –i.e., to maintain normal societal operations, ensure safety of citizens and minimize panic among an uninformed and anxious public.

First responders were further characterized as being in specialized occupations (therefore, making it more difficult to find replacement staff) but, to some extent, interchangeable amongst each other - firefighters and police acting as paramedics). The importance of first responders became particularly salient when participants considered the worst case scenario – a highly anxious and potentially irrational citizenry, and the possibility of dangerous unravelling of the social fabric. The chaotic and disruptive events in New Orleans in the aftermath of hurricane Katrina were referenced in several sessions to illustrate this potential scenario.

> *"Look at Katrina and what happened there. The city of New Orleans that was a fiasco. If it is going to be a pandemic that happens and we are going to run like that. We are not going to have a place of control and everyone will just run. Look at the Super Dome where people were looting and killing each other. If there isn't any control in place it would be chaotic." (Toronto)*

> *I think that there has to be a large group that protects our infrastructure and our communities like our police services, paramedics, fire, ambulance, hydro people. We have to have these people in place, but particularly our front line people including the hospital staff. We do have to have them all looked after. Without them we have anarchy afterwards...when you get to that point in time of panic. It would be like Katrina where they were walking away from their jobs because they were being pulled in two*

different directions. It would create the same situations where people can't help being what they are and there is people who will panic. It needs a broader spectrum to cover the people. We need the essential services to survive. (Winnipeg)

- *"Well, just under the cons I suggested a scenario which in all likelihood would happen and unlike past pandemics on populations, today's populations are more spoiled. We are used to comfort and I don't think we'd be very tolerant to pandemic unlike our ancestors who were able to keep cool and have a conscience at least to want to protect its citizens or care for its citizens. Katrina is another example. Yes, we saw heroes in Katrina but we also saw villains coming out." (Iqaluit)*
- *"There is an influx when society goes into panic. So when those front line workers and the essential workers – the preventative measure is very important to have that system in place and to handle that influx of panicking citizens that will react on any system." (Target Group)*

Less emphasis was placed on this target group among participants in the Montreal group, where only one group chose to identify emergency workers as a priority. As discussed further, Montreal participants were preoccupied by concerns of ethics and equity in the selection of priority groups, and were more apt to limit priority groups to HCW with direct contact and vulnerable populations.

- *We didn't obtain consensus on this, but we added emergency workers and essential workers but only on condition that it would be very strategic and only in situations where the service could not be provided otherwise." (Montreal, translated)*

As with the public, target group and stakeholder participants placed high priority on emergency workers both due to elevated risk of infection (as first responders) and due to the essential nature of the services provided (and the fact that emergency workers could probably not cope with high levels of absenteeism). Some groups also felt that these workers would be particularly essential in a pandemic situation, where fear could affect public behaviour (again drawing parallels to New Orleans).

- *"I think the point is not so much you get it. It is the fact that you don't want these essential workers to not get it. Whether they get it at work or get it in the community. They provide essential service so we want to make sure they are healthy." (Target Group)*
- *"'I think that all we have to do is look at New Orleans to make our decision. Not only are essential workers essential in public health emergency. Crime goes up. There are more fires. There are just more chances for disruption and if we don't have people available to deal with that then look out." (Target Group)*
- *"'I was directly involved with Rita and Katrina. My sole role was looking after members. The members just looked after members. What stood out in my mind was not the majority of the population but how some of the population started to act. It got extremely scary. People that would not be normally aggressive. They became extremely aggressive to the point where they were carrying guns and that sort of thing. The general population - depending on how it escalated – depending on where you went - started to act totally different. It really opened my eyes actually being in New Orleans when this thing went on." (Target Group)*
- *"..preventing further crisis or chaos in the community if we have these essential people always sick."*

Other types of essential services such as utilities were generally not identified by citizens as priority groups in the dialogue (at least not within the top three that participants were instructed to choose). Participants' thinking here often was that a 20 to 25 per cent reduction in staff would not disrupt operations to the extent that public health or safety would be threatened. As well, some groups were considered to have no greater level of exposure to the virus than others (e.g., media) and thus requiring no special protection. Still, in two sessions (Halifax and Toronto), some participants chose to add occupations to the listing of essential services, including snow removal, garbage collection and gas station attendants. In Iqaluit, participants mentioned media, hunters, Elders, church leaders and social counsellors as potentially essential. Some participants made the distinction between essential people and essential services: in some cases a service may be essential, but because the level of skills or type of training is not highly specialized, there may be any number of individuals who could perform these tasks, or ways to economize or reduce operations that, again, would not threaten public health or safety.

- *"We need the essential services to survive. Where is talks about a combination of things not just the health care workers but essential services that are keeping the society going." (Winnipeg)*
- *"I would just like to point out that we live during an age where we have many different types of alternative media, so for some there will have to be some sort of decision made. How to break that down to which are essential medians." (Winnipeg)*
- *"We are looking at a crisis and we are looking at the first part of the crisis. Who are the most important people to be active at that time and what about the support people at the time? What if it is in the winter and doctors need to get to their offices, they need to get to their clinics. Snow plows are necessary to get them there. Taxis are necessary to get them there. So when you look at it from the short-term I am wondering about all these services in respect to: well what about this and what about that. The importance of getting the most important people into the positions to help us is the key." (Halifax)*
- *"…in smaller communities also emergency workers and other essential service personnel are often pretty much the same people. That's again a Nunavut reality, perhaps down south it is different but in smaller communities there is a small core of people running those things." (Iqaluit)*
- *"We discussed other areas that are not listed for example under other essential services. It talks about food production and distribution, language like that could easily include the realities in the North where hunters are large providers to families and play a key role in that food distribution. We highlighted nursing mothers as being vulnerable, church leaders. From smaller communities church leaders, the lay readers and so forth are very important to the spiritual wellbeing that basically focuses people in their own lives and for a large part when you have trauma situation in small communities it's the church leaders who are the first people to know or the first people to approach, they're there for everybody in the communities. Social counsellors that are very important and we can tie that to some of the earlier concerns that can do to society, panic and so forth that you want to avoid." (Iqaluit)*
- *"This is a nice list. I'm not sure it's Nunavut specific and there are other groups that I would like to see that would be important for Nunavut. One of the most important ones would be our CBC radio announcers because they provide information in Inuktitut and without the communicators and the ability to get information in the language we're all going to be in trouble. People like the rangers, water truck drivers, sewage truck drivers, if this approach were to be used there needs to be a group in Nunavut that could identify Nunavut specific key individuals. Certainly in government there is but at the community level they need to look at who are the keys for getting information out there." (Iqaluit)*

Conversely, other essential services such as utilities **were** identified as a priority by many stakeholder and target group members (some of whom were drawn from utilities). As with some citizens, stakeholder and target group participants largely believed that inclusion of these groups in the priority groups should be narrowly focused on only those sectors, jobs or positions which are essential to the ongoing provision of the service and/or where an absenteeism rate of 25 per cent or more could not be absorbed. Participants in some sessions also added to the list of essential services, including for example food distribution (acknowledging food as a basic human need) and waste collection (to prevent further contagion through waste).

- *"What percentage does every workplace need in order to function in every different level of domain in order to obtain a level of service? Would you actually need 100 per cent of your essential workers or police reporting on any given day? You can minimize your risk by indicating who is actually going to come in. Can you function at 50 per cent of your staff or at 75 per cent?" (Stakeholder)*
- *"You ask whether you can run with the increased demand and a 25 per cent absenteeism rate which I am pretty sure they can't and that moves them into my category of emergency workers and other essential workers. You can't separate essential workers from emergency workers." (Stakeholder)*
- *"I would like to mention that about a year ago we had a meeting in Quebec City talking about the NGOs' involvement in the emergency planning preparedness and all. When I am looking at priority recipients I don't see the NGOs. They should be included here because we don't have a plan as of yet about what those NGOs typically will be doing, but if we are talking about churches which covers quite a lot of population we are talking about possible emergency teams. Basically we are talking about elderly care. We are talking about parishes and parishioners, elderly people, nursing homes that are often under the jurisdiction of the parishes. I think that NGOs should in general be included. Their role should be more clarified and they should also be on the list." (Stakeholder)*
- *"Just looking at the phrase other essential service personnel. I think that it is a danger in terms of thinking of personnel in those sectors as really all being equal. All being deserving or all being targets of this. If someone drives a potato chip truck and delivers bags of potatoes for a living they are food production or distribution worker, but their work can hardly be called essential. Financial services – someone who works as a personal financial advisor to society in general is not as essential as someone who stocks the ATM machines and works at the teller. There is some gradiance there. I am worried about the end product sort of lumping things together. It doesn't sort or allocate. On coarse levels, lumping and not taking a finer tune and analysis of them." (Stakeholder)*
- *"..priests and ministers because no matter how you look at it to be it is sociological, physical, mental, food support or be it a funeral service and we are talking a lot of bodies possibility. Being this or that the priests or ministers will be contacting a lot of people. Visiting sick people because they are supposed to be like doctors pretty much for spiritual reasons." (Stakeholder)*
- *"As far as the essential groups though the roles should be specific to the context and fairly narrow. We thought that the groups that were brought forward were fairly broad. They subdivided quite extensively to allow for a bit more fine tuning and allowing the targeting of more specific people. Possibly based on risk of exposure rather than just a broad category." (Stakeholder)*
- *"Essential services personnel has to be redefined. I think that in our group's opinion the garbage man is more important than the banker or the postal worker. For a week if we don't get the mail. If I don't get junk mail I will be okay. If somebody doesn't pick up my junk it isn't okay." (Target Group)*
- *"Government officials and decision makers I am sure should be included." (Target Group)*

- *"Food is a very important item if there is a crisis…people who are working providing food to the population. Even the transporters may be an important part of the population that we don't think about." (Target Group)*

Vulnerable

Finally, vulnerable groups such as children, the elderly and chronically ill emerged as priority recipients. In fact, in some of the small group discussions in the dialogues in Winnipeg and Toronto, these recipients were grouped into a broad "vulnerable" category to be determined based on the incidence of illness and death during the pandemic. Related to this, participants in several groups noted that any approach to the provision of antivirals to vulnerable populations must have an assumed flexibility: vulnerable groups to be defined as the pandemic unfolds, with adjustments in the approach as new information becomes available. Participants noted, however, that these are the groups – children, elderly, chronically ill – that are currently identified as priority recipients now for seasonal flu vaccine – an approach that seems to be effective and acceptable to the general public.

It was compassionate considerations that often led participants to support one or all of the vulnerable groups as priority recipients. Targeting those vulnerable to illness and death was viewed as "caring" and "humane", and to align well with Canadian values. Also, these are individuals who may not be in a position to "help themselves".

- *"I think that the approach of protecting the most vulnerable people based on your calculations that it is the young and the older. I value as a Canadian that our government will identify and do everything they can and to protect our population and therefore this fits in line with my values as a Canadian." (Winnipeg)*
- *"Approach number one. It is humane. It is this group of people who are obviously vulnerable and just knowing that they are vulnerable so you are trying to reduce their effects of contracting the pandemic flu." (Halifax)*
- *"It's a question of ethics, in our society, that we help the vulnerable." (Montreal, translated)*

Vulnerable groups received less emphasis from participants in target group and stakeholder sessions. When selected as a priority, the consideration was more pragmatic than compassionate. Some noted that the elderly are the greatest consumers of health care services and should be protected by antivirals to reduce their demand on the system. Indeed, many felt this group would be less likely to receive treatment as a result of triage decisions in a pandemic (given the lower chance survival).

Several groups identified children as a priority within vulnerable groups, although also noting that they may not necessarily be a vulnerable group depending upon the pandemic situation. In identifying children as a priority, participants focused on protecting the next generation of Canadians (and future economic prosperity), and also on limiting the spread and impact of a pandemic (noting that children tend to spread viruses quickly, and also that parents at home caring for children will be absent from work thus increasing the economic impact of the pandemic).

- *"We should consider the children as society and potentially vulnerable. I also consider the children as being our future so with this approach I think it is important that we protect our future." (Stakeholder)*
- *"There is a whole list of them the elderly and the people that need to be taken care of with certain complications and so on, people who are in contact or household contacts with people risk factors etc. That is fairly well laid out from a scientific point of view. What is not laid out is not the vulnerable but who is going to be spreading the disease and if you look at who spreads these diseases it is children." (Stakeholder)*
- *"..we did add children into that one because we felt that if people didn't feel that children were protected all of these essentials will not necessarily be available or comfortable making themselves available." (Stakeholder)*
- *"The way that we looked at children they are our future. Not only that, if 30 per cent didn't make it for some reason then that would be a crisis down the road in terms of economics.' (Target Group)*
- *"..when kids get sick it becomes a health crisis for the entire family." (Target Group)*
- *"..when kids get sick for whatever reason we have tremendous experience as a huge impact because they need to be looked after. They can't look after themselves." (Target Group)*

Compassionate arguments were particularly salient in selecting children as priority recipients in citizen sessions. The dialogue sessions in Toronto, Vancouver and Iqaluit placed particular emphasis on children.

- *"What would prevent daycare from spreading it. The children get it there and the children then spread it to their parents and children outside of the daycare all in a single day. If children are not able to receive it at one year of age then does the parent become the one to receive it? They may be exposed as well as the children may be exposed to the vulnerable. Again it becomes a problem there as well." (Vancouver)*
- *"There is one other consideration in terms of treating children as vulnerable. Not only that they are more susceptible to get the flu but also they are contrary to the elderly. They are isolated they are also among us and actually spread the diseases a lot easier. They are a good group for containing because if you can actually contain it from the adults from actually getting the diseases." (Vancouver)*
- *"We kept on going back to children and we couldn't decide. We were divided amongst that so then by exchanging the different opinions we all decided that children are our future but what good would our children be if there was no providers for them so what we did was we created our own third which we called the higher risk and that in turn would include whether it be children, elderly, anyone that would be considered a high risk or having a low immune system. Not necessarily focussing on children, men or women, or elderly or older age, but just in general any human person that is considered higher risk." (Toronto)*
- *"Say for example we took care of these health care workers, police, emergency responders, I go down through the list here – that's good if all these people are healthy because obviously the goal is to keep everybody healthy, but if we have 1,000 children home sick, you know it's the police and the emergency responders, all these people have to be home with their children. So it doesn't matter how many drugs you're giving them, if the children in our community are sick our community is going to come down regardless." (Iqaluit)*
- *"If you're talking about children who are sick, family members in general who are sick, then you're getting into the emotional thread of our community and then people don't really use their logical thought then because you act or react with your heart. Again, when I see the word pandemic, you*

take out the 'dem' and you're left with panic and that's what your community is left with when the fabric of your community is falling down. Let's face it children are the core of any community…what is the one thing that really keeps our communities striving, it's the school, it's the children, because that's the one thing we always focus on is keeping our children healthy and letting them grow up so they can take care of us as we get old and generations continue." (Iqaluit)

- *"If we protect our youth by giving them antivirals for preventative reasons to reduce the number of deaths, well, there will be a real impact because there will not be a hole in our population in 20 years time" (Montreal, translated)*

The discussion around the elderly as priority recipients was more complex. The elderly, due to their vulnerability to serious illness and disease are potential priority recipients for compassionate reasons. However, while participants recognized that elderly Canadians may be more vulnerable to influenza-related illness or death due to fragile health, participants also talked about whether the elderly would be inclined to take antivirals for prevention or prefer to see others as priority recipients. Some participants in the groups, themselves seniors, agreed that they would prefer that a limited supply of antivirals for prevention be distributed to younger (or the youngest) citizens.

- *"I am in my high 90s. That questionnaire was very hard to fill out. Choosing who should have it first and who should have it second. I am all for anything - first of all children." (Winnipeg)*
- *"People in the senior homes are finished their careers and the general people in the society - being the young people, middle aged people who are doing the work are important. They are doing a lot of work. I think it is really important to consider that. Some senior may elect not to take the antivirals for that reason. Some might not want to be able to think that clearly but we should be protecting the people who are going to be the backbone of the society." (Vancouver)*
- *"I'm an older guy and I've lived my life I'd go and help out but if someone is responsible for young children even if they are a healthcare worker, if it's certain that contact with this disease is going to be deadly...that's getting kind of scary talking like that but it's possible." (Iqaluit)*

Iqaluit participants placed an emphasis on elders as a priority recipient group for a variety of reasons.

- *"The elders are from my experience in control pretty well of everything for Nunavut. They are pretty well on top of the agenda in our governments, in control of what is going on. That's why I put it as the first priority." (Iqaluit)*
- *"The elderly were top on the list for the simple fact that Nunavut has a different set of values than down south and I think we really appreciate the wisdom that elders offer the communities and they are in one essence the emergency workers of our communities because they keep the community grounded. So if we were developing some for just Nunavut I too felt that elders should be in that top list of recipients however, if we're talking about a Canadian-wide one then it would be different because the values are different down south than they are here." (Iqaluit)*

The chronically ill (and those with weakened immune systems) as an identifiable priority recipient group was less visible in the discussions in the dialogue sessions (with the exception of Halifax). In one group in Vancouver, participants were of the opinion that there would be a significant overlap between the elderly and the chronically ill. In Halifax, while chronically ill individuals were frequently named as priority

recipients, some participants wondered if this group might present logistical challenges in terms of identifying and verifying individuals in this category. There was also a tentative discussion about whether a judicious distribution of publicly-funded antivirals should include terminally ill patients. In some groups, vulnerable children were included in this group.

In addition to compassionate considerations, more pragmatic reasoning was also often at play in identifying vulnerable groups as priority recipients. Assigning priority status to vulnerable groups was seen to be sensible given that these are the individuals most likely to fall ill anyway and, therefore, an effective use of the dose. Preventing serious illness among susceptible groups was thus also perceived to be a pragmatic strategy to avoid overburdening the health care system during difficult pandemic conditions. Similarly, directing prevention efforts toward children was viewed as having the potential to contain or slow the spread of the virus given that children are more susceptible and often spread the virus amongst each other and to their families.

- *"It seems like what we are doing now for the seasonal flu is working. Why not take that kind of approach, obviously we are focusing on the vulnerable being seniors, children, elderly, people who get ill easily. It seems similar to this and the spreading is quite similar. It seems to be working. I would assume it is working and there is less death because of the vaccination and because it is offered the way it is." (Halifax)*
- *"I feel that the children, they go to school, they take it to the school, they bring it home to the parents, the parents take it to wherever they are working. Once your child goes to school you get all these things brought home." (Winnipeg)*
- *"I like the idea that it will be provided to people in places where a lot of these vulnerable people are together such as nursing homes, maybe in school systems and places like that because if the kids are vulnerable to the disease and the elderly are vulnerable to the disease once one gets it it's likely to quickly spread. Then the health care professionals and the teachers and principals in the schools, they would need to get these preventative measures as well because if not and one elderly person or one child gets it, it spreads to the population in that centre whether it's the nursing home or the school. So it spreads rapidly and then the people who are working in those areas are likely to catch it quickly because they're surrounded by the virus and then once they get off work they bring it home to their families and all of a sudden all of the teachers' families are vulnerable and all of the nurses and doctors and health care professionals' families are vulnerable and then those people interact with other people in the community and before you know it the virus has spread so rapidly that you probably won't be able to contain it in a very timely manner." (Iqaluit)*
- *"Medically, the elderly and children are those with the weakest immune systems; children are just developing their immune systems and the elderly are losing theirs with age." (Montreal, translated)*

Finally, curbing serious illness and death during a pandemic (which is most likely to occur among vulnerable groups) was also viewed as contributing toward minimizing public fear and panic.

- *"This is of key importance. This is not only from the moral dilemma. From what I hear from around the table we are pretty committed to doing whatever we have a responsibility to do. But also for practical reasons if you have high death toll in the most vulnerable group which is a logical conclusion we will spin a logical series of panic. Refusal to work and refusal to take medications of all kinds of things that would make us much more vulnerable. Not only do I see one of the positive things about this approach and whether or not it is far reaching enough. I guess we consider in the next proposal is that by targeting the most vulnerable the intent is to reduce death rate. Death rate and loss of life is our*

moral obligation but secondary to that is the unravelling of our society in a situation of fear and I think as a strategy that is very important for governments to consider. No, what I think you will do here is reduce death hopefully and reduced death will help reduce the unravelling of trust and creation of fear for practical reasons. Number one I think is our moral obligations. Number two is the practical situation of increased vulnerability for the community based on the outcome of death." (Winnipeg)

In Halifax, in particular, the economically vulnerable emerged as a priority recipient group under the vulnerable as well. Participants expressed the concern that the poor, in fact, compose a high risk group because of the disparity in health outcomes and presumably their greater vulnerability to serious illness and death in the face of an influenza pandemic.

> *"We felt that if we were going to say to fund publicly antivirus should be provided for prevention we said well if you are one of these three groups that we talked about for our group – chronically ill, immune deficient or you are a health care worker or you are an emergency worker and for some reason you can't afford it then it should be publicly funded or you are one of these people who are economically vulnerable you should be publicly funded." (Halifax)*

Compassionate and pragmatic considerations aside, there were some disadvantages that were identified by participants in targeting vulnerable populations as priority recipients. The first of these centred on logistics, and the challenges and cost of distributing antivirals to such broadly defined groups. Second, the sheer size of these groups was also seen to present difficulties in communicating the importance of and ensuring compliance with the drug administration protocol over a lengthy period of time. Finally, and particularly with respect to children, were concerns about the unknown and possibly negative impacts of antivirals on children's long term health and immunity.

To address the logistics issue, there was some discussion in some sessions about the merits of an institution-based approach for distribution of antivirals to vulnerable groups (the prime example being nursing homes) (Vancouver, Winnipeg). This approach was seen to have several advantages including resolving logistical obstacles associated with broad community distribution and providing a structured setting to ensure compliance. According to the information supplied to participants, antivirals have been provided in nursing homes in the past with success and, therefore, this was perceived to be a continuation of what has been done in the past and thus a pragmatic approach. Note that there were some objections to this strategy which, according to some participants, would unfairly exclude community residents. Another option which received particular attention in Winnipeg was an outbreak-based approach, which would see vulnerable groups targeted as priority recipients, but focused on communities where there was an outbreak.

In contrast to HCWs, there was little discussion of conditions that should be placed on the distribution of antivirals to vulnerable groups as priority recipients. In Vancouver, some additional conditions of distribution included: distribution supported by public education to ensure compliance (and public education itself supported by research to convince recipients of dangers of resistance); and an obligation on the part of recipients to participate in research studies, monitoring and follow-up to determine safety and study long term effects. As mentioned above, in some sessions (Vancouver, Halifax) the rationale for providing antivirals to imminently terminally ill patients was raised, but this was an uncomfortable topic that participants preferred to leave to the discretion of doctors and their patients rather than a matter of policy.

Other Issues

As dialogue participants worked through the exercise to determine priority recipients, there was considerable worry about how decisions would be made "in real life", who would make them and whether decision-makers could be trusted to be reasonable and fair. Determining "essential" workers or even determining health care workers, for example, raised red flags for many participants. Participants acknowledged their own discomfort in discussing these issues during the dialogue and anticipated that individuals with different values, background or experiences may come to quite different decisions on priority recipients. As one participant noted:

> *"I think it is a real risk for the provincial or any government to appear that they are imposing a value of judgement of whose life is more valuable across their citizens. I think there is some risk with this…It would all depend on our background, our experience, and what we think is essential…I don't know how you completely resolve that. That becomes complicated." (Winnipeg).*

Another noted:

> *Now I understand why governments take so long to make decisions. These are not easy decisions to make. Scientific decisions can be made with numbers, data, graphs, etc. but these are based on values, principals, beliefs, which makes it very difficult, but they are decisions that have to be made sometimes". (Montreal, translated)*

This concern led some participants in Toronto to eschew selecting priority recipients at all and for universal access to antivirals for prevention to figure strongly in the point of view of at least a significant minority (and maybe even a majority) of participants. Universal access was rooted in the notion of fairness and access to care as citizens, in keeping with the values of our current publicly funded health care system overall. According to these participants, universal access would circumvent the ethical quagmire of selective distribution and limit the potential for abuse that occur.

In the Montreal session, participants argued that priority groups be very strictly identified, and that the distribution of any antivirals for prevention be practical, ethical and be clearly communicated (the rationale behind priority groups) to the public. Participants in the Montreal group also expressed great concern that any perceptions of inequity in the availability or distribution of antivirals for prevention could jeopardize any sense of solidarity and mutual support among Canadian citizens during a pandemic crisis.

> *"We are all equal and we should all have the same access because, if not, it will create a panic effect in the population. People will say: why him and not me?" (Montreal, translated)*

> *"It is not realistic to expect that we can offer a preventative service equitably across Quebec, and so I think…I don't know if we had consensus but if we cannot do this in an equitable manner, then maybe we should fall back on ensuring that we can provide equitable treatment." (Montreal, translated)*

The concern about selective distribution of antivirals led other groups to place significant importance on supporting distribution with strategies to build trust and understanding among priority recipients themselves and the general public, that is, "selling" the strategy for the distribution of antivirals.

Interestingly, the need to provide a defensible and justified rationale for selective distribution of antivirals occurred more often in the context of distribution to heath care and emergency workers, and less so in the context of provision of antivirals to vulnerable groups.

This issue was raised in the context of ensuring that the public is able to understand and accept the discriminate provision of antivirals to priority recipient groups. In one session, participants noted that it would be important, for example, for health care workers to be able to articulate why they were receiving antivirals for prevention, while other segments of the population were not.

Target group and stakeholder participants also raised concerns regarding the ethics of limiting the availability of antivirals to specific groups. In several groups, concerns were expressed that social biases may enter into the decision-making, placing vulnerable or "have-not" members of society at greater risk. Concerns regarding the social impacts or implications of limiting the availability of antivirals were also raised. As well, as noted, participants emphasized that priority or vulnerable groups cannot be determined with any accuracy in advance, given that each pandemic is unique. The choice of priority groups and response will have to be tailored to the situation.

- *"Ethically and morally how do you make that decision on who you are going to allow to get it and who you are not going to allow to get it?" (Stakeholder)*
- *"It doesn't protect the people on social assistance. It doesn't protect the self employed. It doesn't protect the homeless. It leaves the people who generally most need our help -- out in the cold again. I am empathic to 'we need to keep things functioning and we need to be sure about it', but it makes me very uncomfortable about this question." (Stakeholder)*
- *"I think as a whole this (approach 3) is inadequate in terms of equity. I think that this really exposes the most vulnerable with the suggestions. The other element that I caught is that right now there are, even in the best of times health human resources, doctors, nurses other types of care practitioners that are saying that there is a significant strain in terms of the health human resource. There is going to be huge elements that even in the best of times when you start to consider the additional strain that a pandemic would present to the system and the influx of patients coming into their family physician if they have one to request antivirals. I just shudder to think about the strain on the system. The last point that I highlighted was under the first bullet in support the approach leaves decision makers to those who and I question whether or not these individuals or institutions really react to reality." (Stakeholder)*
- *"I am really struggling with who is vulnerable. I am not sure if that is what is being asked because we don't really know who is most vulnerable until it strikes. Are we actually asking then who do we value the most as a society. It may be children and it may be completely legitimate, but I don't know if we can say who is vulnerable." (Stakeholder)*
- *"I wouldn't support mandatory because it goes against the basic ethics of medical ethics which is basically uninformed consent for any procedure or any intervention being provided to a person." (Stakeholder)*
- *"..we would be going down a very slippery slope if we didn't force people who didn't want to take antivirals if they didn't want to take them. Matt brought up a good point for religious points or whatever yes." (Target Group)*

- *"It is my opinion that these dollars should be spent on the people who can least afford the medication." (Target Group)*
- *"What about the homeless people? They are kind of left out of this deal. They don't have media access. They don't know what is going on. Health care or any of that stuff. Who is looking after their concerns? I would say that they are vulnerable because it is not just their living conditions in general and they are a really good reason of spreading disease. They are still out in the general population. They would probably be good carriers I would expect." (Target Group)*

2.4 Support for Overall Policy Direction

a) Citizen Session Results

Following the discussions about approaches, common ground and priority recipients, citizens were finally asked to explore their views around the primary question: should governments be providing publicly-funded antivirals for prevention? The discussions took place specifically in this order to allow participants time to think about what they liked and did not like about the concept, what their basis for deciding was and who they thought that it would apply to. It ensured that participants had worked through the complexity of the decision before coming to a determination. Participants were also asked to consider the pros and cons of the decision, as well as the considerations that they felt should be key in making the decision.

The question was, nonetheless, a tough one for participants to answer and came with many concerns and reservations. For the most part, citizens decided that antivirals **should** be publicly funded (within the common ground assumptions of the group). This decision was based on concern about the ramifications of a pandemic on the death toll, rate of illness, implications for local and national economies, and general level of fear and panic that could result among Canadians. The overriding view was that a pandemic would result in considerable disruption to society and that governments should be responsible for taking the lead in protecting citizens, instilling confidence, and minimizing fear, panic and social disruption. At the same time, participants wrestled with their concerns for cost (more often expressed in terms of opportunity costs than in absolute costs) and the lack of information available about the efficacy of antivirals and their potential damage (i.e., side effects, and built-up resistance of the virus through long-term or improper use of antivirals).

Participants in all seven citizen sessions convened in small groups to discuss their support (or lack of support for governments funding of antivirals for prevention as shown in the results of the individual sessions. It should be noted, however, that not all groups were unanimous in their decision – where obvious, in the reporting back of results, these have been noted in the table.

Table 2.12: Citizen Group Consensus In Dialogue

Session	Should	Should not	Undecided/Divided
Halifax	4	1	0
Winnipeg	6	0	0
Toronto	4	0	1[4]
Vancouver	3	1	1
Edmonton – First Nations	4[5]	0	0
Iqaluit	5	0	0
Montreal	4	0	1
Total	30	2	3

This fairly unanimous support for publicly funded antivirals was based on a number of values, principles or considerations that they wrestled with in the common ground. Ultimately, the overriding considerations were to:

- mitigate the impact of the pandemic:
  - on the number of citizens that get seriously ill or die;
  - on disruption to economies;
  - on an already fragile and overly burdened health care system; and,
  - on the lives of citizens more generally during a pandemic (when fear and panic would be prevalent).
- ensure that critical functions in society continue (e.g., security);
- ensure that public servants most exposed to the virus (i.e., those placed "in the line of fire" to serve the public) would be protected;
- ensure that fairness and equity would prevail and there would not be differential access based on income or region; and,
- demonstrate leadership to industry to consider the protection of workers, and to citizens to demonstrate planning and control of the situation.

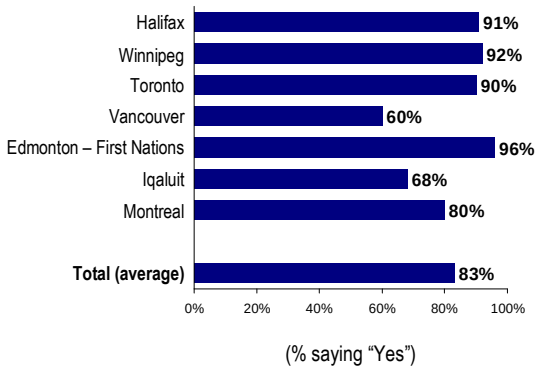
Survey results reflect a similar level of support from citizens for government providing publicly funded antivirals for prevention. Across the seven sessions, 83 per cent of participants said "yes" the government should do this, while 13 per cent said "no" (and four per cent were undecided or did not respond). These (survey) results will be examined more closely later in the section, however, the following exhibit of results by session provides a snapshot of participants' point of view:

[4] Group divided (one yes, one no, and one not stated).

[5] One individual not in agreement.

Support for Antivirals for Prophylaxis

"Government should provide publicly-funded antivirals for prevention"



EKOS Research Associates Inc.

n=162

Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

Following the overall question of support for publicly funded antivirals for prevention in the questionnaire, participants were then asked to indicate their reasons for their answer. Among those who believe that the government should provide publicly funded antivirals, the most often cited reason was to minimize illness and death and curb the spread of the pandemic. Several comments indicated that preparation and prevention of illness is the "right thing to do", giving citizens "peace of mind". Many of the comments made reference to elements of the dialogue common ground, with citizens prepared to support publicly-funded antivirals for specific priority recipients (e.g., for the vulnerable, HCWs, essential services). In their responses, participants who supported antivirals for prevention did so with caveats having to do with ensuring the efficacy of the medications, safety and cost. Others noted that a program of publicly supported antivirals must be accompanied with public education, monitoring of compliance and the ability to distribute the drug in a timely, consistent and fair manner.

Among participants who are not supportive of publicly funded antivirals for prevention, reasons included concerns with regard to side-effects, in particular, the unknown effects of long-term use, as well as issues related to compliance and the potential for developing resistance to the virus. Unknown efficacy and high cost were also concerns mentioned by some. Several participants suggested that the money would be better spent on education and research on vaccines than on antivirals for prevention. A few also believe that publicly funded antivirals would provide a false sense of security about being shielded from the virus and that this could, in turn, shift emphasis away from continuity/contingency planning and reduce the focus on other basic public health prevention measures (e.g., handwashing). Quebec participants in particular emphasized that if antivirals cannot be given to all (ensuring equality of all citizens) then they should not be given to anyone.

The following is a more detailed description of the considerations participants were wrestling with in the dialogues.

Pragmatism

Citizens talked at considerable length about **practical elements** of mitigating the effects of a pandemic on Canadians. They were very concerned with the number of people that could become seriously ill or die as a result of a pandemic and the ripple effect that this could cause on households, businesses, the health care system, and civil society. Containing or limiting the spread of the virus was a central rationale for their overall support of government involvement in antivirals for prophylaxis. Fewer people ill meant fewer people entering hospitals and dying, and less interruption to peoples' lives and businesses. This consideration that society continue to "work" during an influenza pandemic was cast both in terms of maintaining normal operations so that the pandemic itself could be dealt with effectively, and also to avoid social disruption as far as possible.

- *"It is an opportunity to have a healthy population with long-term savings (cost, less ill people, less dead people)." (First Nations)*
- *"Touching on the fact that it would keep society going. Basically it is a fiduciary duty of the government to keep us in good health and to make us stay that way." (First Nations)*
- *"A pro was the economy continues – it will prevent disruption of activity." (Vancouver)*
- *"It would also help to maintain the overall social aspect running." (Toronto)*
- *"The pros - It could reduce the death rate and the severity of the illness. It would give a feeling of security and there would be less fear and promote trust and stability. Cons – if the government decided not to do it there could be a higher death rate." (Winnipeg)*
- *"The pros are: reduce the spreading of the disease, reduce panic and everybody feels safer that they know this antiviral is there." (Winnipeg)*

The lion's share of support for publicly funded antivirals for prevention across the citizen sessions is based more on a strong sense of pragmatism than any other factor. The argument that antivirals, administered in advance of contracting the virus, could reduce the number of Canadians that fall ill and die was the most pivotal factor in convincing citizens of this approach (although this can perhaps be equally attributed to a sense of compassion). Thus, for many, there is an expectation that governments should undertake to provide antivirals for prevention as an important means of protecting citizens.

- *"We think it is good insurance. It is the right thing to do to minimize the loss of life." (Winnipeg)*
- *"I think that we have a mortality rate if they do not take it in advance and the flu would hit them and they die those are the groups that we would want to focus on first. The most vulnerable in terms of mortality. It could be children, it could be elderly it could be the chronically ill as the group." (Vancouver)*

In this context, participants in Toronto and Vancouver saw the use of publicly funded antivirals as "insurance," an investment in the event of a future need (i.e., emergency). In spite of the unknown

elements of a pandemic (i.e., what it will look like, how severe it will be, who it will most affect, when it will occur), such an investment is made on the assumption that an event can occur, that the event would be damaging and disruptive, and that it would be difficult, if not impossible to meet the challenge without some advance investment or preparation.

- *"The pros were if you spend a little now you won't spend a lot later. Even though it is a high." (Winnipeg)*
- *"..that may indeed never happen. However, the chance of this is very good it will happen. The good parallel is to have good life insurance. I have life insurance. I don't expect to die today but I will sometime. A pandemic is going to happen sometime you just don't know when." (Toronto)*
- *"I guess it depends on whether you are looking at it from a purely economical sense that the insurance policy. An insurance policy, you can look at it like an economic point but purely, but the point is that if I died my main concern would be the well being of my family being looked after. It is not purely let's say the monetary aspect. The insurance policy in my point of view that you are taking out the insurance policy in my regard is from a point of view of respect for human life. That sort of government responsibility and their fiduciary duty for life. I think that is what it really boils down to. That is why we have a health care system. We don't have to have one but we do because we are concerned about people's health." (Toronto)*
- *"We decide that the private enterprise will take care of his own and the government will be reliable to provide … Two levels of insurance in that case. What is the risk that everyone will get sick? It is imperative that we take the insurance." (Toronto)*
- *"How much insurance are we going to buy really? Do we have to look in a big context of okay what area to we measure? We have this big pile of money. Is this better spent on something else than we spend too much insurance? We would look at this in a big context as well. Are we allowed to do that as well? In an emergency situation I agree. We have no choice. We have to fix it. We have to fix it. Now we are discussing how much are we going to spend from an insurance perspective. We should look at the context on whether we should buy insurance somewhere else for better use. We may not use it at all." (Toronto)*
- *"Maybe I'm interpreting it a little bit different but I see the third approach of more concern to me. While you were talking I was trying to think of an analogy to describe it. Auto insurance, a lot of people because we're forced and legislated to purchase auto insurance, we all have it. If it were left to a decision would we purchase the appropriate amount of insurance? This is a concern to me where as an institution with a limited budget, if it's their own responsibility to stockpile and how much they stockpile, maybe not all institutions will take the full benefit and in my opinion a logical approach to stockpile a number of antiviral medications. So if the case comes to light to where there is an outbreak then some of these institutions may not have stockpiled. They might have felt it was more important to purchase that MRI machine or that CAT scan machine, whatever the case may be and those drugs will not be available to the general populace. Just to further that, where there is government legislation or control that forces them to stockpile, I would be more comfortable with that." (Iqaluit)*

In fact, for some participants, so fundamental was the importance of minimizing illness and death, that cost or other considerations were irrelevant. In Toronto, for example, there was a common sentiment that antivirals for prophylaxis should be available universally.

- *"There were two pros. The government appears to have the tax dollars to do it so do it. The other one was the program provides personal insurance to maintain social order, social equity and other Canadian values we are so proud of." (Toronto)*
- *"We all agreed that there should be universality. If it is a universal disease think about it as a sore thumb. The first idea is not universal coverage. So far it hasn't been in Canada that is why we have publicly funded health care because money is no object. Ideally the manufacture of the pills should all be done at once. Capacity should be at 100%. The ideal situation." (Toronto)*
- *"The pros would be that there was a general consensus that the government does have a moral imperative to protect society. Also, another pro would be the cost of not, assuming the drug does work, the cost of not investing in this. Things like the idea of a severe recession that would follow the idea of losing a generation of our youth and our members, those kinds of things. In terms of cons, the biggest con is in choosing only a limited number of people according to our consensus we would be going against the universality principle which we feel is quite common in Canada and it's difficult to go against that." (Iqaluit)*
- *"To me what do Canadians believe in? Canadians have always believed in universality and we either all get it or nobody gets it. This business of picking people just seems so wrong." (Iqaluit)*

Another important consideration is the level of **societal disruption** that many participants think of when they think of a pandemic unfolding in our society. Recent images of hurricane Katrina have likely fuelled this concern for society falling apart in the face of a sudden and all encompassing emergency. Antivirals available in large quantities and made available by governments for prevention, would show a measure of planning for and control of the situation and would naturally instil calm and allow people to continue on with their "normal" lives. In particular, there was considerable discussion about some people who might refuse to work (if they felt they were in danger) or might choose to care for their families, which was often highlighted in the media coverage of hurricane Katrina.

- *"..pros were security and mollify the masses." (Vancouver)*
- *"It protects infrastructure of the society because they are going to be needed where people are uninformed. Where people are under the state of the emergency. Having that infrastructure functioning at full force is very important to avoid a breakdown or a more serious situation in communities to help control and help sort out the confusion amongst us. Having that infrastructure is that important. Basically being there to aid the rest of the population and to inform and keep things in order or just keep it in order to keep things moderate. Lets not say crisis but say that people will be acting to it. It will be on everyone's mind and in comes a priority to everyone and so just having there to maintain a sense of normalcy and protecting that." (Vancouver)*
- *"Our idealistic answer was that the government would somehow be able to force the manufacturing of the pills to greater batches – larger quantities to force the issue. Not to accept little implemental shipments, but to take a larger shipment down in order to have enough for everybody because of the premise of universality." (Toronto)*

Citizens voiced concerns for the economy and ongoing functioning of society in the face of a pandemic and felt that antivirals made available by governments for prevention would help reduce absenteeism and ensure that central functions would not be compromised. They specifically addressed the health care system which they recognize is already under constant strain and argued that antivirals (for a range of priority recipients) would help to minimize the additional stress that would inevitably be placed on hospitals, clinics, and health care workers in a range of other facilities.

> *"If we are giving health care workers antiviral drugs especially during the time of a pandemic then we would like them not to be absent. They would be there. They would be working and fulfilling their work, their hours, and their duties."* (Vancouver) [6]

To a lesser extent, some participants did point to the fact that government involvement would bring the price of antivirals down (for anyone buying them), and that government involvement might also mean better quality control assurance. At the same time, although mentioned in most regional sessions, this did not appear to be a driving force behind any final argument in favour of publicly funded antivirals.

> *"I think in terms of economy scale I think people were thinking if something was done in a large way the cost per unit could be done in a lot cheaper way if it is done hundreds of different ways, so in this case stockpile the cost of the drug might be cheaper for stockpile of hundreds of different places with a hundred different agents, I think that was the term." (Halifax)*

> *"I understand you may be coming from a protected sort of budgetary site, but the cost to society, the cost to our culture, the cost to people, it sort of doesn't ring true to me. Second to that, is that if you contracted for more would the price not go down? Is it a fixed cost, an infinite fixed cost or if we're going to contract for you know 33 million people times the prescribed dosage, I'm sure Roche would be more than happy to provide that. I think that if it's the will of the people then government needs to respect that." (Iqaluit)*

Strong Role for Public Education

It is important to note that participants in each session discussed a range of possible prevention or containment methods, including hand washing, limiting group events, and so on and stressed in all groups the importance of ongoing public education regarding effective methods of reducing the spread of the virus. Citizens across all regions indicated the importance of Canadians staying informed about an influenza pandemic, and this issue took on particular prominence in Vancouver and Montreal.

In Vancouver this message emerged during the dialogue and was also reiterated in participants' closing comments. Public education itself was raised in a number and variety of contexts. Participants saw the need for public education even prior to the occurrence of an influenza pandemic about pandemic planning, preventative or general public health measures and individual emergency preparedness. This is an area where government leadership is expected and where expectations are high. Governments are well-placed to communicate information about a pandemic to the public and to guide individual action.

[6] Duplicate quote, found on page 52.

- *"..research which would give us all more information. The pro for research would be we will all do it and we would all have more information. It would create more public information and more public awareness. That is if they do it – yes." (Vancouver)*
- *"The cons were costs – the cost of doing it and also logistics and demonstrating it. We were unanimous to saying yes to the program. What we mean by logistics is getting this out in a timely fashion. There is a lot of preparation that has to be done or has to be… An assimilated run has to be done for it. Any disaster scenario you practice the distribution of the required solution to the problem. Only by doing that will you find where the roadblocks are before you can grant them when the time comes." (Vancouver)*

In Montreal, many participants emphasized that prevention through education may be more cost-effective than using antivirals for prevention, and discussed at length the need for public education campaigns. They argued that "an ounce of prevention is worth a pound of cure", and felt that public education needs to go beyond media campaigns to engage Canadians in communication through work, school and other public venues.

- *"If everyone learned to wash their hands correctly, and learned to cough correctly, that doesn't cost a lot, it's easy to educate people and it gives good results, but to start distributing 13 million pills that will cost hundreds of millions of dollars, that is not the most efficient approach to prevention." (Montreal, translated)*
- *"I think that an information campaign should inform individuals of the gravity of an eventual pandemic, and make each individual take conscience of what they can do hygiene-wise, and that it is their responsibility." (Montreal, translated)*

In addition, citizens talked about public education in the context of an influenza pandemic during the pandemic itself. Many participants highlighted the need for public education to stem public panic during a pandemic, using information and awareness as a way to avoid societal disruptions during a period of uncertainty and fear.

- *"You have to start with education of the public. If we have like you said in case it comes if we have enough supplies to deal with the immediate problem once this flu comes here we can deal with it okay. Since we have the knowledge but to stockpile on some basis that maybe it will come but we don't know when it will come, maybe it will be here which is long-term or short-term. I don't think so educate the public yes so at least they will know what to expect because you can stockpile to the roof, but the public is not educated and if the situation is not there they will become ignorant to you." (Toronto)*
- *"..people will feel more safe if they know there is a safety net so there won't be as much of a fear factor." (Winnipeg)*
- *"Start to educate people about it. Maybe through the media, a firm, or somebody mentioned through tax returns. Somebody has to read about that and make up their mind somehow." (Halifax)*
- *"We thought that the money would be better spend on education, public messages on what a pandemic influenza is, properly training those who come in contact." (Halifax)*
- *"My advice would be (to emphasize) the importance of education because the public is going to be twice as confused. Given the amount of information we were given here and there was still some confusion. Obviously the public needs a lot of education on this." (Vancouver)*

- *"Just from education and just learning about everything. For the decision makers I guess for whatever they choose just make sure that everybody is informed. I know education is the key to every problem so if you know about it you can handle it." (Winnipeg)*
- *"I think it's important and probably of dire need that the results from these consultations, community meetings, be reported back to the public in a fashion that they could easily understand without the jargon, without inciting language, without leading to a panic, but providing hope and resolution for the future, to provide leadership and to make this perhaps an issue that politics could embrace because it is important for the survival of the human race." (Iqaluit)*
- *"I'm very happy to see Health Canada taking a proactive approach to this whole issue rather than a reactive one once it strikes. That was my big surprise here. I was very surprised to be invited and once I got here very surprised to see how far we actually have planned ahead. I think that's a really good thing. Also I think that public education is the key to all of this keeping in mind that too much information would be detrimental and really cause a panic. It's really good to be involved in things like this where you can learn more about the issue and have real insight into what could happen without getting in a panic. So I think it's important for decision makers to know that people of this country need to know a little bit about what's going to happen and how we have prepared not so much to cause a panic but just so people understand and can work through the pandemic when and if it comes." (Iqaluit)*

Compassion, fairness and responsibility

In addition to the pragmatic concerns expressed by participants, there were also discussions that centred around values identified specifically as "Canadian values" such as equity and fairness in decision-making around who would receive antivirals. There was considerable discussion, particularly in some groups, about compassion and ensuring that those who could not fend for themselves would be cared for by the system (as the fundamental premise on which most Canadian social programs are based). This included ensuring that those who are not able to pay for antivirals would be treated no differently in whatever approach was taken.

- *"Also the lack of funds for the people who can't afford it should be given it." (First Nations)*
- *"We felt that the government should provide for those who do not have coverage themselves." (Halifax)*
- *"You don't need to cover everyone. The treatment plans is to cover everyone who needs it. The additional stockpile for prevention only really needs to be concentrated to prevent the spread of it." (Halifax)*
- *"People at highest risk are vulnerable, people who don't have access for buying these themselves. For example, they don't have jobs, children don't have jobs, they depend on society to provide for them. The elderly, normally speaking, are reliant on younger, healthier people in the community to take care of their best interest needs. Is that what I'm hearing, like the vulnerable people are the ones who would be left – maybe I'm just working through this in my own head?" (Iqaluit)*

Related to this was an often cited consideration for making sure that any decisions about who should receive antivirals would be made in an equitable and "blind fashion", controlling for possible

favouritism and abuse (discussed more in the section on priority recipients). This was expressed most clearly with respect to income in participants' discussion of the "third approach" (the decision as to whether to provide antivirals for prevention should be made by those closest to the pandemic). The overwhelming weakness of this approach was seen to be in creating a divide between wealthy Canadians who, through their personal resources, could secure access to antivirals and lower income Canadians would be unable to obtain antivirals due to cost.

- *"The government fund would be available for everybody. Not for certain people who are better off or certain positions." (First Nations)*
- *"Just in addition a PR campaign needs to be done on why those people were selected. There should be some monitoring to make sure it does not start to wander out the back door. Certain groups shouldn't get differential treatment based upon knowing somebody." (Toronto)*

Similarly, with respect to geography, participants in many sessions emphasized that access to antivirals for prevention, whatever the final criteria, should not vary regionally. So, for example, if health care workers with close patient contact were identified as a priority recipient group, then antivirals for prevention should be available to this group equally across provinces and territories. Participants felt that all Canadians must be beneficiaries of a smoothly and fully functioning health care infrastructure during a pandemic.

- *"Make sure that it doesn't all go to one province." (Winnipeg)*
- *"We heard that some provinces may receive it before others. It could cause chaos." (Winnipeg)*

Strong Role for Government

There were a number of considerations around the responsibility of government that were put forward in weighing the decision. As cited above, responsibility to care for those unable to care for themselves, and equitable application are areas seen as responsibilities. Similarly, many participants, across each of the regional sessions, talked about protecting those in harm's way (often described as those who were placed by government in the line of fire, by virtue of their fulfillment of a public servant role).

- *"It opts to take social order. It opts to those who need it first." (Toronto)*
- *"Our answer was a yes based on hierarchy funding. The idea was to provide it to everybody but based upon the discussion it was targeted groups." (Toronto)*

As the third approach to the provision of antivirals was discussed (the decision as to whether to provide antivirals for prevention should be made by those closest to the pandemic), some participants expressed a great deal of wariness about the wisdom of having businesses or individuals responsible for decisions. Some participants forecast gloomy scenarios of citizens competing amongst themselves, motivated by fear and a limited and unregulated supply of antivirals, as well as the potential for the development of a black market for antivirals.

- *"Our group was unanimous that minimizing the government's role in this would not be a good idea. Trusting individuals and that." (Toronto)*

- *"One of the assumptions that this approach makes is that all these people are behaving in an ethical way. There is nothing stopping a correctional officer or water truck driver from say bootlegging this medication or selling it for $10 a pill or doing something other than what they're suppose to with these medications. So I guess that I just want to point out that there is an ethical assumption here that people are going to use the medication, take the medication, and not sell the medication. There are a whole lot of assumptions about human behaviour made in this kind of approach and that may not be how people really behave in practice." (Iqaluit)*
- *"If the government lets the private sector take over it is pretty sure to lead to havoc." (Montreal, translated)*
- *"I cannot accept that a company could offer this service to its employees while other Quebecois would not have access because their company could not afford it." (Montreal, translated)*

Participants talked as well about government providing antivirals for prevention as a method of leading by example, showing businesses, sectors and individuals the importance of being prepared for a pandemic and planning for the protection of staff.

- *"We felt that the governments and their scope of what would happen they would need to take a maximum leadership role." (Toronto)*

Despite the emphasis on a need for public leadership, some Montreal participants did perceive a role for the private sector in assuming some of the costs and responsibility. These participants felt that private medical insurance plans and companies do have a responsibility and role, while the government has an important role to protect and provide for those who are not covered privately. Some also felt that the private sector would be in the best position to identify workers in essential roles that require protection.

- *"We have to remind private insurers of their role. They will have to pay sick benefits, they may have an interest in providing antivirals to those they cover. Leave the responsibility for those who are vulnerable to the state, leave the responsibility to ensure peace and order to the state." (Montreal, translated)*
- *"I am in favour of saying that it is up to each enterprise or essential service to determine their needs in terms of prevention for the delivery of essential services in a pandemic, if we have 75 per cent or 85 per cent capacity." (Montreal, translated)*

Considerations

Over the course of the dialogue as participants worked through the strengths and weaknesses of different approaches and the dilemmas and trade offs, some individuals and small groups in each of the sessions voiced doubts and concerns about the use of antivirals for prevention at all. Even groups that strongly supported the provision of antivirals for prevention in general indicated reservations. The "con" arguments (which small groups in all session where asked to consider irrespective of their view on the overall question) included: cost/opportunity cost; fostering drug-resistant viruses; safety concerns/possibility of side effects; efficacy; logistical challenges (getting antivirals out in timely fashion); and selective distribution of antivirals having the potential to cause chaos. The need to continue to do research into the

safety and effectiveness of antivirals, as well as vaccine technology (so as to produce the vaccine faster) was also strongly noted.

For some participants, the value of upholding the health and safety interests of citizens was expressed in a different manner: here the health and safety implications of the antivirals themselves were key. The long-term safety of using antivirals for prevention, side effects and the potential of the widespread use of antivirals leading to the development of drug-resistant strains troubled many. In some cases, this concern led participants to argue against the provision of publicly-funded antivirals at all (or at least until some of these health and safety issues were better understood). Other participants, due to health and safety concerns, would argue for limited distribution (e.g., under controlled circumstances where side effects, efficacy and compliance could be monitored).

- *"Safety of the drug. Major because we don't know side effects." (First Nations)*
- *"Some of our pros were prevention and saving lives, but we came to this teeter-totter of how are we going to know we can actually save lives unless we do the research. Are we going to learn from our research? The cons would be the cost – human cost and dollar. Just the uncertainty." (Vancouver)*
- *"Resistance. We are taking something that may or may not be fatal and turning it into something that is deadly. That is a big concern because we might be better just riding it out. If we do something like this we might just make it ten times worse." (Vancouver)*
- *"Concern of long term use. I am struggling with this. It is causing quite a lot of distress. I am just wondering if this is giving people a false sense of security." (Winnipeg)*
- *"We are concerned mostly about the extent of secondary effects" (Montreal, translated)*

During the course of the dialogue sessions, many participants asked questions about antivirals that, at this time, simply cannot be answered definitively. The research base is quite limited and, of course, prior experience with the use of antivirals under pandemic conditions non-existent. In their closing comments, several groups urged that significant progress be made on understanding the safety and efficacy of antivirals to improve the confidence of decision-makers and the general public in the appropriate use of antivirals for prevention.

- *"Safety and how well it works. If it doesn't work why are we buying it." (Winnipeg)*
- *"We decided no preventative antiviral for many reasons but the two main ones were lack of concrete evidence in the effectiveness in the long-term or with the safety with the future side effects from taking them long-term." (Halifax)*
- *"Top two considerations, they kind of fall and overlap a bit. Resistance and side effects (safety side effects)." (Vancouver)*

One group in Halifax qualified their argument for publicly funded antivirals by suggesting that it be used for initial containment only during the first few weeks of the pandemic and then stopped to avoid widespread use and misuse which might lead to resistant strains of the virus, as well as excessive cost in this application of antivirals.

- *"We also felt that with the 55 millions dosages already stockpiled for treatment that, that was a safety net for anybody who was chronically ill or became seriously ill from influenza. Also it is not cost-effective because everybody views this as we think it is a one time deal and the shelf live is five years and we think it is an ongoing deal in cost until and especially if something happened and then because we will want to prepare for the next one. I think that we should wait and see what happens with the first one before we decide with preventative antiviral available for everybody." (Halifax)*

In all the dialogue sessions, participants raised their concerns about the decision-making process itself with respect to antivirals for prevention. If there are to be priority recipients, who will decide who they are? As mentioned previously, participants themselves struggled enormously to identify and prioritize groups. They wondered how decision-makers would ultimately decide the "value" of different groups of citizens.

- *"Who will be the major decision makers....I would like to be able to decide for myself, but overall who will have the last say. Who will get and who will not." (Toronto)*
- *"My question is who is going to make that decision. Is it the president or CEO of hydro who will make the decision? How many of those workers? Is it full-time, is it part-time workers? That sort of sets me off when I was reading it. Certain numbers and decisions would be made. My question would be who would be making these decisions?" (Winnipeg)*
- *"If you are going to be selecting, who should be prioritized. In practical reality I don't think people out there would really appreciate certain segments of the population getting the antiviral and they're not and they could be in a panic situation and that could boil over into other problems." (Iqaluit)*

Finally, efficiency considerations were apparent in participants' concerns about the costs of antivirals, particularly given their limited (5-year) shelf-life and the possibility they may never be used. Opportunity costs were raised in all the sessions, but most often in Vancouver where participants were provided more information on potentially broader tradeoffs in spending on antivirals versus other health care priorities.

- *"Why should we stockpile on a product in 1.5 billion dollars for it when it is going to be possibly sitting somewhere and the pandemic doesn't hit. If they are going to have that stuff they are going to have it ready. Why buy it now if it expires." (First Nations)*
- *"Because of the shelf life of the stockpile and you stockpile too soon you are going to be wasting all the tax payers funds or money on something you are going to have to dispose of so it is a total waste you don't know." (Toronto)*
- *"The cost of doing this could be money misspent. It could go to more worthy causes. If we look at the cost and it is an ongoing thing we have to rebuy these stocks every five years. That is a lot of claim that could do a lot better elsewhere. Of course it is a concern. It is money spent on an unproven technology." (Winnipeg)*
- *"Overall cost and also how well does it work. If it doesn't work, can it be modified to adapt to the strain quickly? Shelf life – How are they going to stock it or buy so much a year. Buy one lump some, buy here and there… Cons doing it and not doing it." (Winnipeg)*

Opportunity costs were raised in the context of other medical applications, other public emergencies and also in costs of actions taken in a pandemic. For example, some participants suggested

that this effort be put into the development of treatment (i.e., vaccine production) rather than prevention through an application with unknown efficacy. There were also many participants who suggested that the money and efforts would be better spent in additional efforts at public education, as the most basic (e.g. around handwashing), tried and true method of containing the spread of a virus. Others argued that opportunity cost was difficult to predict, as it was not realistic to assume public dollars would be spent on things such as MRIs since there may not be the political will to spend on other areas of health care as there may be on pandemic preparedness).

- *"We collapsed information and education together. It is hard to put out information without education." (First Nations)*
- *"The possibility of loosing the ability to develop immunity. We all said no to funding. Might be open to it if there is more research." (Vancouver)*
- *"Cons we had cost of the program and fostering resistant bugs that would backfire on us in the future. We said maybe we should focus our research on treating instead of the prevention." (Vancouver)*
- *"In a sense we call it a misallocation of funds. So many more ways that the same money may be spent we thought than on this dicey experiment. There are better kinds of insurance." (Vancouver)*
- *"We thought that the money would be better spent on education, public messages on what a pandemic influenza is." (Halifax)*

In Toronto in particular, a number of participants expressed significant concern for the impact of disposal of outdated antivirals (given the expected shelf life and uncertainty about timing of a pandemic) on the environment. Many wanted to be sure that sufficient consideration was given to a method of dealing with old antiviral stock that would not compromise the environment before any stockpiling takes place.

- *"With these doses there are stockpiles so I mean yes we will have governments stockpile them. When you want them and we dispose them every 5 yrs as they expire how do you expose them in an environment friendly way because these are chemicals?" (Toronto)*

Another concern or consideration is for the freedom of choice that individuals or companies have in the use of antivirals for prevention. Many voiced concern for a publicly funded application that would remove the choice of individuals and companies to make their own decisions about what is best for them. In addition, some suggested that any publicly funded system would remove the responsibility of employers to protect their own workers (who would otherwise have to be more concerned about this), and in some cases subsidize for-profit companies.

- *"That would be a concern that people are allowed to make their own choices. That is a very important and valid concern." (Winnipeg)*

Another consideration voiced in a number of sessions was the strain that provision of publicly funded antivirals would place on the health care system and physicians in particular, since currently antivirals are only available by prescription. Any scheme to provide antivirals (or even make them available as suggested by Approach 3) on a wide-scale, would have to rely on some form of access that does not

require the attention of a doctor. The purpose of antivirals for prevention would be to help alleviate the strain on the health care system, not add to it.

- *"I like the approach that we get the choice, but it is not an individual choice. We need a prescription in order to get it. The reason you would need a prescription is because the government is involved and there are laws to protect everybody. If it was an individual choice you wouldn't need that. You would be able just to get some." (First Nations)*
- *"I am just concerned that when this pandemic does hit are there going to be enough doctors around to give people a prescription." (First Nations)*
- *"I looked at access as whether you had to go to the doctor to get a prescription and whether or not you would have something set up so that you can circumvent the problem. If you don't have family doctors or in the case where someone wanted to purchase it that they could go to a nurse practitioner or a clinic they we would set up." (Winnipeg)*

Most of all, many participants fully appreciated the precarious position of having to plan and take action in advance in order to be prepared, when information is limited about how the antivirals might work in a particular (and unknown) situation and whether they will in and of themselves cause harm (e.g., side effects and resistance). Although these factors were enough to have some participants argue against the use of public funds to use antivirals for prevention under these conditions, most suggested that the investment should be made in order to be prepared. Many of these same participants, however, also urged that any planning efforts be constructed with considerable flexibility in mind, building contingency plans and updating or revising on an ongoing basis as new information about the pandemic, vulnerable groups and antivirals becomes available).

- *"Will the magic bean work. It could be useless, implications from it, side effects, and no proper information." (First Nations)*
- *"We don't know the effects. The unintended effects. The cost and the misappropriation of the funds and energy." (Vancouver)*
- *"When we started talking about considerations, the first one…is the efficacy, is it going to work. The second one, we actually combined a couple, the logistics but we used it in response to the resistance of the drug. We could be our own worst enemy if it's not logistically handled in a correct manner to control the method in which the drug intake is done, completed, we could be mutating the bug ourselves and making our own antiviral medications mute." (Iqaluit)*

b) Target Group and Stakeholder Results

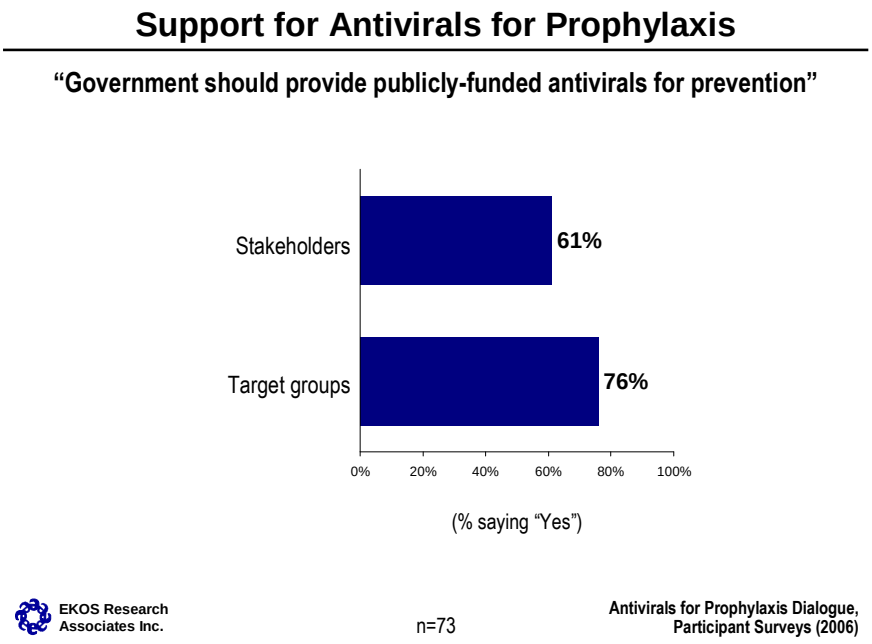
Like citizens, target group and stakeholder participants wrestled with the question, and did not find the answer to be a simple "yes" or "no". Overall, most agreed that yes, the government should provide antivirals for prevention, although they too identified many concerns and considerations which should be taken into account.

An overview of how participants voted during each target group and stakeholder session is as follows:

Table 2.13: Stakeholder and Target Group Voting In Dialogue

Session	Should	Should Not	Undecided/Maybe
Stakeholders 1	7 participants	3 participants	4 participants
Stakeholders 2	2 participants	1 participants	11 participants
Target Groups 1	All/unanimous		
Target Groups 2	1 subgroup	4 subgroups[7]	

Survey results for stakeholders reflect the moderate level of support and indecision and divided opinion expressed by participants, with 61 per cent of participants saying "yes". Survey results indicate a higher level of support among target group respondents (with fully three-quarters saying "yes"), which is reflective of the overall discussion held in these groups. While the vote held during the dialogue in the second group of participants appears at odds with the survey results, this reflects some miscommunication in this group as some did not base their final determination on their common ground and chosen priority recipients, but instead went back to thinking about whether it should be done if more broadly applied. When asked about HCWs and ESWs there was much more agreement that antivirals to these groups should be publicly funded.



[7] This result was due in part to miscommunication as some did not base their final determination on their common ground but instead went back to thinking about whether it should be done if applied to all Canadians. When asked about HCWs and ESWs there was much more agreement that antivirals to these groups should be publicly funded.

Among those who indicated their support for the provision of publicly-funded antivirals in the survey, the key considerations in their point of view most often had to do with fostering a national plan that would see collaboration across governments to devise a systematic and coordinated response – a view particularly prevalent among target groups. Participants in both the stakeholder and target groups addressed their comments to the process for selection of priority recipients (some recommending the inclusion of certain groups, while others simply recommending that priority recipients reflect criteria such as equity across the country, based on a determination of risk/vulnerability). Finally, participants raised other considerations such as effective communications/public education; logistics; compliance; safety; effectiveness of antivirals/cost-effectiveness.

For participants in the stakeholder and target groups who did not support provision of publicly-funded antivirals for prevention, the most common concerns were for the lack of evidence on the effectiveness and safety of antivirals, as well as doubts about the logistics of their distribution – the current evidence not perceived to justify the cost of the program.

The discussion of target group members and stakeholders around the issue of whether or not antivirals should be provided for prevention is best summarized by highlighting the "pro" and "con" arguments they presented, as well as additional considerations they felt should be part of the decision.

Arguments or reasons in favour of a decision to support the provision of antivirals for prevention identified by target group members and stakeholders include:

- National planning: participants emphasized the importance of having some national plan in place, and the importance of national leadership on this issue. Participants in one group noted that once a decision has been made and a plan in place, the federal government can move on to other priorities and issues.
  - *"..whatever decisions are made with respect to antivirals for prevention, there needs to be a very strong and clear context set through public information, education, and publication about not only pandemic influenza but about broad kinds of preparedness." (Stakeholder)*
  - *"An established plan may prevent problems in an event of a pandemic." (Target Group)*
  - *"We thought this whole initiative should be a national coordinated collaborative plan that will benefit our society as a whole. It should be a public plan. It wouldn't be something that we would segregate to the private sector. It should be a public plan. This public plan will maintain the safety and consistency of the product and the supply. It would minimize chaos and disorder. It would ensure equity." (Target Group)*

- Protection of priority groups: Participants in all groups stressed that there is a responsibility or need to protect priority groups, particularly health care workers who will have no control over their risk or exposure to contagion. Participants in several groups also underscore that a government plan will ensure that antivirals are available consistently to all priority groups across the country (while under approach 3 the access may be inequitable).

- *"If you have antivirals given to essential workers it might provide some kind of guaranteed infrastructure." (Target Group)*

- Continued functioning of health care system and society: It is also vital that priority groups be protected to ensure that society continues to function during a pandemic. Protection of health care workers will help ensure that health care services continue to be provided and available during the pandemic (and that the health care system not be paralyzed by the pandemic); while protection of emergency and essential services workers will help ensure that other key services are available.

  - *"I think it is still much cheaper than with dealing with the consequences of high mortality rates and disruption of societal function in general." (Stakeholder)*

- Sound investment: Participants in several sessions indicate that the cost of providing antivirals for prevention is not unreasonable if you consider it an investment over a five to ten-year period; an investment that will reduce the societal and economic impact of a pandemic.

  - *"I think that as a society when we are talking about pandemic planning, it is first and foremost a responsibility of the government to fix this. Well, in some instances, at least in my personal view not in my professional view, this is part of business continuity. It is the cost of doing business." (Stakeholder)*

- The "ethical" and "Canadian" thing to do: Participants in several sessions felt that to not do so would be against Canadian traditions and would not sit well with the public. Others felt that it is the only "ethical" thing to do, and the "right thing to do". Many felt it was simply not an option and that we have to make the best decision we can now based on the evidence available.

  - *"My thing is we need equity. If you leave it to the institutions to do then it won't happen." (Stakeholder)*
  - *"I think there is also something Canadian about it. If we compare to the United States the health care system is a bit different. It is much more privately funded. Whereas in Canada we know that the social programs are better and will be more Canadian if the government actually supports that project." (Stakeholder)*
  - *"We were saying that it is a good way to keep control over what happens. We can do research and learn from it for future planning and that sort of thing." (Target Group)*
  - *"We want to minimize social chaos and disorder. It is the Canadian ethical thing to do and it should be part of wise funding for private policy groups." (Target Group)*

- Control cost and safety: Participants in several sessions also emphasized that a national plan will help control both the cost of antivirals for prevention and the safety of its distribution. By negotiating the price in bulk, governments can ensure the best possible price per dose for antivirals, and also ensure that it is available consistently at the same price to all those

targeted as priority recipients. Governments were also thought to be best positioned to ensure the proper stockpiling and distribution of antivirals, ensuring the safety of the supply.

- *"Control your cost and safety. We were concerned that if it was left to private business where you fend for yourself that there would be a lot of black market opportunity and a lot of stuff sold over the internet." (Target Group)*
- *"I think we need to have government involvement at the federal level to help negotiate contracts with other levels of government and agencies. We are going to have to have federal level of government involvement in the negotiations of drug coverage in terms of third party payment and we need to have federal government involvement to ensure accessibility of the drug as it becomes necessary. It is only through this approach that we are going to ensure safety and availability and accessibility." (Target Group)*

Arguments or reasons against the provision of antivirals for prevention identified by target group members and stakeholders include:

- Lack of reliable data: Participants were concerned at the lack of data available to demonstrate with accuracy the efficacy and side-effects of antivirals, and underscored the need to continue research to improve the data available on which to base a decision.
  - *"I would like to see more information. If possible maybe the government should be funding more research." (Stakeholder)*
  - *"I am still not convinced that the science supports the expense of prophylaxis when you look at the science behind the treatment." (Stakeholder)*
  - *"I am not comfortable given the science that is available in supporting the use of antivirals and prophylaxis." (Stakeholder)*

- Compliance not guaranteed: Many felt that the potential compliance with the regimen needed when using antivirals for prevention is unknown, and cautioned that the government will have wasted money if it turns out that priority groups are unwilling to take the medication as required. Similarly, they expressed concern with the potential for inappropriate use of antivirals, or the possibility that priority groups do not follow instructions (again wasting the investment made).
  - *"Just because you make something mandatory in our population doesn't necessarily mean that they are compliant. We already have that history. If there are thoughts of making something mandatory we know that there is non-compliance of some rate or percentage." (Stakeholder)*
  - *"Generally with our group all the items that were listed like the shelf life, cost, resistance, safety, compliance, logistics, efficacy, all of those were cons." (Target Group)*
  - *"We picked compliance. Being the first one as a concern for us in that it won't be seen through. The elderly won't take it and kids may not like to swallow it." (Target Group)*

- Potential reliance on antivirals for prevention: Participants also expressed concern that people may rely too heavily on antivirals for prevention if they are available and be negligent in other

important preventative measures (such as handwashing and social distancing). This would also limit the potential effectiveness of the antivirals for prevention.

- *"One thing that we have in mind is that as soon as somebody gets a pill they stop doing everything else. If we go and give everybody the prophylaxis antiviral they are going to stop doing the social distance and they are going to stop washing their hands, they are going to stop good coughing and sneezing hygiene. We may have to make sure that those are maintained or else we will see spread because the antivirals probably won't be 100 per cent effective. They are not going to be taken properly by everybody. There are a lot of issues around administering medications. People are going to come into play that are going to reduce the effectiveness." (Stakeholder)*
- *"I am not comfortable given the science that is available in supporting the use of antivirals and prophylaxis especially when there are low tech tools that we know are effective like hand washing which is probably the number one thing that people can do and cough and sneeze etiquette and the things that we know can really help with the transmission as opposed to where the prophylaxis is less questionable. We know it works and hand washing really works." (Stakeholder)*

- Money better spent on prevention and education: Participants in some sessions felt that public dollars would be better spent (and yield greater impact) on public education and prevention, emphasizing other preventative measures.
  - *"Could that money be better spent in prevention in some other way or in some other health related problem that would give us a big bang out of pocket and save more lives? Based upon everything that I have heard the last day or two I don't hear that this is necessarily going to save a lot. It is going to delay perhaps but it doesn't immunize anybody and we are not certain that it is actually going to work. It is an awful lot of money to toss a gamble with, in terms of improving people's health." (Stakeholder)*
  - *"I feel like we have left out that whole piece when you are looking at the triangle in regards to the top of the pyramid. We leave that off. We focus those funds on building healthier and stronger communities so that you are not ready for the pandemic but that our communities are healthy enough to withstand a lot of other assaults. Again you are alluded to that piece of result. I am just really worried that we can get really lost when it comes to end up saying we like this choice or this choice versus we would really like to take the money that is going to the stockpile and look at how we build stronger, healthier, resilient communities." (Target Group)*

- Cost is high for government to assume alone: While many participants felt it is important to have national planning or leadership on the issue, others felt that the costs are simply too high to expect governments to assume alone.
  - *"It is very expensive for the government only." (Target Group)*
  - *"I think it needs to be a collaborative approach between government and on a federal level, provincial level, and various agencies and corporations within the country. We do not have the funds to provide prophylaxis therapy for 3.3 million people and we do not have the resources to actually look after 3.3 million people in hospital." (Target Group)*

- Potential impact of pandemic unknown: Participants in some sessions also acknowledge that the extent and impact of the pandemic is unknown and that the impact may be minimal. If the

pandemic is not serious in terms of impacts, then much money will have been wasted and concern created for nothing.

- *"I find it a bit hard to come up with responses when the risk factor is not known. In other words the risk of adverse reactions for drug experts might be 5, 10, 20 per cent. It is very difficult to know how to respond to that unknown range or risk." (Stakeholder)*
- *"People would see the action by the government as interference and that the government is trying to tell me what to do with my health. That might turn people off from what the government is trying to do. The uncertain outcome. There is just not enough information regarding how effective it is." (Target Group)*

- Cannot be made universally available: Again, in keeping with concerns of the potential impact of limiting access to specific priority groups, an argument against providing antivirals for prevention is that they cannot be made universally available. In part, shelf life of the drugs played into this consideration, if one fifth of the supply would be continually outdated.

Related to these "pro" and "con" arguments, participants identified other considerations they feel should enter the decision of whether or not to provide antivirals for prevention:

- Potential compliance: Again, participants cautioned that potential compliance rates are unknown, and that there is no point in stockpiling antivirals without knowing if priority groups will take them.
  - *"I am very concerned about compliance because history shows that people do not take their medication the way they are supposed to and that is true probably for 50 per cent of them." (Stakeholder)*
  - *"I think it is important to reflect on the fact that you don't obviously know what the compliance is going to be if we in fact do something like this." (Stakeholder)*
  - *"The big issue is compliance. How we ensure that the whole population is being compliant with taking these medications. Particularly with drug resistance." (Target Group)*

- Cost-sharing: In several sessions, participants felt that the possibility of sharing the cost of antivirals for prevention should be explored. While they felt that Approach 3 was not viable on its own (and that national, government leadership is needed), it makes sense that costs be shared with the private sector. In particular, some note that many priority group members would be covered by medical insurance, and that the costs should be shared by insurance companies. They argued that prevention would be a good investment for the private sector to make, as it would reduce sick leave paid and is far cheaper than paying death benefits.
  - *"..funding private companies. Having the expectations that they rely on others other than themselves. That the government is going to insist on doing it. Like Alberta Power it is a private company. It takes care of their employees. The government should provide for them so they can take care of their own. They will still make money off it. They should be responsible as well." (Target Group)*

- *"There is also a need for this to be a collaborative approach involving the federal government, provincial governments and the private sector. The plan should be based on cost sharing. The federal government should negotiate with the provincial government, private sector, drug companies, insurance companies to share the costs and ensure the availability of antivirals in the case of a pandemic." (Target Group)*

- Opportunity costs: Again, participants raised the question of whether there are better ways to spend this money. They caution that public health dollars are limited, and wonder whether a greater return could be obtained by investing in prevention or in other health issues such as tobacco use.

- Public education is vital: Regardless of the approach taken, participants emphasize that public education must be a component of the plan. Citizens should be educated as to proper prevention approaches, and also be informed of the decision taken and why.

  - *"..The population should be educated and you should have television ads that say you should go and get your flu shot but I also think that you should also have education on how you should wash your hands. How often you should do it and so on. I don't think the population in general is aware how important it is so I think we should keep some of the money that would have gone to buying all these antivirals and maybe not wait for the pandemic to arrive. Do it right now." (Target Group)*

  - *"Our group really came down to that it really has to be education. Prevention is the way to go." (Target Group)*

  - *"One piece of advice I would give the decision makers is educate, educate, educate." (Target Group)*

  - *"I do have a much keener appreciation for the education component. Part of all of this that needs to take place." (Target Group)*

- Distribution: The logistics of distributing antivirals to priority groups was a concern for some participants, who felt that this could be complex. They emphasized the need for a practical distribution plan that also addresses issues of safety of the supply.

  - *"The thing about private companies is that you make that decision and they decide who in the company is going to get it versus who isn't going to get it." (Target Group)*

  - *"The second consideration would be distribution. How would you distribute this drug to such a high number of individuals in this time and how would it be regulated?" (Target Group)*

- Evidence-based decision making: Participants in some sessions (particularly among stakeholders) caution that decisions be based on science and evidence rather than politics.

  - *"I hope that decisions will be made on the best of all evidence and criteria, but my fear is that at the end of the day it will be a political decision and not a political decision because of WHO, the US, or France but because the Canadian population will say we want it and our government will say we will give it to you. That is my fear. That is how the decision will be made, and that doesn't mean that they will make the wrong decision but I would prefer to see a decision made based on some values and principles and evidence." (Stakeholder)*

- *"We don't have scientific evidence. Until we do we are really just basing it on values and biases. That is not really good enough." (Stakeholder)*
- *"The decision has to be an informed decision or evidence based to the best of our knowledge at the best point in time." (Stakeholder)*
- *"There is the potential of one billion dollars plus in terms of outgoing cost and if we don't have even one study to show that there is support for us we are on pretty shaky ground. There are a lot of other things that are not being done even though support is there. In terms of research. In terms of medicine, for much less cost. For spending 1.5 billion and I am not saying whether it is right or wrong but we should have the evidence to back that up." (Stakeholder)*
- *"Someone is going to have to do more research and we need more test cases upon which the research would be based." (Stakeholder)*

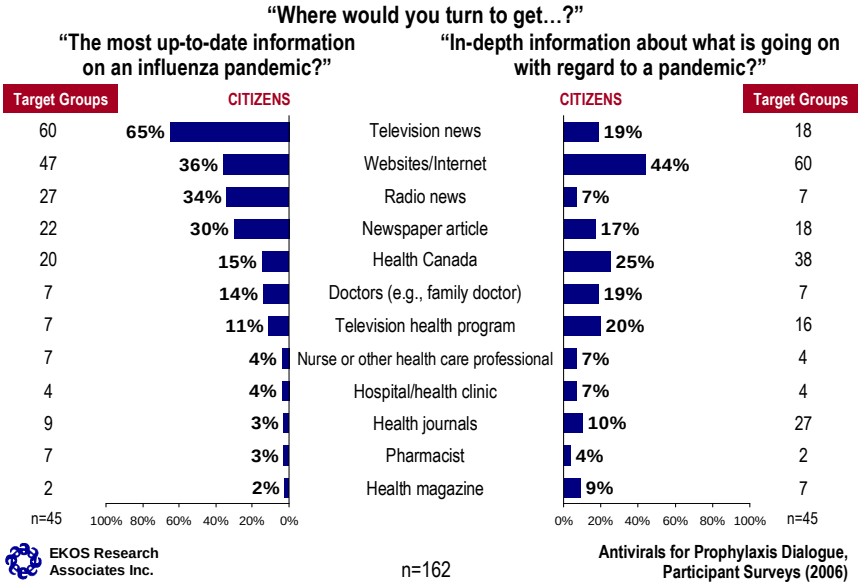
2.5 Other Survey Results – Information Sources (Citizens and Target Groups)

An issue that was addressed in questionnaires given out in the citizens and target group sessions, though not explored in the dialogue sessions was participants' preferences in terms of methods of obtaining information about an influenza pandemic and the rated trustworthiness of different sources of information about an influenza pandemic.

The majority of citizen participants would turn to television news to obtain the most up-to-date news about an influenza pandemic. This is followed by the Internet, radio news, and newspaper. Interestingly, participants' preferred information vehicles differed significantly for in-depth information about a pandemic (e.g., history, context, details, analysis). There is less commonality in the views, with the Internet being identified most often, followed by Health Canada, TV health programs, television news, and doctors. Another tier includes various sources such as the newspaper, books/library, and health journals.

Patterns are similar among target groups, although the Internet is more popular as a "most up-to-date" choice for information, and the clear preference for in-depth information about what is going on, followed by Health Canada (presumably through the website or other means).

Sources of Information



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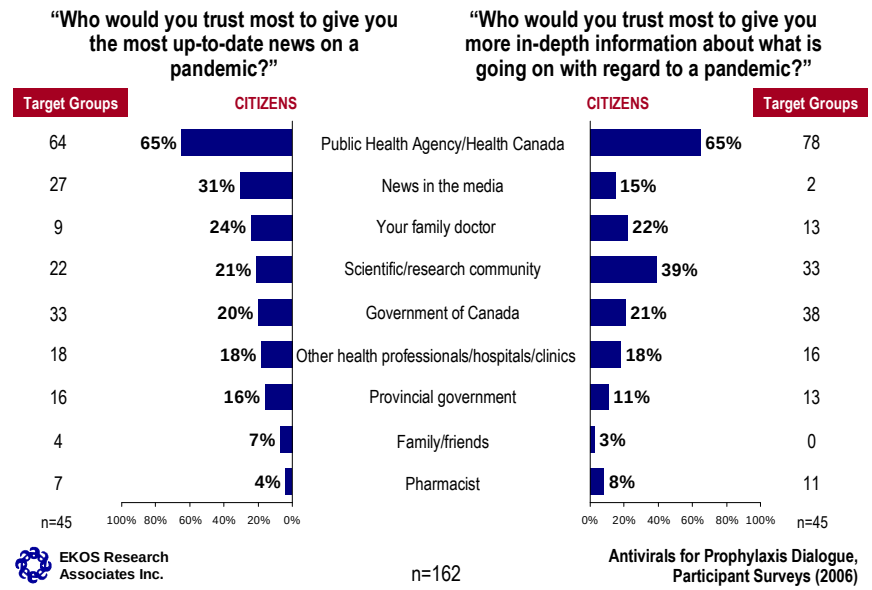
In terms of credibility or trustworthiness of various sources of information, the Public Health Agency of Canada and Health Canada are viewed as highly trustworthy by citizens and target groups alike (significantly more so than the Government of Canada in general) to provide them with up-to-date news on a pandemic. The Agency is similarly selected most often as a trustworthy source to provide in-depth information about a pandemic. The Government of Canada is a greater preference among target groups than among citizens, both for up-to-date and in-depth information The news media is indicated more often as trustworthy to provide up-to-date information compared to in-depth information (and less by target group participants than citizens), while the research/scientific community is more often indicated to be a trustworthy source for in-depth information compared to up-to-date information among citizens and target groups alike.

Trust in Information Sources



2.6 Impressions of the Consultation and Considerations for Decision-Makers

At the conclusion of the session, participants in the citizen sessions were asked to reflect on the discussion, share a key insight from the dialogue and offer any advice to decision-makers. Key insights that were mentioned with greatest frequency across the regions, as well as illustrative quotes included:

Table 2.14: Citizens' Closing Comments and Considerations for Government

Theme Raised	Illustrative Quotes
Learning opportunity. Participants' most frequent closing comment was that they had learned a great deal through the process (e.g., about antivirals, the difference between antivirals and vaccines and so on).	"It was a very good exercise that we had. We got to know a lot of things about antivirals and the vaccines and the infections. I think that you should educate everybody in the population." (Vancouver) "I am going away from here with a lot of information that I didn't have before and that I never really thought about and to me education is the best prevention." (Halifax) "One insight that I particularly noted was the antiviral treatment for treatment as well as for prevention. I was not aware of that before coming here." (Toronto)
Positive feedback on the process. Many participants expressed strong enthusiasm for the dialogue itself and appreciated the opportunity to participate in the exercise and to meet other Canadians. Participants extended kudos to government/organizers for including citizens in decision-making.	"I appreciate the process here. It has been very interesting and it is kind of nice to know that it is going on." (Vancouver) "I enjoyed this. I enjoyed meeting people and learning about this. Not being bull headed about saying my piece and also taking other peoples' ideas and learning and growing from it. It has been an adventure and I appreciate being contacted to represent my community. I feel that it is important that we be acknowledged and I was glad to be a representative of the First Nation." (First Nations) "I would like to thank the facilitators for organizing this. You are very helpful and you did an excellent job." (First Nations) "I appreciate also this opportunity to come and it proves beautifully that when many of us come together that we can really shed light on issues and find solutions to it because of our differences. It think that's the strength in it. It's so beautiful when we can mold this piece together." (Iqaluit) "I enjoyed the experience. I was surprised by that, I did not expect to. This is much more interesting than answering a telephone survey at the dinner hour." (Montreal, translated)
Impressed with level of preparedness. Some participants indicated being impressed with the level of thought, planning and preparation that Canada has undertaken for an influenza pandemic. There were several who indicated feeling comforted and less anxious about a pandemic as a result of the discussion.	"Basically from the inside I am a little surprised about how far ahead we are. Before that I thought that we were not ready so in fact I don't think that is enough education or public information at all. I am a member of the public who was not aware of this and readiness in this program." (Vancouver) ""Knowing that there is actually some kind of action being taken (i.e., that antivirals already exist in Canada and that governments are preparing and considering for our future…..). That is comforting to know….." (Vancouver)

Theme Raised	Illustrative Quotes
	"I am a person who has given to anxiety on certain situations. I have been through a few situations and I know how I would react. Simply knowing how this is being talked about and planned for so thoroughly has lessened my anxiety about this subject considerably." (Winnipeg) "I did find it very educational. My insider's surprise is the fact that I'm not scared to death right at this moment because that's what I thought I would be by the time I heard everything. So that is a big thing for me and I think that points to the next thing which is I believe that communication that there is a plan, maybe not all the details and that there are certain people that are only going to get the preventative drugs that need to be out there but that Canada does have a plan that there have been discussion groups." (Iqaluit)
Ethical complexity. Some participants remarked on the ethical and moral complexities of decision-making in this area.	"I thought that when I came in here I knew the ethical answer to it all but how complex a situation it is. For the decision makers I am glad that I am not one of them. It is a huge job they have. We will come out okay, I am sure, but they have a big job." (Winnipeg) "Yes, we need to know about it and I think this workshop in the last few hours has made me somewhat better educated about pandemics at least and the issues that are related to that and the tough decisions that our decision makers are faced with in terms of not enough medicine, not enough money, how do you distribute it and how do you make it work so you don't make the situation worse." (Iqaluit) "We like to criticize government but now I can see how difficult it is to make these decisions. It is not difficult to make a decision based on numbers and facts, but it is much harder when you have to wrestle with values and ethics." (Montreal, translated)
Sharing common views and values. Several participants observed that though the participants were drawn from different geographical areas and backgrounds they ultimately shared many similar views and priorities on antivirals for prevention.	"My insight was a little bit about being Canadian I guess. I was really impressed by frankly someone cares about what random Canadians have to say and I honestly have been pretty impressed about what my fellow random Canadians… I think we share a lot when you get together and you talk. We have a lot in common when we see how people are to be cared for and what is the right thing to do." (Vancouver) "Everybody has different occupations, different backgrounds, and that sort of thing, but we have a lot of main viewpoints that are very similar." (Vancouver)

By far, participants' most frequent consideration for decision-makers was to keep the public informed. In their comments, participants noted that Canada has done a great deal in preparing for a pandemic, but few people (themselves included prior to their participation in the dialogue) are aware of these efforts. Public education was recommended on many fronts, including education about pandemic preparedness, public health practices to reduce or prevent spread of viruses, individual emergency preparedness, and the role of vaccines and antivirals in responding to a pandemic. If antivirals are used for prevention and distributed selectively to priority recipients, governments, as well as the priority recipients themselves, must be prepared to support these decisions with public education to ensure broad understanding and acceptance. Participants noted that the word "pandemic" carries a potent mix of fear and uncertainty. The sense was that these psychological and sociological aspects (many won't be rational) should be given consideration in decision-making around antivirals and flu pandemic planning in general.

A second common message to decision-makers, particularly among participants in Winnipeg and Vancouver, was to continue to invest in medical/public health research. During the course of the dialogue, many participants were surprised and often frustrated by the lack of definitive knowledge on antivirals (efficacy, side effects). Many participants urged that research in this area move forward quickly and that preparedness planning be adapted as new information comes to light.

Several participants – in Halifax and Toronto specifically – simply urged decision-makers to listen to the values and principles emerging from the dialogue and to ensure planning reflects the concerns of Canadians. This was also accompanied by calls from a number of participants for decision-makers to "do something". At the same time, in Vancouver, for example, some participants also urged governments to move cautiously given limited scientific evidence ("don't do something just for the sake of doing something").

At the conclusion of both stakeholders and one target group session, participants were similarly asked to reflect on the discussion and share a key insight from the dialogue and share any views and considerations for decision-makers. One common theme which arose in the closing comments from all sessions concerns the need to make any federal pandemic plan broader than simply focusing on antivirals, and to include a public education component.

Table 2.15: Stakeholder and Target Group Participants' Closing Comments and Considerations for Government

Theme Raised	Illustrative Quotes
Decision must be based on evidence. Stakeholders in this group emphasized the importance of basing any decision on scientific evidence rather than political concerns or pressure from pharmaceutical companies.	"I hope that decisions will be made on the best of all evidence and criteria, but my fear is that at the end of the day it will be a political decision." (Stakeholder) "I just hope that the government will pay attention to the medical establishment rather than the pharmaceutical interest". (Stakeholder) "The decision has to be an informed decision or evidence-based to the best of our knowledge". (Stakeholder) "A piece of advice to decision makers would be that they use our precious resources in providing evidence-based

Theme Raised	Illustrative Quotes
	practice. Meaning those decisions should be based on previous experience or science". (Target group)
Need for a broader plan. They emphasized that antivirals should be only one element in pandemic planning, and that there should also be an emphasis on education.	"I agree that this needs to be a broader plan. This is just one element." (Stakeholder) "Pay more attention to little things such as washing hands because there is no magic pill that will do the job".
Emphasis on Public Education. Considerable emphasis was placed on the need for public education as a primary component of pandemic preparedness and any efforts at prophylaxis.	"The emphasis should be on good hand washing, a good vaccination program. The pill or antiviral is not the bigger deal". (Stakeholder) "I plan to be more vigilant in hand washing right now". (Stakeholder) "…tools we know are effective like hand washing which is probably the number one thing that people can do as well as cough and sneeze etiquette". (Stakeholder) "One piece of advice I would give to decision makers is to educate, educate, educate". (Target group) "I have been washing my hands an awful lot since I came". (Target group) "There is no magic pill. Education should be an important part of a government plan". (Target group) "I have a much keener appreciation for the education component". (Target group) "We all know that coughs and flu are spread by touching or not washing one's hands. That is really what should be done. We should have a massive campaign." (Target group)
Decision can be fluid, changing. Several participants noted that the decision should be one that can be revisited based on new evidence.	"Right now they can make the decision based on the information they already have but it doesn't have to be the absolute final decision, it can be fluid and change over time". (Stakeholder) "It really can be a flexible plan. We don't have scientific evidence and until we do we are really just basing it on values and biases. That is not good enough." (Stakeholder) "We really need to keep up the research component. All these issues have to be reviewed and revised on a regular basis". (Stakeholder)
Appreciation for the complexity of the issue. In closing comments, participants also reiterated that there are many factors to consider in a plan, and that no one approach may be effective on its own.	"It has been enormously eye opening and helpful to have a range of perspectives such as that of the electricity association and opened up new questions for me". "I think that this [discussion] has certainly brought home the complexity of the issues". (Stakeholder)

Theme Raised	Illustrative Quotes
Importance of protecting HCW. Some participants emphasized the importance of protecting health care workers and giving them the tools needed to support their work and ensure that they could meet the needs in a pandemic situation, particularly as the health system is already taxed.	"We need to ensure that health care workers are protected…It is not just antivirals and vaccines but ensuring that they have the proper tools and infrastructure to support that type of work". (Stakeholder) "We are in a situation where the system is taxed and any little bit of stress such as SARS can exacerbate those situations so a much longer stress can be catastrophic". "There needs to be an investment in their safety and security so that they can continue to work". (Stakeholder)
Uncertainty and dilemma. Participants were not sure that evidence supports a decision to use antiviral for prevention, but some are torn by the need to do something, have some preparation in case.	""I am still not convinced that science supports the expense of prophylaxis". (Stakeholder) "I think we need to be very caution and not give people an overly optimistic view". (Stakeholder) "What worries me is a severe level outbreak in stage one…the dilemma is the struggle between do no harm versus doing no treatment because we don't know enough about these drugs". (Stakeholder) "I have become convinced that the uncertainty is a huge issue". (Stakeholder)
Community emphasis. Pandemic will occur within the community, with contagion occurring at that level, so there needs to be some focus on community preparation.	"What strikes me is that this is more likely a community based issue than we are really talking about here today". (Stakeholder) "I think that the community is where the majority of the pandemic will happen". (Stakeholder)
Session broadened perspective. Many participants noted that the session was an eye-opener in terms of bringing the wide range of factors to be taken into account in pandemic planning.	"I never really thought about shortages in firemen or policemen or that kind of thing. It was interesting to get a perspective from other people as to how important they would be in a pandemic situation". (Target group) "The last couple of days has been really kind of educational…I didn't really see the importance or knowledge behind pandemics". (Target group) "I feel I have learned a lot to help take back in terms of preparation". (Target group) "Well I have been educated. Also the fear of the pandemic isn't as scary as when I came in". (Target group)

3. VIEWS OF THE DIALOGUE (ALL SESSIONS)

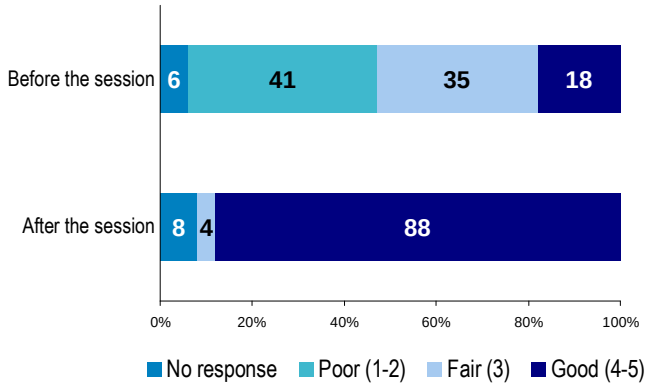
3.1 PARTICIPANTS' POINT OF VIEW

Participation in the dialogue session seems to have had a considerable impact on the knowledge levels reported by all participants - citizens, target groups and (to a lesser extent) stakeholders. Four in ten participants admit to starting the dialogue session with low levels of knowledge of the topics covered, while one-third (35 per cent) had a fair level of knowledge and two in ten report a good level of knowledge.

When asked to consider their level of knowledge after the dialogue session was completed, fully nine in ten participants say they have a good level of knowledge. Four per cent believe their level of knowledge is fair after participating in the dialogue session, and no one reported a poor level of knowledge.

Change in Knowledge

"What was your level of knowledge of the topics covered today?"



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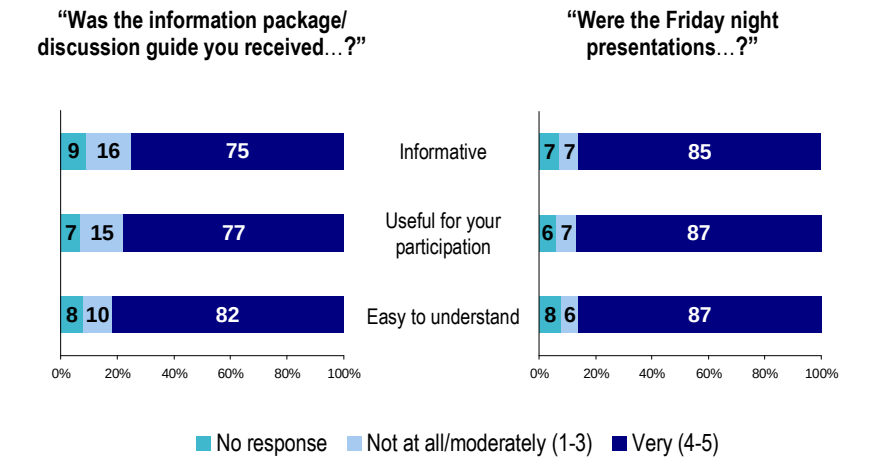
Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

There was positive feedback for both the discussion guide and information package that participants received and the Friday evening presentation. Specifically, 92 per cent say that the discussion guide and information package were easy to understand (82 per cent say it was very easy), 91 per cent state that this information was useful for their participation (77 per cent believe it was very useful), and 90 per cent report that it was informative (75 per cent say it was very informative).

An overall 94 per cent say the Friday evening presentation was useful for their participation (87 per cent believe it was very useful) and the same proportion also found it easy to understand (87 per cent found it very easy to understand). Virtually everyone said the Friday evening participation was informative (85 per cent said it was very informative). The presentation was generally rated more highly among citizens and response from the target group participants was somewhat more muted.

Perceptions of Information



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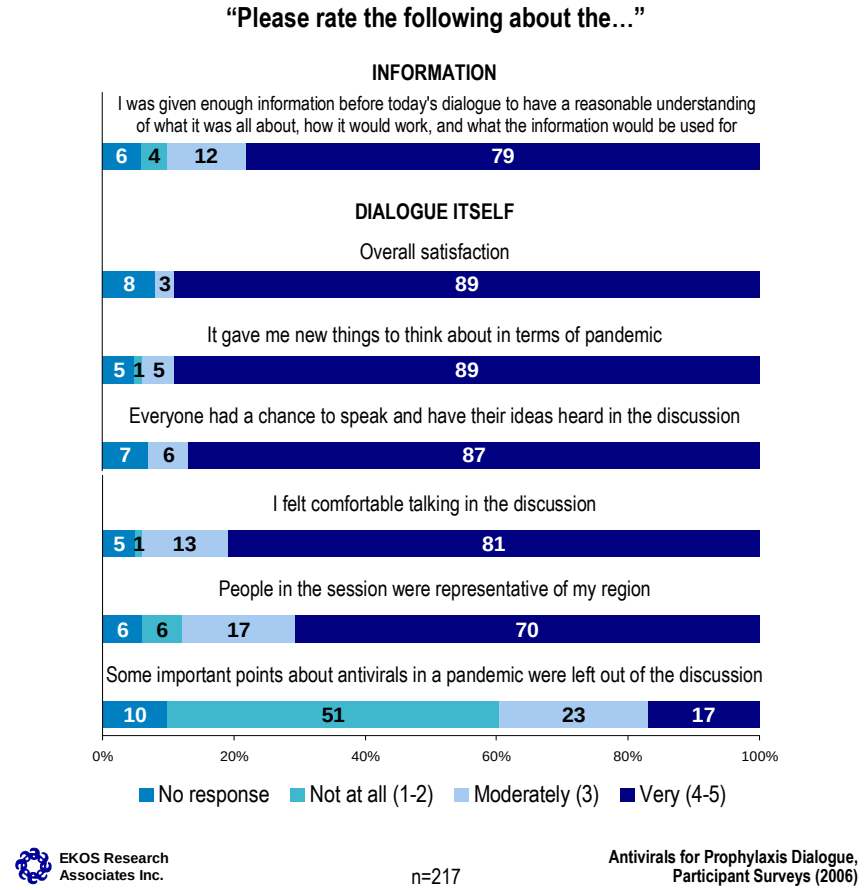
Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

In terms of the dialogue session itself, respondents were generally in agreement on the items identified in the evaluation form after the session concluded.

Most participants (79 per cent) were very satisfied that they were given enough information before the dialogue session to have a reasonable understanding of its content, how it would work, and what the information would be used for (an additional 12 per cent were moderately satisfied). Satisfaction with their ability to give input was even higher; eight in ten say they felt very comfortable talking during the discussion (13 per cent were moderately comfortable). An even higher proportion (87 per cent) report that everyone had a chance to speak and have their ideas heard in the discussion (six per cent believed this to a moderate extent). The only result that was marginally different across the three types of participants was comfort level speaking in the discussion, which was marginally (but not statistically significantly) lower for target groups (76 per cent) and citizens (81 per cent) and highest for stakeholders (100 per cent).

Perceptions of the Quality of the Information/Dialogue



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Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

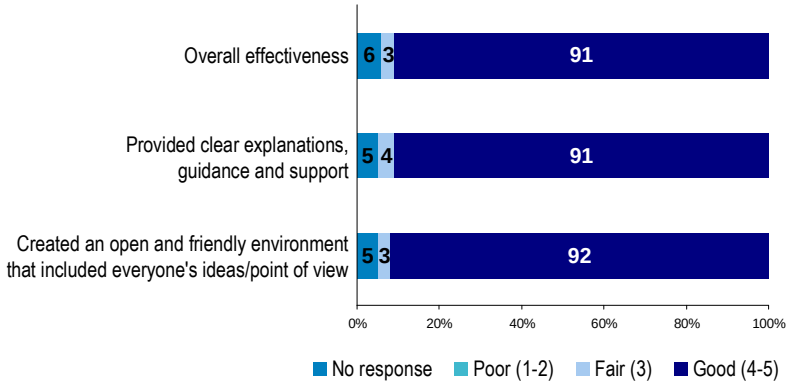
Few participants (17 per cent) strongly agree that important points about antivirals in a pandemic were left out of the discussion, while 23 per cent moderately agree. However, half (51 per cent) disagree completely that important points about antivirals were omitted. In addition, the vast majority (89 per cent) say they very much agree that the dialogue session gave them new things to think about in terms of pandemic.

Finally, over two-thirds (70 per cent) believe the people in their dialogue session were representative of their region, while fewer than two in ten (17 per cent) believe this to a moderate extent, and six per cent disagree entirely with this statement.

Participants were also asked to rate their facilitator on a number of points. Over nine in ten (91 per cent and 92 per cent, respectively) agree both that their facilitator provided clear explanations, guidance and support during their dialogue session, and that their facilitator created an open and friendly environment that included everyone's ideas and points of view. In addition, 91 per cent gave good ratings to the overall effectiveness of their facilitator.

Perceptions of the Facilitator(s)

"Please rate your facilitator(s) on the following…"



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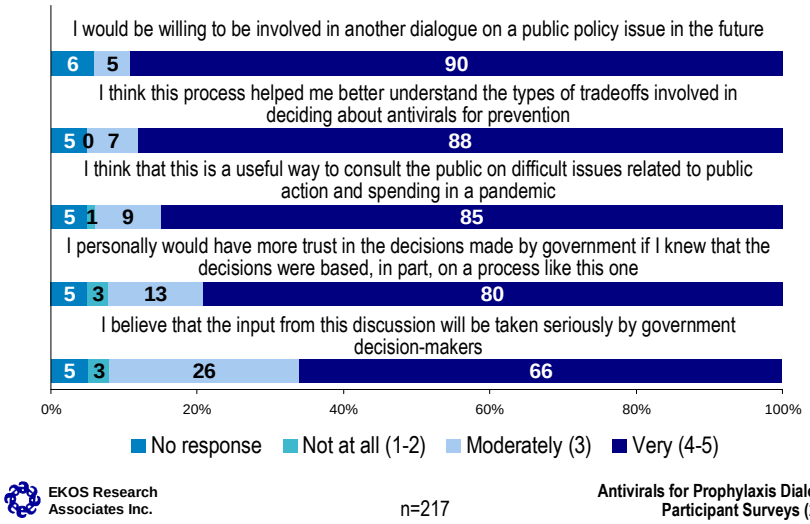
Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

Rating the event overall, participants agreed that it was successful in a number of ways, and supported consulting the public in this way. Eighty-eight per cent very much agree that the process helped them better understand the types of tradeoffs involved in deciding about antivirals for prevention (eight per cent share this view to a moderate extent). Almost as many (85 per cent) strongly believe that the process is a useful way to consult the public on difficult issues related to public action and spending in a pandemic (nine per cent believe this moderately). Similar proportions (80 per cent) say they would personally have more trust in the decisions made by government if they knew that the decisions were based, in part, on a process like this one, while 13 per cent hold this view to a moderate extent.

A smaller proportion – but still a majority - (66 per cent) strongly believe that the input from this discussion will be taken seriously by government decision-makers. It is interesting to note, however, that this is the item that is received with the greatest scepticism. A full one in four (26 per cent) only believe this to a moderate extent. This scepticism was not as high among stakeholders, 80 per cent of whom said that the results were very likely to be taken seriously.

Broader Understanding of Process/Input to Government

"Please rate the following about the event overall…"



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Antivirals for Prophylaxis Dialogue, Participant Surveys (2006)

When asked if they would be willing to be involved in another dialogue on a public policy issue in the future, participants once again underscored their satisfaction with this process; nine in ten say they were very satisfied with the dialogue session, and the same proportion report that they would be very willing to undertake a similar process again (five per cent are moderately inclined).

3.2 RESEARCHER'S OBSERVATIONS

One caveat should be noted about the consultation process. Given the technical nature of the discussion and little pre-existing knowledge of antivirals among participants, the information session would clearly have an important influence on the nature and quality of the discussion. The information session presentation was largely standardized across the centres (with the exception of Vancouver where the presentation was somewhat more detailed and provided opportunity cost equivalents), however, the question and answer period was unique to each session, with different issues being raised depending on the interests and concerns of participants. As well, the sessions occurred in a broader information and media context. In BC, a power outage and run on bottled water, as well as media stories about the possible side effects of Tamiflu closely coincided with the timing of the dialogue session. Similarly, release of a treatment triage protocol for seniors in Ontario took place in the week leading up to the dialogue session in Toronto. The Toronto session was the only one that argued for universality of application of antivirals for prevention as a central theme in their discussion. Perhaps even more remarkable, the support for publicly funded antivirals for prevention (as shown in the results of the questionnaire) is considerably lower in Vancouver, where one theme of the presentation was related to opportunity costs and a wider and different type of public health emergency going on in the community both pointed to other areas that the government could be placing its attention and resources on.

In research of this nature the going-in information among participants could not be completely uniform and does have an impact on the understanding of the problem and participants' conclusions, suggesting that opinion can readily be influenced by other things going on in the environment, presenting considerable challenges for the development of communications strategies. These effects are indicative of the complexity of pandemic communications and the malleability of opinion based on other factors in the broader information environment. In spite of this there was a strong degree of overall consistency in points of view across the different sessions. While there were differences, for the most part, they were not striking in terms of the overall picture or support for a policy decision.

Another related area of note is the strength with which participants in all session emphasized the need for more research and information in order to make the best decisions with regard to this issue. To the extent that new information suggested different possibilities, these same participants might indeed apply a different set of rules or values to their decisions and could ultimately argue for a different outcome.