Canada's Drug Agency
L'Agence des médicaments du Canada

CDA-AMC Summary of Engagement Survey

Appropriate Use of Antipsychotics in Long-Term Care

Key Findings

- Canada's Drug Agency conducted an engagement survey to gather insight from key interested parties about antipsychotic use in long-term care homes. The findings of the engagement survey, along with a literature-based Environmental Scan, helped inform a multidisciplinary panel in developing consensus statements on appropriate antipsychotic use for long-term care (LTC) settings in Canada.
- Overall, survey respondents shared the view that antipsychotics have limited to no role for people without diagnosed psychosis in LTC homes. Many of the key considerations underscored by survey respondents aligned with the findings of the literature-based Environmental Scan.

Context

Recent assessments show a rise in potentially inappropriate antipsychotic use in LTC following the COVID-19 pandemic. To address this issue and support the safety and quality of care in LTC, Canada's Drug Agency (CDA-AMC), in collaboration with Choosing Wisely Canada (CWC), hosted a multidisciplinary panel of 17 knowledgeable individuals to develop evidence-informed consensus statements on a target and an annual improvement goal for antipsychotic use in LTC homes in Canada through a modified Delphi process with 3 rounds (2 surveys and a virtual workshop). We conducted an engagement survey to gather the views and perspectives of the wider community and better understand the use of antipsychotics in LTC homes, to support the panel's deliberations during each round of the consensus-building process. This engagement summary, along with a literature-based environmental scan, was provided to the panel to inform their deliberations and discussions towards consensus.

For more details about the modified Delphi process and the resulting consensus statements, refer to the Appropriate Use of Antipsychotics in Long-Term Care Methods Document and the Expert Panel Guidance on the Appropriate Use of Antipsychotics in Long-Term Care, available on the CDA-AMC website.

Why Did We Do This?

The purpose of the engagement survey was to allow for key interested parties to provide input for panel members to consider in their discussions and deliberations. It allowed the panel to consider a diverse range of perspectives and views, in addition to the findings in the Environmental Scan, to have a more comprehensive understanding of antipsychotic use in LTC homes in Canada. Additionally, engagement increases awareness about the overall project on the Appropriate Use of Antipsychotics in LTC.

What Did We Do?

CDA-AMC and CWC identified and invited resident and caregiver associations, clinical societies, appropriate prescribing groups, and other key interested parties to complete an online survey. We sought their views and perspectives about antipsychotic use in LTC, specifically on:

- the role of antipsychotics for people without a diagnosis of psychosis
- the barriers and facilitators to implement change on antipsychotic use
- the value of implementing a target for antipsychotic use rates in Canada
- existing provincial and territorial targets.

The survey remained open from September 24, 2024 to October 10, 2024. We collated the survey responses in this document for the panel without interpretation or analysis. Refer to Appendix 1 for the full list of engagement survey questions.

Who Did We Hear From?

We received a total of 24 survey responses. We heard from clinicians, researchers, families, and community members affiliated with various groups or institutions across Canada, specifically from Alberta, British Columbia, New Brunswick, Newfoundland and Labrador, the Northwest Territories, Ontario, Prince Edward Island, Quebec, and Saskatchewan.

The survey respondents were affiliated with academia, clinical societies, government, LTC homes, community health settings, and health organizations. We received the most responses from individuals affiliated with provincial and territorial government departments (e.g., health authorities), including members of patient and family advisory committees, followed by individuals working in LTC homes, including those volunteering on resident and family councils. Refer to Appendix 2 for a list of groups or institutions we received responses from.

How Did Panelists Use This Summary?

These findings supported panelists in their reflections and discussions around the consensus statements on appropriate antipsychotic use rates and an annual improvement goal for LTC homes in Canada. All 17 panelists reviewed this summary of engagement, along with the literature based Environmental Scan, prior to Round 1 (Survey 1) of the Delphi process, and were encouraged to consider these findings during each round.

Before the Round 3 online workshop, the CDA-AMC project team met with 2 panel members representing the family and caregiver perspective to ensure key considerations relevant to people

living in LTC and their families from this summary were captured in the presentation of the evidence for the panel to consider in their discussions.

What Did We Hear?

The findings of this engagement survey aligned with the findings of the literature-based Environmental Scan. Overall, survey respondents stated there is limited to no role for antipsychotic use for people living in LTC homes without a diagnosis of psychosis. They also recognized the need for a target for antipsychotic use in LTC homes in Canada.

The respondents noted some key considerations for changing the way antipsychotics are used in LTC that were also detailed in the Environmental Scan, such as health human resources, staff training, person-centred care, culturally safe care, and balancing measures. They also provided us with existing targets for provinces and territories if they were aware of any.

The Role of Antipsychotics for People Living in LTC Homes

Some survey respondents were against antipsychotic use in LTC homes for people without psychosis given the potential harms and side effects. They remarked that antipsychotics can sometimes be used as a chemical restraint to manage behaviours in LTC, especially in the context of limited time for staff and insufficient human resources to balance workloads. A clinical professional in LTC stated that medications should not be used so that staff can finish their tasks.

Some respondents felt that antipsychotics have a limited role in care for people without psychosis. A clinical professional in LTC stated that while medications can be part of the care plan, it should not be the whole plan. Another respondent recommended that all medications should be prescribed with thoughtful consideration of the risks, benefits, and other treatment options.

While the focus of our survey was on the use of antipsychotics in people without a diagnosis of psychosis (i.e., potentially inappropriate use), some respondents also considered antipsychotic use more generally in LTC homes, including potentially appropriate use. Survey respondents noted the following uses of antipsychotics for people living in LTC homes:

- **Behavioural and Psychological Symptoms of Dementia**

  Many participants noted that antipsychotics are used to manage behavioural and psychological symptoms of dementia (BPSD), such as aggression and agitation. Survey participants also noted antipsychotic use when individuals are a safety risk to themselves or others. However, many survey responses raised concerns about the overuse and long-term use of antipsychotics to manage behaviour and agitation in LTC homes. A survey

respondent from a provincial government department stated that LTC homes with a large proportion of people with dementia may find it more challenging to change antipsychotic use.

A government representative cautioned that antipsychotics have limited effectiveness for BPSD and can cause rapid decline, lower an individual's quality of life, and increase the risk of falls because of the side effects of antipsychotics and the compounding effects of polypharmacy. Another respondent working for a government department expressed concern about the tendency to use antipsychotics instead of identifying the root cause of responsive behaviour. They noted that deprescribing antipsychotics in LTC can be difficult once there is record of responsive behaviour.

- **End-of-Life Care**

  Some survey respondents noted antipsychotic use for symptom management during end-of-life care. One physician stated that it can help provide comfort for individuals with end stage dementia, specifically to manage aggressive behaviour.

- **Mental Health Disorders**

  Participants from government departments noted the appropriate use of antipsychotics for individuals with confirmed mental health diagnosis, such as schizophrenia, bipolar disorder, and delusional disorder. It was highlighted that the harms of antipsychotics outweigh the benefits when used without a diagnosis of a mental health disorder. One of these respondents noted that antipsychotics can be used as an adjunct therapy when antidepressants are ineffective and there is a desire to avoid benzodiazepines.

- **As a 'Last Resort' Approach**

  Survey respondents from academia and a government department noted antipsychotic use as a last resort when other treatment options have been exhausted and found to be ineffective for aggressive behaviour (e.g., BPSD). A clinical professional in a LTC home stated that a low dose of antipsychotics can improve an individual's quality of life. However, their response did not specify an indication for use.

Staffing Issues and Staff Consistency

Survey participants emphasized the importance of adequate staff, specifically an appropriate ratio of staff to people living in LTC that allows for 1-on-1 care, non-pharmacological or therapeutic approaches, and activities to prevent aggressive behaviours. Some participants described the use of antipsychotics as opposed to behavioural supports in scenarios of limited

time and staff to balance workloads. Survey participants also emphasized that inadequate staff means less time for staff to dedicate to reduce antipsychotic use (e.g., training).

Survey responses underscored the value of retention strategies to support staff consistency. Staff consistency allows staff a better understanding of their roles and responsibilities and knowledge of the people living in the LTC home, contributing to high quality care. High quality care supports quality of life for the people living in LTC homes and quality of work life for LTC staff.

LTC Training and Education

Survey respondents noted the benefits of training and education to increase understanding among LTC staff about certain behaviours of people living in LTC homes, antipsychotics, their potential side effects, and other treatment approaches. Government representatives expressed that false beliefs among health care practitioners regarding the safety and effectiveness of antipsychotics might lead to inappropriate use. For example, one response noted that certain symptoms are sometimes mistaken for psychosis. While antipsychotics moderate the behaviour, LTC staff might not identify the side effects (e.g., somnolence).

By dedicating time to training, staff can stay informed about antipsychotics and learn about person-centred care and non-pharmacological approaches to manage BPSD. A response from a health charity noted a lack of resources for training and education for LTC staff to support a reduction in antipsychotic use. Another response from a provincial agency highlighted the importance of extending education and training opportunities to casual staff and those working night shifts.

Decision-Making Support

Some survey responses from individuals working in government departments noted tools that can help change the way antipsychotics are used in LTC homes, including clearly developed policies and standards of practice (e.g., quality reviews, audits, behaviour monitoring), treatment guidelines and clear indications around medication use. However, a government representative stated that standardized evaluation and review processes can be a barrier to changing practice. Additionally, a government consultant noted that sharing success stories of efforts to reduce antipsychotic use can help change the way they are used in LTC homes.

Families or Caregivers

Survey respondents noted the impact that family or caregivers can have on antipsychotic use. Responses from academia and a clinical society highlighted the value of educating family or caregivers about antipsychotics. A government consultant noted that policies around

antipsychotic use in LTC should leverage a team-based approach involving families or caregivers, as well as the individual receiving care. A community group member expressed that families and caregivers provide valuable insight that can inform care plans.

Antipsychotics Initiated in Other Settings

Responses from individuals working in LTC homes noted that some practitioners are reluctant to decrease or discontinue antipsychotics, especially when the antipsychotic was initiated in acute care or community health settings prior to LTC admission. In such contexts, physicians receive no to little information as to why the antipsychotic was initiated. A LTC manager stated that family physicians and acute care physicians would benefit from education about antipsychotics.

Person-centred Care and Inclusive Practices

A community group member expressed the need for a person-centred care and inclusive activities that improve the physical, cognitive, emotional, mental, and social well-being of people living in LTC homes. Inclusive activities would also support an individual's sense of belonging.

Survey respondents expressed the importance of culturally safe care for people living in LTC homes. A researcher expressed the need to also consider the race, ethnicity, and language of care staff in LTC homes. Survey responses noted the following groups that require special considerations regarding the antipsychotic use:

- **People Who Speak a Language Other Than English or French**

  Providing culturally safe care includes accommodating language needs to facilitate communication between LTC care professionals and people in LTC homes and their caregivers, such as leveraging technology for translation. It was noted that language discordance can prevent care providers from getting to know people in LTC and identifying the cause of concerning behaviour.

- **People With Experiences of Significant Trauma**

  Survey participants noted that people with experiences of significant trauma may fear and resist being given medications, such as survivors of sexual abuse. A government director also noted that such people may include those with dementia and post-traumatic stress disorder (e.g., individuals with military background).

  A government employee noted that people with experience of significant trauma (i.e., related to removal from community and undergoing involuntary drug and disease testing) can have severe distrust in the health care system. The same respondent emphasized the importance of building trust and ensuring that these individuals feel safe when accessing

care. They also noted that intergenerational trauma can alter an individual's brain chemistry, and it is unclear how these changes in the brain can interact with antipsychotic use.

- **Younger Older Adults**

  A LTC manager indicated that 'younger' older adults may be misdiagnosed and sent to psychiatry instead of a geriatrician, which leads to increased antipsychotic use. Often, younger people living in LTC homes have a history of brain injuries and may respond to medication differently.

- **Immigrants and Newcomers**

  A nursing consultant noted that immigrants and newcomers experience mental health inequities and lack options for culturally safe care in their preferred language.

- **Individuals With No Advocates**

  A respondent from a patient and family advisory committee noted that people in LTC with no advocates (e.g., family or caregivers) may be more likely to be treated with pharmaceutical approaches.

- **Individuals with Mental Health Disorders**

  Survey respondents from a provincial government and academia emphasized that persons with mental health disorders need special consideration regarding antipsychotic use, including those without psychosis but are diagnosed with mental health disorders for which antipsychotics are indicated.

- **Other Groups**

  A government employee highlighted other groups that require special consideration regarding antipsychotic use include people with intellectual disabilities, and brain injuries.

A quality improvement specialist suggested collecting information about a broad range of sociodemographic data through a standardized form to be filled during LTC admission. Collecting sociodemographic can help identify existing disparities in LTC.

A Target for Antipsychotic Use LTC in Canada

All survey respondents agreed that there is a need for a target for antipsychotic use for people without a diagnosis of psychosis in LTC in Canada, except for 1 response from a community group member.

Survey respondents who feel there is a need for a target expressed that it would support appropriate use of antipsychotics in LTC and help improve safety, quality of life, and quality of care. Participants noted that a target would:

- reduce the variation in antipsychotic use across Canada.
- motivate LTC homes to improve their performance
- facilitate quality improvement methods, as it allows for the LTC sector to understand, monitor, and compare their performance.
- allow the LTC sector to identify antipsychotic use trends, as well as gaps, challenges, and successes.
- increase awareness about antipsychotic use and potential harms, as well as prioritize deprescribing.

Some survey respondents affiliated with health authorities noted the importance of setting an achievable target to motivate change. However, of these, one survey respondent underscored that targets represent "a level of excellence" and should exceed average performance. Some survey respondents provided their opinion on what they would propose as a target value. Of note, none of the survey respondents that proposed a target value provided supporting evidence for that value.

A government consultant stated that the target should be 0 for individuals without a psychiatric diagnosis. This survey respondent expressed that there is no role for antipsychotic use in LTC beyond psychosis and a mental health diagnosis.

However, some survey respondents noted that the quality indicator measured by the Canadian Institute for Health Information, 'Potentially Inappropriate Antipsychotic Use in LTC', includes individuals taking antipsychotics for appropriate reasons such as a last resort approach. A clinical professional stated that the LTC homes they work for use antipsychotics as a last resort for people exhibiting responsive behaviours that pose a risk of harm to themselves and others. While the LTC home continues to strive for reduced antipsychotic use for people without a diagnosis of psychosis, the responder expressed uncertainty as to whether a target of 0 is achievable.

A government consultant suggested a target ranging from 0% to 15% for individuals without a mental health diagnosis. They also expressed that a range for the target that considers the variation in LTC population size is appropriate. A medical lead stated that 10% to 15% would be a reasonable target. Another government representative noted that 30% would be too high for a target.

The respondent who disagreed with the need for a target expressed that LTC staff are often using antipsychotics for people with dementia. Educated staff and a proper physical environment will

have a better impact on care than a target. Their response expressed that the care staff who provide hands-on care in LTC homes often pressure clinicians to prescribe antipsychotics. However, they are provided with limited support, such as education and training to manage behavioural issues, in addition to receiving lower salaries. Another survey respondent from a government department suggested target setting for each individual home instead of setting one target for all homes. They indicated that some LTC homes face more challenges to reducing antipsychotic use. The same survey respondent underscored the need for additional support (e.g., staffing and resources) to ensure LTC homes can meet the target. Otherwise, LTC homes may find it difficult to make improvements and contribute to progress on a target.

For existing provincial and territorial targets, we were informed of a provincial target of 27.5% for Saskatchewan, which was then added to the Environmental Scan. Other existing provincial and territorial targets identified by this survey were already identified from the literature prior to the survey.

Non-Pharmacological Approaches

A government consultant emphasized the importance of non-pharmacological approaches in consensus statements regarding antipsychotic use. Additionally, they suggest avoiding referring to non-pharmacological approaches as 'alternative measures' as it may suggest the use of alternative medicine.

Time Fallacy

A government consultant noted an overestimation of time needed to implement supportive measures and a tendency to discount the time spent providing medications.

Deprescribing and Withdrawal

A government employee cautioned about withdrawal symptoms when long term use of an antipsychotic is stopped abruptly. They expressed that antipsychotics should be reduced and stopped gradually (over weeks to months). Stopping long-term use of antipsychotics can impact an individual's quality of life, their risk of falls, pain levels, and may exacerbate their symptoms.

Balancing Measures

A provincial agency representative expressed the need to consider related indicators that might be impacted with the development of a target to support the use of antipsychotics, such as the potential to affect the use of physical restraints.

Data Sources

A researcher noted the importance of seeking information beyond quantitative sources and feedback from diverse perspectives.

Continuity of Care

A survey respondent from academia stated that poor continuity of care in the health care system can make it difficult to change the way antipsychotics are used.

Ethical Considerations

A survey respondent from a provincial health authority noted that consensus statements regarding antipsychotic use for people without diagnosed psychosis should speak to the principles of dignity and quality of life.

Appendix 1: Engagement Survey Questions

Personal Information

1. Full name:
2. Title:
3. Name of Group or institution:
4. Email address:
5. How would you describe your group:
    - Long term care facility
    - Resident or family council
    - Clinical society of profession
    - Community group of health charity
    - Private company or industry
    - Government department
    - Other:

Survey Questions

6. What role do you think antipsychotics have for people without a diagnosis of psychosis who live in a long term care facility?
7. What makes it difficult to change the way these medications are used? What would make is easier?
8. Equity-deserving groups include but are not limited to: People who speak a language other than English or French, women, racialized groups, Indigenous Peoples, people with disabilities, 2SLGTBQ+ community members.

    The panel may need to consider issues that specifically impact people from equity-deserving groups. Examples may include, but are not limited to:

    - a lack of data on race, ethnicity, and language which is a barrier to understanding possible disparities in long-term care facilities in Canada.
    - an observation that 'younger' older adults living in long term care facilities are more likely to be prescribed antipsychotics than those older than 85 years.
    - the need for increased resources in LTC facilities in lower income neighbourhoods or rural or remote communities.

Are there any special considerations about the use of antipsychotics in people from equity-deserving groups without a diagnosis of psychosis in a long-term care setting that should be brought to the attention of the panel?

9. Is there a need for a target for antipsychotic medication for use for people who do not have a diagnosis of psychosis in long-term care settings?
    - No
    - Yes
10. Please describe why you answered "yes" or "no" for question 9:
11. Are you aware of a target rate for antipsychotic medication use for people who do not have a diagnosis in long-term care settings?
    - No
    - Yes
12. If yes, what is the target date?
13. Is there any other information you would like the panel to consider when developing their consensus statements related to the use of antipsychotics medications in people without a diagnosis of psychosis in long term care?
14. Would you like to hear more about this project from Canada's Drug Agency and Choosing Wisely Canada?

Appendix 2: Survey Respondents Group or Institution Affiliations

We would like to thank the clinicians, researchers, families, and community members affiliated with the following groups or institutions for their time and insights when completing the engagement survey. Their individual perspectives provided important considerations for the panel to reflect upon during their deliberations.

- Newfoundland and Labrador
  - Government of Newfoundland and Labrador
- Prince Edward Island
  - Health Prince Edward Island
- Ontario
  - Ontario Health
  - University of Toronto and Deprescribing.org
- Saskatchewan
  - Sherbrooke Community Centre
- Alberta
  - Alberta Health Services
  - University of Calgary
- British Columbia
  - Health Quality British Columbia
  - Maple Ridge Senior Village
  - Patient Advisory Committee, Interior health
  - Vancouver Island Health Authority
- Northwest Territories
  - Government of the Northwest Territories
  - Northwest Territories Health and Social Services Authority
- Canada
  - Alzheimer Society of Canada
  - Choosing Wisely LTC Steering Committee