



# What We Heard

Proposed Changes to the Extended Health Benefits Policy

# Ce que nous avons entendu

Modifications proposées à la Politique relative au régime d'assurance-maladie complémentaire

Le présent document contient la traduction française du sommaire.

JANUARY • JANVIER | 2023

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# **Executive Summary**

#### Introduction

The *Extended* Health *Benefits Policy 49.07* has seen little change in the last 34 years and no longer meets the objectives of fairness and equity as a publicly funded benefit program. Publicly funded programs are built on principles of fairness and equity and providing a safety net for residents with limited financial means to access products and services not covered by the public health care system. The intention of a publicly funded supplementary health benefit program is to ensure equitable access to benefits that will improve or maintain health and likely result in reduction of higher cost acute care services delivered by the health system.

The overarching goal of the Government of the Northwest Territories' (GNWT) Department of Health and Social Services (Department) is to promote, protect and provide for the health and well-being of the people of the Northwest Territories (NWT). The Department is responsible for developing legislation, regulations and policies as part of the governing framework to support its goals.

#### **Objectives**

The purpose of the public engagement was to gather information about proposed changes to the health benefit programs currently provided under the *Extended Health Benefits Policy* and how those programs could better support the needs of residents.

From August 29, 2022 to November 23, 2022, the Department sought input and feedback from the public and stakeholders on the proposed changes outlined in the discussion paper, titled "Supplementary Health Benefits Policy Framework."

The results of the public and stakeholder engagement are summarized in this *What We Heard Report* and will be used to re-envision the GNWT's supplementary health benefits policy framework including proposed amendments to the *Extended Health Benefits Policy* and new programs.

#### **Audience**

The audience identified for public engagement included residents with chronic conditions and residents with low-income. Stakeholders identified were the NWT Disabilities Council, Inclusion NWT, YWCA-NWT, Alternatives North, NWT Seniors' Society and the NWT Pharmaceutical Association.

#### Methodology

Materials for the public engagement were designed to elicit feedback from residents currently using the Specified Disease Conditions program and low-income residents currently without access to supplementary health benefits through an employer or similar insurance plan.

The following materials were developed and made available to the public on the GNWT's *Have Your Say* website;

- A discussion paper;
- 'Frequently Asked Questions';
- Illustrative (comics) scenarios;
- A survey; and
- A 'Proposed Extended Health Benefits Calculator', which provided an opportunity for residents to see an estimate of how the proposed changes to the Extended Health Benefits Policy could affect them financially.

Direct communication with Memebers of the Legislative Assembly and identified stakeholders to invite their engagement and feedback also occurred.

#### **Results**

In total, 729 responses were received:

- 674 responses to the online survey;
- 12 written submissions received via email;
- 24 comments provided on the GNWT English and French Facebook posts;
- 3 in-person meetings with stakeholder representatives; and
- 22 participants and 16 questions / comments during the virtual Townhall discussion held November 16, 2022.

Throughout the engagement, residents and stakeholders identified areas of concern and suggested ways to ensure access to supplementary health benefits is made more equitable. Common themes included:

- Support for expanding coverage to provide all NWT residents with access to supplementary health and drug benefits, but not by removing existing programs or reducing coverage for residents currently on the Specified Disease Condition program. Many noted that they believed it wasn't fair or equitable to require people to pay to access drug or supplementary health benefits.
- Support for taking into account the high cost of living in the NWT. Support for including additional living and medical costs incurred for persons with disabilities

and persons living with chronic medical conditions or rare diseases when considering thresholds and cost-sharing requirements for the proposed Drug Benefit Plan.

- Support for financially supporting residents above the low-income threshold who require costly medical supplies and equipment.
- Concerns that third party insurance may be more difficult or expensive to get, and not as comprehensive for those with pre-existing conditions, or those who are older.
- Concerns that persons who require high cost drugs for rare diseases have exceptional needs that don't fit under the current proposed programs. Support for persons who have conditions that require costly medications to receive their medications free, regardless of income, to reduce barriers to accessing health benefits.
- Requests for the program to ensure residents can still access their medications
  without delay, and that program assessment is timely, seamless and easy for
  applicants; suggestions for having a process in place to reassess income should an
  individual or family's situation change.

#### **Next steps**

The results of this public and stakeholder engagement, together with the results of the Department's preliminary scoping exercises, cross-jurisdictional reviews, and additional policy research will inform the development of new policy provisions and programs and corresponding amendments to the *Extended Health Benefits Policy*.

### Sommaire

#### Introduction

La Politique relative au régime d'assurance-maladie complémentaire (49.07) a peu changé au cours des 34 dernières années et ne répond plus aux objectifs de justice et d'équité d'un régime de prestations financé par l'État. Les régimes financés par l'État reposent sur des principes de justice et d'équité, offrant un filet de sécurité aux résidents dont les moyens financiers sont limités pour accéder aux produits et services qui ne sont pas couverts par le système de santé public. L'intention d'un régime d'assurance-maladie supplémentaire financé par l'État est d'assurer un accès équitable aux prestations qui amélioreront ou maintiendront la santé et qui entraîneront probablement une réduction des services de soins de courte durée plus coûteux fournis par le système de santé.

L'objectif primordial du ministère de la Santé et des Services sociaux du gouvernement des Territoires du Nord-Ouest (GTNO) (ci-après, le « ministère ») est de promouvoir, de protéger et d'assurer la santé et le bien-être de la population des Territoires du Nord-Ouest (TNO). Le ministère est chargé d'élaborer des lois, des règlements et des politiques dans le cadre de la gouvernance pour soutenir ses objectifs.

#### **Objectifs**

Les échanges avec le public visaient à recueillir des informations sur les modifications proposées aux régimes d'assurance-maladie actuellement offerts en vertu de la Politique relative au régime d'assurance-maladie complémentaire, et sur la façon dont ces régimes pourraient mieux soutenir les résidents.

Du 29 août au 23 novembre 2022, le Ministère a sollicité les commentaires du public et des intervenants sur les modifications proposées décrites dans le document de discussion « Cadre stratégique pour le régime d'assurance-maladie supplémentaire ».

Les résultats de ces échanges avec le public et les intervenants sont résumés dans le présent rapport et seront utilisés pour repenser le cadre stratégique pour le régime d'assurance-maladie supplémentaire du GTNO, y compris les modifications proposées à la Politique relative au régime d'assurance-maladie complémentaire et aux nouveaux régimes.

#### **Public cible**

Les résidents atteints de maladies chroniques et les résidents à faible revenu constituaient le public cible. Le Conseil pour les personnes handicapées des TNO, Inclusion NWT, le YWCA des TNO, Alternatives North, la Société des aînés des TNO et l'Association des pharmaciennes et des pharmaciens des TNO étaient les intervenants visés.

#### Méthodologie

Les documents destinés aux échanges avec le public ont été conçus pour recueillir les commentaires de résidents qui bénéficient actuellement du régime d'assurance-maladie complémentaire pour maladies spécifiques et de résidents à faible revenu qui n'ont pas accès à des prestations d'assurance-maladie supplémentaires par l'entremise d'un employeur ou d'un régime d'assurance semblable.

Les documents suivants ont été élaborés et publiés sur le site Web des échanges avec le public du GTNO :

- un document de discussion;
- une foire aux questions;
- des scénarios illustrés par bandes dessinées;
- un sondage;
- un calculateur du régime d'assurance-maladie complémentaire proposé qui a permis aux résidents d'obtenir une estimation des répercussions financières que les modifications proposées à la Politique relative au régime d'assurance-maladie complémentaire pourraient avoir sur eux.

Une communication directe avec les députés de l'Assemblée législative et les intervenants visés a également eu lieu pour les inviter à participer et à formuler des commentaires sur le régime proposé.

#### Résultats

Au total, 729 réponses ont été reçues :

- 674 réponses au sondage en ligne;
- 12 observations écrites reçues par courriel;
- 24 commentaires en anglais et en français dans des publications Facebook du GTNO;
- 3 rencontres en personne avec les représentants des intervenants;
- 22 participants et 16 questions soulevées lors de l'assemblée publique virtuelle tenue le 16 novembre 2022.

Tout au long de ces échanges, les résidents et les intervenants ont fait connaître leurs préoccupations et ont suggéré des façons d'assurer un accès plus équitable aux prestations d'assurance-maladie supplémentaires. Voici les thèmes communs mis en relief :

 Soutien visant à élargir la couverture afin de permettre à tous les Ténois d'avoir accès à des prestations d'assurance-maladie et d'assurance-médicaments supplémentaires, sans toutefois supprimer les régimes existants ou limiter la couverture pour les Ténois qui sont actuellement prestataires du régime d'assurance-maladie pour maladies spécifiques. Bon nombre d'intervenants ont indiqué qu'il n'était ni juste ni équitable d'obliger les gens à payer pour avoir accès à des prestations d'assurance-maladie ou d'assurance-médicaments supplémentaires.

- Soutien visant à tenir compte du coût élevé de la vie aux TNO et visant à inclure les frais de subsistance et les frais médicaux supplémentaires engagés par les personnes handicapées et les personnes atteintes de maladies chroniques ou de maladies rares lorsque sont établis les seuils et les exigences en matière de partage des coûts pour les prestations du régime d'assurance-médicaments proposé.
- Soutien visant à apporter une aide financière aux résidents dont le revenu est supérieur au seuil de faible revenu qui ont besoin de fournitures et d'équipement médicaux coûteux.
- Inquiétudes relatives au fait qu'il serait plus difficile et coûteux de souscrire une assurance auprès de tiers et que cette couverture ne serait pas aussi étendue pour les personnes qui souffrent de problèmes de santé préexistants ou pour les personnes âgées.
- Inquiétudes relatives au fait que les personnes qui dépendent de médicaments coûteux pour des maladies rares ont des besoins exceptionnels qui ne cadrent pas avec les régimes proposés actuellement. Soutien aux personnes qui sont aux prises avec des problèmes de santé qui nécessitent des médicaments coûteux afin de leur permettre de les obtenir gratuitement, et ce, peu importe leur revenu, dans le but de réduire les obstacles liés à l'accès aux prestations de santé.
- Demandes visant à s'assurer que les résidents puissent toujours avoir accès à leurs médicaments sans délai, ainsi qu'à assurer que l'évaluation en vertu du régime soit rapide, transparente et facile pour les demandeurs; il a été suggéré de mettre en place un processus de réévaluation du revenu si la situation financière d'une personne ou d'une famille change.

#### **Prochaines étapes**

Les résultats de ces échanges avec le public et les intervenants, ainsi que les résultats des exercices préliminaires d'établissement de la portée, des examens intergouvernementaux et des recherches supplémentaires sur les politiques du ministère, serviront de base à l'élaboration de la Politique relative au régime d'assurance-maladie complémentaire.

## Introduction

The Department is working to update the *Extended Health Benefits Policy* and programs to ensure residents are provided support to access a suite of supplementary health benefits when needed. There has been little change to the *Extended Health Benefits Policy* over the last 34 years and, as such, it no longer meets the policy objective of equity or sustainability, nor does it reflect the changes in pharmaceutical technology. The intention of publicly funded supplementary health benefits is to provide a safety net for residents with limited means to access benefits and assure a level of equitable access that will improve and maintain health status. This will ultimately help reduce the use of the health system for acute care services.

The proposed changes are intended to:

- Provide coverage to people who have limited financial means and currently do not have access to coverage through an employer or other insurance plan.
- Manage potentially high drug costs for all individuals and families by capping the outof-pocket costs they pay for their drugs. Family maximums have been proposed
  according to income level to reduce the amount that must be paid each year.
- Ensure an efficient and sustainable program into the future.

To provide more equitable access to benefits for NWT residents, the discussion paper proposed replacing the existing Specified Disease Conditions program with two new programs - the Supplementary Health Benefits Program and the Drug Benefit Program.

To create equity of access, eligibility for the proposed new programs is to be determined through income-testing. An income-testing model typically involves establishing income thresholds and cost sharing mechanisms. Income-testing is used to determine whether a financial barrier (need) exists that could prevent access to important benefits and drug therapies.

In this model, individual or family income is to be assessed to determine which program they are eligible for, and if they are subject to a cost-share to access the Drug Benefit Program.

Residents assessed below the established low-income thresholds are eligible for both the Supplementary Health Benefits Program and the Drug Benefit Program.

For residents assessed above the established low-income levels, they will be eligible for the Drug Benefit Program once an employer, spouse's or other insurance plan is exhausted, and cost-sharing amounts are paid. The two new programs are intended to support the greatest number of people possible.

This *What We Heard Report* outlines the main themes and concerns brought forward through the public and stakeholder engagement held between August 29, 2022, and November 23, 2022.

The views represented in this report reflect the priorities and concerns of respondents. Responses from the public are presented as they were received and, conclusions or recommendations based on the feedback are not addressed in this Report. The feedback from this engagement will be taken into account as the Department further develops revisions to the GNWT's *Extended Health Benefits Policy* and programs.

# Public and Stakeholder Engagement

The public and stakeholder engagement was initiated on August 29, 2022. A discussion paper titled *Supplementary Health Benefits Policy Framework* was posted on the GNWT's *Have Your Say* website and the engagement period was open for feedback until November 23, 2022. The engagement period was extended twice because of the high level of public interest and to ensure ample time was provided for feedback.

The goal of the engagement was to elicit feedback from the public and stakeholders on the proposed changes to the Extended Health Benefits Policy. The discussion paper provided an overview of publicly funded supplementary health benefit programs across Canada as well as outlined the changes being proposed, why changes were being considered, and the benefits and potential financial impact of moving to an income-tested model with cost sharing requirements for the Drug Benefit Plan.

The public engagement focused on providing information to the public to generate feedback on the proposed changes. The engagement consisted of five components:

- 1. A discussion paper, survey, *Frequently Asked Questions*, and illustrative scenarios (comics) were posted to the GNWT's *Have Your Say* website. Instructions for submitting feedback included by email, mail, or fax, and/or participating in an online survey that contained specific questions for consideration.
- 2. The online *Proposed Extended Health Benefits Calculator* was provided to help residents understand the potential financial impacts of the proposed change.
- 3. Targeted stakeholder engagement by way of a letter sent to the NWT Disabilities Council, Inclusion NWT, the NWT Pharmaceutical Association, and other stakeholders inviting them to provide feedback on the discussion paper.
- 4. The Minister of Health and Social Services sent letters to Members of the Legislative Assembly to invite them to participate by providing feedback and encouraged them to share the discussion paper with their constituents.
- 5. A virtual public Townhall meeting was held November 16, 2022, which provided an opportunity for the public to receive an overview of proposed changes and to ask questions and provide feedback.

A number of communications approaches were taken to promote the public engagement. The GNWT issued a public service announcement inviting residents to provide their input and ongoing advertising occurred on social media throughout the three-month engagement period. The Townhall was advertised through social media, a public service announcement and the online *Have Your Say* public engagement webpage.

### What We Heard

The Department requested feedback on the discussion paper, which provided:

- An overview of current Policy and why it needs to change
- An overview of supplementary health benefit programs across Canada
- Proposed elements of a new supplementary health benefit policy framework including:
  - o Two new program streams
  - Income Testing
  - Cost Sharing Mechanisms
- Alternative threshold options and cost-sharing models considered

The online survey used nine multiple choice statements and two open ended response questions to elicit feedback from the public. There was the option to skip questions.

A *Frequently Asked Questions* document was used to help answer questions about the proposed changes. It was updated once during the engagement to respond to common questions and clarify different aspects of the proposal.

#### The Responses:

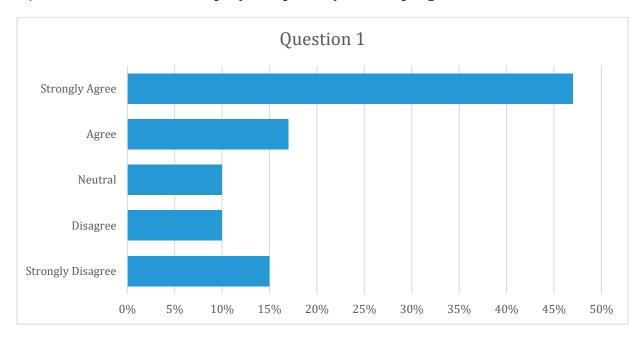
- Total survey responses: 674
- Total written submission responses: 12
- Total in-person and virtual Townhall responses: 19
- Total Facebook responses: 24

Summaries of the responses are provided below and are broken down by method of response (i.e., online Facebook post, written submissions).

#### **Online Survey**

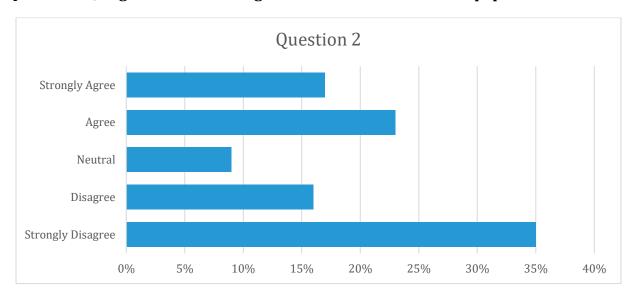
The Department received 674 responses to the online survey.

# Q1 – The current Extended Health Benefits Policy is 34 years and no longer meets the objectives of fairness and equity as a publicly funded program.



Overall, **64%** (429) strongly agreed or agreed that the current Extended Health Benefits Policy no longer meets the objectives of fairness and equity as a publicly funded program. **25%** (171) strongly disagreed or disagreed. **11%** (72) chose neutral.

#### Q2 - Overall, I agree with the changes outlined in the discussion paper.

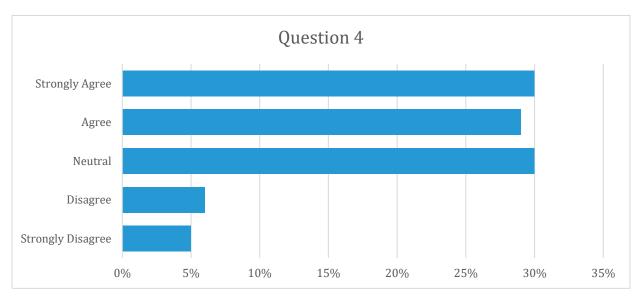


**51%** (323) strongly disagreed or disagreed with the changes outlined in the discussion paper. **40%** (251) strongly agreed or agreed. **9%** (53) chose neutral.

#### Q3 - If you disagree, why?

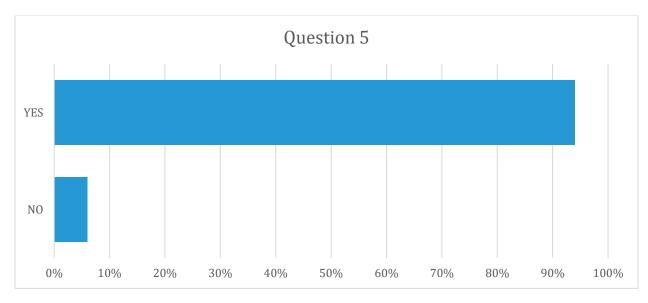
- Support for expanding coverage to provide all NWT residents with access to supplementary health and drug benefits, but not by removing existing programs or reducing coverage for residents currently on the Specified Disease Condition Program. Many noted they believed it wasn't fair or equitable to require people to pay to access drug or supplementary health benefits.
- Some residents felt Seniors and Métis Health Benefits should also be subject to proposed changes such as income testing to make changes equitable for everyone.
- Concerns were noted that the new program could increase administrative burden
  on families to fill out paperwork yearly and create barriers to accessing necessary
  benefits. Requiring tax returns may risk some residents such as young adults or
  elders who are behind in tax reporting from accessing benefits. Plus, if
  applications weren't processed in a timely matter, this could delay access to
  necessary, life-saving medications.
- Cost control measures and policies should be put in place to ensure people continue to access their insurance plans and program costs are controlled.
- Many responses noted they believed all supplementary health benefits, or certain
  drugs like PrEP, or high-cost drugs for rare diseases should be free for all,
  regardless of income, to reduce barriers to accessing health benefits. Many also
  noted that the high costs of medication for some diseases like cystic fibrosis,
  diabetes, Crohn's disease or multiple sclerosis are not affordable, regardless of
  income level.

# Q4 - At this time, phasing in changes so that current seniors' benefits are not impacted by the new policy is the right approach.



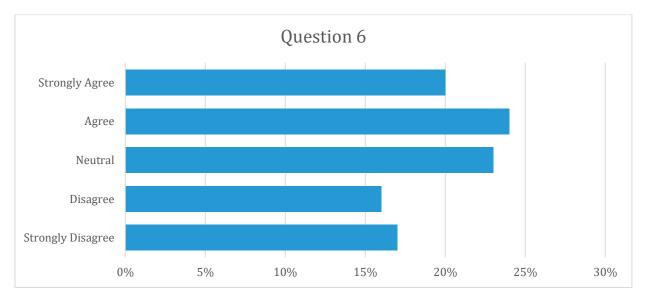
**59%** (353) strongly agreed or agreed that phasing in changes so the current seniors' benefits are not impacted by the new policy is the right approach. **11%** (67) strongly disagreed or disagreed. **30%** (178) chose neutral.

# Q5 - I am aware that existing benefits for Indigenous residents under the federal Non-Insured Health Benefits programs and the GNWT Métis Health Benefits program also remain in place and are not part of this discussion.



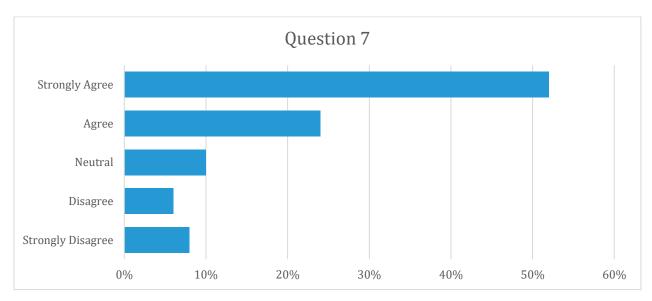
Over **94%** (554) were aware that existing benefits for Indigenous residents under the federal Non-Insured Health Benefits programs and the GNWT Métis Health Benefits program remain in place and are not part of this discussion.

Q6 - Providing supplementary health benefits based on an individual's or family's ability to pay (income testing) is a fair and equitable approach.



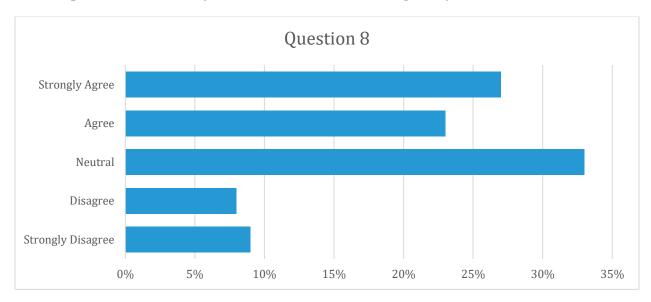
**44%** (251) strongly agreed or agreed that providing supplementary health benefits based on an individual's or family's ability to pay (income testing) is a fair and equitable approach. Whereas **33%** (190) strongly disagreed or disagreed with this approach. **23%** (136) chose neutral.

Q7 – With adjustments for the higher costs of northern living, an annual net income of \$32,601 is the poverty line set out by Statistics Canada for most regions of the NWT. Residents who earn that amount or less should qualify for no-cost health and drug benefits.



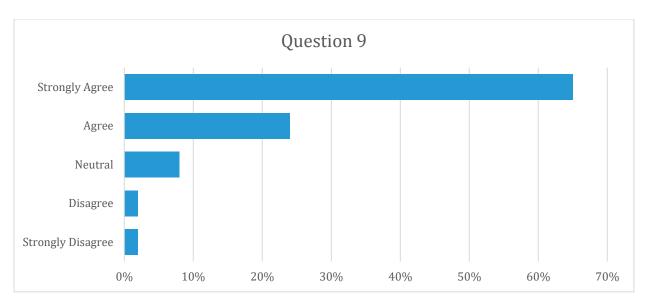
**76%** (441) strongly agreed or agreed that residents below the \$32,602 poverty line should qualify for no cost health and drug benefits. **14%** (81) strongly agreed or disagreed. **10%** (60) chose neutral.

Q8 – Given the high cost of living in the NWT, it is fair and reasonable to add \$9,451 for each dependent to a family's income to determine eligibility for health benefits.



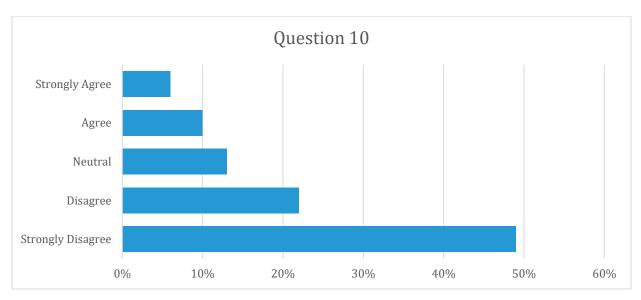
**50%** (287) strongly agreed or agreed that it is fair and reasonable to add \$9,451 for each dependent to a family's income to determine eligibility for health benefits. **17%** (55) strongly disagreed or disagreed. **33%** (192) chose neutral.

Q9 – I am in favour of drug benefits being extended in some form to all residents of the NWT.



**89%** (507) were in favor of drug benefits being extended in some form to all residents of the NWT. **4%** (23) were not in favor. **7.6%** (45) chose neutral.

Q10 – Residents who do not meet the low-income threshold and do not have other health insurance should not be eligible for the NWT Drug Benefit Program unless they purchase personal health insurance from a provider, and exhaust at least \$3,000 in drug benefits annually.



**71%** (401) Strongly disagreed or disagreed that residents above the low-income threshold should have to purchase and exhaust at least \$3,000 in drug benefits annually. **16%** (91) strongly agreed or agreed. **13%** (75) chose neutral.

# Q11 - Do you have any additional concerns about the proposed changes to the supplementary health benefit policy framework in the Northwest Territories? If so, please list them below.

- With the high cost of living in the NWT, the proposed thresholds of \$32,601 with the adjustment per dependent and spouse of \$9,451 was too low.
- Third party insurance may be more difficult or expensive to get and adds to the financial burden people with chronic conditions already have due to expensive medication and medical costs. Some medications are not covered under private / employer insurance.
- Some medications are too expensive, and that out-of-pocket costs will be too high for individuals to afford, even with the 70:30 co-insurance model.

- Income testing doesn't take into account other costs that individuals and families have, such as debt, living costs, inflation and other medical expenses, especially for people with disabilities or who have chronic medical conditions. Higher income doesn't necessarily mean having more disposable income, and any increase in medical costs can place additional burden on these individuals and families.
  - "For example, raising a child with disabilities means paying for a number of expenses (ie. special food, adaptive clothing, multiple footwear to accommodate braces, therapeutic tools for at-home interventions, specialized respite), out of pocket as they are not covered under any insurance or benefit plan."
  - Persons who require high-cost drugs for rare or chronic diseases have more complex and exceptional needs that don't fit under the current proposed income tested programs.
- Suggestion to provide a mechanism for reassessment of one's financial situation, should it change throughout the year.
- Suggestions that drugs currently not covered under the Extended Health Benefit program be added to the list of covered drugs, including contraceptives, the HIV prophylactic drug PrEP, and specific drugs to treat Lyme disease.
- Some residents felt the proposed changes penalized residents with moderate to higher incomes, as their cost share was higher; noting they already contribute more taxes to support government programs.

#### **Written Submissions**

The Department received 12 written submissions from organizations and individual citizens.

- Organizations 4
- Individual Citizens 8

In general, while the majority of written submissions agreed some changes to the policy were needed, and that providing drug benefits to all NWT residents in some form is beneficial, they expressed concerns over certain aspects of the proposal.

#### **Organizations**

The specific organizations and what we heard from them is broken down below.

#### **NWT Disabilities Council**

The NWT Disabilities Council provided an in-person briefing as well as a detailed written response to the proposed changes. While they believe there is a need to reform this program to better meet the needs of all people with disabilities, they noted that the proposed changes embedded discrimination as it wasn't based on the needs and life experiences of people with disabilities. Due to the focus of proposed changes based solely on income-based criteria. They outlined their concerns including:

- Residents with some medical conditions above the low-income threshold may still need
  access to financial support for costly medical supplies and equipment. Removing
  coverage for medical supplies and equipment for higher income earners may impose
  costs families can't afford, which may lead to further disablement, and poorer physical
  and health outcomes. They recommended the GNWT incorporate a scheme of coverage
  for medical supplies and equipment for these higher income earners.
- Concern that requiring private insurance to be exhausted before accessing the Drug Benefit Plan creates an adverse distinction between people with and without medical conditions. Concerns raised that private insurance may be difficult or expensive to get, and not as comprehensive for those with pre-existing conditions, or those who are in the older age category.
- Recommended that low-income families with third party insurance be automatically covered for all benefits, with the Supplementary Health Benefit Program becoming a secondary insurer with direct billing option. This would prevent low-income families from having to pay costs out of pocket and incurring greater costs than those without third party insurance.
- Suggested that if the GNWT requires moderate-high income residents to purchase third party insurance, the GNWT should explore co-ordinating an insurance plan. One that will

provide universal standard coverage with premiums that don't discriminate based on age, disability, or other protected ground. Due to the diversity of employer sponsored and private benefit plans, this would help ensure fairness for beneficiaries.

- Definition of household and family for income testing purposes should not include adult children, or relatives, as this could push low-income families over the threshold, as well as potentially disincentivize parents housing children or adult children with disabilities at home.
- Supported the proposed base income be the higher threshold of \$36,925 (the Market Basket Measure for the most expensive region), due to families residing in remote communities, who face greater barriers in meeting medical needs. They noted that the benefit rates should be increased yearly by the rate of inflation.
- Urged the GNWT to provided modified thresholds to account for the increased costs of living associated with disabilities.
- Urged the GNWT to provide full medical travel coverage for low-income earners and scaled co-payment for moderate-high income earners.

#### **Cystic Fibrosis Canada**

Cystic Fibrosis Canada provided detailed responses in writing to the survey questions. Overall, they were not in favor of the proposed changes as they didn't believe it was equitable or fair to treat people who live with rare conditions in the same manner as others living with more common, treatable ailments.

They noted that Cystic Fibrosis (CF) is an expensive disease, and most individuals and families who live with CF need financial support to access their treatments, both symptom management drugs and especially highly effective and expensive modulators, such as Trikafta. They noted people with rare diseases have special access and care needs regardless of income, or private insurance coverage. They outlined their concerns including:

- Residents who require high-cost medications for rare diseases may need support under the Drug Benefit Plan for a particular drug. Often these high-cost drugs are not covered under a private or employer insurance plan, or their annual or lifetime insurance limits are reached quickly. Cystic Fibrosis Canada believes the NWT should have a special access program for this special type of drugs free of charge.
- Agreed that people who are near or below the poverty line should qualify for no-cost health and drug benefits. In addition, they noted those with high needs relative to income should too, and those who need life-changing drugs for rare diseases should be able to access the drug benefits free of charge.

Cystic Fibrosis Canada agreed that fair and reasonable adjustments should be made for
each dependent to a family's income to determine eligibility for health benefits. In
addition to cost-of-living adjustments, they recommended that the overall costs people
incur annually for medicines and medical care relative to household income should also
be considered.

#### **NWT Pharmaceutical Association**

The NWT Pharmaceutical Association provided a detailed response to the proposed changes. Overall, they believe the current model is superior to the current proposal as it is easy to understand, requires minimal administration and reduces financial barriers to accessing medications and medical supplies. They believe it is an effective policy to optimize health outcomes and mitigate costly future acute care treatments.

The Association makes the following recommendations to address gaps in the current model rather than changing approaches:

- Include mental health diseases (clinical depression, clinical anxiety, attention deficit disorder) in the list of specified diseases. Plus investigate if other prominent medical conditions are currently not on the Specified Disease list.
- Implement a low-income threshold that qualifies a person/family for extended health benefits coverage, regardless of if they have a disease on the specified disease list. Consider using co-pays in the form of deductibles or copays on each prescription (ie. \$3.00) for any patient not under income assistance.

The NWT Pharmaceutical Association noted the following concerns and recommendations should the proposed model go forward:

- Provide a dedicated phone line and office(s) where residents and Pharmacists can ask
  questions and receive help with the application process. Establish a well trained,
  revamped health administration department to handle program changes.
- Provide one-year advance notice of changes for individuals on the Specified Disease Program, to allow time to adjust for the increase in health care costs.
- Send annual reminders out to residents to reduce the risk that sudden changes in health status may create financial burdens or delays in treatment.
- Consider all implementation costs for the government, including a tracking system for deductibles, administration, training additional hardware and software expenses, communication costs, and a possible increase in provider costs.

• Does not support requiring individuals to have private insurance coverage, due to the potential for high costs and denials of coverage, which they believe creates a barrier to effective primary care treatment.

#### **Alternatives North**

Alternatives North provided a detailed response to the proposed changes. While they support making improvements to ensure residents can access necessary health benefits, they noted they believed the current proposal was inadequate, and advocated for a single, Universal Plan that was free for all residents.

Alternatives North noted the only way health programs will be accessible, equitable and easy to understand is if they are universal and funded through a progressive tax system. They believe that access to health programs should never be income tested or have other barriers to free access.

Other benefits of a single Universal plan include reducing the complexity of the plan, avoiding the costs of duplication and reduce staffing requirements. Their recommended solution is to use a phased in approach to expand EHB benefits for all residents over time. By starting the enhanced coverage for those earning less than \$30,000 per year immediately and raising that cut-off \$10,000 per year until the entire population is eligible. Extra costs could be paid for by the establishment of a progressive tax system in the NWT.

The organization provided the following feedback should the GNWT not implement a Universal Plan, and continue on this path to expand the EHB Program:

- Supported a unified program for both the Supplementary Health Benefit Program and the Drug Benefit Plan as both are essential contributors to a person's health status and would reduce paperwork.
- Raised concerns that applying annually creates barriers given some people may not file
  their taxes every year, or fail to apply for a variety of reasons, including oversight, lack of
  awareness of the requirement, literacy and language barriers. Additionally, situations
  may change over the year, so inquired whether there would be an appeal or reassessment
  mechanism to address this.
- Raised concerns over requiring insurance, including cost and availability. As well as
  noting private insurers can unilaterally stop coverage, increase their prices or otherwise
  restrict access or coverage, leaving residents at risk.
- Noted that there is merit in using income to determine cost sharing and coverage levels as long as the cost sharing burden on individual northerners is not so high that it stops low-income earners from accessing needed drug or other health coverage.

- Agree with the use of the Northern Market Basket Measure as a low-income marker, but support a more phased in approach to thresholds, by using the \$9,451 between each income threshold as well. Alternatives North also supports using a more graduated approach to the co-insurance payment starting at 75% for the government to pay and 25% for the family to pay, then moving to 50/50 and then 25/75, as family income increases. A graduated approach would help avoid situations where people are cut off from benefits.
- Expressed concern that the discussion paper says that it is "at this time" that it doesn't apply to Seniors. They believe reducing current coverages provided to seniors would be a step backward.
- Noted that while each cost sharing model has faults, the premium model would be the least likely to work for low-income earners who would likely prioritize current expenses over coverage for unforeseen health related problems.

#### **Individuals**

The Department received eight written submissions from individuals:

- Five responses had questions or comments relating to their specific situation, as they, or family members were currently on the Specified Disease Condition List.
- Three responses did not agree with changing the program to an income tested model, especially for people who are currently on the Specified Disease Condition Program.

Themes from the individual feedback included:

- Support for expanding coverage to provide all NWT residents with access to supplementary health and drug benefits, but not by removing existing programs or reducing coverage for residents currently on the Specified Disease Condition Program.
- Request for a mechanism for reassessment of one's financial situation, should it change throughout the year.
- Request to take into account the additional living, debt and medical costs persons with medical conditions may have, when considering thresholds, as well as the cost-sharing requirements for the proposed Drug Benefit Plan.
- Request to consider a phased approach for those on existing programs, to allow residents time to seek incremental funding/payment options where needed.

- Request to ensure residents can still access their medications without delay, and that program assessment is timely, seamless and easy for applicants.
- If income testing the new programs, then suggestion that all GNWT supplementary health benefit programs be income tested, including the Seniors program, Métis Health Benefit program and the Non-Insured Health Benefit (NIHB) program.

#### **In-person and Virtual Townhall**

Three in-person meetings were held with the public and stakeholders. In summary:

- The NTHSSA Rehabilitation Team expressed concern that removing coverage for highcost medical supplies and equipment would create financial barriers for residents over the low-income threshold.
- The NWT Disabilities Council presented their concerns outlined in their written response (see written response).
- One individual provided an overview of the potential impact on their family of removing the Specified Disease Condition Program and replacing it with an income tested and cost sharing model.

The virtual Townhall was held November 16, 2022. The Department provided an overview of the proposed changes feedback to date. There was also time for questions.

- Concerns that many people who are on or have dependents on Specified Disease Conditions Program don't know about potential changes. Requested that people on the program be contacted directly.
- The NWT Disabilities Council provided a link to their feedback paper, noting they believe the changes are not equitable, and are harmful and will be partnering with unions, organizations, individuals and families to stop this proposal as presented.
- One comment mentioned this may force people to stay in poverty because they can't
  afford to lose their benefits. Questioned how this plan accounts for all the additional costs
  associated with having a diagnosis that are not prescriptions, such as higher costs for
  childcare, pain medication, and electricity.
- Concern that private insurance would cost significantly more for people with pre-existing conditions. Questioned whether there really are affordable, private insurance options out there that don't have a detailed application process that includes health information.

- Higher rates of diabetes, obesity, smoking and alcohol use in the NWT than in other
  provinces in Canada; believes that if people are at a higher risk of developing these
  illnesses simply by living here does it not make sense to continue to have full benefits for
  these people.
- Concern that removing medical equipment and devices for any income above the threshold will be systemically discriminatory to people aging; asked for the rationale behind this.
- Support may be needed for people who may have a hard time making yearly applications.
- Questioned how many people the Department has estimated this will affect and what will the cost be for this to the Department.
- Concern that proposed changes may increase acute care use for people above the lowincome threshold who can't afford their cost share.

#### **Facebook**

The Department received 24 written comments on the GNWT's social media posts (Facebook).

- Some noted they believed drugs and supplementary health benefits should be free for everybody.
- With the high cost of living in the NWT, some noted they thought the proposed base threshold of \$32.601 was too low.
- Concerns were noted about people currently on the Specified Disease Condition Program losing benefits, and/or being required to now pay for a portion of their costs. Examples included residents above low-income with medical conditions losing access to required supplementary health benefits such as medical supplies and equipment.
- Noted the "comics" focused on people who would now receive benefits but didn't explain the impact to people currently on the Specified Disease Condition Program.

## Next steps

The results of this public and stakeholder engagement, together with the results of the Department's preliminary scoping exercises, cross-jurisdictional reviews, and additional policy research will inform the development of new policy provisions and programs and corresponding amendments to the *Extended Health Benefits Policy*.

## Conclusion

The *What We Heard Report* provides a high-level summary of the input received throughout the public engagement period. It has been compiled to provide an understanding of the areas of support, concern, and other ideas raised by NWT residents and stakeholders respecting the proposed supplementary health benefits policy framework and changes to the *Extended Health Benefits Policy*.