

Summary of Proceedings Public Hearing

Held on Wednesday, March 20, 2024, from 10:15 a.m. to 11:59 a.m.

Venue: Arnold Thomasos West Meeting Room, Second Floor, Parliamentary Complex, Cabildo Building, St Vincent Street, Port of Spain. (**Hybrid Meeting format**)

Subject matter: An inquiry into Trinidad and Tobago's response to the prevalence of non-communicable diseases with a specific focus on diabetes, cardiovascular diseases and cancer.

The **objectives of the inquiry** are as follows:

- 1. To examine the efforts of the state to counteract the effects of specific non-communicable diseases, NCDs, within the population, including diabetes, heart disease and cancer;
- 2. To examine the efforts of civil society to counteract the effects of non-communicable diseases or specific non-communicable diseases within the population, including diabetes, heart disease and cancer; and
- 3. To determine the main policy changes, actions, and interventions that are necessary to effectively respond to the increase in non-communicable diseases in Trinidad and Tobago.

Committee Members

The following Committee Members were present:

- Dr. Paul Richards Chairman
- Mr. Roger Monroe, MP Vice Chairman
- Mr. David Nakhid Member
- Ms. Vandana Mohit, MP Member
- Ms. Pennelope Beckles, MP Member
- Mr. Esmond Forde, MP –Member

The following Committee Members were excused:

- Mr. Avinash Singh Member
- Mr. Rohan Sinanan Member

Witnesses who appeared

The following officials of the **Diabetes Association of Trinidad and Tobago** appeared:

• Dr. Andrew Dhanoo

President

Ms. Shoha Dookeran

1st Vice President

The following official(s) of the **Trinidad and Tobago Cancer Society** appeared:

• Dr. Asante Le Blanc

Chairperson, Trinidad and Tobago Cancer Society

The following official(s) of the **Trinidad and Tobago Heart Foundation** appeared:

• Mr. Amit Maharaj

Manager

Opening Statements

The chief officials of the aforementioned entities made brief opening remarks.

Key Issues Discussed

The following are the main themes arising from discussions with the <u>Diabetes Association of Trinidad and Tobago (DATT):</u>

General Information

- i. According to the International Diabetes Federation, 15% of the population in Trinidad and Tobago is living with Diabetes.
- ii. The last time a National Study was conducted was in 2011.
- iii. There is a noted increase in Type 2 Diabetes in older persons, but there is also an increased prevalence of Type 2 Diabetes in younger people.
- iv. There is a noted increase in the prevalence of risk factors which lead to Type 2 diabetes and the increasing number of consequences, such as amputations, renal disease and loss of eyesight.
- v. Someone with a diabetic foot problem is using most hospital beds in Trinidad and Tobago. This problem, as well as foot diseases, are significant issues.

Membership of the Diabetes Association of Trinidad and Tobago

- i. Thirty per cent of the membership is men.
- ii. The Association stated that the higher percentage of female members is not exclusive to their organisation.

- iii. Men do not tend to seek healthcare until it is too late, this is one of the reasons men do not live as long as women.
- iv. The Association has been encouraging more men to take proactive measures regarding their health. This is mainly through sporting activities and community groups that the Association has.
- v. The Association stated that they have 20 branches of community groups throughout the organisation.
- vi. DATT has been struggling to get more men to participate.
- vii. Despite the challenges, they have found that when women participate, they return to their homes and advise the men.
- viii. DATT believes the main challenge with male participation is cultural, and there is not much they can do to shift the culture.
- ix. The DATT hosts events that are more targeted toward men. When they host 5 K races, more men participate than women. They also host screening activities specifically geared towards men.
- x. While there is still a lot to be done, exclusively working with men has not been at the top of the DATT's agenda right now.

Outreach Initiatives

- i. DATT is usually invited to have a booth or to participate in the planning process with the Ministry of Health's TT-Moves initiative
- ii. DATT has also collaborated with RHA's outreach initiatives, such as 5 Ks. In some cases, the Association is a part of the planning committee.
- iii. It was reported that there is usually a good turnout at the events; however, it is challenging to measure tangible results because no monitoring and evaluation framework has been established within the event.
- iv. Outreach initiatives encourage individuals to undergo screening, but their effectiveness is not always guaranteed.
- v. Outreach initiatives, such as health fairs, do not guarantee significant participation or membership in the Association.
- vi. Activities hosted by the DATT are conducted annually and the Association has recently started new projects.
- vii. The Sixth Form Internship programme started three years ago and assists sixth form students with becoming involved in volunteer work. The Association teaches these students everything they need to know about being a health NGO, including research, fundraising, marketing, and development. During the first year of the programme, they had 150 registered students, but they were only able to accommodate 35 students. Similarly, last year, they had 600 registered students, but were only able to accommodate 35. This is the only programme like this in the Caribbean.
- viii. DATT has over 100 young people in their youth arm.
- ix. The Accredited Diabetes Educator Programmes is another programme offered by the DATT. The programme is from the International Diabetes Federation, which is the umbrella organisation for all diabetes associations. The programme is twofold, comprising both online and in-person components, and the Association paid for and trained certified diabetes educators. From this, the Association developed plans for diabetes educators that educators can use at health centres. They have trained 35 people. They are now implementing the rollout, where educators will visit health centres to teach people about taking medication, insulin, foot care, and how to test, as well as when to test. It was stated that this is the kind of information patients typically do not receive from their doctor or nurse.

- x. the Chief Medical Officer has approved DATT to deliver lectures and talk to persons living with diabetes.
- xi. DATT does not have the money and resources to analyse the effectiveness of public awareness programmes. They do agree that, in some cases, the messages that are being put out may not be targeting the right people.

Collaboration with the Ministry of Education

- i. DATT collaborates closely with the Ministry of Education and has developed a close working relationship in terms of project implementation.
- ii. The Association has decided to target as many age groups as possible. They began with the 6th Form Programme, followed by the National Diabetes Primary School Quiz, which is for Standard 3 students. Last year, they started a debate for Form 4.
- iii. DATT believes that they need to intervene much earlier. They are considering intervening with toddlers.

Competing with other organisations for limited resources

- i. DATT mentioned that there is often competition among NGOs for access to limited resources.
- ii. There are limited resources that NGOs have access to, both at the government level and in the private sector.
- iii. Since the Cancer Society gets support from Republic Bank and Scotia Bank, the Diabetes Association cannot receive funding from them.
- iv. DATT has sponsors including Tatil, Tatil Life, Blue Waters. They work with the Ministry of Health. Some sponsors work exclusively with certain organisations because it better aligns with their mandate.

Operating Costs

- i. The DATT stated that their operating costs are approximately \$ 1.5 million; however, this amount fluctuates because most of the costs they incur are for events. This is not from the Government, and the Association is trying to raise as much funding as possible so it can complete its work.
- ii. DATT currently has two paid staff members and relies on on-the-job training (OJT) and volunteers for support.
- iii. The Government subvention is 400,000 per year; however, the DATT receives funds from the TT-Moves programme, which supports health services for activities such as camps for children with diabetes, camps for overweight children, the National Diabetes School Quiz, and the Diabetes Symposium.
- iv. Last year, they received approximately \$500,000 for these activities. This is in addition to the \$400,000.

Lack of response by the public to access screening

- i. It was stated that the general hesitancy is because many people are afraid to find out whether they are diabetic.
- ii. Many of the late-stage diabetic complications are because people are getting screened or seeking care early enough.

Challenges with screening

- i. It was stated that not all screening tests are performed locally. DATT further elaborated that this meant at the point of care.
- ii. DATT is advocating for point-of-care testing, specifically for HbA1c. Haemoglobin A1c provides the average blood sugar level for the last three months. Obtaining this reading is crucial for doctors to make any necessary adjustments to the patient's medication. Instantaneous A1c readings enable doctors to adjust medication immediately.
- iii. Last year, the Minister of Health said that they were acquiring HbA1C machines, point of care, for every health centre. DATT is hoping that this materialises this year.
- iv. Many of the late-stage diabetic complications is because people are not getting screened or seeking care early enough.

Increase in unsubstantiated non-medical claims

- i. DATT states that there has been an increase in alternative medicine practitioners who may be misguiding many persons. While DATT is accepting of complementary and alternative medicines, they state there is a major challenge with some practitioners who have been making unsubstantiated non-medical claims to cure all diseases.
- ii. They believe that strong legislation is needed to address these individuals, and more decisive interventions are required.

Support for stringent government policy interventions

- i. DATT stated that many interventions can be done, which have been proven to increase the health of the population.
- ii. This includes taxation, limited marketing, and front-of-package labelling. Specifically, for Trinidad and Tobago, DATT believes that front-of-package labelling and limited marketing of unhealthy foods will be most effective.
- iii. DATT is advocating for a specific government policy to limit the marketing of unhealthy foods in school cafeterias.
- iv. In terms of policy, DATT has not worked with the Ministry of Education; however, it has worked with the Ministry of Health by advocating for front-of-package labelling.
- v. DATT is a part of the NCD steering committee, and they can champion and provide thoughts about interventions

Type 1 Diabetes

- i. DATT states approximately 200 to 250 children are living with type 1 diabetes in Trinidad and Tobago. These children will have to take insulin for the rest of their lives.
- ii. DATT has reengaged the Ministry of Health and the Ministry of Education on a policy for children living with diabetes. The policy has not been acted upon; however, some of the initiatives DATT wanted to implement included training teachers on how to deal with children with Type 1 Diabetes, especially in cases of diabetic emergencies.
- iii. DATT is now collaborating with TTUTA and NPTA, and they hope to implement the programme this year.
- iv. Last year, DATT launched their continuous glucose monitors which provides blood sugar readings throughout the day. CGMs are very expensive, and DATT is aware that the Minister of Health is trying to acquire them for children. DATT commends the efforts by the Ministry.

Availability of Drugs via CDAP

- i. Newer drugs that have been proven to have a better effect on patients are not on the CDAP formulary due to their cost. Since medication is provided free of charge via the CDAP programme, the purchase of medicines for the programme must be economical.
- ii. Lantus, a long-acting insulin, is no longer on the CDAP formulary due to its cost and has been replaced with 70/30 or mixed insulin. DATT is advocating for Lantus and other analogues to be added to the formulary for children.
- iii. Many persons have opted not to use CDAP-provided medication and insulin, instead purchasing their own.

Availability of Ozempic

- i. There is currently a global demand for Ozempic, and some medical distribution agencies in Trinidad and Tobago have been attempting to source it; however, the producer is not expanding into new markets because they cannot keep up with the demand.
- ii. There is a lot of "suitcase trading" with Ozempic and other GLP-1 inhibitors.
- iii. DATT stated that these drugs are advertised as weight loss remedies and have more side effects than the public is aware of. If they are being used for weight loss, to maintain that weight loss, these drugs would need to be taken for the rest of their lives.
- iv. Ozempic has been used and is highly successful in managing type 2 diabetes; DATT hopes to have it locally.
- v. Besides Ozempic other manufacturers are making very similar types of drugs and DATT is hoping to have those drugs locally as well.
- vi. DATT warned of suitcase traders who are present in Trinidad currently selling these drugs.

The following are the main themes arising from discussions with the <u>Trinidad and Tobago</u> <u>Cancer Society (TTCS)</u>

General Information

- i. The Society has observed growing inadequacies and inefficiencies in the public healthcare sector regarding the screening, diagnosis, and treatment of cancer.
- ii. TTCS also noted the lack of enforcement of the Tobacco Control Act which, they state, now needs to include vaping. Smoking and vaping have a substantial negative impact on all NCDs, and especially cancer.
- iii. There is a loss of life, not only among the older generations, but also among the younger members due to NCDs. It is a significant problem.

International Affiliations

- i. TTCS became affiliated with the American Cancer Society in 2023, specifically for the Global Relay for Life.
- ii. The Global Relay for Life is both a funding event and a campaign that raises awareness about screening, hope, and survivorship worldwide.
- iii. At this point, the affiliation enables the society to network with the worldwide community in the fight against cancer. It also allows for sharing information and exchanging ideas on what can be done policy-wise in countries. The network also enables them to brainstorm and effect proper change in each country, providing

support to bring about change both nationally, regionally, and internationally in the fight against cancer.

Outreach Initiatives

- i. The TTCS conducts screenings as part of their outreach initiatives through their clinic.
- ii. The clinic is highly subsidised through Government subvention, which allows for high-quality screening services at a very subsidised price to the public.
- iii. The TTCS offers screening at both their clinic, located at #69 Dundonald Street, and their mobile screening units.
- iv. At the clinic they offer on-site mammograms and breast ultrasounds, clinical breast examinations, Pap smears for cervical cancer, the FIT for colorectal cancer and the DRE and PSA for prostate cancer.
- v. At the mobile screening units, they offer clinical breast exams and DRE and PSA for prostate.
- vi. The TTCS hopes to offer and improve more in future.

Value of Government Subvention

- i. TTCS faced a challenge five or six years ago where their subvention was extremely delayed. They previously received 1.5 million and then did not receive any subsidies for years.
- ii. Through negotiation, TTCS forfeited the subvention that was missing for years and then accepted \$750,000 per year.
- iii. TTCS has attempted to initiate talks with the Ministry to increase the subvention but has been unsuccessful. While it is not enough, they manage. They understand the government's position and appreciate what they are getting.
- iv. It was stated that operating costs for the TTCS were approximately \$300,000 per month. This generally covers salaries for staff, maintenance for imaging equipment, and other related expenses.
- v. TTCS stated that they could do so much more if they received more, but they try to make up for the shortfall through private sponsorship with corporations.

Corporate Funding

- i. Through the assistance of the business community, TTCS has several main fundraisers, including the flagship CIBC event for prostate cancer.
- ii. They usually receive \$150,000 from CIBC, however, last year they received a little over \$100,000
- iii. For the Scotiabank Foundation, they offer women's breast cancer screening and received \$250,000 from them.
- iv. They were given half a million dollars from Republic Bank, not only for screening, but also for the Power to Make a Difference programme, which is where they conduct their flagship fundraiser, "Bubbles for Life." From there, they raised approximately \$300,000 net, and after all expenditures are deducted, the remainder goes towards the screening and operations of the TTCS.
- v. TTCS may also receive grants from people who have died or from donations from persons who may buy a tree of life or a leaf of life. TTCS sells leaves/branches online and receives donations that way.
- vi. They primarily receive funds through corporate sponsorships and fundraising events.

- vii. Despite the support received, corporate sponsorship does not cover the shortfall of funds, and they are still in debt.
- viii. TTCS continuously seeks opportunities for collaboration to increase campaigns, funding and support.

TTCS's role in the NCD Alliance

- i. TTCS was one of the core members that formed the NCD Alliance.
- ii. It was stated that the NCD Alliance is not able to effect anything because the Alliance is not as cohesive as it should be. It was further explained that this was because NGOs are competing against each other to ensure that their independent organisations can meet their mandates in terms of their mission and vision.
- iii. It was stated that the Ministry's point person meets with the Alliance more frequently, allowing for better collaboration. Meetings need to be better planned. There is a lot of talk but no action.
- iv. It was stated that for the NCD Alliance to work, NGOs must be given a seat at the table. There is also a need for greater cohesion and collaboration among stakeholders.

Recommendations for Improving Trinidad and Tobago's Response to NCDs

- i. TTCS recommended mandatory reporting of NCDs in both the public and private sectors.
- ii. The timeliness and accuracy of local NCD data are needed. The TTCS is currently initiating data collection on its website, which is being conducted through its Electronic Medical Record (EMR).
- iii. Effect the Tobacco Control Act and include vaping as it is a major contributor to NCDs, not only cancer. The current format of the legislation does not accommodate vaping, and despite the negative effects of vaping, it is still advertised as an alternative to smoking.
- iv. Through the Ministry of Education and the Ministry of Health, the TTCS has conducted public awareness campaigns in schools, titled "Can't Fool Me" and "No Smoking, No Vaping," in collaboration with Scotia Bank and Republic Bank, respectively. However, in terms of continuous campaigns, the TTCS has not had support from either Ministry. Initiatives are done independently or in collaboration with corporate sponsors.
- v. Improved communication among NGOs and the point lead for the NCD Alliance.

Feedback from the membership about dysfunctional equipment

- i. It was claimed that there are challenges with dysfunctional equipment at all regional health authorities. It was mentioned that there were challenges with the mammogram equipment, as well as a significant delay in colonoscopies.
- ii. TTCS stated that it greatly affects their membership because persons are unable to access the services they need. It was further stated that they are aware of persons who have waited years for mammograms and colonoscopies.
- iii. TTCS stated that they were approached once by the NWRHA last year regarding the equipment challenges and possible ways to support. It was further explained that TTCS offered the NWRHA a subsidised price to support with the challenges, however, TTCS has not heard from them since.

Feedback from the membership about drug shortages

- i. It was claimed that based on feedback from TTCS' membership, there is always a shortage of breast cancer and prostate cancer drugs.
- ii. It was further expressed that some oncologists have stated that, although they have approved newer drugs for treatment and these drugs are on the formulary, they are still not available, so patients are given outdated drugs.
- iii. Patients are often forced to go to private medical institutions to pay for the drugs they need to save their lives.
- iv. It was claimed that a possible reason why the drugs aren't available is because of lack of funds.
- v. A drug company stated that they were willing to talk to the government and provide the drugs for free, but it is not happening in the public sector.

Cannabis usage and links to Cancer

- i. It was agreed that there is a correlation between Cannabis usage and Cancer. It was further explained that "the heat consumed" when smoking cannabis can cause cancer.
- ii. Similarly, the heat generated in electronic cigarette devices, as well as other chemicals, causes popcorn lung and, inadvertently, cancer
- iii. Smoking marijuana in any form, because of the heat, will inadvertently put persons at risk for cancer and other NCDs.

Tobacco Control Act

- i. TTCS was instrumental in creating the Anti-Tobacco Bill of 2009
- ii. While the Act was passed, the Tobacco Control Unit could not implement the Act properly from the Ministry of Health's perspective.
- iii. TTCS has been in constant contact with the Tobacco Control Unit.
- iv. One successful outcome was limiting supermarkets to one cigarette dispenser. While this is commendable, TTCS believes there is still more to be done.
- v. TTCS stated that there is a need to clamp down on importation and the suitcase trade of Tobacco. There should also be increased Taxes.
- vi. Vaping also needs to be included in the amendment of the Act.

Challenges with multi-sectoral collaboration

i. Better communication is needed between the Government and Non-governmental actors.

Potential Collaborators

- ii. TTCS mentioned greater consultations are needed with the NCD Alliance, Healthy Caribbean Coalition and all NGOs
- iii. It was recommended that there should be a Cancer point lead at the Ministry of Health.

Increase in unsubstantiated non-medical claims

i. While there is a Medical Act in Trinidad and Tobago which prohibits people who have not received medical training through a recognised medical institution from calling

- themselves doctors or claiming to be able to cure diseases, the Medical Board does not seem to be able to enforce this Act.
- ii. The public needs to understand and differentiate between supplement medicine and herbal medicine.
- iii. Persons making unsubstantiated non-medical claims should be stopped.
- iv. Supplements that the Ministry of Health has approved are then advertised as a cure which is not right.
- v. TTCS strongly believes that there should be some form of legislature and effecting of that legislation.
- vi. There is a space for complementary medicine, but it needs to be regulated.

The following are the main themes arising from discussions with the <u>Trinidad and Tobago</u> Heart Foundation.

General Information

- i. The Foundation focuses on the preventive aspect of cardiovascular disease through education and awareness, facilitating initiatives such as lectures and public health fairs to educate the public in various modes across Trinidad and Tobago.
- ii. The Foundation is not primarily medical in terms of being integrated into the public healthcare system; however, due to its proximity to working within hospitals and with the Ministry of Health, it has observed challenges with wait times for testing and treatment related to cardiovascular diseases.
- iii. The mandate of THF is education and awareness, which is achieved through health fairs, lectures, and the dissemination of information to the public.
- iv. The TTHF is a member of the InterAmerican Heart Foundation, the American Heart Association, and the World Health Federation, through which it receives a significant amount of research and information that the Foundation disseminates nationwide to the public.
- v. Another branch of the TTHF's initiatives involves testing through the 'Know Your Numbers' campaign and encouraging individuals to actively monitor their blood sugar, blood pressure, BMI, and other key statistics.
- vi. They are not a medical foundation per se, in that the aspect of heart disease is not directly integrated into their mandate; however, they do attempt to assist individuals in obtaining the necessary resources for testing.

Challenges with testing

- i. It was stated that they have encountered many people who have not gotten the testing they require when they are diagnosed with heart disease.
- ii. These include stress tests, echocardiograms, the ECG, and EKG
- iii. There are long wait times for testing in the public health care system. Patients' conditions may have worsened due to the delay in diagnosis and treatment, which can be prolonged by the time it takes to assess and treat them; in some cases, this delay may have been years.
- iv. In most cases immediate testing can be done privately, however this is dependent on whether persons can afford it.
- v. Stated that the public system is relatively overpopulated, so the quality of time for each person depreciates with each person who enrols in the clinic system.

Increase in unsubstantiated non-medical claims

i. There has been misinformation and claims from people without a medical background, and funds are being diverted from where they should be invested towards the proper care of persons with medical conditions.

Key Recommendations emanating from discussions

The following are key recommendations from discussions:

i. Public Awareness and Health Promotion

- Enhanced Health Campaigns:
 - o Diversify outreach strategies to include sports events, cultural festivals, and other large gatherings to target men and hard-to-reach populations.
 - Increase public messaging around complications such as diabetic foot issues and the risk of amputations.
- School-based Interventions:
 - Implement education and awareness campaigns in schools to inform children about NCDs from an early age.
 - o Train at least one teacher per school to manage diabetic emergencies and support students with chronic illnesses.

ii. Data Collection and Policy Development

- Mandatory Reporting:
 - o Implement mandatory NCD reporting in the public sector to enable accurate local data collection.
- Establishment of National Registries:
 - o Develop a comprehensive cancer registry and improve general health data infrastructure.
- Effectiveness of Awareness Campaigns:
 - o Conduct evaluations to assess the impact of existing public awareness campaigns and adjust messaging and outreach strategies accordingly.

iii. Communication and Collaboration

- Improved Coordination with the Ministry of Health:
 - Strengthen communication between the Ministry of Health and NGOs to facilitate more effective planning and implementation of campaigns.
 - Ensure timely and inclusive stakeholder consultations with groups such as the NCD Alliance and the Healthy Caribbean Coalition.
- Multi-sectoral Collaboration:

o Foster ongoing partnerships across ministries (e.g., Health and Education) and with private sector stakeholders to create sustainable, multi-pronged interventions.

iv. Funding and Resource Allocation

- Increased Subventions for NGOs:
 - Reassess and increase government subsidies for NGOs such as the Trinidad and Tobago Cancer Society and the Diabetes Association.
- Private Sector Partnerships:
 - o Encourage partnerships with private sponsors and assess opportunities to bridge funding gaps.
- Review of Budgetary Support Mechanisms:
 - o Integrate NGOs into health budget planning to ensure adequate support for community health initiatives.

v. Legislation and Regulatory Reform

- Tobacco Control Act Enforcement:
 - Enforce the Tobacco Control Act more effectively, including stricter measures against suitcase trading of cigarettes.
 - o **Include Vaping in Legislation:** Amend the Act to explicitly include and regulate vaping and electronic nicotine delivery systems.
- Regulation of Unlicensed Practitioners:
 - o Investigate and take action against individuals offering unproven cures without medical qualifications.

vi. Access to Screening, Diagnostics, and Treatment

- Equipment and Service Reliability:
 - o Address persistent equipment failure in public health facilities (mammograms, colonoscopies) to ensure timely and accessible screenings.
- Shortages of Cancer Treatment Drugs:
 - Investigate and resolve ongoing drug shortages by improving funding allocations and considering private sector donations or partnerships to address these issues.
- Streamlining Public Health Referrals:
 - o Expedite testing and treatment timelines for cardiovascular and cancer patients through public-private collaboration.

vii. Nutrition and Marketing Regulations

- Front-of-Package Labelling:
 - o Introduce clear, standardised front-of-package labels to alert consumers about high levels of sugar, salt, and fats in processed foods.
- Marketing Restrictions:

o Limit marketing of unhealthy food and beverages, particularly those targeting children in schools and sporting events.

This public hearing can be viewed on demand via our YouTube Channel.

21st Meeting - JSC Social Services & Public Administration - Mar 20, 2024 NCDs- YouTube

Contact the Committee's Secretariat

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Committees Unit

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