The Experiences of People Living With NCDs in the Caribbean During the Coronavirus (COVID-19) Pandemic

HCC
Healthy Caribbean Coalition

The Experiences of People Living With NCDs in the Caribbean During the Coronavirus (COVID-19) Pandemic

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CONTENTS

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EXECUTIVE SUMMARY

Background

The new coronavirus (COVID-19) pandemic has caused illness, loss of income, and loss of life in countries around the world. It has resulted in disruptions in many aspects of life at national, regional, and global levels, and national health systems have not been spared. Studies have shown that people living with noncommunicable diseases (NCDs) are at higher risk of serious illness, complications, and death due to COVID-19.

NCDs, such as cardiovascular disease (including heart disease, high blood pressure, and stroke), cancer, diabetes, and chronic respiratory disease (including asthma and chronic obstructive lung disease), are the major causes of death in the Caribbean. An estimated 29% of the population in the Caribbean is living with a noncommunicable disease, requiring continuous care to manage their conditions, as well as being at higher risk of severe COVID-19 and premature death. In order to fight the spread of COVID-19, most Caribbean countries halted movement across their borders, instituted national curfews to restrict movement, and closed or placed restrictions on a wide variety of businesses and services, including several related to health and education. These measures, and fear of contracting COVID-19, affected many people, including people living with NCDs, in various ways.

The Healthy Caribbean Coalition (HCC) implemented this survey, with people living with NCDs in May 2021 over one year into the COVID-19 pandemic, to learn about the experiences of people living with NCDs during the COVID-19 pandemic. The survey focused on changes in health-related behaviours (such as diet, physical activity, alcohol use and tobacco consumption); access to continuous care, essential medicines, and life-saving treatments; changes in mental health; and attitudes to vaccination. Perspectives on sources of information, education and communication, and on what is needed from governments and civil society in the future were also examined.

Methods

This survey was launched by HCC via an online data collection tool and sent to the HCC membership inviting responses. In The Bahamas, participants were recruited by Short Message Service (SMS). In other countries, the survey was distributed amongst the HCC's partners by email. Data were collected between May and September of 2021.

The target population was residents of one of the five selected CARICOM countries (Antigua and Barbuda, The Bahamas, Barbados, Jamaica and Trinidad and Tobago), aged 18 years or over, and who have, or care for someone who has, a NCD.

To account for different response rates by country, a weighting scheme was applied.

Study participants

The sample comprised 415 people from five countries: Antigua & Barbuda, The Bahamas, Barbados, Jamaica, and Trinidad & Tobago. Forty-six percent had two or more NCDs, with the most common being hypertension (62%), overweight / obesity (33%), and diabetes (31%). Females were over-represented in the sample (84%), and ages ranged from 18 to 93, with the average being 52. A substantial proportion (27%) of respondents were between 18 and 39 years old; they had a similar range of NCDs to the wider sample. The sample size did not allow for stratification by age or sex.

Five percent had been previously diagnosed with COVID-19.

Executive Summary

Main findings

- COVID-19 has caused widespread disruption to livelihoods, with almost two-thirds of households (62%) reporting a drop in income. Almost one in five households (19%) faced a severe reduction in income of 50% or more. Yet only 4% received government support, and of those only 22% (less than 1% of all respondents) said the support was adequate.
- More than half of all respondents (55%) reported being concerned about their mental health since the start of the pandemic, with 10% reported requiring prescription medication to help with their mental state. The results highlight an unmet need for mental health services during the pandemic, with 14% needing but not receiving counselling or therapy. When summing up their experiences of the pandemic at the end of the survey, the most common spontaneous answers referred to mental health.
- Continuity of care is an area of concern, with 37% of those surveyed reporting that their routine medical care was interrupted. Those who experienced interruptions reported worse NCD control: 38% reported that their NCD was poorly controlled since the start of the pandemic, compared with 1% of those who said their care was uninterrupted.
- Telemedicine appears to be an acceptable alternative to face-to-face visits among those who used it: only 4% of respondents were either unable or unwilling to receive this kind of consultation. 84% of respondents had had a phone or video call consultation, and the majority (92%) considered this mode of delivery acceptable.
- As a result of the pandemic, half of respondents missed at least one routine screening test. These disruptions affected a wide variety of services, from pap tests (18%) and mammograms (17%) to cholesterol screenings (17%) and eye exams (17%). Almost 1 in 5 missed essential treatments (17%), including 4% who missed either urgent medical treatments or urgent surgeries.
- One in five respondents ran out of medication during the pandemic. This commonly occurred for treatment of the following conditions: hypertension (67%), lung disease, including asthma (34%), and diabetes (21%). The most frequently reported reasons included: not realising they were running out until it was too late (45%); medicine was unavailable (39%); could not access pharmacy or healthcare centre (38%). This included sixteen percent of those who ran out of medication cited COVID-19 mobility restrictions as the cause. Most respondents (96%) were able to pay for their medication during the pandemic.
- The pandemic shifted food consumption patterns towards healthier food sources and types: people ate takeaway and restaurant food less often, and homecooked and food from the garden more often. Consumption of fresh meat and fish and fresh fruit and vegetables increased, whereas consumption of their canned or processed equivalents decreased. Consumption of sugary drinks and sweets and desserts decreased.
- Respondents wanted governments to work to provide local healthy food options at affordable prices, and to educate the public on the benefits of healthy eating and instruct them in the preparation of healthy food.
- Despite the reported improvements in diet, 35% of respondents said they had gained weight, compared to only 21% losing weight.
- The pandemic has adversely impacted physical activity levels: 56% report a decrease in physical activity, compared to 18% reporting an increase.
- Overall, self-reported alcohol consumption appears to be reasonably stable amongst those surveyed: only 23% reported a change since the start of the pandemic, with the same proportion reporting an increase as a decrease (11%). The remaining 1% reported that they stopped drinking
- Approximately one in eight of those surveyed are members of a Civil SocietyOrganisation (CSO), with the majority of those (59%) having received support during the pandemic. Of those who received support, much of this support (53%) has been online psychosocial support, indicating the important role these organisations can provide to their members during times of crisis.
- Respondents would like to see CSOs engaging in community outreach, and expanding existing online support mechanisms.
- Vaccine hesitancy was low in this sample (11%). Just over half of those surveyed were already vaccinated (52%), while a further 36% were willing to be vaccinated. The main reasons for hesitancy cited were concern about potential side effects and safety.

It should be noted that, while the survey contributes to a better overview of the impacts of the pandemic, the data are limited by the low response rate and therefore cannot be considered to be representative of the Caribbean region. Furthermore, the use of a web-based questionnaire limits inputs from those without connectivity.

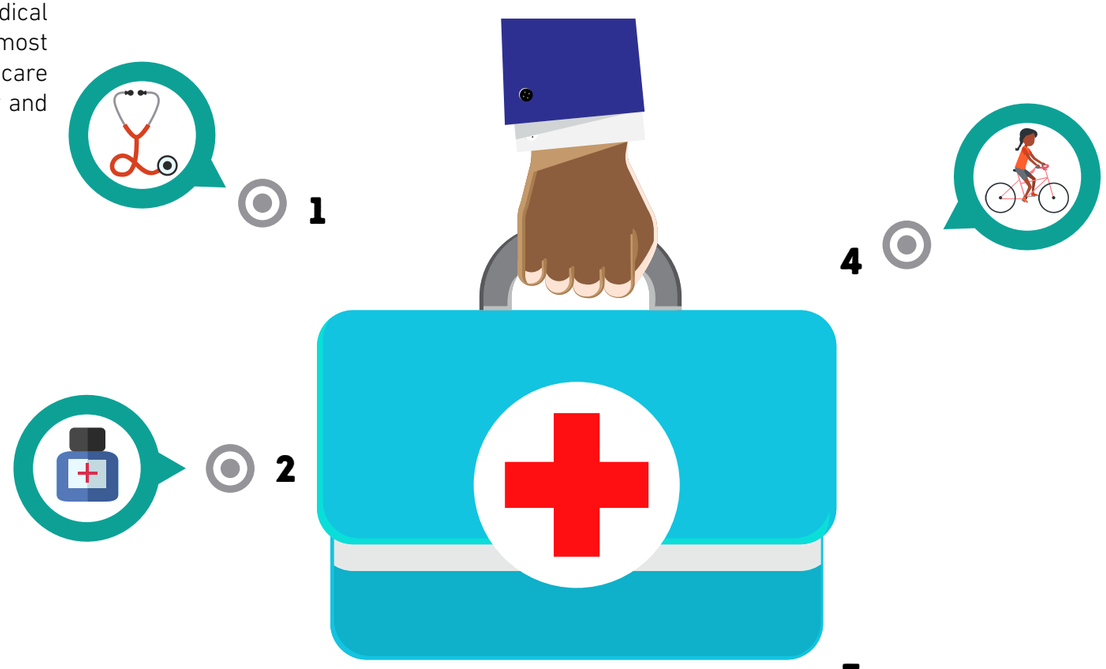
Executive Summary

Priorities for public health action

Ensure continuity of care. There is a need to better adapt to the pandemic and minimize interruptions to routine medical care. Telemedicine was considered acceptable to most respondents and may be a feasible option, although care must be taken to ensure those with poor digital literacy and complex medical problems are not left behind.

Address medication non-adherence. Prior to the pandemic, medication non-adherence was recognised as a major obstacle to effective NCD management. The pandemic has further exacerbated issues around medication supply and access. As well as addressing the root causes of non-adherance, additional research is required to develop strategies to ensure continuous supplies of medicines, research which could benefit various other emergency scenarios such as hurricanes. those with poor digital literacy and complex medical problems are not left behind.

Address unmet need for mental health care. Most respondents have been concerned for their mental health during the pandemic, with some seeking support and not obtaining it. Respondents reported that the overriding impact of the pandemic had been on their mental health, and felt that CSOs and governments need to work together to support those suffering from mental health issues, as well as to educate on, and to destigmatise these conditions.



Educate patients about the importance of being physically active. The COVID-19 pandemic has created an environment that discourages habitual physical activity due to self-isolation and quarantine requirements, reduced opportunities to remain physically active, and fear of being infected. Clinicians and other health-care practitioners should take a proactive stance in improving education and prescribing physical activities to their patients: this should be considered a standard component of NCD management. Respondents expressed a desire for safe outdoor spaces for recreation; governments should invest in these spaces, and opportunities for partnering with stakeholders responsible for urban planning and land use policy should be enacted to ensure equitable access to sport and recreation facilities and amenities.

Improve access to healthy foods. Crises often cause widespread disruptions to food supply chains. This indicates the need for more resilient food distribution systems. Where possible, the focus should be on improving access to locally-produced healthy foods; however, improving access to healthy imported foods to supplement local supplies may also be necessary. Providing outlets for foods directly from local communities, whether via traditional farmers' markets or digital marketplaces, builds greater resilience into the food systems by shortening supply chains. Healthy eating habits should also be encouraged via public education campaigns.

BACKGROUND

The overarching aim of this study was to examine the situation of PLWNCDs in the Caribbean region during the COVID-19 pandemic, including: changes in health-related behaviours (such as diet, physical activity, alcohol use and tobacco consumption); access to continuous care, essential medicines, and life-saving treatments; changes in mental health; and attitudes to vaccination. Perspectives on sources of information, education and communication, and on what is needed from governments and civil society in the future will also be described.

In March 2020, the World Health Organization (WHO) declared the COVID-19 outbreak a global pandemic. Since then, its impact has been unprecedented: at the beginning of October 2021, deaths surpassed 4.8 million, with over 237 million cases reported globally (1). The Caribbean region has not been spared, and at the time of writing (8th October 2021), is experiencing a surge in cases and deaths: 8% of all cases and 10% of all deaths have been reported in the previous two weeks (2).

Prior to the approval of vaccines, global public health efforts to mitigate the spread of SARS-CoV-2 focused on minimising contact between people through measures such as lockdowns, social distancing, and travel restrictions, and these have caused tremendous disruption to people's lives, to economies, and to health systems. The Caribbean, despite the availability of COVID-19 vaccines, continues to rely on non-pharmaceutical interventions, as vaccination rates amongst CARICOM member states remain below 50% (3).

People living with noncommunicable diseases (PLWNCDs) are particularly vulnerable to risks brought about by the disruption and stress associated with emergency and disaster situations. A substantial proportion of mortality in post-disaster phases has been attributed to the failure of health care services to account for the needs of PLWNCDs (4). This vulnerability has been further intensified in the COVID-19 pandemic, as the presence of noncommunicable diseases (NCDs) is associated with worse COVID-19 disease outcomes (5–7). Results from a recent meta-analysis confirm that a previous diagnosis of diabetes, chronic obstructive pulmonary disease, hypertension, and dementia were all associated with increased odds of death from SARS-CoV-2 infection (8).

Strengthening NCD management and care during the pandemic is crucial to reducing the morbidity and mortality caused by COVID-19. However, NCD care in healthcare systems, already limited in capacity, has been under further stress, as resources and personnel have been diverted toward control and management of COVID-19. In a survey of Ministries of Health in 163 member states, including 14 Caribbean territories, the WHO found that the COVID-19 pandemic had severely interrupted prevention and treatment services for NCDs: 122 countries reported service disruptions due to the pandemic (9). More than half (53%) of the countries surveyed reported having partly or completely disrupted services for hypertension treatment, 49% for diabetes and diabetes-related complications, and 31% for cardiovascular emergencies. In 94% of countries, the Ministry of Health staff working in NCDs were partly or fully reassigned to support the COVID-19 response. Population health screening programs have also been interrupted (10).

The WHO has emphasized the need for PLWNCDs to maintain healthy behaviours (e.g. regular exercise, nutritious diet, etc.) (11). At the same time, social distancing and isolation have made it more challenging to maintaining an active lifestyle, and a multitude of factors, including economic factors such as reduced income and job loss, has changed eating behaviour and nutrition (12).

METHODS

The questionnaire was developed using standardised tools where possible, as shown in **Table 1**. A copy of the questionnaire has been included in the appendices.

Table 1: Composition of the survey tool

SECTION NAME	NUMBER OF QUESTIONS	SOURCE
Non-communicable disease status	3	Created for this survey
Demographic information	8	WHO STEPS questionnaire
COVID-19 vaccine acceptance	3	Standard tool used in several surveys
Accessing and consuming healthy and nutritious food	5	Created for this survey
Smoking	8	Standard questions provided by PAHO
Physical activity	1	Created for this survey
Alcohol consumption	4	Standard questions provided by PAHO
Continuity of care and access to essential medicines and life-saving treatment	20	WHO Household survey to measure access to and use of medicines
Mental health and coping	5	CDC Household Pulse Survey
Perspectives on what is needed from governments and civil society moving forward	6	Created for this survey

The questionnaire was converted to an online data collection tool, and distributed amongst the HCC's partners by email. It was planned to further distribute the survey by SMS, but except for the Bahamas, this effort was unsuccessful within the study timeframe. In the Bahamas, a local telecommunications provider sent a link to the survey by SMS to all customers.

Our original target population included all 20 of the CARICOM member states. Due to a poor response to email recruitment, it was decided to focus our efforts in 5 countries, which were selected informally to reflect the variation in population size across the region. The selected countries were Antigua and Barbuda, The Bahamas, Barbados, Jamaica, and Trinidad and Tobago. Respondents were resident in one of these countries, were 18 years or older, and either had an NCD or cared for someone who did.

Participants were asked to give their consent before taking part, and no identifiable information was collected. The survey was approved by the University of the West Indies, Cave Hill/Barbados, Ministry of Health Research Ethics Committee/Institutional Review Board and by the PAHO Ethics Review Committee.

Data collection occurred between May and September of 2021.

Statistical methods

A range of sample size calculations were performed, the details of which may be found in the appendices. This type of wide-ranging survey does not have a primary outcome measure, but rather has several outcomes of interest. The most stringent calculation assumed a 50% prevalence of the outcome of interest (the "worst case scenario" for sample size calculations), a margin of error of +/- 5%, and an uncertainty level of 95%. Using these parameters, the sample size was estimated to be 385 in each sub-group of interest. For example, to stratify by gender, a minimum of 385 men and 385 women would be required. However, due to poor recruitment, the required sample size for subgroup analyses was not achieved. Pooled results for the five countries are presented, and with the sample size of 415, the minimum precision would be expected to be +/- 4.5% (assuming a prevalence of 50%; for all other prevalences, the precision would be increased).

Ideally, response rates would be similar between countries and the total number of participants from each country would be proportional to the population size of that country. To account for differing response rates, a weighting scheme was applied that forced the distribution of the country of residence in the sample to match the distribution of population sizes of the countries. Data from open-ended questions were exported from the survey software, and a code frame of patterns and themes in the responses was devised. Where applicable, responses were allocated to one of these codes, and these codes were added to the original data file

LIMITATIONS OF THE SURVEY

Despite its limitations, the findings of the survey remain valuable. This is the first survey of its kind in the Caribbean and it provides important insights into the plight of people living with NCDs during the COVID-19 pandemic. The findings highlight priorities for public health action, and point out potential avenues for future research that would benefit this vulnerable population.

It is important that the results of this survey are interpreted within the context of its limitations. These include:

- Difficulties with the proposed use of SMS recruitment impacted the final sample size, which meant that potentially useful subgroup analyses were not possible. For example, it would have been useful to stratify results by age group and gender; however, this would have led to inadequate precision.
- Many participants were recruited through the mailing lists of CSOs of which they were members. Members of such organisations are likely to be more engaged with management of their NCD than the general population of NCD sufferers. Further selection bias will have been introduced through the use of an online reporting tool, which will limit responses from those without connectivity, or without the ability to use the technology. Women (84%) and the highly educated (50% had a graduate university degree) were overrepresented in the sample. A common way of correcting imperfections in the sampling is the use of survey weights. Survey weights to account for the differences in numbers of respondents from each country; the small sample size did not support the addition of weights to account for other characteristics.
- All data were self-reported, and, as such, are subject to a number of errors. Respondents might be inclined to under-report weight gain or alcohol consumption, and feedback on NCD control is purely subjective. Furthermore, this type of data is prone to inconsistencies, and without an interviewer to probe and verify answers, some discrepancies between data points are inevitable.
- Fieldwork was conducted over a period of over 4 months and participants were asked to report their experiences over "the pandemic", a period of around 18 months (March 2020 to September 2021). This long recall period limits accurate reporting, particularly as public health restrictions will have changed several times.
- At approximately 30-40 minutes, the completion time of the study instrument was longer than ideal for obtaining high-quality data.
- The section of the questionnaire that addresses continuity of care and access to essential medicines and life-saving treatment was based on the WHO Household survey to measure access to and use of medicines. This questionnaire was not developed to assess the impact of COVID-19, but it was decided to leave the questions unchanged in order to compare the results of this survey to other settings where the WHO survey was implemented. In retrospect, this survey's aim would have been better achieved by adapting the questions to address the impact of the pandemic, rather than prioritising standardization.

RESULTS

Study population

The sample comprised 415 people from five countries: Antigua & Barbuda, The Bahamas, Barbados, Jamaica, and Trinidad & Tobago. The weighted distribution of country of residence is shown in **Table 2.**

The majority of respondents had 1 NCD **(Figure 1)**, with the most common being Hypertension (62%), Overweight / Obesity (33%), and Diabetes (31%) **(Figure 2)**.

Eighty-four percent of the sample was female **(Figure 3)**, and ages ranged from 18 to 93 years, with the average being 52 years **(Figure 4)**. Twenty-seven percent of respondents were in the youngest group (18 to 39 years); they had a similar NCD profile to the wider sample.

Educational attainment and employment status prior to the pandemic are shown in **Tables 2 and 3**.

Five percent had a previous diagnosis of COVID-19.

Table 2: Country of Residence of Respondents

Country	Number	Weighted Percentage
Antigua and Barbuda	29	2
The Bahamas	216	8
Barbados	73	6
Jamaica	42	58
Trinidad and Tobago	55	27
Total	**415**	**100**

Figure 1: Number of NCDs

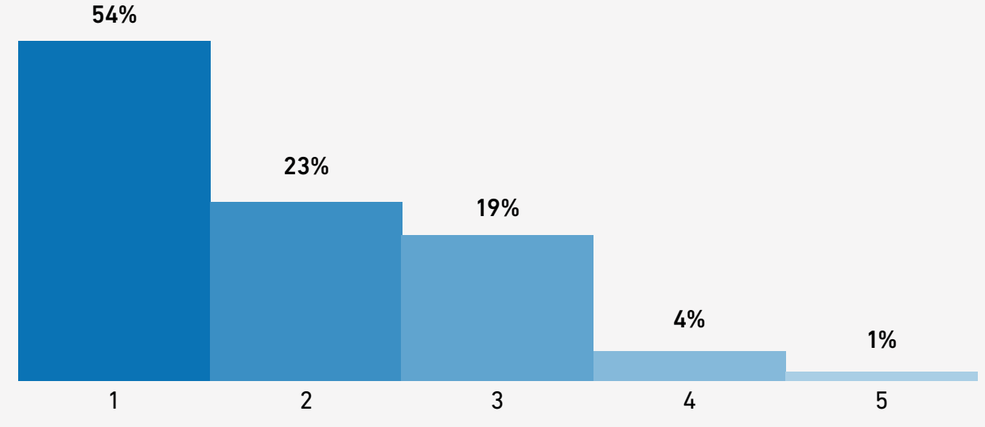


Figure 2: Type of NCD and Overweight/Obesity

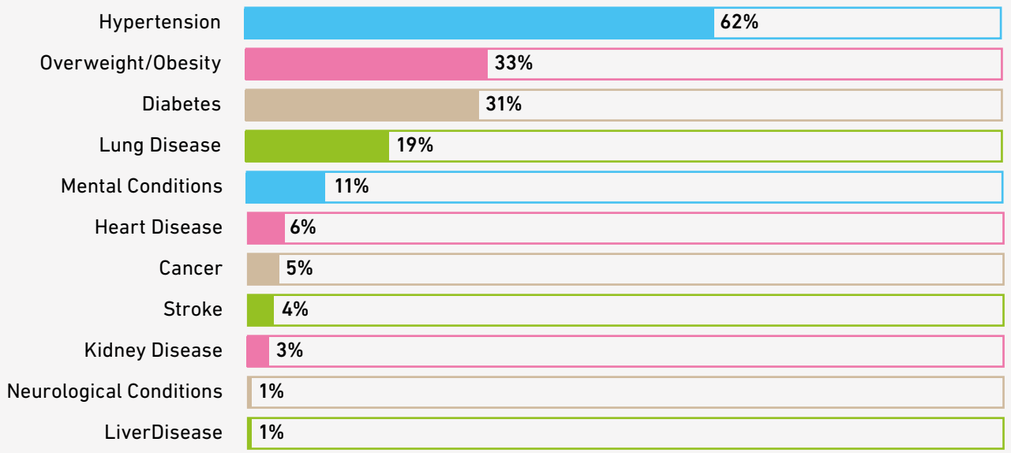


Figure 3: Sex

Figure 4: Age distribution

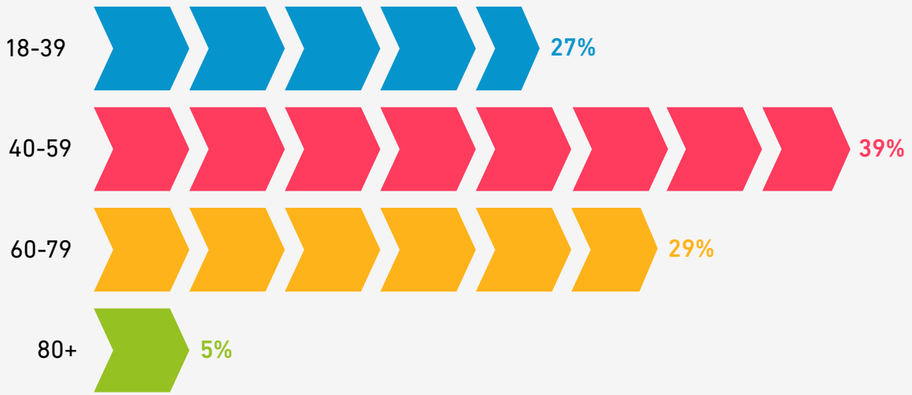


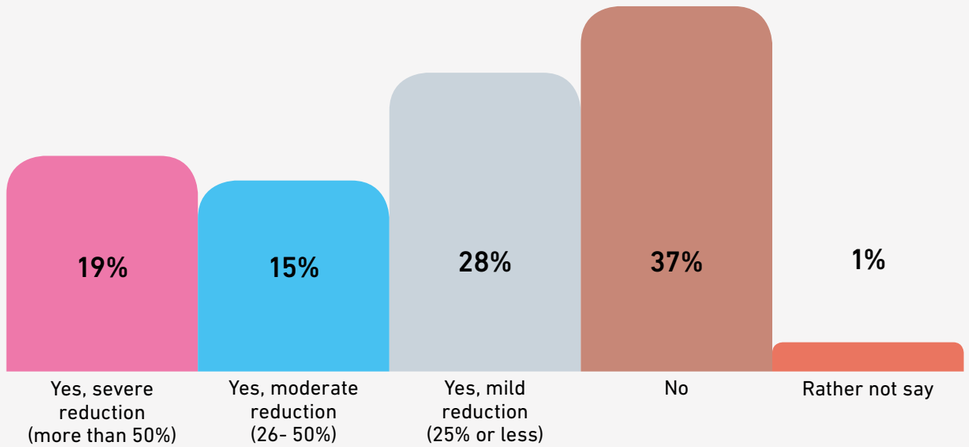
Table 3: Education level and Employment Status

		Number	Weighted Percentage
Education Level	Primary school	5	2
	Secondary school	97	17
	Vocational or community college	90	13
	Undergraduate university degree	92	20
	Graduate university degree	129	50
	No formal schooling	2	0
Employment Status	Government employee	89	19
	Non-Government employee	143	39
	Self-employed	50	14
	Unpaid / Volunteer work	3	0
	Student	5	1
	Homemaker	6	1
	Retired	60	14
	Unemployed (able to work)	33	6
	Unemployed (unable to work)	17	2
	Rather not say	9	4

Financial Toll of the Pandemic

Almost two-thirds of respondents (62%) had experienced a drop in household income, with 19% experiencing a drop of 50% or more. Yet only 4% had received government support, and of those only 22% (less than 1% of all respondents) reported that the support was adequate. Those reporting a severe drop in income were similar in terms of age and NCD profile to the wider sample.

Figure 5: Change in Income since Start of Pandemic



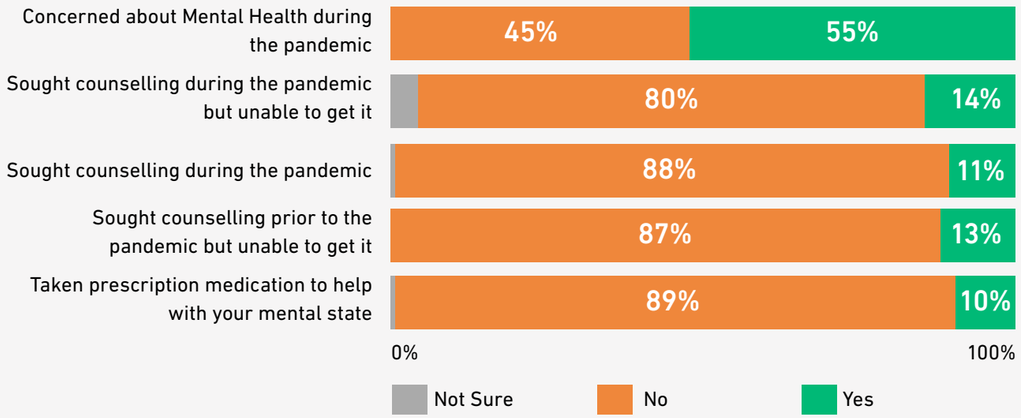
Mental Health Care

Over half of all respondents (55%) were concerned about their mental health since the start of the pandemic, with one in ten having taken a prescription medication **(Figure 6)**. There was a small decrease in the proportion who accessed mental health services during the pandemic (13% to 11 %), and 14% reported that that they needed counselling or therapy but did not get it. These results suggest that there is an unmet need for mental health care.

Indeed, when asked if there was anything else they wished to add at the end of the survey, the majority of those who answered spontaneously mentioned that their overriding concern was for the impact the pandemic had had on their mental health:

> ***Everything has changed and [been] made more challenging because of COVID-19. I often felt as if I was drowning emotionally and stuck.***

Figure 6: Mental Health Care



Pre-COVID Management of NCDs

Over one quarter (27%) were not receiving care for their NCD prior to the pandemic. Of the 73% who were receiving care, nearly all of these (69%) were taking medication.

The mix of healthcare providers is varied (**Figures 7 and 8**). Whilst 68% visit private healthcare providers, private insurance covers the full cost of medication for only 1%. At the other end of the scale, 11% rely solely on public healthcare providers, and have all their medications paid for out of public funds. The majority pay for their medications through some combination of public and private insurance, and their own contributions, though almost a quarter have no insurance of any kind. Most of this group (20%) can usually afford their medications, but 3% struggle to pay for their NCD medications, and sometimes have to borrow money or sell things to pay for it.

Figure 7: Type of Healthcare Provider

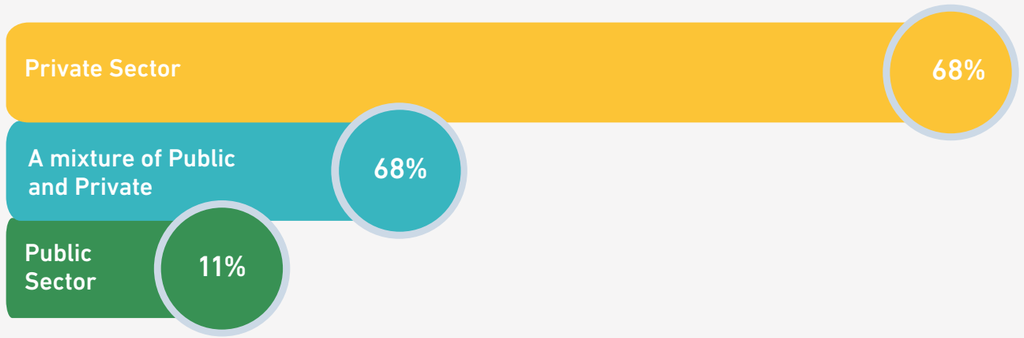
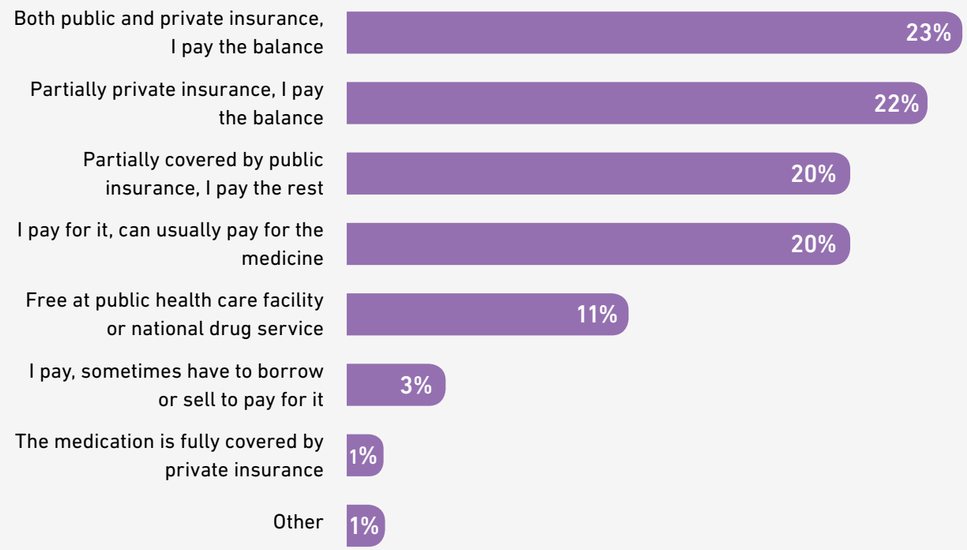


Figure 8: Paying for NCD Medication



Impact of COVID-19 pandemic on NCD Management

Almost two-thirds of respondents (63%) who were seeking care for their NCD said their routine care remained unchanged during the pandemic. This was mostly because they had been able to see their physician as usual, though 12% said it was due to them having remote consultations, either by phone or using telemedicine **(Figure 9).** These remote consultations were well-received, with only 8% being unhappy or very unhappy with their use (though an additional 4% were either unable or unwilling to receive this kind of consultation) **(Figure 10)**. Of the reasons given for the disruption of care, most centred around availability of consultations (offices closed, appointments cancelled, rescheduled, or unavailable), though the single most-commonly cited reason was that patients were unwilling to attend through fear they might contract COVID-19 **(Figure 11)**.

For the 37% of respondents whose care was disrupted, the effects on control of their NCD were pronounced: 38% said their NCD was less well-controlled, compared to only 1% of those whose care was uninterrupted; indeed, 18% of those who said their care was unaffected also said their NCD was better controlled now than it was at the start of the pandemic **(Figure 12)**.

Of those who had been advised to take medication for their NCD, the vast majority (85%) reported that they had continued to do so throughout the pandemic. Among those who hadn't, lack of affordability was given as a reason by 14%, lack of availability was mentioned by 8%, and lack of access was mentioned by 24%, but many also did so by choice: 28% decided to take something else, and 22% claimed their symptoms had got better **(Figure 13)**.

Although 85% claimed to have taken their medications as prescribed, 20% also admitted to having run out of medication during the pandemic. Hypertension (67%), lung disease, including asthma (34%), and diabetes (21%) were by far the most common conditions for which patients ran out of medication **(Figure 14)**. Of those who ran out of medication, 24% said their NCD was less well-controlled than it was before the start of the pandemic, compared to 12% of those who did not run out of medication **(Figure 15)**.

The reasons why people ran out of medication are summarised in Figure 16. While 45% of those who ran out of medication said it was simply because they didn't realise until it was too late to obtain more, 39% said it was because the medication was unavailable, either from private pharmacies or through the public healthcare system, and 38% said they could not get to, or did not have time to get to a pharmacy or healthcare centre.

The majority of respondents reported that they could afford to pay for their medication (96%). For most (54%), this resulted in them rationing what they had, though 28% said they tried alternative medicines.

To avoid them having to visit a pharmacy / healthcare centre, half (51%) of those on medication were given more than one month's supply: 41% received 2 months' supply, 49% got 3, and 10% were given more than 3 months' worth of medication.

As a result of the pandemic, half of respondents missed at least one routine screening test **(Figure 17)**. These disruptions affected a wide variety of services, from pap tests (18%) and mammograms (17%) to cholesterol screenings (17%) and eye exams (17%). Almost 1 in 5 missed essential treatments (17%), including 4% who missed either urgent medical treatments or urgent surgeries **(Figure 18)**.

Figure 9: Reasons for Continuity of Care:

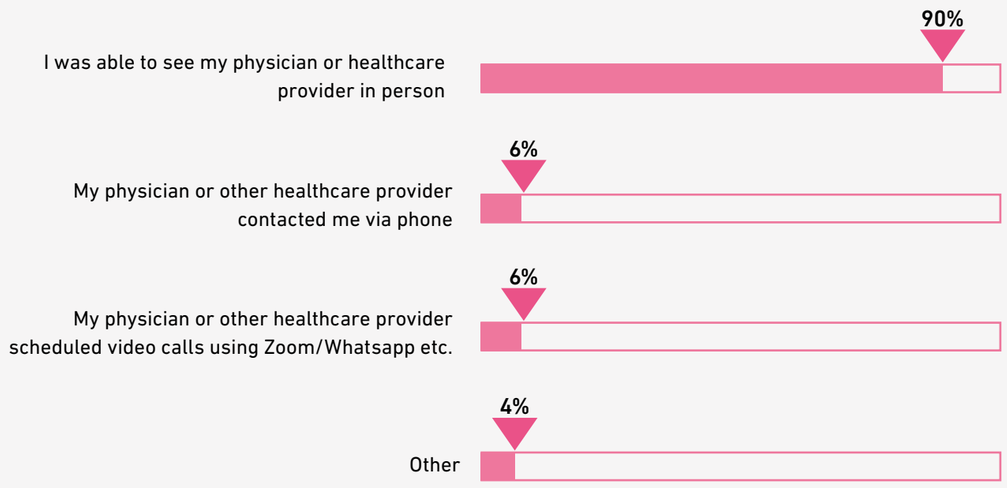


Figure 10: Satisfaction with Remote Consultations

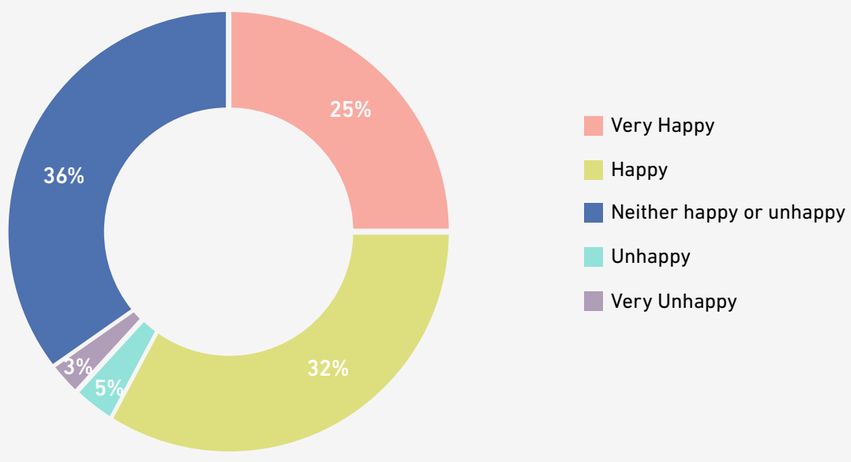


Figure 11: Reasons for Change in Care

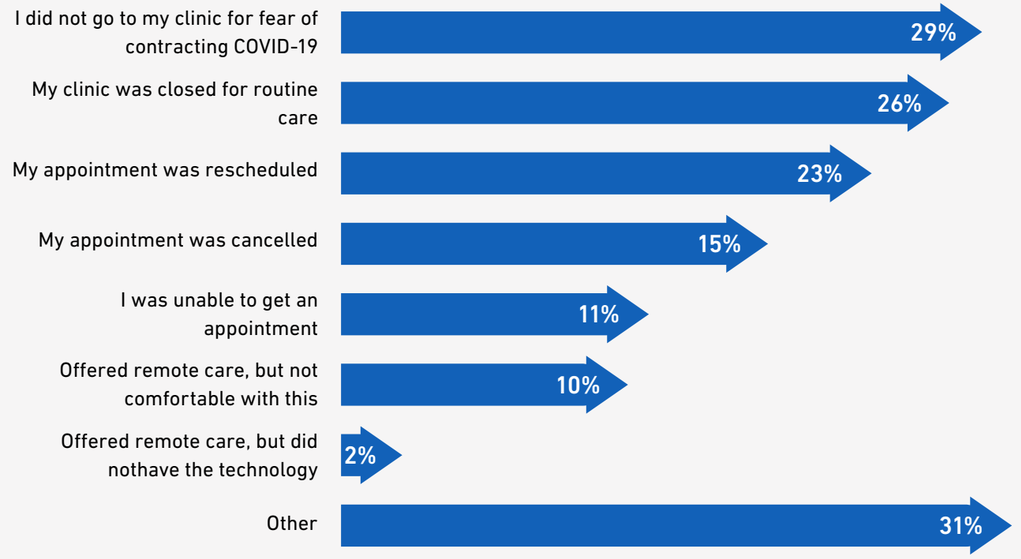


Figure 12: Change on control of NCD by Continuity of care

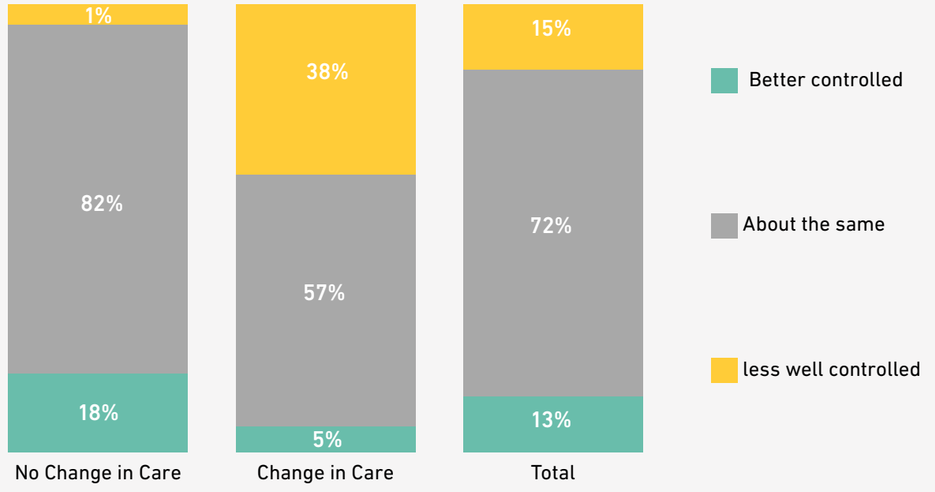


Figure 13: Reasons for not Taking Medications as Prescribed

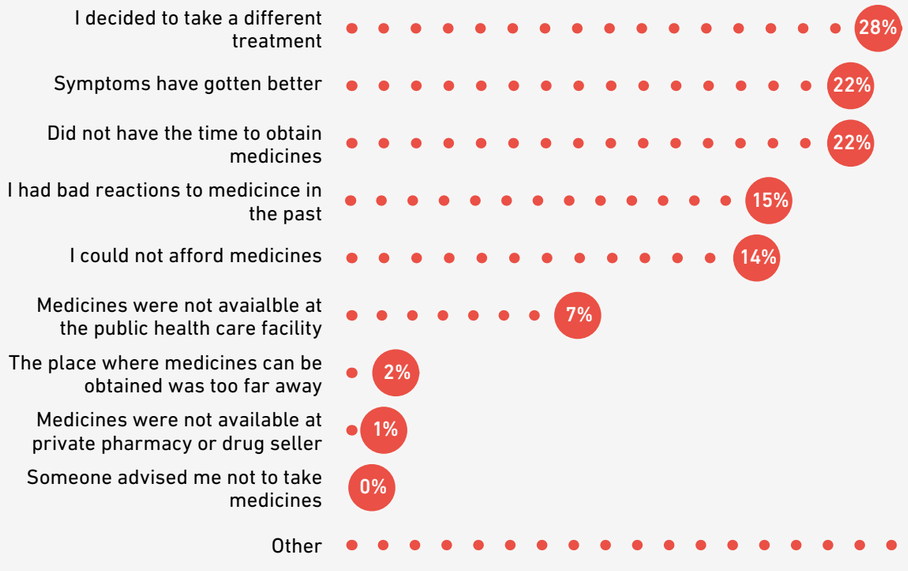


Figure 14: NCD for which Respondent Ran Out of Medication

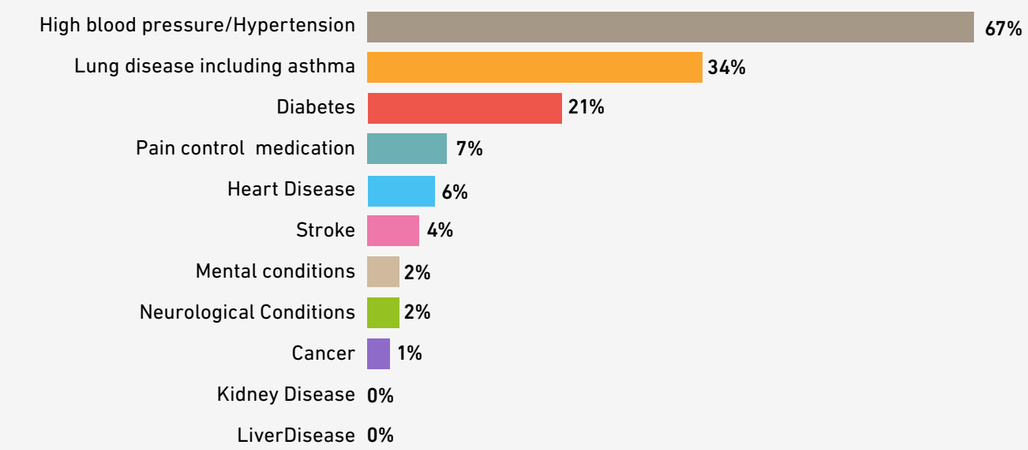


Figure 15: Change in control of NCD stratified by whether respondent ran out of Medication

Figure 16: Reasons for Running Out of Medication

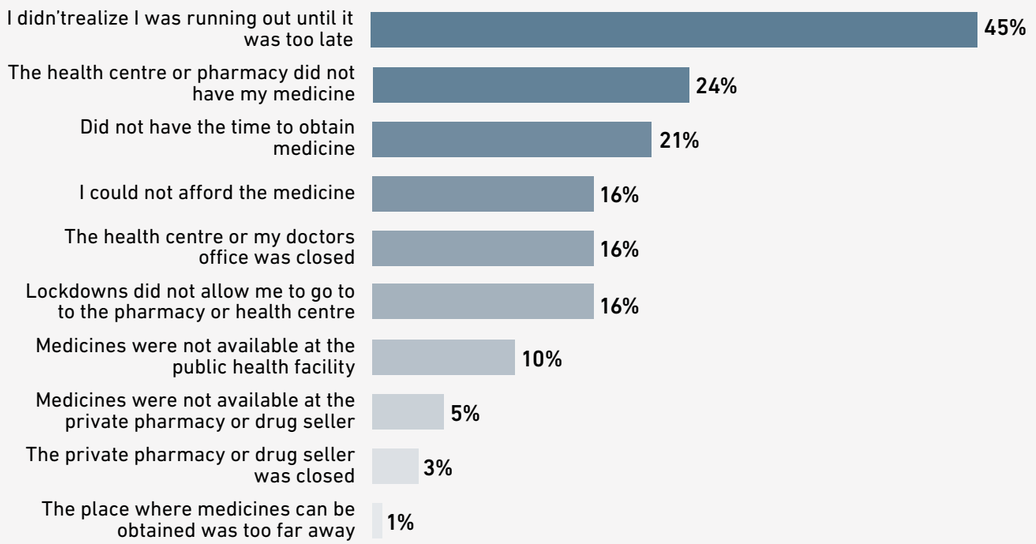


Figure 17: Routine Screening / Tests Missed since Start of Pandemic

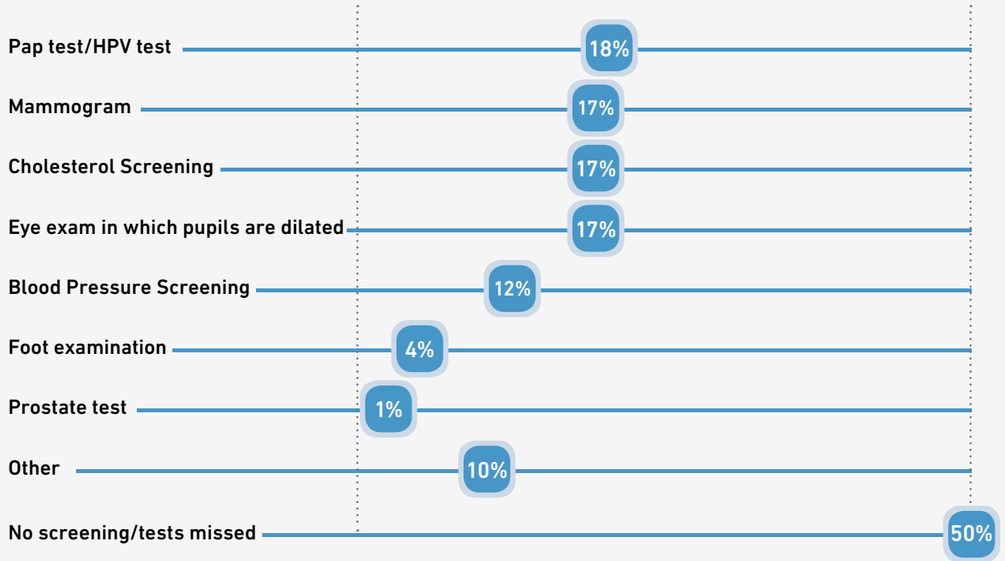
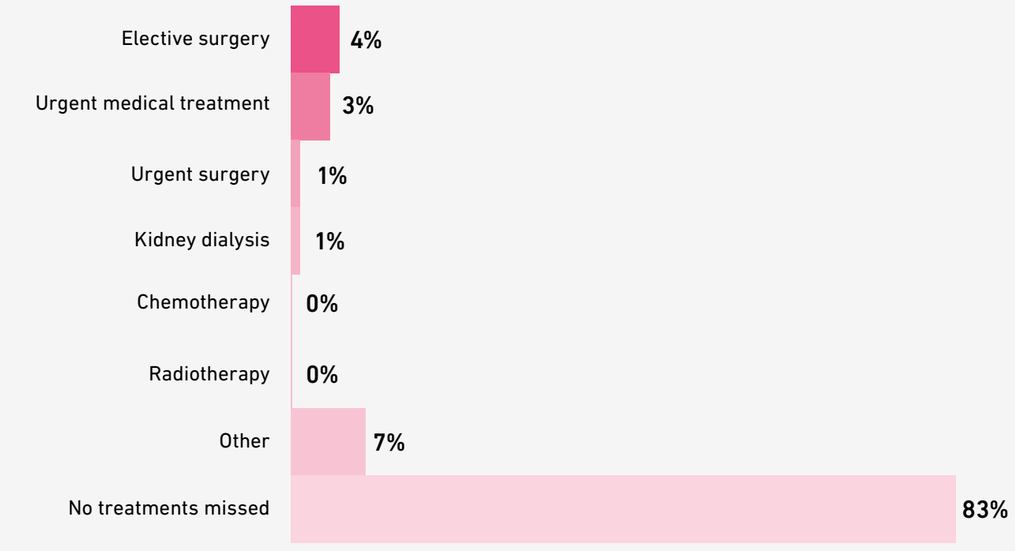


Figure 18: Essential Treatments Missed since Start of Pandemic



Health Behaviours

Respondents reported somewhat mixed effects of the pandemic on health-related behaviours: there was a shift towards healthier diets, whilst physical activity decreased and more people gained than lost weight.

- People reported eating takeaway and restaurant food less often (57% and 60% respectively). Correspondingly, 67% are eating more homecooked food, and 33% are eating more food from the garden **(Figure 19)**.
- The types of food people eat have also seen some improvements **(Figure 20)**. The net frequency of consumption (percent who say they eat more, minus the percent who say they eat less) of fresh meat and fish (+26%) has improved compared to their processed (-23%) and canned (-6%) equivalents. Similarly, there is a net increase in frequency of consumption of fresh fruit and veg of +35%, compared to frozen (-5%), and canned (-7%). These changes have been reported despite 10% of respondents saying they have struggled to get fresh produce during the pandemic.
- The pandemic has adversely impacted physical activity levels: 56% report a decrease in physical activity, compared to 18% reporting an increase **(Figure 23)**. This could have contributed to the reported weight gain.
- Despite the reported improvements in diet, 35% said they had gained weight, compared to only 21% losing weight **(Figure 21)**.
- The reported improvement in diet is unexpected, particularly in light of the reported weight gain and because other surveys in the region have documented a shift towards unhealthier foods and greater food insecurity (13,14). There are several potential explanations. First, our respondents are PLWNCDs, rather than the general population, and may adjust their health-related behaviours differently in a pandemic. Additionally, selection bias may play a role: recruitment occurred primarily through the mailing lists of CSOs. Members of CSOs are likely to be more invested in the management of their NCDs than the remainder of the population of PLWNCDs. The results may also be affected by social desirability bias, i.e. the tendency to underreport socially undesirable attitudes and behaviours and to over report more desirable attributes. Another explanation may be that people may have shifted their diet towards eating healthier food types, but may be consuming more calories overall. Whilst we assessed how often people ate different foods, we did not attempt to quantify the amounts they ate. Quantifying food intake is notoriously difficult and is beyond the scope of this survey. We did, however, assess reasons for dietary changes, and found that 60% said their diet has changed due to stress or anxiety **(Figure 22)**. Further research is required to better understand the impact of the pandemic on diet, physical activity and weight gain in PLWNCDs.
- Self-reported alcohol consumption appears to be reasonably stable **(Figures 24-27)**: 75% either never drank, or reported no change in consumption, and the same number (11%) said their consumption has decreased as said it has increased. Thirteen percent are drinking more than once a week, while 8% are considered as heavy episodic drinkers (i.e. report drinking 5 or more drinks in a session once a month or more).
- Smoking was rare amongst respondents, with 1% reporting daily tobacco consumption **(table 4)**.

Figure 19: Change in Source of Food

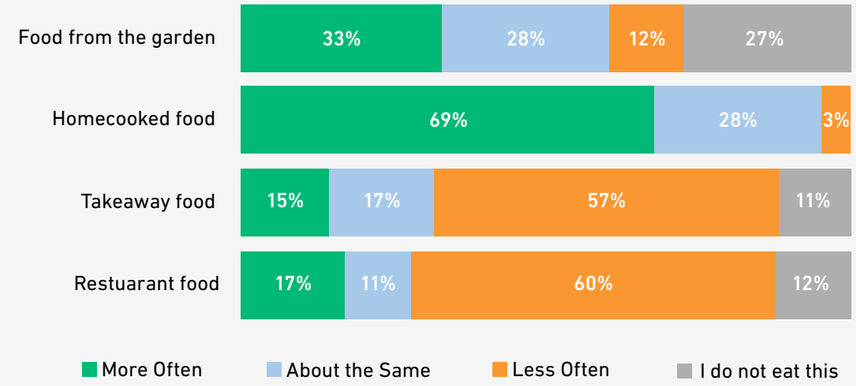


Figure 20: Change in Types of Food Eaten

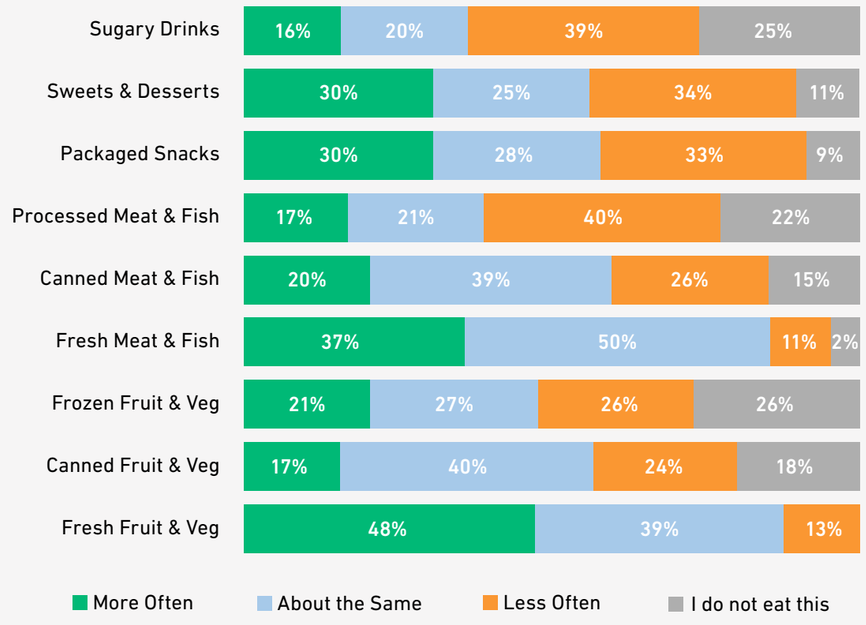


Figure 21: Change in Self-reported Weight

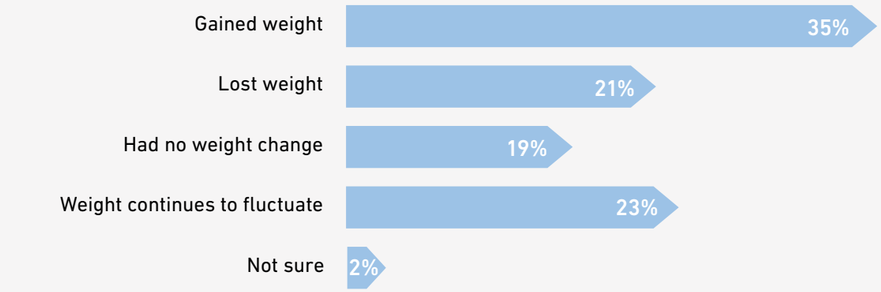


Figure 22: Reasons for Change in Diet

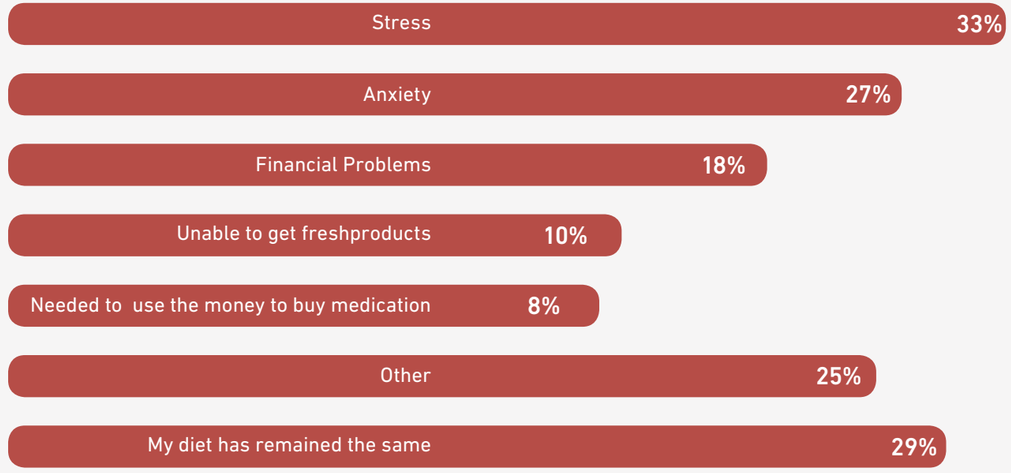


Figure 24: Frequency of Alcohol Consumption in Last 12 Months

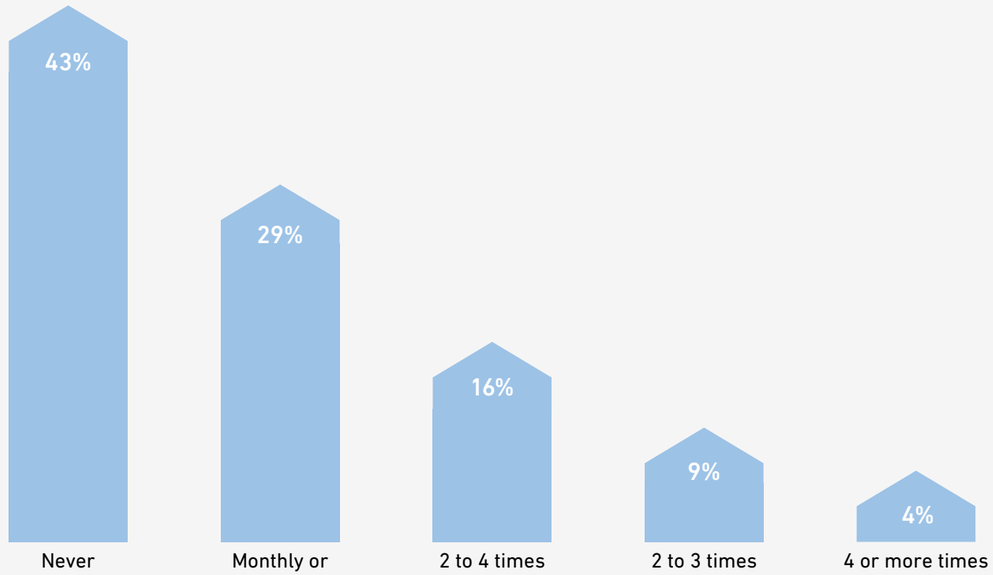


Figure 25: Change in Alcohol Consumption Since Start of Pandemic

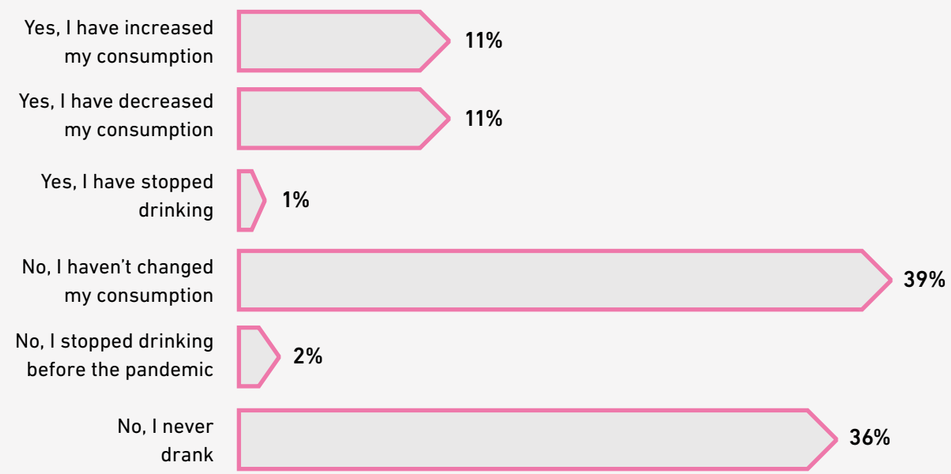


Figure 26: Number of Alcoholic Drinks per Session among those reporting alcohol consumption in the last 12 months

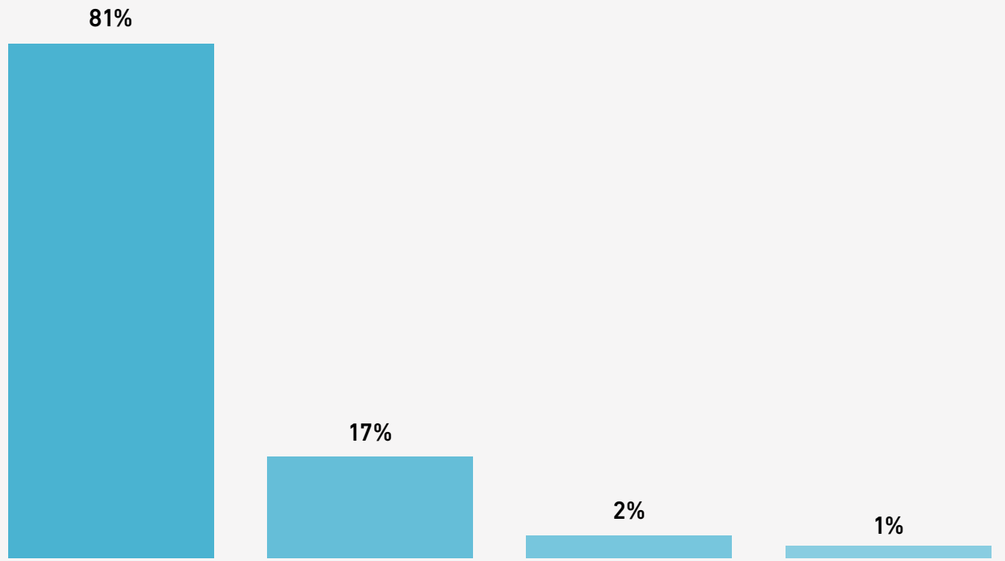


Figure 27: Frequency of having 5 or more Drinks

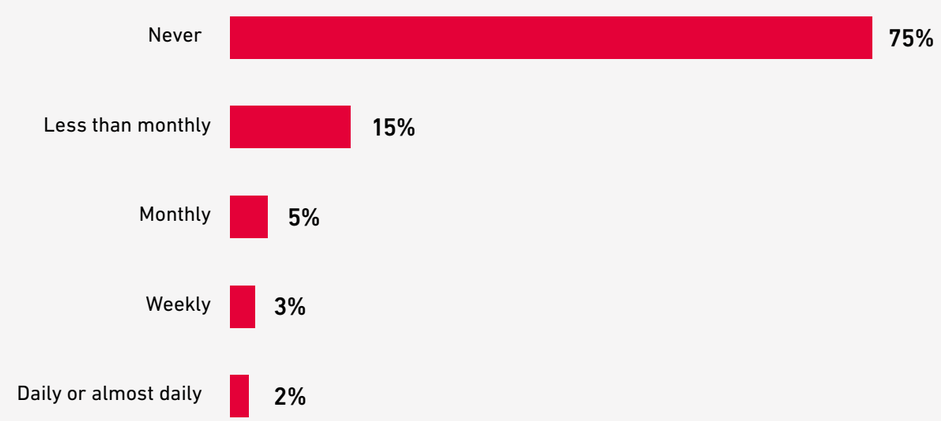


Table 4: Prevalence of Smoking

Do you currently smoke tobacco	
Daily	1%
Less than daily	2%
Not at all	97%
Do you currently use electronic cigarettes or any other vaping device on a daily basis, less than daily, or not at all?	
Daily	2%
Less than Daily	0%
Not at all	98%

Civil Society Organisations

Approximately 1 in 8 of those surveyed are members of a CSO, with the majority of those (59%) having received support from a CSO during the pandemic (Figure 28). Much of this (53%) has been online psychosocial support, indicating the important services these organisations can provide to their members during times of crisis. Other assistance was in the form of advocacy (45%), and other online services such as physical activity programmes (25%).

Respondents provided a number of recommendations for ways in which CSOs could further help those living with NCDs during the pandemic. The single most common recommendation was to engage in active community outreach programmes – reaching out to their most vulnerable members, and going out into communities to give dedicated support to those who otherwise might not be able to access it. In general, the support provided has been good, though a lot could be gained by continued promotion of the information and resources already available; there is a feeling that people are missing out through lack of awareness.

> ***More resources to assist with better outreach to persons infected and affected with NCDs.***
>
> ***Advocate for members needs and offer more support. These activities need to be made known to the persons who can benefit from these services. Often times service is available, but are not fully utilised, because only a few are aware of their existence.***

The online support provided, in particular, has been well- received, and there is a desire for more of this to be made available, whether it be through peer support groups, exercise tips, or mental health support. There is limited demand for more face-to-face support.

> ***Hold weekly or monthly group session with other persons experiencing the same challenges or issues would help persons cope.***

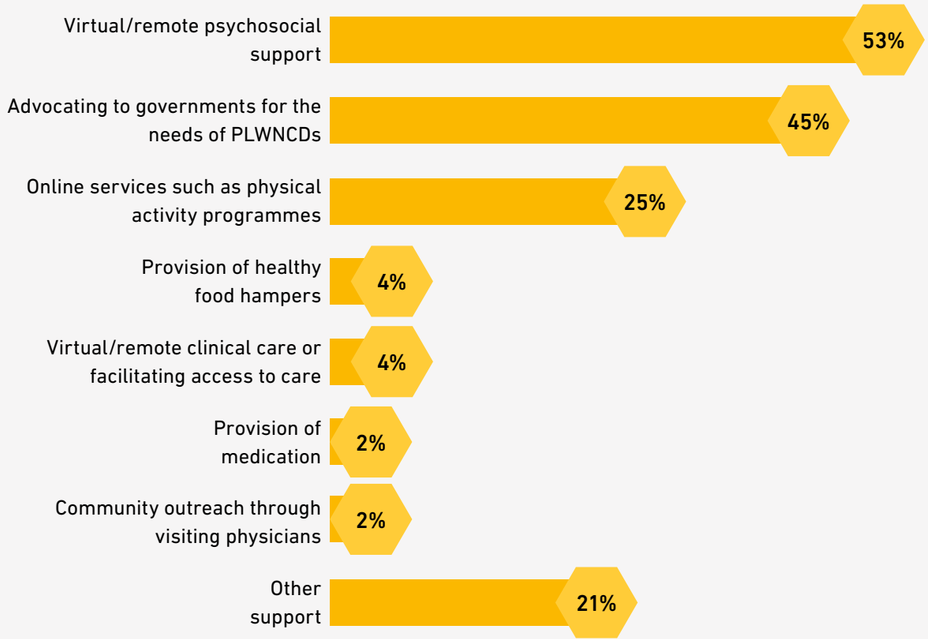
One topic that came up frequently was the desire for education targeting those without NCDs. This could take the form of support for carers or families of those already suffering, but it extended into wider concerns about informing the public on NCDs and mental health issues, with a particular focus on destigmatising these conditions.

> ***Destigmatize NCDs and mental illness through widespread education.***

Other requests were for education on healthy eating, homegrown food and exercise, as well as for advocacy, particularly for those with rarer NCDs, who feel they often get left out of the mainstream NCD discussions.

> ***Agitate to get all NCD on the national health insurance pharmacy plan***

Figure 28: Type of Support received from CSO



Vaccine Hesitancy

Vaccine hesitancy was low in this sample (11%) **(Figure 29)**. Just over half of those surveyed were already vaccinated (52%), while a further 36% were willing to receive the vaccination. The main reasons for hesitancy cited were concern about potential side effects and safety **(Figure 30)**.

Figure 29: Willingness to be Vaccinated

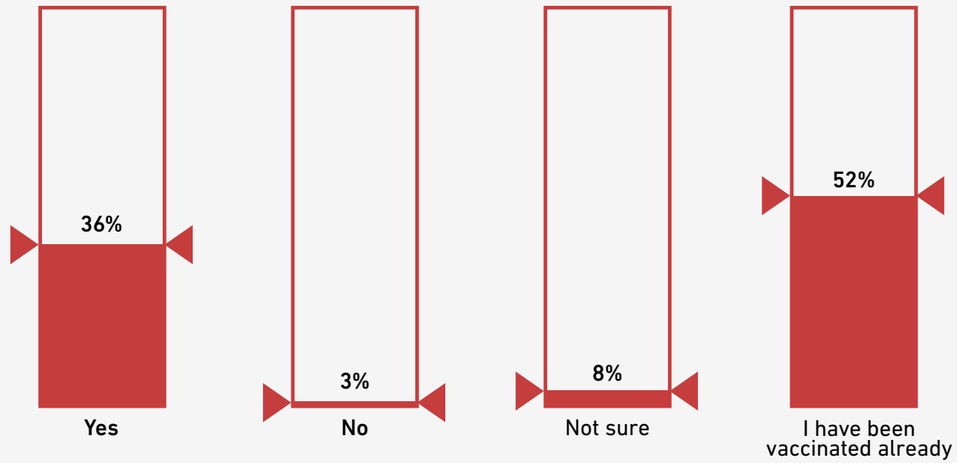
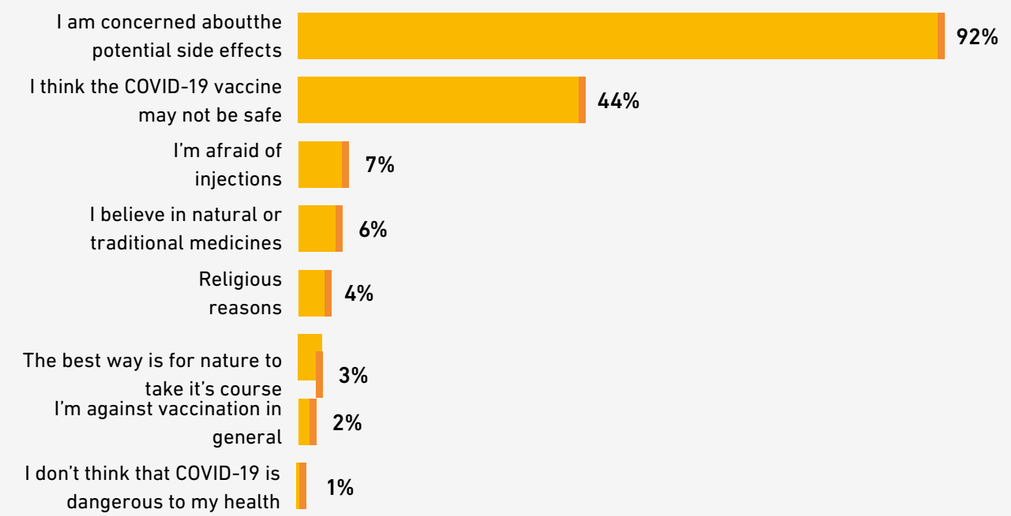


Figure 30: Reasons for Vaccine Hesitancy



The Role of Governments

When asked what else governments should be doing, there were strong opinions, many of which centred around healthy food. People want their governments to encourage local agriculture, with the aim of making healthy alternatives cheaper and more accessible. They wanted education on the benefits and preparation of these ingredients, starting at school, and continuing through all ages. Correspondingly, several expressed the desire to see unhealthy alternatives disincentivised or discouraged, either through taxes, or through front-of-label packaging.

> ***Encourage/empower the growth of our agriculture sector, which will provide more quality food for us to consume (and thus reduce our import bill for food).***
>
> ***Work mainly with schools. Engage more teachers to work with students on how local dishes, mainly fruits, vegetables and ground provisions are prepared.***
>
> ***Ban the sale of unhealthy food and drinks in school cafeterias and vendors who sell to children.***

People also wanted opportunities to exercise, whether in a local park, a safe space to walk the dog, or access to the sea, for a 'sea bath'. Again, it was felt that education on the benefits of physical activity formed a crucial part of this measure.

> ***More emphasis on physical activity and ensuring that all public grounds and community centres are properly maintained.***

The final key request for governments was to ensure consistent access to healthcare was available again – many had missed appointments or screenings, and wanted the resumption of routine care This included requests for dedicated services for those with NCDs.

> ***System on how to get back to routine visits to e.g. heart clinic. How to make up an appointment missed because of the Covid?***

The final question in the survey gave respondents the opportunity to add any other comments they wished. There were a few complaints about government's response, or about vaccines, but the vast majority (especially essential workers) took this opportunity to reiterate the extent to which the pandemic had impacted their mental health. For some, these concerns centred around money, for others, health, and others still spoke of their faith as being important. However, but in general, the most common comment was a general one as to the significant overall toll the last 18 months have taken on respondents.

> ***A very lonely and Isolated period in ones life***

> ***Lack of income means life or death***

> ***Fairly stressful, but trying to use resilience, and plenty Faith to cope with the various changes, adjustments, and adaptations to this 'new normal'***

> ***As a frontline worker, there are no support for us mentally, physically, or even financially. We are expected to face this pandemic head on but are neglected. Who cares for the carers***

> ***Shutting down the vendors really restricted my ability to access fruits and vegetables during COVID and much of the produce went to waste. Steps must be taken to prevent this from happening again***

> ***Covid sucks***

CONCLUSIONS AND RECOMMENDATIONS

1. **Ensure continuity of care. There is a need to better adapt to the pandemic and minimize interruptions to routine medical care. Telemedicine was considered acceptable to most respondents and may be a feasible option, although care must be taken to ensure those with poor digital literacy and complex medical problems are not left behind.**

2. **Address medication non-adherence. Prior to the pandemic, medication non-adherence was recognised as a major obstacle to effective NCD management. The pandemic has further exacerbated issues around medication supply and access. As well as addressing the root causes of non-adherance, additional research is required to develop strategies to ensure continuous supplies of medicines, research which could benefit various other emergency scenarios such as hurricanes.**

3. **Address unmet need for mental health care. Most respondents have been concerned for their mental health during the pandemic, with some seeking support and not obtaining it. Respondents reported that the overriding impact of the pandemic had been on their mental health, and felt that CSOs and governments need to work together to support those suffering from mental health issues, as well as to educate on, and to destigmatise these conditions.**

4. **Educate patients about the importance of being physically active. The COVID-19 pandemic has created an environment that discourages habitual physical activity due to self-isolation and quarantine requirements, reduced opportunities to remain physically active, and fear of being infected. Clinicians and other health-care practitioners should take a proactive stance in improving education and prescribing physical activities to their patients: this should be considered a standard component of NCD management. Respondents expressed a desire for safe outdoor spaces for recreation; governments should invest in these spaces, and opportunities for partnering with stakeholders responsible for urban planning and land use policy should be enacted to ensure equitable access to sport and recreation facilities and amenities.**

5. **Improve access to healthy foods. Crises often cause widespread disruptions to food supply chains. This indicates the need for more resilient food distribution systems. Where possible, the focus should be on improving access to locally-produced healthy foods; however, improving access to healthy imported foods to supplement local supplies may also be necessary. Providing outlets for foods directly from local communities, whether via traditional farmers' markets or digital marketplaces, builds greater resilience into the food systems by shortening supply chains. Healthy eating habits should also be encouraged via public education campaigns.**

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APPENDICES

Appendix A: Questionnaire

HEALTHY CARIBBEAN COALITION

SURVEY OF THE EXPERIENCES OF PEOPLE LIVING WITH NCDs IN THE CARIBBEAN DURING THE CORONAVIRUS (COVID-19) PANDEMIC

About the Survey

The new coronavirus (COVID-19) pandemic has caused illness and loss of life in countries around the world. It has resulted in disruptions in many aspects of life at national, regional, and global levels, and national health systems have not been spared. Studies have shown that people living with noncommunicable diseases (NCDs) are at higher risk of serious illness, complications, and death due to COVID-19.

NCDs, such as cardiovascular disease (including heart disease, high blood pressure, and stroke), cancer, diabetes, and chronic respiratory disease (including asthma and chronic obstructive lung disease), are the major causes of death in the Caribbean. In order to fight the spread of COVID-19, most Caribbean countries stopped movement across their borders, instituted national curfews to restrict movement, and closed or put restrictions on a wide variety of businesses and services, including several related to health. These measures, and fear of contracting COVID-19, have affected many people, including people living withNCDs, in various ways.

The Healthy Caribbean Coalition (HCC) in collaboration with the Pan American Health Organization (PAHO), is undertaking this survey to learn about the experiences of people living with NCDs during the COVID-19 pandemic.

How will the results be used?

The Results of this survey will be used to formulate recommendations for health systems to 'build back better' in the context of COVID-19. The survey seeks to capture the experiences of people living with NCDs across the following key areas: accessing and consuming healthy and nutritious food; continuity of care and access to essential medicines and life-saving treatments; mental health and coping; physical activity; information, education, and communication; and perspectives on what is needed from governments and civil society moving forward.

What will participating in this study involve?

Your participation in this survey is voluntary. You may choose not to participate. If you decide to participate in this survey, you may withdraw at any time. If you decide not to participate in this survey or if you withdraw from participating at any time, you will not be penalized.

This online survey will take approximately 30 minutes to complete.

How Will We Protect Your Privacy?

To help protect your confidentiality, the survey does not contain information that will personally identify you. The survey does not ask for your name, address, or any other specific identifying information, and the results will therefore be reported anonymously. All data is stored in a password protected electronic format. The results of the survey will inform research and advocacy to Caribbean governments at the highest levels, seeking to strengthen NCD prevention and control, and improve the lives of Caribbean people.

By submitting this form, you are indicating that you have read the description of the study, are over the age of 18, and that you agree to the terms as described.

If you have any questions, or would like a copy of this consent letter, please contact the Principal Investigator Christina.Howitt@cavehill.uwi.edu.

You may also contact the University of the West Indies Research Ethics Board:

Chair: Dr Michael Campbell

Telephone number: 429-5112

ResearchEthics@cavehill.uwi.edu

Thank you in advance for your participation!

I. CONSENT

1. I agree to participate in the research study. I understand the purpose and nature of this study and I am participating voluntarily. I understand that I can withdraw from the study at any time, without any penalty or consequences.

2. I grant permission for the data generated from this interview to be used by the Healthy Caribbean Coalition and Pan American Health Organization for advocacy and research purposes.

3. I understand that to protect confidentiality, the survey does not contain information that will personally identify me such as my name.

II. NON-COMMUNICABLE DISEASE STATUS

THIS SURVEY IS FOR PEOPLE LIVING WITH CHRONIC NON COMMUNICABLE DISEASES/ CONDITIONS OR THOSE CARING FOR PEOPLE LIVING WITH CHRONIC NON COMMUNICABLE DISEASES/CONDITIONS.

1. Have you ever been told by a doctor or other health worker that you have a chronic disease(s) or noncommunicable disease(s) (NCD)? Please check all that apply

I. Heart disease (e.g. heart attack or heart failure)

II. Stroke

III. Cancer

IV. Lung disease, including asthma
V. Diabetes (also called high blood sugar)
VI. Mental conditions (e.g. depression)
VII. Neurological conditions (e.g. dementia)
VIII. Overweight/obesity
IX. High blood pressure/hypertension
X. Kidney Disease
XI. Liver Disease
XII. None of the Above

2. If none of the Above: Are you a caregiver to someone with an NCD? (if you are a caregiver, please answer on behalf of the person you care for)

I. Yes

II. No

If No, then finish survey here

3. Which of the following NCDs does the person you care for suffer from? Please check all that apply

I. Heart disease (e.g. heart attack or heart failure)
II. Stroke
III. Cancer
IV. Lung disease, including asthma
V. Diabetes (also called high blood sugar)
VI. Mental conditions (e.g. depression)
VII. Neurological conditions (e.g. dementia)
VIII. Overweight/obesity
IX. High blood pressure/hypertension
X. Kidney Disease
XI. Liver Disease
XII. None of the Above

III. DEMOGRAPHIC INFORMATION:

4. In which country do you currently live?

I. Anguilla
II. Antigua and Barbuda
III. The Bahamas
IV. Barbados
V. Belize
VI. Bermuda
VII. British Virgin Islands
VIII. Cayman Islands
IX. Dominica
X. Grenada
XI. Guyana
XII. Haiti
XIII. Jamaica
XIV. Montserrat
XV. St Kitts and Nevis
XVI. St Lucia
XVII. St Vincent
XVIII. Suriname
XIX. Trinidad and Tobago
XX. Turks and Caicos Islands

5. What is your date of birth?

dd/mm/yyyy

Don't know

6. [If respondent does not know date of birth] How old are you?

_____years

(End survey if under 18)

7. What gender are you?

I. Female
II. Male
III. Other/Prefer not to say

8. What is the highest level of education you have completed?

I. Primary school
II. Secondary school
III. Vocational or community college
IV. Undergraduate university degree
V. Graduate university degree
VI. No formal schooling

9. Which of the following best describes your main work status prior to the COVID-19 pandemic?

I. Government employee
II. Non-Government employee
III. Self-employed
IV. Unpaid / Volunteer work
V. Student
VI. Homemaker
VII. Retired
VIII. Unemployed (able to work)
IX. Unemployed (unable to work)
X. Rather not say

10. Has your household experienced a reduction in income since the start of the pandemic?

I. No
II. Yes, mild reduction (25% or less)
III. Yes, moderate reduction (26-50%)

IV. Yes, severe reduction (more than 50%)
XI. Rather not say

11.Have you received, or are you currently receiving any government support to supplement or replace your income during the pandemic?

I. Yes
II. No

12. If YES, is it adequate for your needs during the pandemic?

I. Yes
II. No

IV. COVID-19 VACCINE ACCEPTANCE

13. Would you be willing to get vaccinated against COVID-19 if a vaccine were available?

☐ Yes
☐ No
☐ Not Sure

14. If no or not sure, what are your main reasons?

☐ I'm concerned about potential side effects
☐ I think the COVID-19 vaccine may not be safe
☐ The best way is for nature to take its course
☐ I don't think that COVID-19 is dangerous to my health
☐ I'm afraid of injections
☐ I believe in natural or traditional remedies
☐ I'm against vaccination in general
☐ Religious reasons

15.Have you been diagnosed with COVID-19?

I.Yes

II. No

III. Don't know

V. HEALTH-RELATED BEHAVIOURS, INCLUDING DIET, PHYSICAL ACTIVITY, AND TOBACCO CONSUMPTION

16.Since the start of the COVID-19 pandemic, have you (please check the appropriate box):

I. Gained weight

II. Lost weight

III. Had no weight change

IV. Weight continues to fluctuate

V. Not sure

17. For each of the following types of food, please indicate whether you have been eating it more or less often since the start of the pandemic.

	Much more often	Slightly more often	About the same	Slightly less often	Much less often
a. Restaurant food					
b. Takeaway / fast food					
c. Home-cooked food					
d. food from your yard / kitchen garden					

18. For each of the following types of food, please indicate whether you have been eating it more or less often since the start of the pandemic.

	Much more often	Slightly more often	About the same	Slightly less often	Much less often	I do not eat this
a. Fresh fruit and vegetables						
b. Canned fruit and vegetables						
c. Frozen fruit and vegetables						
d. Fresh meat or fish						
e. Canned meat or fish						
f. Processed meat or fish (e.g.nuggets, hot dogs)						
g. Packaged snacks (chips, cookies etc)						
h. Sweets or desserts						
i. Sugary drinks						

19. If your diet has changed, what is/are the main reason(s)? Check all that apply

I. Anxiety

II. Financial problems (inability to afford)

III. Needed to use money to buy medication

IV. Unable to get / limited availability of fresh products

V. Other

20. Has your level of physical activity changed during the pandemic?

I. Yes, it has increased
II. Yes, it has decreased
III. No, it has stayed the same
IV. I don't engage in regular physical activity

Smoking tobacco refers to products where you burn the tobacco as you smoke it., including cigarettes, cigars, pipes, waterpipe with tobacco. Electronic cigarettes are asked about separately.

21. Do you currently smoke tobacco on a daily basis, less than daily, or not at all?

I. Daily (go to Q26)
II. Less than daily (go to Q26)
III. Not at all (Go to Q29)

22. During the past 12 months, have you tried to stop smoking?

I. Yes
II. No

23. Have you visited a doctor or other health care provider in the past 12 months?

I. Yes – Go to Q28
II. No – Go to Q29.

24. During any visit to a doctor or health care provider in the past 12 months, were you advised to quit tobacco smoking?

I. Yes
II. No

25. Do you currently use electronic cigarettes or any other vaping device on a daily basis, less than daily, not at all?

I. Daily
II. Less than daily
III. Not at all

26. During the past 12 months, have you tried to stop use electronic cigarettes or any other vaping device?

I. Yes
II. No

27. Have you visited a doctor or other health care provider in the past 12 months?

I. Yes – Go to Q32
II. No – Go to Q33.

28. During any visit to a doctor or health care provider in the past 12 months, were you advised to stop use electronic cigarettes or any other vaping device?

I. Yes
II. No

VI. ACCESS TO CONTINUOUS CARE, ESSENTIAL MEDICINES, AND LIFE-SAVING TREATMENTS

Continuity of medical care

29. Prior to the COVID-19 control measures, were you seeking and receiving routine medical care for your NCD(s)?

I. Yes
II. No [Skip to state of control question – q35]

30. Prior to the COVID-19 pandemic, was your usual healthcare provider

I. Public sector
II. Private sector
III. A mixture of public and private

31. During the COVID-19 control measures, did you experience any changes in your routine medical care for your NCD(s)?

I. Yes
II. No

32. If YES, please indicate reason(s) (check all that apply):

I. My clinic or doctor's office was closed for routine care

II. My appointment was rescheduled

III. My appointment was cancelled

IV. I was unable to get an appointment at my clinic or doctor's office

V. I did not to go to my clinic or doctor's office for fear of contracting COVID-19

VI. My physician or health provider offered remote care, but I was not comfortable with this option

VII. My physician or health provider offered remote care, but I did not have the required technology

VIII. Other

33. If NO, please indicate reason(s)

I. I was able to see my physician or healthcare provider in person

II. My physician or other healthcare provider contacted me via phone

III. My physician or other healthcare provider scheduled video calls using special audiovisual communication platforms (Zoom / WhatsApp etc)

IV. Other

34. If you received consultations via phone or video call, how happy would you be for this type of consultation to be incorporated into your care in the future (i.e. for some but not all consultations to be via phone or video call)

I. Very happy

II. Happy

III. Neither happy nor unhappy

IV. Unhappy

V. Very unhappy

35. Prior to the start of the pandemic, how would you describe the state of control of your NCD(s)?

I. Well controlled

II. Moderately controlled

III. Poorly controlled

IV. Not sure

36. And how has the control of your NCD(s) changed since the start of the pandemic?

i. Better controlled

ii. About the same

iii. Less well-controlled

37. During the COVID-19 control measures did you miss/choose not to attend any annual or routine screening tests?

I. Mammogram

II. Pap test / HPV test

III. Prostate test

IV. Cholesterol Screening

V. Blood Pressure Screening

VI. Eye exam in which the pupils are dilated

VII. Foot examination

VIII. Other

IX None of the above

38. At any point since the start of the pandemic, have you had to delay any of the following treatments/services? [select all that apply]

I. Chemotherapy

II. Radiotherapy

III. Kidney dialysis

IV Elective surgery

V.Urgent surgery

VI. Urgent medical treatment

VII. Other

VIII. None of the above

Access to essential medicines

39. Prior to the COVID-19 pandemic, had you been told by a doctor or other health provider that you should be taking medicines to treat your NCD(s)

I. Yes

II. No

40. How do you usually pay for your NCD medicine?

I. I get the medication for free at the public health care facility or through the national drug service

II. The medication is partially covered by public insurance and I pay the uninsured portion out of my pocket.

III. The medication is covered both by public and private insurance and I pay the balance out of my pocket

IV. The medication is fully covered by private insurance.

V. The medication is partially covered by private insurance and I pay the uninsured portion out of my pocket.

VI. pay for it and I can usually afford to buy the medicine that I need.

VII. I pay for it but I sometimes have to borrow money or sell things to pay for my NCD medicine.

VIII. Other

41. Sometimes people cannot take all medicines as directed. During the COVID-19 pandemic, did you usually take all medicines as recommended?

I. Yes

II. No

42. There are a number of reasons that people do not always take medication as recommended.

Please select all that apply

i. Symptoms have gotten better

II. I could not afford the medicines

III. Did not have the time to obtain medicines

IV. I decided to take a different treatment

V. The place where medicines can be obtained was too far away

VI. Medicines were not available at the public health care facility

VII. I had bad reactions to medicines in the past

VIII. Medicines were not available at private pharmacy or drug seller

IX. Someone advised me not to take medicines.

X. Other

43. During the COVID-19 pandemic did you run out of medication for your NCD(s)?

I. Yes

II. No

44. If YES, for which of the following conditions did you run out of medication? Select all that apply

I. Heart disease

II. Stroke

III. Cancer

IV. Lung disease, including asthma

V. Diabetes

VI. Mental conditions

VII. Neurological conditions

VIII Pain control medication

IX. High blood pressure/hypertension

X. Kidney Disease

XI. Liver Disease

45. What were the main reasons that contributed for you running out of medicine? Select all that apply

I. Mobility restrictions imposed during COVID (Lockdowns) did not allow me to go to the pharmacy or health centre for a refill.

II. The health centre, or my doctor's office was closed.

III. The private pharmacy or drug seller was closed

IV. I could not afford the medicine

V. The health centre or pharmacy did not have my medicine.

VI. I didn't realize I was running out, until it was too late

VII. Did not have the time to obtain medicines

VIII. The place where medicines can be obtained was too far away

IX. Medicines were not available at the public health care facility

X. Medicines were not available at private pharmacy or drug seller

46. To avoid you visiting the health centre/ pharmacy during the pandemic, were you provided more than one (1) month of prescription for your NCD(s)?

I. Yes

II. No

III. Don't know

47. If YES, please indicate how many months' supply you were given:

I. Two (2) months' supply

II. Three (3) months' supply.

III. More than three (3) month's supply

48. Have you been able to pay for your usual NCD medication throughout the COVID-19 pandemic?

I. Yes

II. No

49. If NO, what action(s) did you take?

I. I had to obtain my medication through another source (community programme, relative, physician, friend)

II. I had to substitute a cheaper medication

III. I had to ration the medication that I had (for example, taking it every other day or every few days)

IV. I had to stop taking the medication and try alternative medicines such as herbal remedies

V. I had to stop taking the medication altogether

VI. Other action(s)

VII. MENTAL HEALTH AND COPING – REMEMBER THAT ALL ANSWERS YOU GIVE ARE CONFIDENTIAL AND ANONYMOUS

50.Have you felt concerned since the start of the pandemic?

I. Yes

II. No

51. If YES, please indicate What you have been concerned by:

I. Contracting COVID19 because I have an NCD

II. That my loved ones may contract COVID19

III. My NCD(s) because I have not received my routine health care

IV. My NCD(s)on because I have to defer my life-saving treatments

V. My general health because I have missed routine health check-ups and screenings

VI. My general health because I have missed urgent or elective surgery

VII. My NCD(s)because I have not been able to take my medication properly

VIII. My immune strength because I have not consumed as many healthy fruits and vegetables as I normally consume

IX. Because I have not been able to engage in my regular physical activity routine

X. Other

53. At any time since the start of the pandemic, did you take prescription medication to help you with any emotions or with your concentration, behavior or mental health?

I. Yes

II. No

III. Not sure

54. At any time since the start of the pandemic, did you receive counseling or therapy from a mental health professional such as a psychiatrist, psychologist, psychiatric nurse, or clinical social worker? Include counseling or therapy online or by phone.

I. Yes

II.No

III. Not sure

55. At any time since the start of the pandemic, did you want counseling or therapy from a mental health professional, but not get it for any reason?

I. Yes

II. No

III. Not sure

56. Have you started using, or increased your use of, alcohol during COVID-19 to assist with coping since the pandemic?

I. Yes

II. No

III. Not sure

VIII. PERSPECTIVES ON CIVIL SOCIETY'S ROLE IN NCD PREVENTION AND CONTROL

57. Are you a member of a civil society organisation (CSO), such as a diabetes or cancer association, that deals with NCDs in your country?

I. Yes

II. No

58. If you are a CSO member, has your CSO provided support to you since the start of the COVID19 pandemic?

I. Yes

II. No

59 If YES, what kind of support has your CSO provided? (Please check all that apply)

I. Virtual/ remote psychosocial support

II. Virtual/ remote clinical care or facilitating access to care

III. Community outreach through visiting physicians who go to patient homes so patients can stay home and maintain physical distancing

IV. Provision of medication

V. Provision of healthy food hampers

VI. Online services such as physical activity programmes

VII. Advocating to governments for the needs of PERSONS LIVING WITH CHRONIC DISEASEs

VIII. Other support

60. If you have any suggestions about what CSO services should look like after COVID-19 for PERSONS LIVING WITH NCDs, please feel free to list them below. You can list up to three (3)

a.

b.

c.

61. As regional governments begin to develop COVID-19 recovery plans, the HCC will be advocating for a strong focus on NCDs. If you have any suggestions for actions that your government should take to strengthen NCD prevention and control, please feel free to list them below. You can list up to Three (3)

a.

b.

c.

58. Would you like to add anything else regarding your COVID-19 experience? If YES, please do so in the space below

Thank you very much for taking the time to complete the survey. Your results will help us support those living with NCDs during this pandemic.

Appendix B: Sample size calculations

This is a CARICOM-wide, cross-sectional survey that aims to document the experiences of people living with NCDs (PLWNCDs) during the COVID-19 pandemic.

We calculated sample sizes for estimating prevalence in one group, rather than a group comparison. This is appropriate for a descriptive survey that is not hypothesis testing. In order to calculate the sample size required for prevalence in one group, we need the following information:

1. Size of population being studied. This is the number of people living with an NCD in each territory. We estimated this based on the size of the population in 2020 (source: United Nations World Population Prospects) and the prevalence of hypertension, which is the most common NCD (source World Health Organization Noncommunicable Diseases Progress Monitor 2020).
2. Effect size. This is the expected prevalence of each outcome and is usually estimated based on similar studies in the literature. For this study, very little has been published on these outcomes, so we calculated the sample size required for a range of scenarios. A prevalence of 50% yields the highest estimates, so we used this in the main calculation in order to account for the worst case scenario.
3. Precision. We defined a margin of error of +/- 5% as acceptable.
4. Acceptable level of uncertainty. We defined this as 95%.

The three scenarios and their associated sample sizes are shown Opposite. Our target sample size is between 350 and 384 participants per territory. This is based on scenario 1, i.e. effect size: 50%; margin of error +/- 5%; uncertainty: 95%.

	population[1]	prevalence of NCDs[2]	Population with NCD	Required sample size; estimate 1[3]	Required sample size; estimate 2[4]	Required sample size; estimate 3[5]
Anguilla	15002	29%	4381	353	94	233
Antigua and Barbuda	97928	24%	23503	378	96	243
Bahamas	393248	34%	134884	383	96	245
Barbados	287371	21%	58911	382	96	245
Belize	397621	18%	71572	382	96	245
Bermuda	62273	33%	20799	377	96	243
British Virgin Islands	30237	36%	11006	371	95	241
Cayman Islands	65720	26%	16890	376	95	242
Dominica	71991	32%	23109	378	96	243
Grenada	112519	38%	42870	381	96	244
Guyana	328000	not available	124968	383	96	245
Haiti	11402533	34%	3922471	384	96	246
Jamaica	2961161	31%	912038	384	96	246
Montserrat	4999	not available	1905	320	91	218
St Kitts and Nevis	53192	35%	18617	376	96	243
St Lucia	183629	27%	50131	381	96	245
St Vincent and the Grenadines	110947	20%	22300	378	96	243
Suriname	740000	20%	148000	383	96	245
Trinidad and Tobago	1399491	26%	368066	384	96	246
Turks and Caicos	38718	not available	14752	374	95	242

[1] Population in 2020 (Source UN WPP)

[2] Taken as prevalence of hypertension, the most common NCD (World Health Organization Noncommunicable Diseases Progress Monitor 2020)

[3] Effect size: 50%; margin of error +/- 5%; uncertainty: 95%

[4] Effect size: 50%; margin of error +/- 10%; uncertainty: 95%

[5] Effect size: 20%; margin of error +/- 5%; uncertainty: 95

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