



LEAVE NO ONE BEHIND

Ensuring inclusive NCD responses

Spotlight on endocrine-related conditions

Edited by NCD Alliance, December 2021

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Executive Summary

Universal health coverage (UHC) ensures all people, everywhere, can get the quality health services they need without financial hardship. Every 12 December advocates worldwide mobilise on UHC Day to call for strong, equitable health systems that leave no one behind. On the occasion of **Universal Health Coverage Day**, 12 December 2021, this policy brief aims to facilitate a better understanding of the needs and priorities of people living with a broad range of noncommunicable diseases (NCDs) with a focus on endocrine-related conditions. **Drawing on the expertise and experience of people living with endocrine-related conditions, with a particular emphasis on thyroid and kidney diseases**, it puts forward recommendations on approaches to facilitate a more inclusive NCD agenda.

The global health policy approach to NCDs has a focus on **five diseases** - cardiovascular diseases (CVD), cancer, diabetes, chronic respiratory diseases and mental health, and **five modifiable risk factors** - tobacco, alcohol use, unhealthy diet, physical inactivity and air pollution. This is known as the '5x5' approach, but it overlooks several NCDs, such as thyroid and kidney diseases, and the reality that many people live with multiple chronic conditions. This means that many people living with NCDs are at risk of being left behind in terms of access to care.

NCDs often exist in clusters, with common risk factors and causal relationships. There are also bidirectional relationships between NCDs and infectious diseases. The COVID-19 pandemic put people living with NCDs at higher risk of severe disease or death. The endocrine system is believed to be susceptible to damage by COVID-19 and associated inflammatory processes. In the policy brief, a spotlight is put on endocrine health and case studies are provided on thyroid disorders and kidney disease. The brief summarises key takeaways from a global survey carried out to further understand the impact of this wider range of NCDs.

Tackling NCDs requires an approach that is tailored to people, rather than diseases. This entails a fundamental paradigm shift in the way healthcare is designed and delivered. This brief presents recommendations to ensure more inclusive NCD responses.

This policy brief is part of the NCD Alliance series on an inclusive NCD agenda and complements the discussion paper entitled **The need for a person-centred, inclusive NCD agenda** and the publication **Towards an inclusive NCD agenda: A Collection of lived experiences from around the world**.

Setting the scene

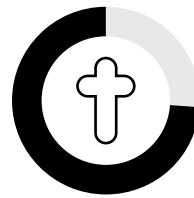
The overlooked impact of NCDs

A snapshot of the current NCD policy context

“Non 5x5 NCDs are often ignored despite some of them having catastrophic consequences. Living with an NCD has been challenging physically, emotionally and financially. It affects the important areas of my life, and this takes a heavy toll on me. But it is encouraging to know that with the proper assistance and knowledge these challenges can be overcome and quality of life improved. I have made it my business to advocate for better NCDs management and control and disseminate knowledge about living well with NCDs.”

Mr John Gikonyo, President of the Renal Patients Society of Kenya, living with Kidney Disease

Noncommunicable diseases (NCDs) are the biggest contributor to death and disability worldwide,



all NCDs together accounted for **74% of DEATHS GLOBALLY in 2019.**¹

The world's biggest killer is **ISCHAEMIC HEART DISEASE**, responsible for



16% of the WORLD'S TOTAL DEATHS.

Since 2000, the largest increase in deaths has been for this disease, rising by more than 2 million to 8.9 million deaths in 2019. **Stroke and chronic obstructive pulmonary disease are the 2nd and 3rd leading causes of death**, responsible for approximately 11% and 6% of total deaths respectively.²

KIDNEY DISEASES

have risen from the world's 13th leading cause of death to the 10th.

MORTALITY HAS INCREASED

from

813 000
in 2000

to

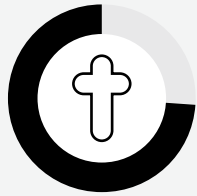
1.3 million
in 2019.³



1 WHO: The top 10 causes of death, 9 December 2020: <https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death>

2 Ibid 1.

3 Ibid 1.



Approximately
77% of all NCD
deaths are in low-
and middle-income
countries.⁴

Each year, more than 15 million people die from a NCD between the ages of 30 and 69 years;



85% of these “PREMATURE”
DEATHS occur in low- and middle-
income countries.⁵

It is estimated that NCDs will cost
the global economy approximately
USD \$47 trillion
between 2010 and 2030,
resulting in a significant impact on GDP.⁶

**NCDs are also a key cause of disability,
and have been the main driver of
disability growth over the last 20 years.**

It is estimated that
80%
of disabilities
are related to NCDs.⁷

DISABILITY IS ON THE RISE



Heart disease, diabetes, stroke,
lung cancer and chronic obstructive
pulmonary disease were collectively
responsible for nearly 100 million
additional healthy life-years lost in
2019 compared to 2000.⁸

4 WHO Fact Sheet on Non-Communicable Diseases: <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases>

5 Ibid 4.

6 Bloom, D.E. et al. The Global Economic Burden of Noncommunicable Diseases. Harvard School of Public Health and World Economic Forum. September 2011: http://www3.weforum.org/docs/WEF_Harvard_HE_GlobalEconomicBurdenNonCommunicableDiseases_2011.pdf

7 Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2017. Seattle, WA; 2018.

8 WHO reveals leading causes of death and disability worldwide: 2000-2019: <https://www.who.int/news/item/09-12-2020-who-reveals-leading-causes-of-death-and-disability-worldwide-2000-2019>

The initial global policy response to NCDs at the United Nations High-Level Meetings (UN HLMs) in 2011 and 2014 focused on **four leading causes of premature NCDs death – cardiovascular diseases (CVD), cancer, diabetes, and chronic respiratory diseases** – and **four main modifiable risk factors – tobacco and alcohol use, unhealthy diet, and physical inactivity**.^{9, 10} This ‘4x4’ approach’ is also the focus of the WHO Global Action Plan for the Prevention and Control of NCDs (2013 – 2020). This has now been extended to 2030.¹¹

In 2018, the third UN High-Level Meeting on NCDs also formally recognised **mental health** and **air pollution** as core components of the NCD response, thereby introducing the ‘5x5’ approach.¹²

NCDs within the ‘5x5’ approach	
Diseases	Modifiable risk factors
Cardiovascular diseases (CVD)	Tobacco
Cancer	Alcohol use
Diabetes	Unhealthy diet
Chronic respiratory diseases	Physical activity
Mental health	Air pollution

Gaps brought about by focusing on the ‘5x5’ approach

- Absence of several NCDs, such as thyroid and kidney diseases
- Lack of focus on quality of life - morbidity and multimorbidity
- Lack of focus on people younger than 30 or older than 70 years

While the transition to a more comprehensive ‘5x5’ approach is laudable, it remains insufficiently inclusive. Many NCDs can be prevented, delayed or managed through early diagnosis, quality care and support. However, lack of a truly inclusive NCD approach hinders the goals of achieving Universal Health Coverage (UHC) and sustainable development more generally.

9 UGA (66th sess: 2011-2012). Declaration of the High-Level Meeting of the General Assembly on the Prevention and Control of Non-Communicable Diseases: 2011 Sep 16; <https://digitallibrary.un.org/record/710899>

10 UGA (68th sess: 2013-2014). Outcome document of the High-Level Meeting of the General Assembly on the Comprehensive Review and Assessment of the Progress Achieved in the Prevention and Control of Non-Communicable Diseases: 2014 Jul 7; <https://digitallibrary.un.org/record/774662>

11 NCD Alliance. The Need for a Person-Centred, Inclusive NCD Agenda, 2020. <https://ncdalliance.org/resources/the-need-for-a-person-centred-inclusive-ncd-agenda>

12 UGA (73rd sess: 2018-2019) Political declaration of the 3rd High-Level Meeting of the General Assembly on the Prevention and Control of Non-Communicable Diseases: 2018 Oct 17; <https://digitallibrary.un.org/record/1648984>

THE '5X5' APPROACH

Gaps brought about by focusing on the '5x5' approach



The quest for Universal Health Coverage (UHC)

The principle of ‘**leaving no one behind**’ is inherently underpinned by the 2030 Sustainable Development Agenda and the concept of UHC. UHC means that everyone, everywhere, can access quality health services without incurring financial hardship, and people are by definition at the heart of UHC.¹³ The importance of NCD prevention and control is specifically acknowledged by Sustainable Development Goal (SDG) target 3.4, which was based on the WHO Global Monitoring Framework with a focus on premature mortality from the four major NCDs.¹⁴ The 2019 UN Political Declaration on UHC also recognises the fundamental role of UHC (SDG 3.8) to achieving sustainable development.¹⁵

Sustainable Development Goals (SDGs)

SDG 3 Good Health and Well-Being¹⁶



TARGET 3.4



REDUCE MORTALITY FROM NON-COMMUNICABLE DISEASES AND PROMOTE MENTAL HEALTH

By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being.

TARGET 3.8



ACHIEVE UNIVERSAL HEALTH COVERAGE

Achieve **universal health coverage**, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

INDICATOR 3.8.1

Coverage of **essential health services** (defined as the average coverage of essential services based on tracer interventions that include reproductive, maternal, newborn and child health, infectious diseases, **non-communicable diseases** and service capacity and access, among the general and the most disadvantaged population).

13 NCD Alliance. NCD Alliance Advocacy Priorities for the 2019 UN HLM on UHC, 2019; https://ncdalliance.org/resources/NCDA_priorities_HLM_UHC_2019

14 UN. Transforming our world: the 2030 Agenda for Sustainable Development (70th sess: 2014-2015); 2015; <https://undocs.org/en/A/RES/70/1>

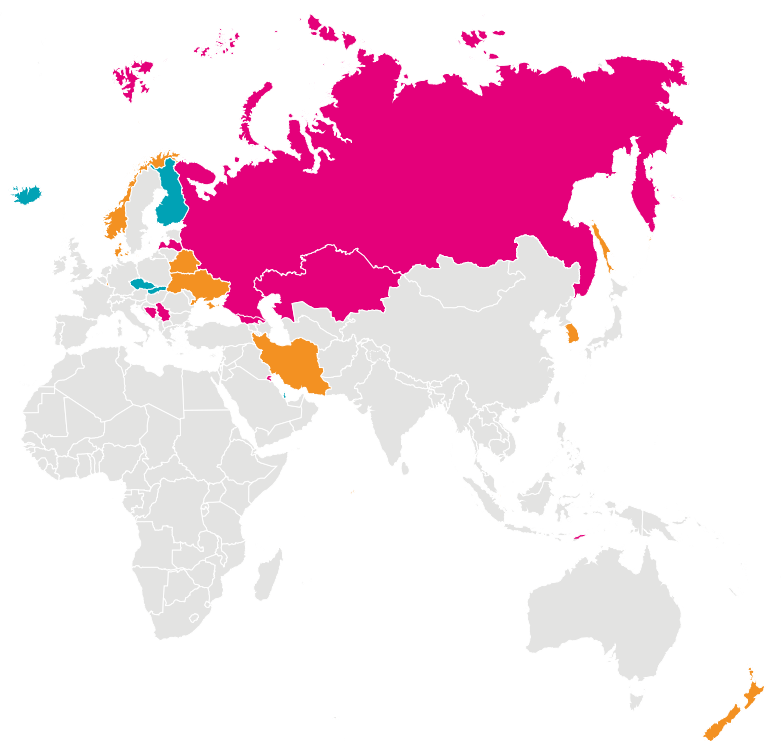
15 UN. Political Declaration of the High-Level Meeting on Universal Health Coverage (74th sess: 2018-2019); 2019. <https://undocs.org/en/A/RES/74/2>

16 SDG 3: Ensure healthy lives and promote well-being for all at all ages; <https://sdgs.un.org/goals/goal3>

Many countries are falling behind on global commitments to tackle premature deaths from chronic diseases, such as diabetes, cancer, respiratory conditions and heart disease. **The countries currently on track to meet SDG target 3.4 of one-third reduction in NCD mortality by 2030 for women and men remains limited.**

Countries currently on track to meet SDG target 3.4 of one-third reduction in NCD mortality by 2030¹⁷

Women	Men
Belarus	Bahrain
Bosnia and Herzegovina	Belarus
Denmark	Czech Republic
Iran	Denmark
Kazakhstan	Finland
Kuwait	Iceland
Latvia	Iran
Luxembourg	Kazakhstan
Maldives	Luxembourg
New Zealand	Maldives
Norway	New Zealand
Russian Federation	Norway
Serbia	Singapore
Singapore	South Korea
South Korea	Slovakia
Timor-Leste	
Ukraine	



The **WHO Progress report on NCDs in 2021** states that more could be done to align responses to NCDs to broader health and development agendas, as articulated in terms of UHC and the SDGs. It highlights that countries have made little progress in introducing evidence-based national guidelines/protocols/standards for the management of major NCDs through a primary care approach.¹⁸

17 Lancet: Supplementary appendix: [https://www.thelancet.com/cms/10.1016/S0140-6736\(20\)31761-X/attachment/75f73b7c-382f-457e-925d-ba81ab090715/mmc1.pdf](https://www.thelancet.com/cms/10.1016/S0140-6736(20)31761-X/attachment/75f73b7c-382f-457e-925d-ba81ab090715/mmc1.pdf) to: NCD Countdown 2030 collaborators. NCD Countdown 2030: pathways to achieving Sustainable Development Goal target 3.4. Lancet 2020; published online Sept 3. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)31761-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)31761-X/fulltext)

18 WHO. Political declaration of the third high-level meeting of the General Assembly on the prevention and control of non-communicable diseases, Mid-point evaluation of the implementation of the WHO global action plan for the prevention and control of noncommunicable diseases 2013–2020, World Health Assembly, 15 April 2021; https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_10Add1-en.pdf

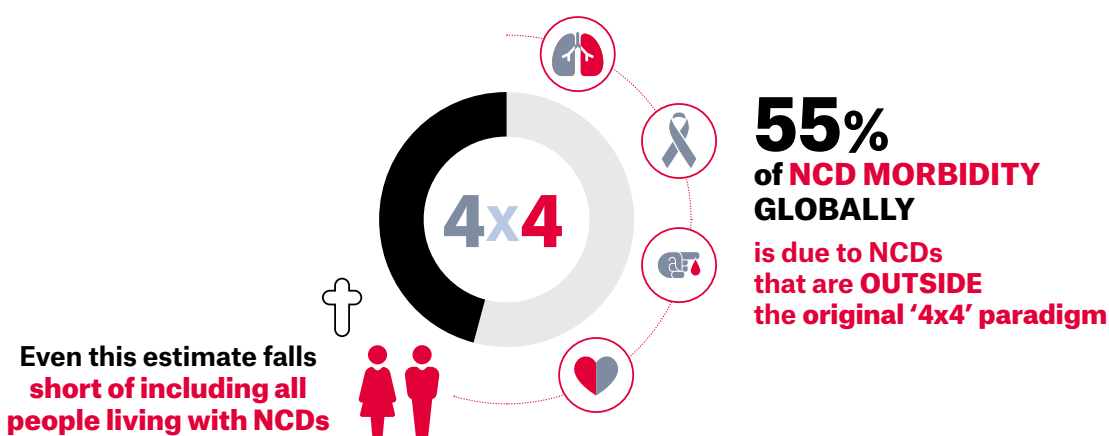
Towards a more inclusive NCD agenda

NCDs in the current '5x5' framework are high on the policy radar, but the absence of several NCDs has led to concerns that many people living with NCDs are falling between the cracks. The scope of conditions which fall outside '5x5' approach is varied.

It is estimated that 55% of NCD morbidity globally is due to NCDs that are outside the original '4x4' NCD paradigm.¹⁹ These include a diverse set of causes and conditions, but among them are musculoskeletal disorders, especially low back and neck pain, depression, substance use disorders, cirrhosis of the liver, chronic kidney disease, asthma, various digestive diseases including peptic ulcer, anxiety disorders, congenital anomalies and haemoglobinopathies.

Even this estimate falls short of including all people living with NCDs. Conditions such as oral diseases, for example, affect 3.5 billion people globally, vision impairment or blindness caused by NCDs affect roughly 2.2 billion, and 1.6 billion people are thought to be at risk of thyroid disorders worldwide.^{20, 21, 22}

Mental health is now included in the '5x5' approach, but neurological conditions, such as stroke, migraine, and Alzheimer's disease and other dementias, have not thus far been given the same prioritisation as NCDs and have been treated as a subset of mental health. However, WHO is currently developing an intersectoral global action plan on epilepsy and other neurological disorders.²³



3.5
BILLION PEOPLE
ORAL DISEASES



2.2
BILLION PEOPLE
VISION IMPAIRMENT
OR BLINDNESS



1.6
BILLION PEOPLE
RISK OF THYROID
DISORDERS

19 Lopez A, Williams T, Levin A, et al. Remembering the forgotten non-communicable diseases. BMC Medicine. 2014; <https://bmcmedicine.biomedcentral.com/track/pdf/10.1186/s12916-014-0200-8>

20 Peres MA, Macpherson LMD, Weyant RJ, et al. Oral diseases: a global public health challenge. The Lancet. 2019;394:249-60; [https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(19\)31146-8.pdf](https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(19)31146-8.pdf)

21 NCD Alliance, The Fed Hollows Foundation. Integrating eye health into the NCD response. People-centred approaches to prevention and care, 2020; <https://ncdalliance.org/resources/integrating-eye-health-into-the-ncd-response-people-centred-approaches-to-prevention-and-care>

22 Khan A, Khan MM, Akhtar S. Thyroid disorders, etiology and prevalence. J Med Sci 2002; 2: 89–94; <http://www.scialert.net/fulltext/?doi=jms.2002.89.94&org=11>

23 Web-based consultation on the first draft of the Intersectoral global action plan on epilepsy and other neurological disorders, 2021; <https://www.who.int/news-room/articles-detail/Web-based-consultation-on-the-first-draft-of-the-Intersectoral-global-action-plan-on-epilepsy-and-other-neurological-disorders>

The bidirectional nature of NCDs

People living with NCDs often experience conditions in clusters (e.g. heart disease, high blood pressure, diabetes, depression, anxiety and chronic kidney disease), and there are bidirectional relationships between certain NCDs and infectious diseases e.g. diabetes and Tuberculosis (TB); cervical cancer and Human Immunodeficiency Virus (HIV).^{24,25} This has been well illustrated most recently by the interactions between NCDs and COVID-19.

The prevalence and recognition of people living with more than one NCD has steadily increased over the past 20 years to the extent that it is now the norm in high-income countries and an ever-increasing issue in low-income countries.²⁶ Multimorbidity is therefore a growing public health concern and speaks to the need to break down siloes, as each disease may trigger or worsen other conditions, synergistically lowering the quality of life for the individual affected.²⁷



24 Clark A, Jit M, Warren-Gash C, et al. Global, regional, and national estimates of the population at increased risk of severe COVID-19 due to underlying health conditions in 2020: a modelling study. *Lancet Global Health*. 2020; <https://www.thelancet.com/action/showPdf?pii=S2214-109X%2820%2930264-3>

25 The Academy of Medical Sciences. Multimorbidity: a priority for global health research, 2018; <https://acmedsci.ac.uk/policy/policy-projects/multimorbidity>

26 Clark A, Jit M, Warren-Gash C, et al. Global, regional, and national estimates of the population at increased risk of severe COVID-19 due to underlying health conditions in 2020: a modelling study. *Lancet Global Health*. 2020; <https://www.thelancet.com/action/showPdf?pii=S2214-109X%2820%2930264-3>

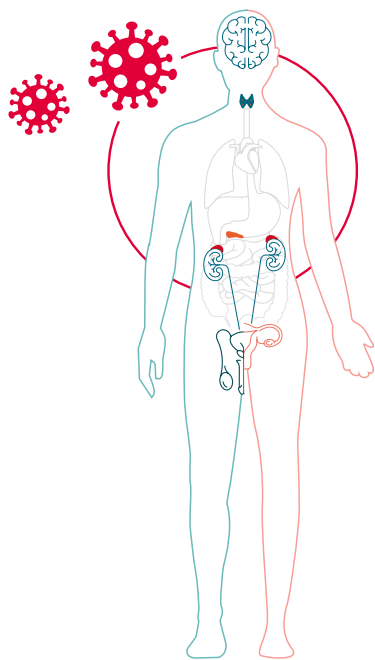
27 The Academy of Medical Sciences. Multimorbidity: a priority for global health research, 2018; <https://acmedsci.ac.uk/policy/policy-projects/multimorbidity>

28 The link between chronic kidney disease and cardiovascular disease, *J Nephropathol*. 2014 Jul; 3(3): 99–104; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4119330/>

NCDs and COVID-19 When two pandemics collide

“Two categories of disease are interacting within specific populations—infection with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and an array of non-communicable diseases (NCDs). COVID-19 is not a pandemic. It is a syndemic. The syndemic nature of the threat we face means that a more nuanced approach is needed if we are to protect the health of our communities.”

Dr Richard Horton, Editor-in-Chief of The Lancet²⁹



The COVID-19 pandemic has underscored the need for further attention to interventions in NCDs, as people with underlying NCDs are at higher risk of severe illness and death from COVID-19.

People with NCDs face a ‘double threat’: they are more vulnerable to complications and death from COVID-19, and they experienced indirect health effects from disruptions in essential care. Many non COVID-19 patients were unable or reluctant to access needed care during the first wave of the pandemic, which resulted in delayed diagnoses, delayed care or foregone care.³⁰

Towards the end of 2021, the pandemic’s true death toll has been estimated at over 20 million, taking into account excess deaths around the world, including NCD deaths due to delayed care and diagnosis.³¹

To build back better health systems during and after the crisis, governments need to commit and ensure that people living with NCDs do not experience disruptions to essential health services. Countries need to tackle the impacts of NCDs in their national COVID-19 response and preparedness plans and develop strengthened health systems with integrated NCD care for future health emergencies. NCD prevention and management is the insurance policy to improve population health and mitigate the impact of any future crisis.³²

People with underlying **ENDOCRINE DISORDERS** such as diabetes, obesity or autoimmune thyroid disease, face an **increased risk of infection from COVID-19**

29 The Lancet, offline: COVID-19 is not a pandemic, 26 September 2020: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)32000-6/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)32000-6/fulltext)

30 OECD Policy Responses to Coronavirus (COVID-19). Strengthening the frontline: How primary health care helps health systems adapt during the COVID 19 pandemic, February 2021; <https://www.oecd.org/coronavirus/policy-responses/strengthening-the-frontline-how-primary-health-care-helps-health-systems-adapt-during-the-covid-19-pandemic-9a5ae6da/#section-d1e177>

31 The Economist, The pandemic’s true death toll: <https://www.economist.com/graphic-detail/coronavirus-excess-deaths-estimates>

32 WHO. The impact of the COVID-19 pandemic on noncommunicable disease resources and services: results of a rapid assessment, 2020; <https://apps.who.int/iris/bitstream/handle/10665/334136/9789240010291-eng.pdf>

COVID-19 has preyed on people living with NCDs, and most of the deaths recorded globally have been amongst people living with chronic underlying conditions, including those not captured by the '5x5' approach. For example, the human endocrine system is believed to be a target for damage by COVID-19 and its inflammatory activities.

People with underlying endocrine disorders such as diabetes, obesity or autoimmune thyroid disease, face an increased risk of infection from COVID-19.³³ In addition, COVID-19 has been associated with post-infection multi-system effects, with evidence of mild impairment in the function of the kidneys, liver, pancreas, spleen, and adrenal glands.^{34,35} COVID-19 can cause pancreatic damage through a cytokine storm in the pancreas resulting in pancreatic endocrine and exocrine damage.³⁶

33 Lisco G, De Tullio A, Jirillo E, Giagulli VA, De Pergola G, Guastamacchia E, et al. Thyroid and COVID-19: a review on pathophysiological, clinical and organizational aspects. *J Endocrinol Invest*. 2021 Mar 25; <https://pubmed.ncbi.nlm.nih.gov/33765288/>

34 NCD Alliance. Briefing note: Impacts of long COVID on health systems and NCD care, 2021; <https://ncdalliance.org/resources/briefing-note-impacts-of-long-covid-on-health-systems-and-ncd-care>

35 Puig-Domingo M, Marazuela M, Yildiz BO, Giustina A. COVID-19 and endocrine and metabolic diseases. An updated statement from the European Society of Endocrinology. *Endocrine*. 2021 May 1;72(2):301–16; <https://pubmed.ncbi.nlm.nih.gov/33963516/>

36 Interplay between endocrinology, metabolism and COVID-19 infection, *Clin Med (Lond)*. 2021 Sep; 21(5): e499–e504; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8439497/>



Endocrine Health

Vital to the functioning of the body

Endocrinology is the field of medicine that relates to hormonal systems. The endocrine system plays an important role in the body's ability to maintain fundamental processes for life including heartbeat regulation, bone/tissue structure and growth, energy intake and expenditure, as well as the ability to conceive. Disorders of the endocrine system are linked to conditions such as diabetes, obesity, atherosclerosis, thyroid disease, growth disorders, hypertension, osteoporosis, infertility and sexual dysfunction, endocrine cancers and a host of other endocrine-related illnesses.³⁷

Hormone-producing glands in the human body include the hypothalamus, the pineal gland, the pituitary gland, the brain, the thyroid and the parathyroid glands, the adrenal gland, the pancreas, the ovaries and the testes.³⁸ However, hormones are also secreted by almost any other tissue in the body such as adipose cells (fat cells), gut, heart, kidney, lung, muscle, skin and bone – all of which have an important role in the regulation and function of the body.³⁹

Symptoms of endocrine system disorders can be vague and related to other medical problems. This means that many people living with endocrine disorders are unaware of their condition or remain undiagnosed. Fatigue and weakness are common symptoms found in many endocrine disorders. Other symptoms may include weight changes, blood glucose level fluctuations, abnormal cholesterol levels and mood changes. Endocrine disorders are usually diagnosed after matching signs and symptoms with blood tests that include hormone levels.

Endocrine diseases have a considerable impact on public health from an epidemiological point of view and because they may cause long-term disability and alter the quality-of-life of the affected patients. Today, both the developed and developing world face serious public health challenges caused by the most common endocrine disorders.

“Endocrine issues can impact a child’s healthy growth and development. Children face latent diagnosis due to the stigma that growth patterns are something less than vital as indicators of health. Pituitary and brain tumours and other life threatening issues could be addressed much earlier if this simple visual indicator of childhood growth was more seriously regarded.”

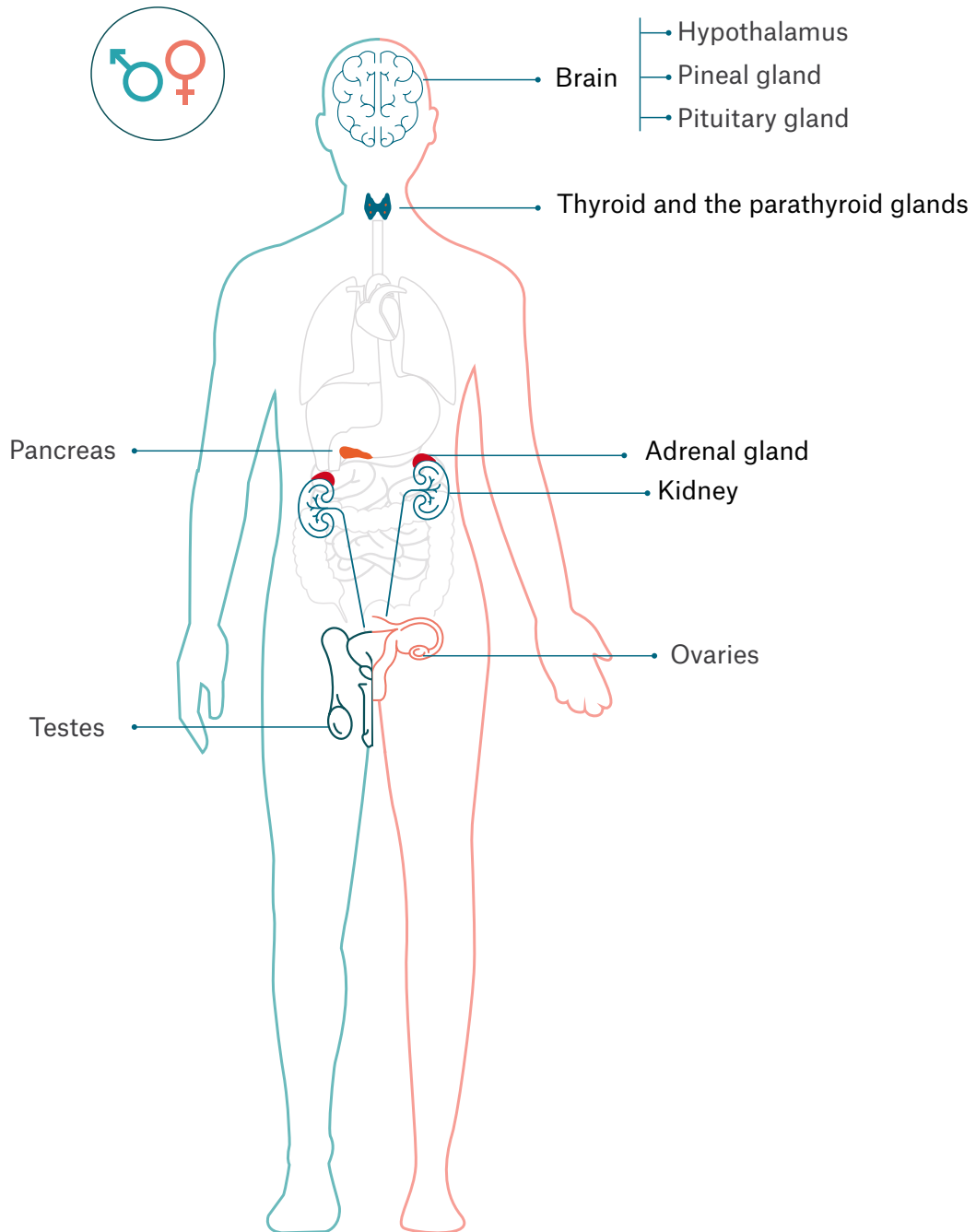
Ms Jamie Harvey, CEO of the International Coalition of Organizations Supporting Endocrine Patients (ICOSEP)

37 WebMD. Endocrine Disorders; <https://www.webmd.com/diabetes/endocrine-system-disorders>

38 Hormone Health Network, Fact sheet “What is Endocrinology ? – The Endocrine System” <https://www.hormone.org/what-is-endocrinology/the-endocrine-system>

39 European Society of Endocrinology. Hormones in European Health Policies: How endocrinologists can contribute towards a healthier Europe, 2021; https://www.es-e-hormones.org/media/3220/ese-white-paper_04052021-web.pdf

The endocrine system



COVID-19 and endocrine health

Research shows that endocrine related conditions impact the outcomes of patients with COVID-19.⁴⁰ There is recent evidence that people suffering from hormone conditions, such as diabetes and obesity, have more severe symptoms and health outcomes including death.^{41,42} It has been proven that people suffering from underlying endocrine-related diseases, who are infected by COVID-19 are more likely to suffer severe symptoms, be admitted to intensive care units (ICU) as well as have an increased risk of death. Moreover, endocrine systems could suffer in the long-term from the impact of COVID-19.⁴³

The endocrine system is strongly involved in COVID-19 - so much so that evidence of an “endocrine phenotype” of COVID-19 has emerged.⁴⁴

It is possible that the effects of COVID-19 on the endocrine system are underreported due to lack of awareness by the public, primary care givers and specialists, and there is still much to learn about the damaging effects of the virus on the endocrine organs. More follow-up research is required to determine the possible long-term effects of COVID-19 on the endocrine system.⁴⁵



40 Artl W. et al., “Endocrinology in the time of COVID-19”, *European Journal of Endocrinology*, 2020, vol. 183, no. 1, pp E1–E2; <https://doi.org/10.1530/EJE-20-0386>

41 Barron, E. et al., “Associations of type 1 and type 2 diabetes with COVID-19-related mortality in England: a whole-population study”, *The Lancet Diabetes & Endocrinology*, 2020, vol. 8, no. 10, pp 813–822; [https://doi.org/10.1016/S2213-8587\(20\)30272-2](https://doi.org/10.1016/S2213-8587(20)30272-2)

42 Lockhart, S.M. and O’Rahilly, S., “When Two Pandemics Meet: Why Is Obesity Associated with Increased COVID-19 Mortality?”, *Med*, 2020; <https://doi.org/10.1016/j.medj.2020.06.005>

43 European Society of Endocrinology. Studies show strong links between the endocrine system and COVID-19 incidence and mortality, 2020; <https://www.newswise.com/articles/studies-show-strong-links-between-the-endocrine-system-and-covid-19-incidence-and-mortality>

44 European Society of Endocrinology. New expert statement confirms strong links between our hormones and COVID-19, 2021; <https://www.eurekalert.org/news-releases/632194>

45 *Clin Med (Lond)*. 2021 Sep; 21(5): e499–e504. Interplay between endocrinology, metabolism and COVID-19 infection; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8439497/>

Thyroid disorders

“When the first problems with my health started the diagnosis was hyperthyroidism and nodular goiter. Since I am a professional athlete the best solution was to completely remove my thyroid because the standard of care treatment was unsuccessful and this process would be lengthy and I would need to stop training. Even though I don’t have a thyroid, I never gave into the thought that I was missing an organ and how to live without it. Life is short and we should all try to live life to the fullest. When you condition your mind to believe that anything is possible then no challenge becomes too difficult.”

Ms Ivana Habazin, Vice President of the Croatian Society of Thyroid diseases, lives with thyroid conditions (hyperthyroidism, nodular goiter) and a professional athlete (boxer)

The thyroid gland is a butterfly-shaped organ located at the base of the neck, in front of the windpipe. It is the “master controller” of metabolism, and plays a key role in health and wellbeing. Too little thyroid hormone (hypothyroidism) or too much thyroid hormone (hyperthyroidism) can lead to health issues.

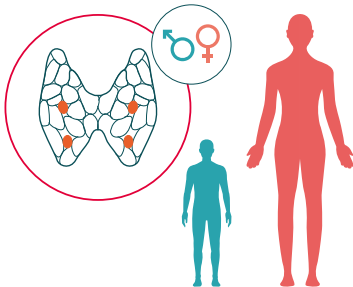
Worldwide, 1.6 billion people are thought to be at risk of thyroid disorders, with one in eight women developing thyroid problems in their lifetimes.^{46,47} Too little or too much thyroid hormone can cause disrupted menstrual cycles and ovulation and problems getting pregnant and during pregnancy, and can lead to early menopause. However, thyroid disease, especially hypothyroidism, is more likely to develop after menopause.⁴⁸

Thyroid diseases afflict far more women than men. Hypothyroidism and hyperthyroidism are about 10 times more common in women than men.⁴⁹

Patients with an underactive thyroid need continuous care, as poor health management can lead to several health complications, including obesity, depressive spectrum disorders, and increased risk of female infertility.⁵⁰

1.6
BILLION PEOPLE
are thought to be at risk
of thyroid disorders

**Thyroid diseases afflict far
more women than men**



**Hypothyroidism and
hyperthyroidism are about**

10 TIMES MORE
common in **WOMEN** than men

46 Khan A, Khan MM, Akhtar S. Thyroid disorders, etiology and prevalence. J Med Sci 2002; 2: 89–94; <http://www.scialert.net/fulltext/?doi=jms.2002.89.94&org=11>

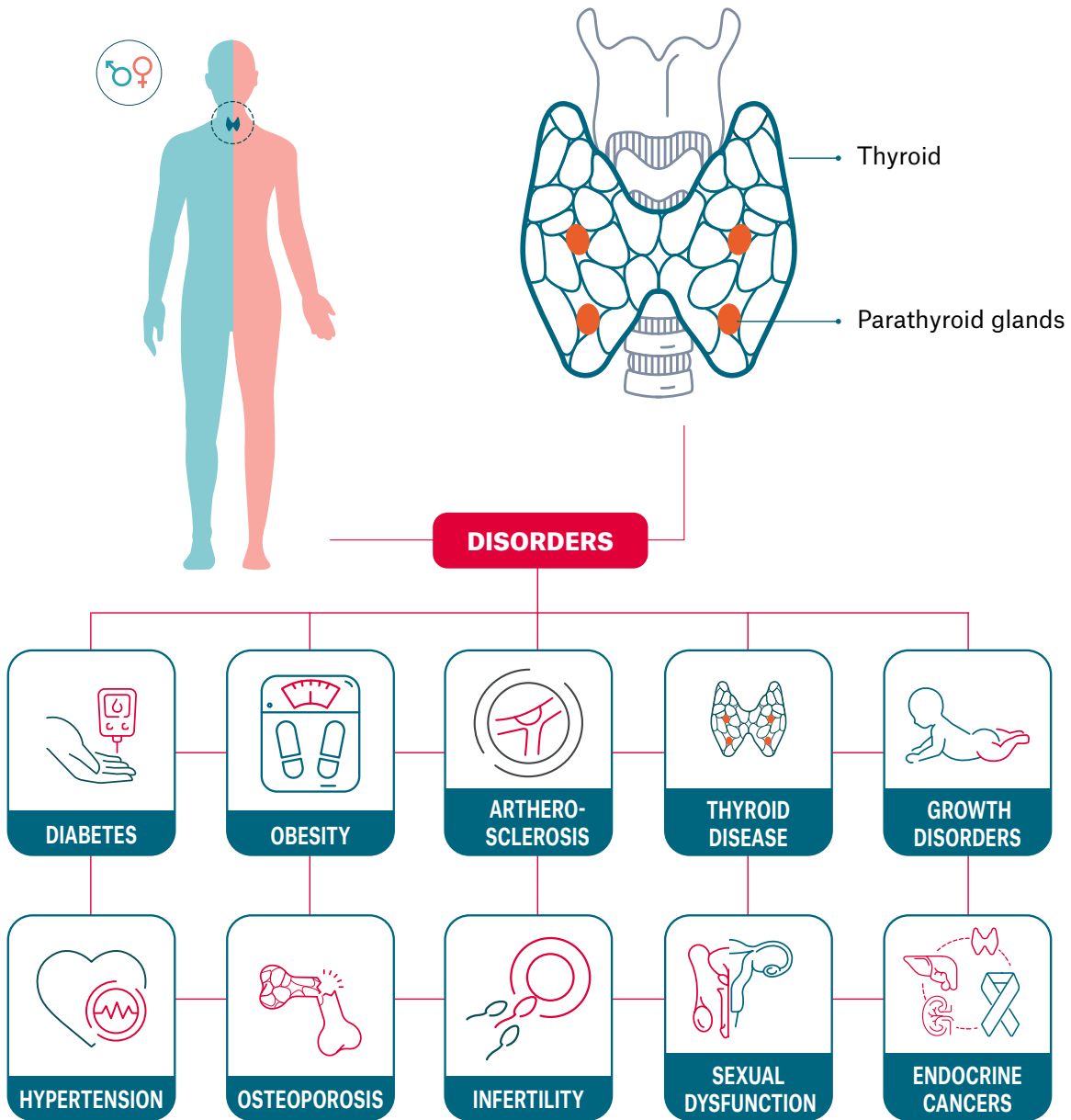
47 Thyroid Awareness: What Happens When This Little Gland Goes Haywire, 2020; <https://www.healthywomen.org/content/article/thyroid-awareness-what-happens-when-little-gland-goes-haywire>

48 Ibid 51.

49 McAninch EA, Glueck JS, Bianco AC. Does Sex Bias Play a Role for Dissatisfied Patients With Hypothyroidism?. J Endocr Soc. 2018;2(8):970-973. Published 2018 Jul 9. doi:10.1210/js.2018-00169

50 Womens Health Rep (New Rochelle). 2021; 2(1): 182–194, Improving the Quality of Life of Patients with an Underactive Thyroid Through mHealth: A Patient-Centered Approach; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8243709/>

Thyroid disorders



“Thyroid patients are struggling in finding adequate care in current healthcare systems. Why is this important? Thyroid hormone is needed for every cell in the body to operate and to function properly. Without proper levels of thyroid hormone, the following disorders and conditions occur or have an increased risk of occurring: depression/anxiety, heart issues, obesity, metabolic issues, relentless fatigue, attention deficit hyperactivity disorder (ADHD), digestive conditions, diabetes, polycystic ovary syndrome (PCOS), adrenal dysfunction, and others.”

Ms Denise Roguz, living with a thyroid condition (hypothyroidism), Patient Advocate - ThyroidChange, United States

The long-term impacts of uncontrolled hypothyroidism can be deadly. They include a **13% increased risk of ischemic/coronary heart disease, 15% increased risk of heart attack (myocardial infarction) and almost doubled increase of cardiac mortality.**⁵¹

Many thyroid dysfunctions are common and easily treatable. However, if undiagnosed, they can significantly affect health due to the vital role that thyroid hormones play in regulating heart and gastrointestinal function, brain development and function, physical development, and cellular metabolism.⁵²

Iodine deficiency in daily nutrition is the main cause of endemic goiter (enlargement of the thyroid gland in the neck) and hypothyroidism, an issue of extreme concern since one third of the world's population lives in iodine-depleted areas.⁵³ The World Health Assembly (WHA) called for a strengthening of efforts to eliminate iodine deficiency disorders globally in a 2005 Resolution.⁵⁴

“Iodine deficiency sets into motion many aspects of thyroidal disorders. Its prevention - through the use of adequately iodized salt - is so simple and inexpensive but often overlooked. My patients with thyroid problems live with chronic disorders affecting their quality of life and productivity, with loss of economic opportunities. Thyroid disorders do not receive enough attention.”

Dr Teofilo O.L. San Luis Jr, Doctor, Quezon City, Philippine Thyroid Association

In 2011, the UN included hypothyroidism (and specifically congenital hypothyroidism) in its communication on NCDs *Deemed [a] Development Challenge of 'Epidemic Proportions'*.⁵⁵

In 2019, the WHO included thyroid disorders in its global guidance on medicines and diagnostic tests to address health challenges, prioritize highly effective therapeutics, and improve affordable access.⁵⁶

51 Ning Y, Cheng YJ, Liu LJ, et al. What is the association of hypothyroidism with risks of cardiovascular events and mortality? A meta-analysis of 55 cohort studies involving 1,898,314 participants. *BMC Med.* 2017;15(1):21. Published 2017 Feb 2. doi:10.1186/s12916-017-0777-9

52 Taylor PN, Albrecht D, Scholz A, Gutierrez-Buey G, Lazarus JH, Dayan CM, et al. Global Epidemiology of Hyperthyroidism and Hypothyroidism. *Nat Rev Endocrinol* (2018) 14(5):301–16. doi: 10.1038/nrendo.2018.18; <https://pubmed.ncbi.nlm.nih.gov/29569622/>

53 Foresight Global Health. The thyroid, the organ below the radar, 2021; <https://foresightglobalhealth.com/the-thyroid-the-organ-below-the-radar/>

54 WHA58.24 Sustaining the elimination of iodine deficiency disorders, Ninth plenary meeting, 25 May 2005, (Committee A, sixth report): https://apps.who.int/gb/ebwha/pdf_files/WHA58/WHA58_24-en.pdf

55 UN 2011: <https://www.un.org/press/en/2011/ga11138.doc.htm>

56 WHO 2019: <https://www.who.int/news/item/09-07-2019-who-updates-global-guidance-on-medicines-and-diagnostic-tests-to-address-health-challenges-prioritize-highly-effective-therapeutics-and-improve-affordable-access>

Academics and medical professionals have called for national hypothyroidism strategies, especially newborn screening. In India, experts have called hypothyroidism, *an easy-to-detect and inexpensive-to-treat disease that remains undetected and untreated*.⁵⁷

The European Society of Endocrinology (ESE) and European Thyroid Association (ETA) have put forward a policy call to action, proposing to formulate a petition addressed to the European Commission stressing the necessity to acknowledge thyroid diseases as NCDs.⁵⁸

In countries where hypothyroidism is not prioritised in the context of NCDs, patient groups are advocating for increased attention on hypothyroidism. For example, in Canada, Thyroid Patients Canada were disappointed at the governments non-inclusion of thyroid diseases in an information and awareness campaign on chronic diseases.⁵⁹

The thyroid can of course be connected to other NCDs. Thyroid cancer develops from the tissues of the thyroid gland and is the most pervasive endocrine cancer worldwide.⁶⁰ Globally, the incidence of thyroid cancer has increased substantially in the past three decades.⁶¹

“While at my local doctor’s surgery for something else, my GP checked my neck to feel my pulse. Thankfully, she found it – but she also found a lump. I had a total thyroidectomy (surgical removal of the whole thyroid gland). I was told after the surgery that the tumour was the size of a plum, and that the cancerous cells had spread. Several months later I underwent radioactive iodine treatment. I have a thyroid function test every 3-6 months – it’s been a struggle to find the right balance of thyroxine. I’ve had some extreme swings between having too much or too little – both come with side effects. I’m hopeful we’ll get it right.”

Joan, had thyroid cancer, United Kingdom, credit [‘The British Thyroid Foundation.’](#)

1/8
WOMEN
develops
thyroid
problems in her
lifetime

DISRUPTED
MENSTRUAL
CYCLES AND
OVULATION

PROBLEMS
GETTING
PREGNANT
AND
DURING
PREGNANCY

Thyroid disease,
especially
HYPOTHYROIDISM,
is more likely to
develop after
menopause.

57 The Lancet, 2014: Hypothyroidism in India: more to be done; [https://www.thelancet.com/journals/landia/article/PIIS2213-8587\(14\)70208-6/fulltext](https://www.thelancet.com/journals/landia/article/PIIS2213-8587(14)70208-6/fulltext)

58 See Page 34, European Society of Endocrinology. Hormones in European Health Policies: How endocrinologists can contribute towards a healthier Europe, 2021; https://www.es-e-hormones.org/media/3220/ese-white-paper_04052021-web.pdf

59 Thyroid Patients Canada, 2019, <https://thyroidpatients.ca/2019/06/10/hypothyroidism-is-not-a-chronic-disease-in-canada/>

60 JAMA Netw Open. 2020 Jun; 3(6): e208759, Global Burden of Thyroid Cancer From 1990 to 2017; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7320301/>

61 The Lancet Diabetes & Endocrinology. Comment. Volume 9, Issue 4, P193-194, April 1, 2021, A worldwide journey of thyroid cancer incidence centred on tumour histology; [https://www.thelancet.com/journals/landia/article/PIIS2213-8587\(21\)00049-8/fulltext](https://www.thelancet.com/journals/landia/article/PIIS2213-8587(21)00049-8/fulltext)

COVID-19 and thyroid disorders

In the earlier stages of the COVID-19 pandemic, there was no data suggesting that thyroid patients were at higher risk of COVID-19, but this needed further research and data analysis.⁶² There is still a need for further studies to determine the risks and severity of COVID-19 infection among patients with a thyroid disorder.⁶³

Thyroid disease does seem to be associated with an enhanced risk of severe COVID-19 infection.⁶⁴

COVID-19 infection can lead to exacerbation of pre-existing autoimmune thyroid disease.⁶⁵ Therefore, early diagnosis and management of thyroid disorders during the pandemic might help to reduce any potential risks and improve the clinical outcome of COVID-19 infection in patients with previously undiagnosed thyroid disease.

COVID-19 infection has been found to affect thyroid function as well as the management of thyroid disease. Therefore, frequent and thorough evaluation of thyroid profile in COVID-19 patients is vital as it will facilitate a planned proper treatment.⁶⁶

In terms of COVID-19 vaccination roll out, the European Thyroid Association (ETA) and others recommended that vulnerable thyroid patients should be considered for a prioritised vaccination.⁶⁷ The COVID-19 pandemic has deeply altered the conventional management of outpatient thyroid disorders as a consequence of social distancing policy, cut or closure of non-emergency health services, overburdened primary care, unavailability of diagnostic tools and treatments. In this context telemedicine could enhance specific aspects of thyroid care.⁶⁸

The thyroid gland and the virus infection with its associated inflammatory-immune responses are known to be engaged in complex interplay.⁶⁹ COVID-19-induced smell dysfunction could be triggered by a direct viral attack of both the olfactory nerve and the thyroid gland.⁷⁰ Until more is understood regarding the impact of coronavirus on the thyroid gland, it seems advisable to monitor patients with COVID-19 for new thyroid disease or progression of pre-existing thyroid disease.⁷¹

“Thyroid conditions, from thyroid cancer to thyroid eye disease, can prevent people from being able to work. People living with thyroid related issues had to be extra careful in COVID-19 pandemic as it is an autoimmune disease.”

Ashok Bhaseen, President Thyroid Federation International

62 Endocrine. 2020; 68(3): 471–474, Thyroid disease in the time of COVID-19; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7275975/>

63 Journal of Medical Virology. Letter to the editor. The association between biochemically confirmed thyroid gland disorder and morbidity and mortality in patients with COVID-19, July 2021: <https://onlinelibrary.wiley.com/doi/10.1002/jmv.27213>

64 Diabetes Metab Syndr. 2020 September-October; 14(5): 1429–1430, Thyroid disease is associated with severe coronavirus disease 2019 (COVID-19) infection; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7387272/>

65 Lui DTW, Lee CH, Chow WS, et al. Thyroid dysfunction in relation to immune profile, disease status, and outcome in 191 patients with COVID-19. J Clin Endocrinol Metab. 2020;106(2): e926-e935; <https://pubmed.ncbi.nlm.nih.gov/33141191/>

66 Clinical Case Reports. Thyroid disease and covid-19 infection: Case series, June 2021; <https://onlinelibrary.wiley.com/doi/10.1002/ccr3.4225>

67 European Thyroid Association. Vaccination and Thyroid Disease. <https://www.eurothyroid.com/files/download/ETA-PHB-Vaccination.pdf>

68 Chatterjee S, Ghosh R, Biswas P, Dubey S, Guria RT, Sharma CB, Kalra S. COVID-19: The endocrine opportunity in a pandemic. Minerva Endocrinol. 2020;45(3):204–27. <https://doi.org/10.23736/S0391-1977.20.03216-2>

69 Scappaticcio, L., Pitoia, F., Esposito, K. et al. Impact of COVID-19 on the thyroid gland: an update. Rev Endocr Metab Disord (2020). <https://doi.org/10.1007/s11154-020-09615-z>

70 Tsigvoulis G, Fragkou PC, Karofylakis E, et al Hypothyroidism is associated with prolonged COVID-19-induced anosmia: a case–control study Journal of Neurology, Neurosurgery & Psychiatry 2021; 92:911-912; <https://jnnp.bmj.com/content/92/8/911>

71 Leonidas H Duntas, Jacqueline Jonklaas, COVID-19 and Thyroid Diseases: A Bidirectional Impact, Journal of the Endocrine Society, Volume 5, Issue 8, August 2021, bvab076; <https://doi.org/10.1210/jendso/bvab076>

Kidney disease

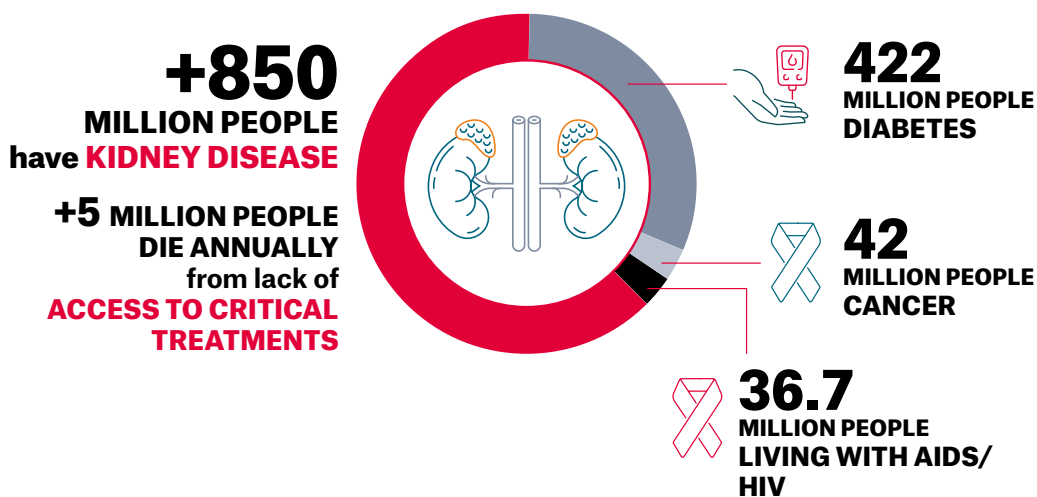
The kidney is traditionally regarded as an exocrine gland, but it also performs multiple endocrine roles; producing various hormones. The kidney is often affected by other endocrine diseases. Thyroid disorders can also affect the renal structure and function.⁷²

Chronic Kidney Disease (CKD) is increasingly recognised as a global public health problem. Kidney failure is the most severe form of CKD, and is fatal if not treated by renal replacement therapy (RRT), which can be dialysis or kidney transplantation. The prevalence and associated burden of CKD is rising worldwide; with the fastest growth occurring in low-income and middle-income countries.⁷³

Globally, the total number of people suffering from kidney disease exceeds 850 million⁷⁴ and, more than 5 million people die annually from lack of access to critical treatments for kidney disease. By 2040, chronic kidney disease is projected to be the fifth leading cause of death worldwide.⁷⁵

Every year millions die prematurely of complications related to CKD. If CKD is detected early and managed appropriately, the deterioration in kidney function can be slowed or even stopped. High blood pressure (hypertension) and diabetes are the most common causes of kidney disease. The majority of individuals with early stages of CKD go undiagnosed.⁷⁶

CKD can lead to the development of other conditions, such as heart failure or cardiovascular problems. Approximately 10% of the world's population is living with CKD; however, CKD incidence and prevalence differ significantly across countries and world regions. Although people of every age and race are affected by CKD, people from disadvantaged populations may be at higher risk for the condition (and associated morbidity and mortality) due to socio-economic factors and limited access to care.⁷⁷



72 Indian J Endocrinol Metab. 2012 Mar-Apr; 16(2): 154–155. Renal endocrinology: The new frontier; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3313729/>

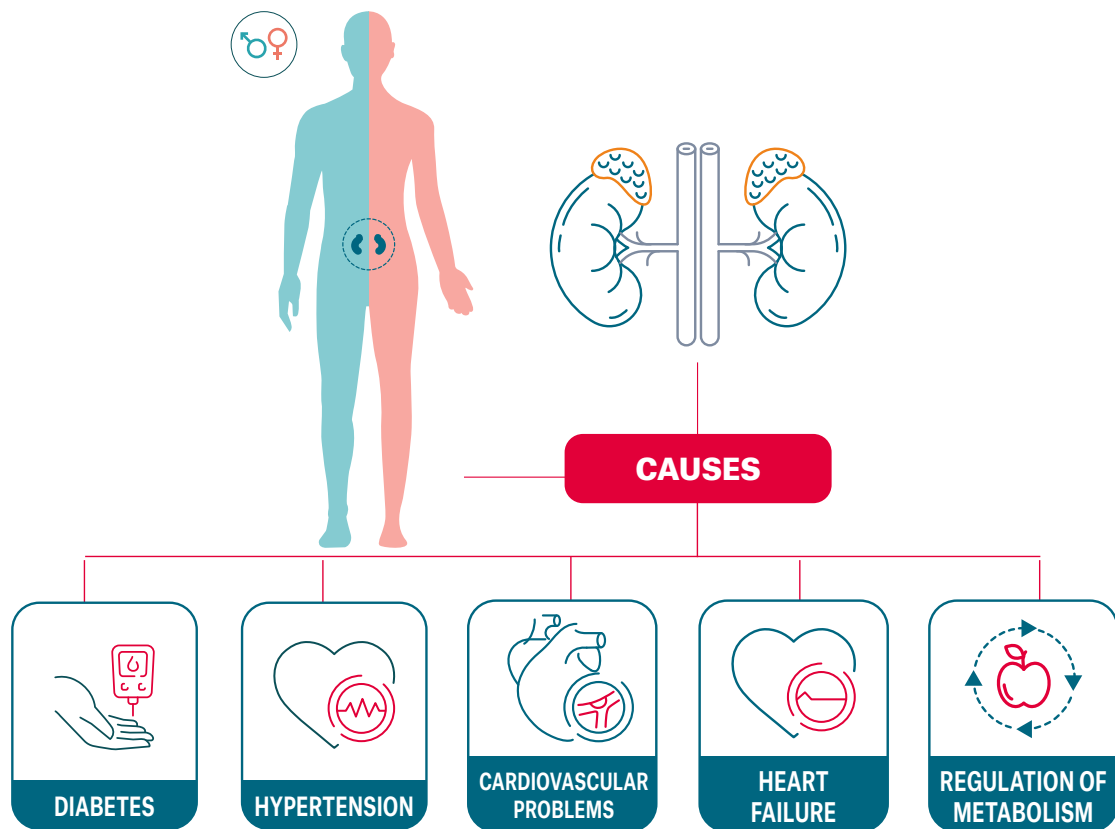
73 The Lancet. Review, Volume 390, Issue 10105, P1888-1917, October 21, 2017, Global kidney health 2017 and beyond: a roadmap for closing gaps in care, research, and policy; [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)30788-2/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)30788-2/fulltext)

74 <https://www.theisn.org/blog/2020/11/27/more-than-850-million-worldwide-have-some-form-of-kidney-disease-help-raise-awareness/>

75 Luyckx, V.A., Al-Aly, Z., Bello, A.K. et al. Sustainable Development Goals relevant to kidney health: an update on progress. Nat Rev Nephrol 17, 15–32 (2021). <https://doi.org/10.1038/s41581-020-00363-6>

76 World Kidney Day. Chronic kidney disease (CKD); <https://www.worldkidneyday.org/facts/chronic-kidney-disease/>

77 https://www.theisn.org/wp-content/uploads/2021/05/GKHAAtlas_2019_WebFile-1.pdf



“Unfortunately, despite the global burden of kidney disease and the millions of related deaths that occur each year, the critical role that kidneys play in our overall health is not often recognised by the public, who, frequently, does not perceive kidneys to be essential organs that must be monitored and kept healthy.”

Ms Maria Rita Milanese, Advocacy & Projects Officer, International Society of Nephrology (ISN)

The increase in CKD as a cause of death may reflect the rising prevalence of CKD globally related to population ageing as well as improving access to diagnosis in lower-income settings, but may also reflect the need to further invest in kidney disease to bring innovations to the patients.⁷⁸

Patients’ involvement in nephrology clinical trials is limited, despite the fact that their inclusion helps guarantee that the data generated is aligned with their priorities, maximises recruitment and retention, and assesses the research’s impact on practice and policy.⁷⁹ A remarkable example of the exclusion of kidney patients from clinical trials is the absence of people undergoing dialysis treatment in any of the COVID-19 vaccine trials globally.⁸⁰

78 Clinical Kidney Journal, Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney, Volume 14, Issue 7, July 2021, Pages 1719–1730; <https://doi.org/10.1093/ckj/sfab070>

79 <https://www.theisn.org/blog/2019/07/19/kidney-patients-are-neglected-in-clinical-trials/>

80 Kidney International. The urgent need to vaccinate dialysis patients against severe acute respiratory syndrome coronavirus 2: a call to action. February 11, 2021. <https://doi.org/10.1016/j.kint.2021.02.003>

Substantial gaps in research, care, and policy that severely compromise outcomes of patients with CKD around the world. Targeting CKD will be an important consideration for reaching the SDGs.⁸¹

The number of people receiving kidney replacement therapy exceeded 3 million in 2017 and is projected to grow to 5.4 million by 2030.⁸² Kidney replacement therapy comes at a high societal cost and costs will rise further due to the projected growth in patient numbers.⁸³

“There is far not enough attention and awareness for our issue, kidney disease, which is still considered an ancillary issue, whereas societal cost and burden to patients is huge (as much as for cancer). Yet, there is much less investment in innovation and research, and we remain stuck with “historical” solutions like dialysis, which come far too late during the patient’s course.”

Prof. Raymond Vanholder, President of the European Kidney Health Alliance (EKHA) - The Decade of the Kidney™ campaign has been launched to put the spotlight on kidney disease.⁸⁴

Kidney disease remains a major cause of catastrophic health expenditure even where UHC is in place. Beyond UHC, further efforts are needed to ensure sustainable access to NCD care.⁸⁵ Close attention to the delivery of quality care (the lack of which is a major cause of NCD deaths) is critical, incorporating adequate training and support of the health care workforce, as well as ensuring reliable infrastructure and supplies.

The social and psychological impact of CKD: the disease and its human and financial burdens are unknown to many, the intangible nature of how the kidneys function and the difficulty of capturing public attention. The Decade of the Kidney™ campaign has been launched to put the spotlight on kidney disease.⁸⁶

“Kidney disease is both a healthcare and labour force issue. Kidney disease can directly impact your ability to maintain an income and career - and dialysis can very often force a person to depend on disability income or charitable assistance. Because kidney disease results in many other comorbidities - the cost, even with insurance can be high because of co-pays, out of pocket medical supplies and devices as well as high food costs if you are trying to maintain a low salt, renal friendly diet. The economic cost of kidney disease also has tremendous psycho social costs for patients who become unable to work and dependent on disability - there is great stigma and guilt, as well as isolation from co-workers and other friends.”

Mr Paul Conway, Chair of Policy and Global Affairs, and Immediate Past President, of the American Association of Kidney Patients (AAKP), living with Chronic Kidney Disease (CKD), United States

81 Carney, E.F. The impact of chronic kidney disease on global health. *Nat Rev Nephrol* 16, 251 (2020). <https://doi.org/10.1038/s41581-020-0268-7>

82 ISN Global Kidney Health Atlas, 2019; [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)00732-7/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00732-7/fulltext)

83 *Clinical Kidney Journal*, Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney, Volume 14, Issue 7, July 2021, Pages 1719–1730; <https://doi.org/10.1093/ckj/sfab070>

84 EKHA. The Decade of the Kidney. <http://ekha.eu/the-decade-of-the-kidney/>

85 *Kidney 360*. Equity is key to Build Back Better after COVID-19: prioritize non-communicable diseases and kidney health, February 2021; <https://kidney360.asnjournals.org/content/kidney360/early/2021/02/01/KID.0006932020.full.pdf>

86 EKHA. The Decade of the Kidney. <http://ekha.eu/the-decade-of-the-kidney/>

COVID-19 and kidney disease

The COVID-19 pandemic is exerting an enormous impact on people living with kidney disease, including disruptions to care and the impact on mental health.⁸⁷

- CKD is one of the most prevalent risk factors for severe COVID-19.⁸⁸
- Patients with severe forms of CKD have a very high risk of COVID-19 mortality.⁸⁹
- In addition, a growing body of evidence suggests that COVID-19 can induce kidney damage.⁹⁰
- Kidneys are often impacted in patients with acute COVID-19 infection, and inflammation and injury may persist for many months, resulting in a progressive decline in kidney function which can lead to chronic kidney disease.⁹¹
- Over a quarter of patients hospitalised with COVID-19 have been reported to develop acute kidney injury (AKI).⁹²
- People who have recovered from COVID-19 have a greater risk of kidney disease, even if they only experienced mild to moderate COVID-19 symptoms and were not admitted to hospital.⁹³
- People living with long COVID - even those who experienced mild cases—are at significantly increased risk for substantial declines in kidney function, such as organ damage and chronic and end-stage kidney disease (ESKD).⁹⁴
- Dialysis patients faced the dual challenge of being both at higher (up to 20 times greater than the general population) risk of infection from COVID-19, due to their inability to self-isolate as a result of requiring regular in-centre care and having a disproportionately higher level of suffering from adverse outcomes once infected. This results in a risk of death several times greater than those infected and hospitalised from the (age adjusted) general population.⁹⁵

“In general, patients with renal disease are more susceptible to contract coronavirus and COVID. Dialysis patients require hospital treatments 3x per week and have to travel a lot. Transplant patients are more at risk because of their immunosuppressive drug use.”

Dr Jasper Boomker, Dutch Kidney Foundation

87 JKC. ‘Worried sick’—the impact of COVID-19 on people living with kidney disease: findings from a patient survey, Published Online:29 Jul 2020; <https://doi.org/10.12968/jokc.2020.5.4.176>

88 ERA-EDTA Council, ERACODA Working Group, Chronic kidney disease is a key risk factor for severe COVID-19: a call to action by the ERA-EDTA, Nephrology Dialysis Transplantation, Volume 36, Issue 1, January 2021, Pages 87–94, <https://doi.org/10.1093/ndt/gfaa314>

89 Gansevoort, R.T., Hilbrands, L.B. CKD is a key risk factor for COVID-19 mortality. *Nat Rev Nephrol* 16, 705–706 (2020). <https://doi.org/10.1038/s41581-020-00349-4>

90 Nature. COVID-19 and nephrology, 2021; <https://www.nature.com/collections/gggidgechf/>

91 Yende, S., Parikh, C.R. Long COVID and kidney disease. *Nat Rev Nephrol*(2021). <https://doi.org/10.1038/s41581-021-00487-3>

92 Legrand, M., Bell, S., Forni, L. et al. Pathophysiology of COVID-19-associated acute kidney injury. *Nat Rev Nephrol* 17, 751–764 (2021). <https://doi.org/10.1038/s41581-021-00452-0>

93 *BMJ* 2021;374:n2189, Covid-19: Infection increases the risk of kidney disease even in mild cases, finds study; <https://doi.org/10.1136/bmj.n2189>

94 COVID long-haulers may be at risk for severe kidney disease, September 2021; <https://www.cidrap.umn.edu/news-perspective/2021/09/covid-long-haulers-may-be-risk-severe-kidney-disease>

95 *Kidney International*. The urgent need to vaccinate dialysis patients against severe acute respiratory syndrome coronavirus 2: a call to action. February 11, 2021. <https://doi.org/10.1016/j.kint.2021.02.003>

Survey findings on inclusive NCD responses

Methodology

The NCD Alliance carried out a global survey to further understand the impact of conditions which fall outside the '5x5' approach.

The survey was distributed to the NCD Alliance membership and network, including, the participants of the Peer Learning Advocacy Network (PLAN) on an Inclusive NCD Agenda, the International Society of Nephrology, the International Society of Endocrinology, and members of the "Our Views, Our Voices" Initiative. Thyroid Federation International, the International Coalition of Organizations Supporting Endocrine Patients, the Federation of International Nurses in Endocrinology and the World Alliance of Pituitary Organizations were also consulted.

The survey gathered over 40 responses from participants from Africa, Asia, Europe and the Americas, as well as global and EU levels. The survey was developed using an online questionnaire, by means of closed/open survey questions, to gather experiences and expectations on inclusive NCD responses. The survey was disseminated and replies collected from October-November 2021. The survey replies were complemented with additional qualitative insight gathering from selected survey participants.

The survey highlighted how NCDs and conditions outside the '5x5' approach can hinder different aspects of life. It highlighted the following key themes:

- Impact on quality of life
- Socio-economic impact
- Ensuring more inclusive NCD responses

Impact on quality of life

People living with NCDs were asked to highlight any aspects from a quality of life perspective (bearing in mind what quality of life means to them). Challenges were emphasised on a number of fronts, from lack of diagnosis, access to care, the impact of symptoms on day-to-day life to the effect on family members.

"I struggled unnecessarily for many years with debilitating symptoms from thyroid disease and chronic illness. Around 2009, after I completed my master's degree at Michigan State University, my life began to unravel. I always struggled with depression, anxiety, fatigue, muscle pain, and cognition problems, but suddenly these symptoms were becoming major challenges to my daily existence. I knew something was horribly wrong, but no doctor could diagnose me despite the classic symptoms of hypothyroidism. Daily troubling symptoms soon deteriorated into a life of being mostly bed- and couch-bound. I was completely disabled. Finally, I was diagnosed with a thyroid condition after the results of a full thyroid function test."

Ms Denise Roguz, living with a thyroid condition (hypothyroidism), Patient Advocate - ThyroidChange, United States

“My experience living with thyroid disease was more difficult prior to my surgery. After surgery I felt like I was reborn, but I still have to be careful. Since I am a professional athlete and train 6 hours every day, I’m used to working hard, during training or normal things like walking or just resting, various symptoms began to appear: sweating of the palms, constant heat episodes, I would sweat when going from warm to cold temperatures and vice versa. Tachycardia occurred during training. I wouldn’t sleep for weeks. I was constantly chronically tired but I couldn’t sleep. I had pain in my eyes and was sensitive to light which bothered me. After surgery I received therapy that I have to take for the rest of my life. 3 months after my thyroid removal I was involved in a professional fight. Although my hormones in those three months were not 100% in order, I personally felt ten times better and very quickly I continued my training. It took 8 months after my surgery to reach an adequate dose and to get my hormones back in order.”

Ms Ivana Habazin, Vice President of the Croatian Society of Thyroid diseases, lives with thyroid conditions (hyperthyroidism, nodular goiter) and a professional athlete (boxer)

“My husband suffers from Chronic Kidney Disease (CKD). As a caregiver I recently developed a thyroid disorder (hypothyroidism). I also suffer from a skin condition and anxiety. I feel that the caregiver should be in the forefront and allowed to take leave from work. It has been a highly challenging time for us as a family - compromising mental, physical and financial wellbeing. My husband lives on immunosuppressants after his kidney transplant and is extremely vulnerable. My own health has been neglected - I experienced lower productivity at work, breathlessness, fatigue, and hair loss, which just demoralised me. I’m on regular medication, but my bones ache and I don’t feel energetic like before.”

Seema, living with a thyroid condition (hypothyroidism), a skin condition and anxiety, caregiver for her husband who lives with Chronic Kidney Disease (CKD), India

“I’ve suffered from lupus and chronic kidney disease for more than ten years. I take medicine every morning and go to see my doctor every three months, which is critical for me to remain healthy and stable. As with the ability to work, I took a whole year off when I was very ill. My disease really had a great impact on me and my family when my son and my husband had to take turns taking care of me back then. I have been impacted by the pandemic because I was afraid my disease might have become worse if I was infected by COVID-19. I know it’s relatively more important that I get medical care consistently.”

Ching-Ying, living with Lupus and Chronic Kidney Disease (CKD), Taipei, Taiwan

“Quality of life to me means having a choice in the treatment options that best help me pursue my aspirations - without being limited by my disease. This is a constant fight - because kidney disease is vicious. I have been able to have an amazing career - but I have had to fight every day to manage my disease. I have lived with chronic kidney disease for 41 years, including 13 years of kidney failure, 3 years on home dialysis, and 25 years on a kidney transplant. I have suffered from severe anaemia, bone disease, gout, mineral deficiency, coronary artery disease, heart attacks and heart stents.”

Mr Paul Conway, Chair of Policy and Global Affairs, and Immediate Past President, of the American Association of Kidney Patients (AAKP), living with Chronic Kidney Disease (CKD), United States

Impact of the COVID-19 pandemic

Some respondents shared that they were forced to isolate as they were immunocompromised. Some experienced disruptions to essential care. Telehealth became very important. The majority of people who participated in the survey were given priority access to the COVID vaccine.

The fact that kidney patients and immunosuppressed kidney transplant patients were not included in the COVID-19 vaccine trials was raised as a major issue of concern.

Socio-economic impact

People living with NCDs were asked to highlight any specific aspects from a socio-economic perspective (e.g. out of pocket payments for health services/medicines, impact on employment/restricted ability to work, household struggles).

Payment for care, rising costs, impact on income and career place huge burdens on people living with conditions outside the '5x5' approach.

“Coverage of medications for children with growth issues is often not covered by various authorities. Payments by families for medical treatments are often impossible or very challenging. Not treating children with growth impacting care may lead to a lifetime of more serious issues.”

Ms Jamie Harvey, CEO of the International Coalition of Organizations Supporting Endocrine Patients (ICOSEP)

“For several years, I suffered so badly [from my thyroid disorder] that I was left completely bed and couch-bound and was unable to work. I lost my job, my marriage, and I was forced to rely on Social Security Disability. All of that changed once I got optimal on thyroid hormone replacement, but it took nearly two decades to find a good doctor. It shouldn't have to be this way for patients.”

Ms Denise Roguz, living with a thyroid condition (hypothyroidism), Patient Advocate - ThyroidChange, United States

“The healthcare system in Croatia is socialised and covers most things. Unfortunately, because of this many times one must wait in order to be seen by doctor. Personally there are times when I must go and pay for private doctors when my conditions requires immediate attention. Of course private doctors are more expensive, but saving time is an advantage. Personally when it comes to one's health I think it is essential to react in a timely manner regardless the cost.”

Ms Ivana Habazin, Vice President of the Croatian Society of Thyroid diseases, lives with thyroid conditions (hyperthyroidism, nodular goiter) and a professional athlete (boxer)

“Living with an NCD has been expensive. Because I was diagnosed with stage 5 end stage renal disease, I needed dialysis immediately. My insurance took a while to accept to pay for my care, which made my initial days of dialysis stressful. With costs rising, and uncertainty, it affected my mental health. I started to wonder if there was any point living when my treatment meant I lived in debt. I was lucky the insurance eventually started paying for my treatment, but it made me wonder about people living with NCDs who aren’t as lucky. What happens to them? From then I started advocating for affordable health care as quality of life means we can access the healthcare we need when we need it without facing financial hardship.”

Mr Joab Wako, Executive Director of Transplant Education Kenya, living with Chronic Kidney Disease (CKD)

“Kidney disease is one of the most expensive diseases to manage. In Kenya, it costs \$10,000 to dialyze one patient per year. This cost is out of reach to many. The disease also affects one’s ability to work as lots of time is spent on dialysis, further dwindling a patient’s income and employability. These challenges spill over to relationships leading to stress and breakups.”

Mr John Gikonyo, President of the Renal Patients Society of Kenya, living with Kidney Disease

Ensuring more inclusive NCD responses

All survey participants were asked for their views on how to ensure more inclusive NCD responses at global/country levels. These have helped to inform the recommendations presented in this policy brief.

“There are so many gaps on NCDs outside the ‘5x5’ approach. I think addressing, improving medical training and raising awareness of rare diseases, including rare endocrine conditions is vital.”

Ms Arlene Smyth, Executive Officer, Turner Syndrome Support Society UK

“In the U.S. decisions for treatment are too narrow so teaching those who approve treatments for insurance companies could help those with conditions outside the 5X5 have access to needed treatments and/or afford them.”

Ms Cindy Scurlock, President of the Turner Syndrome Society of the United States, caregiver for her daughter who lives with Turner Syndrome

“Thyroid disorders rarely get the publicity of more well-known disease groups, but can lead to tragic consequences, especially in mothers and children. Ensuring that they are categorised as a distinct group of NCDs, could make them easier to combat.”

Dr Teofilo O.L. San Luis Jr, Doctor, Quezon City, Philippine Thyroid Association

“We need to create more awareness for the interdependencies of different NCDs. Many are related. For instance, diabetes and CVD are risk factors for kidney disease and vice versa. Mental problems occur more often in people suffering from chronic disease.”

Dr Jasper Boomker, Dutch Kidney Foundation

“More inclusive NCD approaches means being open to changing status quo thinking, transcending bias and looking at NCDs in terms of not simply medical conditions - but also patient burdens and societal costs.”

Mr Paul Conway, Chair of Policy and Global Affairs, and Immediate Past President, of the American Association of Kidney Patients (AAKP), living with Chronic Kidney Disease (CKD), United States

“We need more funding for kidney disease research, particularly for issues that patients living with kidney disease actually care about with a focus on:

- **Identifying outcomes specific to ageing and supportive care - understanding further the causes of the known age-accelerated cognitive impairment in kidney disease**
- **The outcomes of older adults receiving various different types of dialysis or conservative kidney management**
- **The Pathophysiology of the high prevalence of pain and/or fatigue in kidney disease, novel, non-pharmacologic strategies to treat kidney disease without dialysis**
- **Treating symptoms, both physical and psychological, in kidney disease**

Currently patients are not given as much of a voice in selecting funding priorities. Also, there is limited outreach to patients with poor access to healthcare for engagement in research. We should develop a patient research registry with patient priorities and patient-reported assessments, as well as patient peer networks, and further research and policymaker community outreach to patients for involvement.”

Dr Devika Nair, Assistant Professor of Medicine, Department of Medicine, Division of Nephrology and Hypertension, Vanderbilt University Medical Center, United States

RECOMMENDATIONS

to realise a more inclusive NCD agenda

This policy brief and the testimonies gathered show that significant barriers exist for people living with NCDs outside the '5x5' approach, by putting a spotlight on endocrine health and providing case studies on thyroid disorders and kidney disease. Barriers exist across a number of fronts: inclusion in policy agendas, healthcare professional awareness, prevention of diseases and complications, access to screening, timely diagnosis and care, data collection, research and funding.

The impact of the COVID-19 pandemic on people living with NCDs has further illustrated the need for significantly more investment in disease prevention, in primary care, and in ensuring health system resilience to maintain essential services, to leave no one behind. Building back better implies a stronger focus on healthier populations and on designing health systems that are more responsive to people's needs, including for those living with multiple chronic conditions, and those at higher risk during epidemics.

NCDs and the Policy Agenda

Most countries have an NCD action plan, policy or strategy in place or in development, but prioritisation of NCDs outside the '5x5' approach remains unclear for many countries. However, in some countries, such as Kenya, non '5x5' NCDs are starting to gain traction.

The **Kenyan National Strategic Plan for the Prevention and Control of NCDs** (2021/22-2025/26) is the first in the country to include non 5x5 NCDs. This is partly thanks to the involvement of people living with NCDs in the development of the Strategic Plan.⁹⁶ It followed the development of a Kenyan national advocacy agenda of people living with NCDs, supported by NCD Alliance.⁹⁷

The scope of NCDs covered by the **Kenyan Strategic Plan** include; cardiovascular diseases, cancer, diabetes, chronic respiratory diseases, mental health conditions, violence and injuries, hemoglobinopathies, haemophilia and other bleeding disorders, auto immune diseases, chronic renal diseases, epilepsy and other neurological disorders, chronic skin conditions and oral diseases and conditions. It equally addresses seven risk factors; tobacco use, harmful use of alcohol, unhealthy diets and toxins, physical inactivity, indoor air pollution, environmental pollutants and toxins and stress. Further to this, it applies a life course approach for the prevention, control, and management of NCDs.

96 Kenyan National Strategic Plan for the Prevention and Control of NCDs (2021/22-2025/26): <https://www.health.go.ke/wp-content/uploads/2021/07/Kenya-Non-Communicable-Disease-NCD-Strategic-Plan-2021-2025.pdf>

97 NCD Alliance. The Advocacy Agenda of People Living with NCDs in Kenya, 2018. <https://ncdalliance.org/resources/the-need-for-a-person-centred-inclusive-ncd-agenda>

Meaningfully involve people living with NCDs in decision-making

Meaningful involvement is when organisations or institutions recognise the value of the lived experience and of the community. It ensures that people living with a wide range of NCDs and those with multiple chronic conditions are actively involved in all aspects of the NCD response that affect them, including governance, policies, programmes, services and evaluation.

The **Global Charter on Meaningful Involvement of People Living with NCDs** outlines guiding principles and calls on decision-makers at all levels, including national governments, regional bodies and WHO, to provide meaningful opportunities for people living with NCDs to inform the decisions which affect them, their families and their communities.

In this context, this includes for example:

- Governments and health system planners should seek the expertise of people living with NCDs, including with thyroid disorders and kidney disease, and their care partners to provide the insights and knowledge of the lived experience and patient journeys from onset of symptoms, referral to a specialist, diagnosis, disease management and treatment, and living with the conditions. Jointly identify the main hurdles and solutions to improve access to diagnosis and treatment and to improve quality of life.
- It is especially important to engage those communities who experience the highest barriers to accessing essential health services.
- Governments, researchers and academics should engage people living with NCDs, to shape tangible research and funding priorities, including patient research registries.
- Governments, in partnership with civil society and private sector actors, can develop public information campaigns with people living with NCDs as advocates, to raise awareness of lesser known NCDs.



Develop an inclusive NCD policy agenda

The impact of NCDs around the world are barriers to delivering on global health commitments and a wide range of Sustainable Development goals related to poverty, nutrition, equity, gender and education. Strategies which are inclusive of all NCDs are essential to deliver on these goals, and in particular the recognition of an inclusive NCD agenda to achieve universal health coverage, leaving no one behind. As the powerful testimonies in this brief attest, around the world this is not yet the case for people living with endocrine-related conditions.

- Decision-makers, including national and subnational governments, WHO and global health and development donors are called on to include endocrine-related conditions, including thyroid and kidney diseases, in their NCD strategies and policies, and in programmes and tailored technical support to improve primary healthcare and achieve universal health coverage.
- NCD strategies, policies, health programmes and services should reflect the reality for most people living with NCDs that conditions occur in clusters, in many cases driven by the major NCD risk factors. Increasing numbers of people worldwide are living with multimorbidity, but often have to seek separate services for related conditions, noting that access and cost borne out-of-pocket varies for different health conditions, adding to the expense and stress.
- Taking into account the impact and cost of NCDs beyond the '5x5', governments should prioritise primary and secondary prevention of NCDs, by taking action on the common risk factors and ensuring access to timely screening and treatment to prevent development of complications and comorbidities. Governments are called on to implement the tried-and-tested 'Best Buys'⁹⁸ and recommended policy interventions included in the WHO Global Action Plan for the Prevention and Control of NCDs.
- WHO is developing an implementation roadmap to offer tailored technical support to governments to implement measures to make rapid progress towards the globally agreed NCD targets for 2025 and 2030 (SDG 3.4). WHO can support governments to provide access to testing and guideline-based treatment to those identified to include thyroid disorders and kidney diseases at all levels of healthcare.
- Organisations engaged in education and continuous development of healthcare professionals can raise awareness on the necessity of a more inclusive NCD approach, and provide guidance on support with diagnosis and standards of care.

98 <https://apps.who.int/iris/bitstream/handle/10665/259232/WHO-NMH-NVI-17.9-eng.pdf?sequence=1&isAllowed=y>

Data & research for decision-making

Decision-makers and governments need accurate and regularly updated data on disease burden, as well as comorbidities and complications, and costs and benefits of policies to make the investment case for prevention and care for NCDs. These data are often missing, particularly in low- and middle-income countries. This data gap is a major barrier to action and investment and should be tackled as a priority.

- WHO can promote and support national capacity for high-quality data gathering, research and development for the prevention and control of all NCDs, including thyroid disorders and kidney disease.
- Research institutions, governments and global health actors can gather statistics on patient numbers, to ensure that decision-makers are aware of the impact and urgency of these conditions. Research roadmaps adapted to country specific needs should be created. Collecting data on complications and multimorbidity should be incorporated into planning processes. These data should be reported regularly and transparently included in global burden of disease reporting.
- Multisectoral partnerships can play a key role in gathering data (in particular, patient insight data, real world evidence and patient reported outcome data) on NCDs to increase awareness among decision-makers and the public, especially at-risk groups.
- Evidence is required to support priority setting - cost-effectiveness and financial risk protection strategies must be based on local, relevant data and considerations of how findings will be translated into local practice.
- Academia and policy makers should further explore implementation research to support cost-effective interventions for people living with NCDs beyond the '5x5' approach.
- Include people living with NCDs, including kidney patients, in relevant clinical trials (e.g. vaccines) so that new valuable therapies can be approved by regulatory authorities for people at higher risk.

Person-centred health systems & resources

Governments and health authorities should be supported to adopt a systematically person-centred approach to health services that ensures the early identification of people at risk of or living with NCDs, including endocrine-related conditions. People living with or at risk of these conditions should be supported to effectively manage and monitor risk factors, complications, and multimorbidity. It will be important to ensure that NCDs, including thyroid disorders and kidney disease, are an integral part of efforts to achieve UHC and are fully integrated into SDG strategies.

- Scaling up primary health care interventions is essential to achieve UHC. Primary care can help promote awareness, prevention, improve early case detection, provide integrated care, and ensure effective referral systems.
- Primary health services should be strengthened to ensure equitable coverage, including essential public health functions, with an adequate and well-equipped multi-disciplinary health workforce, especially including community health workers and nurses.
- Screening should be targeted to high-risk groups to ensure early diagnosis and treatment and to reduce risk of disease progression, and preserve quality of life.
 - Availability of standardised testing for early detection of thyroid disorders and kidney diseases should be expanded to primary care
 - Expansion of testing should be accompanied by improved access to non-pharmacological and pharmacological options for primary and secondary prevention
 - Low-income countries and lower-middle-income countries need particular support to make this happen – which may include financing and technical support.
- In terms of the COVID-19 response and future pandemic preparedness, governments are called on to commit to and ensure that strategies and resources are in place to minimise disruptions to essential, life-sustaining health services for all people living with NCDs. This includes timely access to guideline-based care including for complex treatment options, like kidney transplantation and dialysis.



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