

# PAYING THE PRICE

A deep dive into the household economic burden of care experienced by people living with noncommunicable diseases

**POLICY RESEARCH REPORT**



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Cover photo: A woman donates blood at a blood donation street point in Kampala, Uganda. © Shutterstock.

## Acronyms and abbreviations

|             |                                  |
|-------------|----------------------------------|
| <b>CKD</b>  | Chronic kidney disease           |
| <b>HIC</b>  | High-income country              |
| <b>HLM</b>  | High-level meeting               |
| <b>LMIC</b> | Low-middle-income country        |
| <b>NCDs</b> | Noncommunicable diseases         |
| <b>NCDA</b> | Noncommunicable Disease Alliance |
| <b>OOP</b>  | Out-of-pocket                    |
| <b>SDGs</b> | Sustainable Development Goals    |
| <b>UHC</b>  | Universal Health Coverage        |
| <b>US\$</b> | United States dollar             |

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# Executive summary

## 01

### SCENE-SETTING



The economic burden of noncommunicable diseases (NCDs) on households poses major challenges to achieving Sustainable Development Goal (SDG) 1, which calls for an end to poverty in all its manifestations by 2030, as well as SDG Target 3.8 on Universal Health Coverage (UHC). Many governments, particularly in high-income countries (HICs), directly finance healthcare costs for their populations, while this is more rarely the case in low- and middle-income countries (LMICs). However, various mechanisms, particularly public insurance, have been introduced by several countries to reduce household out-of-pocket (OOP) expenditures. This report aims to determine what the impact of these mechanisms has been for people living with NCDs.

## 02

### METHODS



We conducted two overviews of systematic reviews (or umbrella reviews) to understand the household economic burden faced by people living with NCDs, in order to support the development of strategies to relieve this burden around the globe. Using predefined search criteria, a double blinded review process and COVIDENCE software, we focused on systematic reviews published between 2009 and 2022. Additional articles identified from a related review on the household spending burden were added for screening during the full-text review.

This was complemented by a secondary review of the NCD Diaries, a multimedia storytelling project of the NCD Alliance's Our Views, Our Voices initiative. The diaries are created by people living with NCDs, sharing their experiences on themes such as the affordability of care. Diary data was extracted and then coded to understand how people around the world cope with the financial burden of ongoing treatment. An extraction codebook was created to facilitate synthesis of data across methods.

## 03

### PAYING THE PRICE



The reviews revealed significant variations in economic burden among people living with NCDs. Broadly, burdens appeared to be greater in LMICs compared to HICs, with substantial in-country variation. Those facing the highest household economic burdens were the very old and very young, people from lower socio-economic backgrounds, living in rural areas, men, and those experiencing highly chronic NCDs like cancer that require long-term treatment and medication.

In most cases, the costs of treatment were the highest expense and most often associated with catastrophic expenditure, defined as health spending that exceeds 40% of income. However, spending on drugs and diagnostics, as well as travel, were frequently cited as expenses that accrue as a burden over time.

## 04

### RIPPLE EFFECTS



The reviews considered in this report show that the economic burden of living with NCDs has far-reaching effects; for instance, the loss of income or employment, which affects entire households. This in turn leads to discontinuation of treatment; reduced spending on food, education (of children) or social activities; reduction in and reliance on savings; and borrowing from family and friends, as well as reliance on fundraising, crowdsourcing and peer and community level support. Additionally, the economic burden of living with NCDs - along with the diseases themselves - can lead to negative mental health impacts and stigmatisation by communities.

## 05

### TRANSFERRING THE COST



Health insurance is generally seen as the entry point into UHC, and crucial to reducing the economic burden of living with NCDs. Recent evidence seems to suggest that public and social health insurance access does avert catastrophic expenditure in certain cases. However, the literature also confirms that there are major gaps within and between countries when it comes to the ability to access insurance and the extent of coverage. Those who have insurance still report facing challenges such as limited facilities included under insurance schemes, and limited service coverage within them; non-coverage of outpatient services (especially drugs); and exclusion of rare diseases. Implementation of planned care network arrangements as well as improvements to models of care in facilities targeting the underserved, show promise as solutions for the reduction of household spending on NCDs, and merit further investigation.

## 06

### CONCLUSIONS and recommendations



The economic burdens faced by people living with NCDs are substantial. In our review they were more pronounced among marginalised groups who are most at risk of being left behind by UHC. Any way forward requires consideration of people living with NCDs as experts to guide policy. Led by this, governments can steer UHC reform to offer the appropriate range of services – in particular to populations in need – alongside financial risk and social protection measures. Disaggregated data, collaborative research and advocacy in partnership with people living with NCDs across varying contexts can also ensure that on the path to UHC, we 'leave no one behind'.

# 01

## Scene-setting

Around the world, NCDs are responsible for 74% of all deaths, or 41 million annually. By 2030, it is anticipated that this number will rise to 52 million (1). Every year, 17 million people under the age of 70 die from NCDs, with 86% of them in low- and middle-income countries (LMICs) (2). This makes NCDs into far more than a health issue – they are a major human rights and equity issue, as they disproportionately burden the poorest and most vulnerable populations. Global health funders have thus far paid limited attention to NCDs, with only 1% to 2% of all development aid for health over the past 20 years allocated to them. This leaves poorer countries to manage the chronic disease burden on their own, often passing on the cost of treatment to individuals and their households (1).



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Cancer often incurs a high or even catastrophic economic burden for those who live with this NCD.

Poverty disproportionately exposes people to both behavioural and environmental risk factors for NCDs, and as NCDs tend to be chronic, they lead to long-term or even lifelong expenses, which frequently trap poor households in cycles of debt and financial hardship that perpetuate health and socio-economic inequalities over generations. This makes NCDs both a cause and a consequence of poverty.

The economic burden of NCDs on households has only partially been quantified, but we know that it poses major challenges to global poverty alleviation efforts (3). The costs of NCD treatment and care is too frequently shouldered by individuals, especially in LMICs (4,5). Government transfers in high-income countries (HICs) cover up to 48% of health spending, while in LMICs government transfers account for only 34%. In low-income countries (LICs), government spending is even lower — 21% of total spending (6).

Globally, out-of-pocket (OOP) spending for NCDs is estimated to be twice as high per visit to a health facility than for infectious diseases (7). People living with NCDs in LICs and LMICs therefore face a substantial burden of OOP costs for their care, risking deferment of care or forgoing it altogether for financial reasons. This burden is also unevenly distributed: in HICs, 21% of health spending comes from OOP payments, while in LICs 44% is from OOP payments (8,9).

People living with NCDs in LMICs are also more at risk of catastrophic health expenditure — health spending that exceeds 40% of income (11). This is the case for more than 60% of people living in some LMICs with cancer, cardiovascular disease and stroke. According to the World Health Organization (WHO) and the World Bank, half a billion people were being pushed (or further pushed) into extreme poverty because of catastrophic OOP health expenditure before the COVID-19 pandemic. (12). The pandemic has significantly worsened the situation by reducing adherence to long-term treatment, increasing abandonment or interruption of treatment, and impairing quality of life (12).

Both before and after the pandemic, a high proportion of people living with NCDs in LICs, especially women, have reported not taking the medication they require due to costs (13). This is concerning as NCDs have become the main cause of mortality and morbidity for women, killing 18 million annually (14). Women face the added challenge of reproductive and maternal conditions that interact with communicable and noncommunicable diseases and lead to poor health. Women also experience other challenges in accessing prevention, early diagnosis, treatment and care due to a multitude of other factors, including but not limited to caring responsibilities (15). The financial toxicity they face is associated with reliance on adjuvant therapies, later diagnosis (a proxy for delayed care), lower incomes and younger ages at the onset of illness (16).

Achieving Universal Health Coverage (UHC), including for people living with NCDs, is a critical means of addressing these unjust economic burdens. This has been recognised as part of the UN 2030 Agenda for Sustainable Development and is set forth in Target 3.8 (17). UHC is about ensuring that people have access to healthcare of reasonable quality without suffering financial hardship. It is linked to numerous Sustainable Development Goals (SDGs): related to poverty (SDG 1), gender equality (SDG 5), inequality (SDG 11) and more (12).

**As the world works towards realising the SDG agenda, it is important to investigate the extent of financial hardship faced by people living with NCDs as well as to understand how they are impacted by existing measures to increase financial risk protection, the cornerstone of UHC. To fill this gap, The George Institute for Global Health conducted a mixed methods exploratory study with the following aims:**

1. To assess the extent to which people living with NCDs across the world are having to pay OOP for their NCD care;
2. To highlight the impact these expenses and related coping strategies are having on the health and quality of life of people living with NCDs, as well as on progress towards SDGs;
3. To assess the mechanisms introduced to reduce economic burden for people living with NCDs; and
4. To provide recommendations to policy makers and health programming organisations to reduce OOP costs and their impact on people living with NCDs.

This assessment is relevant for policymakers and advocates in preparation for the United Nations High-Level Meeting (HLM) on UHC (2023), the Second Global Financing Dialogue on NCDs (2023) and the UN HLM on NCDs (2025).

# 02

## Methods used in this analysis

This analysis relied on two main methods: umbrella reviews of systematic reviews of evidence related to **the household economic burden of NCDs** and strategies to mitigate this burden, and a secondary analysis of qualitative data generated under the NCD Diaries project of the NCD Alliance (NCDA) and people living with NCDs, as part of the Our Views, Our Voices initiative.



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Members of Mexico's Salud-Hable Coalition. NCDA supported the organisation to develop the national Advocacy Agenda of People Living with NCDs, another Our Views, Our Voices project that gathers the perspectives of people living with NCDs in order to drive change.

Pre-defined search criteria were created for two umbrella reviews of systematic reviews (i.e. a 'review of reviews') published between 2009 and 2022, using the PubMed database (see PRISMA flow chart in the Annex). For both reviews, articles were screened by two reviewers using a blinded review process. Conflicts were resolved by a third independent reviewer who was not involved in the initial screening process. For want of time, quality assessment of included systematic reviews was not done, although information on quality of evidence was included in extraction. Based on a pre-determined template, data were extracted by a group of four researchers with each shortlisted article being extracted by a single researcher. Data was compiled in narrative format and then reviewed by a team of six researchers (Full dataset and codebook is available upon request).

**Umbrella Review 1** aimed to describe the **household economic burden of NCDs**, and included systematic reviews that investigated OOP expenses, their impact on households and the coping strategies used by people living with NCDs. Our search strategy yielded 666 references, of which 68 appeared to meet criteria in title and abstract review, and 53 met criteria upon full review. In addition, we added 22 new references cited in included reviews, which were double screened and found to be relevant.

Twenty-nine of the studies in this review included results from a mix of HICs and LMICs (16,18–45), 22 studies had data from only HICs (46–67), and another four were focused on LMIC settings (15,68–70). Additionally, five had regional scope (71–75). Beyond this, there were nine studies focused only on the US (76–84), two on China (85,86), and one each from Japan (87), India (88), Canada (89) and Australia (90). Twenty-six reviews were related to cancer (16,22,25,28,32,34,35,44,46,51,52,54,57,65–68,71,76–78,83,86,88,90,91), six to chronic kidney disease (CKD) (36–38,63,63,87), five to chronic lung disease (18,19,42,64,89), six on diabetes (40,41,69,72–74), four on mental health (20,47,58,75) and one on hypertension (29). Eight studies reported on multimorbidity (23,27,31,55,60,62,79,84). Apart from this, 16 studies reviewed the evidence on highly specific conditions like chronic head pain, psoriasis, rheumatoid arthritis and others (15,21,24,26,30,33,39,43,45,49,50,53,56,59,61,70,80–82,85). Reviews were published from 2009 onwards as per our inclusion criteria, but individual papers in reviews had been published as far back as 1998.

**Umbrella Review 2** aimed to identify **strategies intended to reduce household economic burden for people living with NCDs**. Our original search strategy yielded 524 references, of which 40 were found to meet criteria based on title and abstract review, and only 13 were found to be relevant after full text review. One additional study was added to the review from the reference lists of included articles.

This review revealed evidence mostly from HICs, with three studies reporting data from one or many LMICs (92–94). Five reviews were related to cancer (92,95–98), three explored myriad NCDs or chronic disease (94,99,100), two covered diabetes and/or hypertension (29,101), one was concerned with chronic lung disease (102), while the remaining three were on inclusion of the chronically ill in social insurance (93), osteoarthritis (103) and lymphedema (104), respectively. Most studies referenced adult or older persons living with NCDs in hospital and home-based settings.

Household spending data from individual studies included in the systematic reviews were extracted individually where available. There were 56 reviews containing 93 extractions of data pertaining to household expenditure on NCDs that met inclusion criteria. Most extracted evidence originated from HIC settings, although we had extractions from LMIC contexts, as well as some regional analyses focused on the Eastern Mediterranean region, on African countries and individual reference to countries including India, Pakistan and Sudan.

Sixteen reviews provided standardised expenditure in US dollars (US\$) or international dollars for a single year (22–24,43,45,52,56–59,69,70,77,81,64,84), but the remaining reported across years in varying currencies, ranging from Chinese Yuan to Euro, Australian and Canadian dollars. A range of cost or burden measures were reported. These include: a) monthly costs per capita – either for overall treatment, or for drugs or transport), b) mean direct costs per person (medical services overall, or for a single service like dialysis), c) annual costs per patient, d) average lifetime costs per patient and, e) others (like average incremental OOP costs per annum). For instance, Bovolenta and colleagues, in their useful methodological paper on cost studies related to Parkinson's disease, point out that costs could be: direct medical (related to hospitalisation, medication, tests and diagnostics); direct non-medical (related to transport, food or other adjustments); indirect (related to loss of productivity); intangible (psychological and psychosocial); and personal (costs paid OOP when there are gaps in coverage of direct medical costs) (39). Considering the different definitions of what is included in costs, reporting across reviews was difficult, as was determining what thresholds would define high expenditure. We have therefore reported cost data as indicated in these studies, and to give an idea of thresholds we have included information on comparisons across population subgroups or time when indicated. For relative ease of comparison, where non-US\$ currencies were being reported, we used conversion rates from the publication year of the reported review and indicated values.

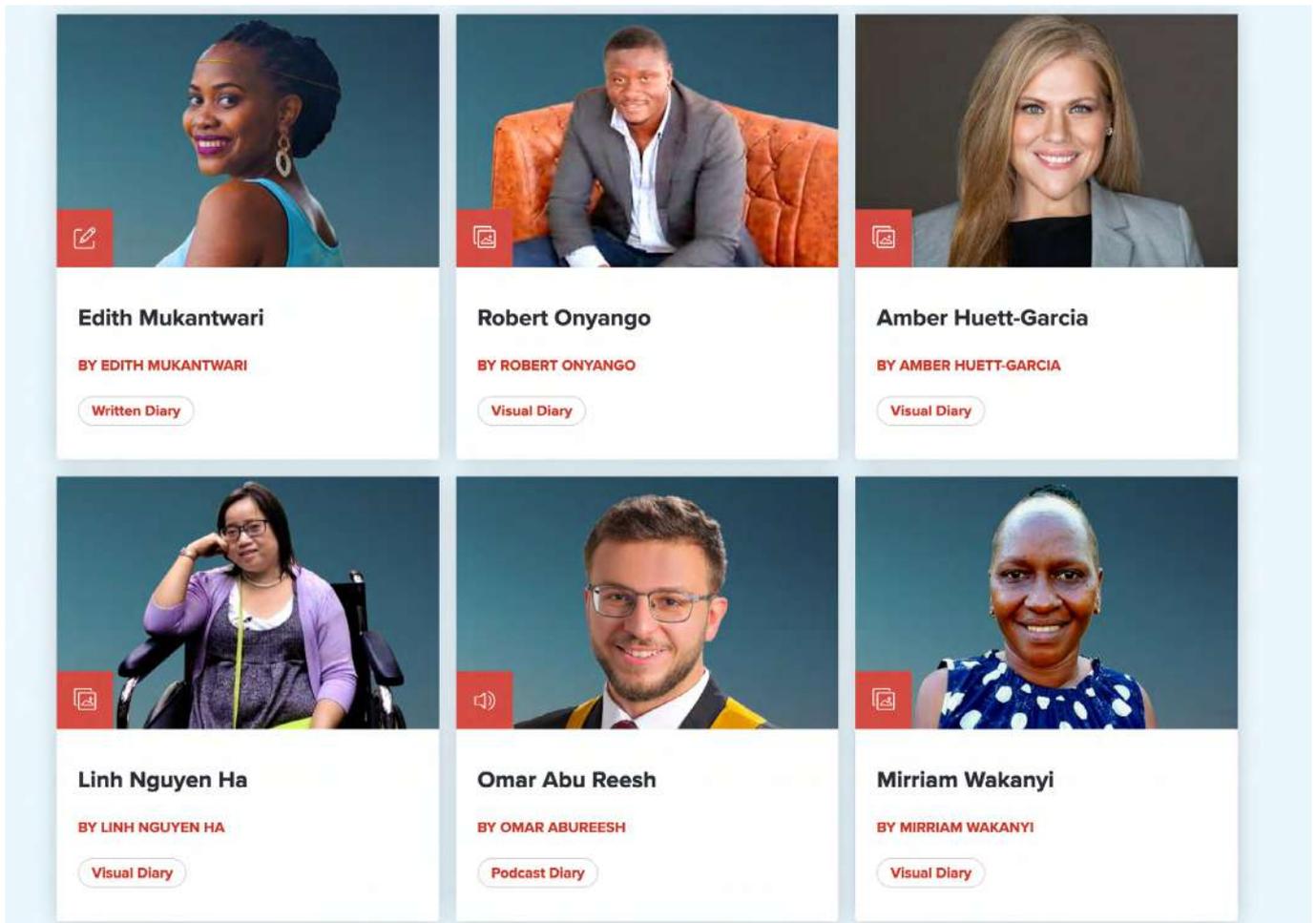
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These overviews are not without limitations. For one, given this umbrella review approach, we did not look at primary studies. We may have therefore missed some of the latest contributions to the evidence base. Further, we lacked time to carry out quality assessments of reviews, which may have allowed us to interpret evidence with levels of confidence. Further, there may have been reviews referencing overlapping studies, which may have been interpreted as additional rather than duplicate evidence of burden or related to strategies. While this is less of a concern in a narrative review of this nature, it is still possible that it has affected interpretation.

The other major method employed in this analysis was secondary analysis of data from the Our Views, Our Voices NCD Diaries project. We were interested in lived experiences of household economic burden, coping strategies to mitigate this burden, and impact of those strategies from the perspective of people living with NCDs. In 2021, NCD Alliance initiated a global storytelling project to enable people living with NCDs to share their challenges and calls for change. Since the project's launch there have been four series of the NCD Diaries, all under different themes. The process for each series

included launching an expression of interest across the NCD Alliance network and then selecting applicants based on individual scores against selection criteria, which were provided by members of the Our Views, Our Voices Global Advisory Committee, who also assessed each application. Diarists were then invited to provide content, with the shared understanding that Diaries would be used as lessons learned, to drive advocacy, and to promote citizen leadership and contributions to international platforms. The four series so far have focussed on Multiple chronic conditions, Affordability of care, Relationships with healthcare providers and Prevention through the lived experience lens, and have used visual, audio and written formats based on the preference of contributing Diarists. For our study, one researcher extracted data from the first three series of the NCD Diaries. We developed a codebook corresponding to the extraction template used in the umbrella review. Two researchers analysed 120 Diary extracts written by 37 individuals from 23 countries with lived experience. Many Diarists wrote about living with multiple chronic conditions, while others reflected on single diagnoses like breast cancer, leukaemia, sickle cell disease, endometriosis or multiple sclerosis.



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Participants of the NCD Diaries project, part of NCD Alliance's Our Views, Our Voices initiative, provided valuable qualitative data for this analysis, based on their own lived experiences. People living with NCDs are essential for understanding the impact of the economic burdens of NCDs.

# 03

## Paying the price

### Out-of-pocket payments experienced by people living with NCDs

In reviews covering countries of all income levels, NCDs were reported to incur significant economic burdens for individuals and households. Although our method of synthesis does not allow for direct comparison of study results, our review suggests that OOP payments were greater among very young and older persons living with NCDs, those from lower socio-economic backgrounds, and rural dwellers. They were higher among men, since women are more likely to forego care altogether in order to avoid any expense, and for certain NCDs (especially cancers). OOP payments were also higher at greater severity/ later stages of disease, for treatments of long duration and high complexity, when branded drugs were prescribed, and for those without insurance.



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Pictured outside the window is Sally Agallo from Kenya, who has lived with HIV and survived cancer three times. She was also a participant in the first series of the NCD Diaries.

## PAYING THE PRICE

A deep dive into the household economic burden of care experienced by people living with noncommunicable diseases

The costs of living with NCDs are often more burdensome in LMICs compared to HIC contexts given the lack of a basic safety net, limited insurance coverage and higher cost of care for a number of NCD treatments. A study on the treatment burden (financial and non-financial) of multimorbidity, or living with more than one chronic condition, pointed out that “the size of the burden was associated to the workload of demands (number of conditions, number of medications and health status), the capacity (cognitive, physical and financial resources, educational level, cultural background, age, gender and employment conditions) and the context (structure of healthcare and social support)” (60). There were important intersections in particular contexts as well: for example, greater spending among men as compared to women was seen in a review on melanoma care in high-income countries (22) while an Eastern Mediterranean region study found that costs were greater among male diabetes patients, patients with family history and those seeking longer-term treatment (74). In Kenya, a study reported in Sum (2018) found that having three or more NCDs meant an almost 100-fold increase in OOP spending for those below the age of 65 (27).

Across studies, the main categories of expenditure reported were treatment; drugs and diagnostics; and other non-medical expenses such as travel. In most cases, the costs of treatment tended to be higher and more often associated with catastrophic expenditure. However, spending on drugs and diagnostics was chronic in nature, and as with travel, accrued as a burden over time.

## Spending on treatment

Treatment is widely reported as the highest cost of living with NCDs, and the expense most likely to be catastrophic to households.

We focused on reviews that specified costs borne by patients, that used payer perspectives, or where there was specific discussion of the impact or magnitude of economic burden from patients or their households. The reviews reported that treatment is costly, although thresholds for deciding whether a cost was high or low varied — most often high costs were determined by comparing countries, NCD conditions, stage of



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Free NCD care for people in Pasuruan, Indonesia helps avoid economic burden.

disease or treatment options for a single condition (18,22,48,80,81). Many reviews found increasing costs with advanced stages of disease, irrespective of the disease (22).

In LMICs, a 2022 study reported that the mean direct cost of care ranged from US\$ 1,953 to US\$ 3,527 per cancer patient throughout the course of illness, with substantial variation by type of cancer (breast cancer patients paying a mean of US\$ 476 and prostate cancer patients paying on average US\$ 14,181) (68). An earlier review, from 2013, reported that hepatocellular carcinoma patients in China were paying on average US\$ 5,297 (33,044 CNY) per patient per year (86). This review further noted that OOP spending accounted for nearly 50% of the previous year's household income and that for carcinoma patients, the economic burden was considered overwhelming (86). An NCD Diarist from the US conveyed her view:

**“Hearing the word ‘cancer’ in a diagnosis is terrifying enough, but here is another scary thought — the treatment method is likely to be dictated by your insurance coverage.”**

Among the reviews where cost of treatment was reported for specific diseases, cancer led to the highest spending on treatment (23,35,77,90,91) followed by multimorbid conditions (23). A 2022 global review on economic burden of multimorbidity found that patients with cancer along with mental health conditions could have health care expenses as high as Intl \$85,820 within the first year of their treatment (23). This finding aligns with a 2020 US study which found that costs of health care for HIV and comorbid conditions was as high as US\$ 6,608 per month (79) – which comes close to the per annum figure in the previously mentioned global study. In the case of HIV patients, treatment costs of comorbidities were also reportedly greater than those for non-HIV patients, and authors noted the significant ripple effects this could have for those who need to stay on HIV medication while also dealing with new morbidities (79). Other studies reported on expenses associated with complications (73) and adverse events like opportunistic infections costing on average US\$ 8,495 per event for cancer patients in the US (79).

Several reviews noted that kidney diseases result in the highest catastrophic health expenditure compared to other disease groups, affecting roughly 188 million individuals from low- and lower-middle-income countries annually (105-107). For CKD dialysis, treatment could cost as much as twice the minimum monthly wage of a Nigerian government employee or 25-68% of total spending in the average Thai household (37). In a global review, Roberti and colleagues reported that poverty and unemployment were associated with foregone or interrupted CKD treatment (36), while another review showed that such interruptions in care actually resulted in a higher cost of treatment over time (38). In Japan,

greater medical spending was reported in a 2013 study among those with moderate kidney dysfunction, as compared to those with mild dysfunction or normal function (US\$ 5,886 (¥536,027) normal, US\$ 7,136 (¥649,865) mild, US\$ 8,539 (¥777,623) moderate) (87).

In South Asia, catastrophic expenditure (i.e. surpassing 40% of household monthly income) on cardiovascular disease treatment expenses was reported in as many as 90% of households (71). Elsewhere in the world, costs of treatment for rarer conditions like non-alcoholic steatohepatitis were about US\$ 257 per person yearly and increased greatly among those over 80 years of age, although authors in this study from Hong Kong did not specify the level of coverage of costs by the system for this condition (85).

## Spending on drugs and diagnostics

Along with treatment, the cost of drugs and diagnostics were frequently cited in reports as being a cause of significant economic burden to households. Studies showed greater spending on drugs with increasing severity of disease (81) and more complex classes of drugs (26). Similar variations were reported in diagnostic costs, particularly for cancer detection in LMICs (68) and the US (78).

Spending on drugs was substantial for cancer patients, upwards of US\$ 2,700 (over 2,500 Euros) per treatment session for a single patient and ranging from US\$ 3,871 to 12,789 per patient per annum (the evidence was largely from high-income settings) (35,77). Costs of asthma medication (89) were found in a global review to be as high as US\$ 221 (232 CAD) per patient per annum. Over the course of one's lifetime, the cost of treating asthma becomes a substantial burden on households, with existing subsidies not necessarily offering the depth or duration of financial protection needed.

In a study focused on the African region, the average annual spending was US\$ 283 per child for children living with Type 1 diabetes, over a third of which was spent on insulin (72). In a more recent review of costs of Type 1 diabetes management among adults in the region, drug costs were a significant burden of total cost, given that doctors tended to prescribe branded medication (73), a feature also seen with cancer treatment in another review (34). An NCD Diarist from Bangladesh lamented:

**“Despite being a doctor and public health expert, medication for my cardiac problem and diabetes costs me a large amount of money every month and creates economical strain for me. In this pandemic hour, even the shortage and high price of imported medicines is being noticed.”**

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In the Eastern Mediterranean region, it was found that the combined medication cost for diabetes per patient per annum was US\$ 289 with high variation (74). In the case of hypertension, Maimaris et al concluded that cost of medication was a barrier to adherence in countries as diverse as China, USA and Nigeria (27).

In a review of chronic daily headache in HICs, OOP spending on drugs was as high as US\$ 172 (171.25 Euros) per year, nearly 35 times higher than drug expenses for episodic headache (53). In the case of conditions like sickle cell disease, a Diarist pointed out that a single test, which “only few hospitals and private laboratories could perform...” could cost US\$ 70-100.

**“This was compounded with the fact that few doctors were familiar with sickle cell disease and medications were expensive.”**

Another review found that multimorbid older persons on the US Government Medicare programme were spending up to 5.6 times as much as those with no NCDs on medicines (27).

## Spending on travel and other non-medical expenses

Travel can be a significant health-related expense, especially in settings where health centres are few and difficult to reach. This is most commonly the case in LMICs and for those living in remote areas, but can also create economic burden for people living with NCDs in HICs.

One review noted that countries with larger geographies, like Canada, the US and Australia, may report greater travel spending. For example, in the US

travel costs for cancer care ranged from US\$ 250 to \$900 a month (52). Across large and small countries, rural dwellers faced heightened cost and financial burden of travel (51,52,78). These costs were also seen as significant among those with multimorbidity (31,55), CKD (36) and chronic pain (50). Several studies, mostly of HICs, described expenses of cancer treatment related to transport (and accommodation), which for example accounted for as much as 13% of all OOP spending in Australia (90). Some studies assessed annual indirect costs, including consideration of lost labour market productivity for people living with systemic lupus erythematosus, indicating a range of US\$ 2,239-35,540 (24). In the US, routine care for those living with incontinence (purchase of pads, diapers, laundry, dry cleaning and more) also introduced non-medical costs that were substantial (82).

Unexpected essential ancillary costs can pile up, as a Diarist from Burundi with asthma, diabetes, high blood pressure and cancer diagnoses explained:

**“Those lucky enough to get insulin had to deal with the lack of refrigerators for storage. They would be forced to store it at the nearest centre, or in a way that was not safe. The lack of facilities for medicine storage decreases the supply and therefore increases their cost.”**

In Malawi, a Diarist seeking dialysis care noted:

**“As it was a private hospital, the Malawi government agreed to cover dialysis costs for myself and the others living with kidney failure for one year. However, as the unit was in a rural area, travel was difficult as many of us live below the poverty line and without cars.”**



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People in rural areas are among those most affected by the economic burden of NCDs.

# 04

## Ripple effects

### The impact of out-of-pocket spending on people living with NCDs

The reported impacts of out-of-pocket spending on people living with NCDs are deep and extensive, with loss of income or employment having negative effects on entire households. Methods of coping with economic burden were often highly detrimental as well; for instance, discontinuation of NCD treatment, or reduced spending on food and stopping children's education or social activities in order to pay for it. A number of distress financing strategies were also reported, such as reliance on savings, borrowing from family and friends, and peer or community fundraising. Mental health impacts and stigmatisation as a result of financial difficulties were common as well.



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People wait for care at a hospital in India. People living in low-resource settings are often the least protected against out-of-pocket spending for NCDs.

## Overall economic burden of NCDs

Multiple reviews reported on the **loss of income or employment** associated with having NCDs. A number of cancer reviews reported reduced work and income (44,46,51,52,54,67,76,83) with attendant productivity losses (46), typically computed as indirect costs in cost-of-illness reviews. A Ghanaian NCD Diarist noted that high medical bills related to her breast cancer treatment forced her to close her own shop. Among cancer patients in Australia, loss of employment attributed to disease created a spiral effect of amplified financial distress (nearly a third of Australian families who had lost a child to cancer fell below the poverty line due to loss of income) (90). A 2017 review featuring studies from the UK, the US, Canada, Australia, Japan and Pakistan found 15% of participants dropping below the poverty line due to loss of income (25). Gordon (2017) found in their global review that cancer patients had more than twofold the likelihood of going bankrupt than age matched people without cancer (16).

Another review reported costs of loss of income and of functional impairment attributed to occupational asthma (89). This burden was born by family members as well, reported Giacomini's review (19). Persons living with CKD, diabetes (which disproportionately affected persons of working age), and a host of other NCDs (like Barrett's oesophagus, psoriasis and urinary incontinence), as well as their care-givers, faced lost income and employment (15,21,36,72,80–82). A study in South Asia (71) saw 8% of persons falling into poverty for asthma care.

Eight reviews identified **detrimental mental health impacts** due to the economic burden of NCDs. One review reported struggles with uncertainty, frustration over changed lives and fear of suffering, along with feelings of futility, stress and exclusion, as well as the fear of being a burden on family (55). The mental effects, stigma and shame were experienced not only by patients, but their family members, relegated as 'charity cases' (15).

## Coping with economic burdens

The economic burden of NCD care required adjustment of care-seeking pathways. Two reviews reported on the trade-off **between seeking care in the public and private sectors**. Reporting from an HIC context, Basile (51) noted that patients had to adjust to long waiting times in the public system, weighing this up against the cost of the private system. Boby (2021) noted in the case of India that NCD care in the private sector could cost almost three-fold what it did in the public sector (57). In some cases, the trade-off was manageable, as a person living with cancer from Sri Lanka wrote in her Diary:

**"All [my care] occurred in the private health sector, which I chose to avoid the long wait in the public health system. The private system was an affordable option for me, and I felt that choosing this route would give somebody else a better chance in the public system."**

**Discontinuation of treatment** was a negative consequence of the high cost of treatment, reported in reviews on cancer (16,25,88,90), multimorbidity (27,55), CKD (37), chronic illness (15), and rheumatoid arthritis (26). In Bygrave's review of cancer patients in Australia (90), a study reported that 12% of patients used alternatives to prescribed medicines because of prohibitive cost. A Kenyan Diarist noted that while dialysis was covered by the National Health Insurance Fund, immunosuppressants were not – this in turn led people **"to remain on dialysis and miss out on the improved quality of life that comes with a transplant."** One study reported **reduced treatment** in the form of reduced frequency of haemodialysis (37).

Several reviews reported coping mechanisms that had detrimental impacts – and this was seen across NCDs. These included **reduced spending on food, education or social activities** due to cancer, chronic illness or CKD expenses (15,37,61,88,90), as well as **reductions in money spent on children's education** and recreational activities (15,54,88).

Strategies to meet the costs of medical care for NCDs that were identified in the literature included **reliance on savings** (15,52,54) and selling assets (15,71,90) — the evidence coming largely from cancer patients and their households in both HIC and LMIC contexts. A reduction in savings due to indirect costs from a cancer diagnosis showed that the likelihood of losing family savings was higher amongst people with lower socio-economic status (61).

Reviews also found that in the case of cancer care, borrowing from families and friends was common (52,76), referred to by Rijal (71) as "distress financing."

One review on CKD across multiple countries and another on cancer in Australia also found dependence on emergency care or fundraising to cover life-saving treatment (36,90). A Diarist from Kenya living with cancer described her strategy:

**"Without National Health Insurance Fund cover, I had to find a way to raise the funds, so I started a fundraiser on the platform M-Changa, using a traditional Kenyan fundraising concept called 'Harambee'.... I'm grateful that the cost of the mastectomy and further treatment was fundraised through family, friends and well-wishers."**

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In fact, in LMICs it was common to seek **community level support** from workplaces, neighbourhoods, churches and non-governmental organisations for cancer (68) and other chronic illnesses (15). It was found that female-headed households and ones with more older persons were more likely to receive family gifts or support to finance chronic illness care-seeking than male-headed households (15).

Community as well as government initiatives were making a difference. One strategy not reported in the reviews but evident from the testimonials of many Diarists was the establishment of **self-help initiatives and collectives**, an example of which was described by a Kenyan Diarist living with breast cancer:

*“Ways that we tackled the challenge of financial support as a group included creating a table banking initiative where we could loan each other cash to set up income generating activities. This helped not only me, but us collectively as a group, to pay the monthly NHIF fees. As NHIF only partially covers cancer treatment costs and only some services for other NCDs, this initiative also allowed members to borrow saved money from the group to cater for additional hospital bills. Through NCD Alliance Kenya (NCDAK) trainings and financial support we were able to create a bigger support group accommodating all NCDs in Isiolo County.”*

This Diarist also reported that support of US\$ 3,000 had been offered to newly diagnosed persons and for drugs, upkeep and funerary rites, all important financial needs and considerations for persons with an NCD diagnosis. A Diarist in Malawi noted similar services offered by a cancer survivors group to persons not covered by insurance. Patient societies and support groups have been a major ad hoc strategy to offer social and financial support to persons living with NCDs. But as a Kenyan Diarist noted,

*“These interventions offer relief from the economic burden of living with chronic kidney disease. However, to reach sustainable solutions we strongly advocate for Universal Health Coverage.”*

Murphy (2019) found that for chronic illnesses a **combination of strategies** had to be adopted to finance OOP expenses given the high costs involved (15).



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Community and government run health programmes are shown to help make care more accessible.

# 05

## Transferring the cost

### Mechanisms to reduce out-of-pocket payments experienced by people living with NCDs

In most countries, health insurance is seen as the primary intervention or entry point into UHC. This was reflected in our literature review, in which the reduction of out-of-pocket spending for people living with NCDs was centred mainly on publicly funded insurance coverage, as well as private and community/micro-insurance.

The literature indicated gaps and entry points related to population, service and amount of risk protection offered by this major intervention. More recent evidence also seems to suggest that the impact of insurance on reduction of financial burden is mixed/unclear. Many reviews took the view summarised by Van Hees et al that “from a social inclusion viewpoint, health insurance has not yet shown to serve as an optimal tool to UHC,

in a way that vulnerable groups are covered, from being aware and enrolled in health insurance schemes to proven impact on financial protection and improved health outcomes once carrying a health insurance card” (93). Apart from this, some models of care in HICs (mostly focused on cancer care) have been effective in reducing economic burden.



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Drugs and other supplies for NCD treatment and care are often paid for out-of-pocket, making it difficult for many households to access them.

## Insurance

A number of reviews explored the relationship between insurance and NCD economic burden, with great variation in population and service coverage of schemes. Overall, public and social health insurance access seemed to avert catastrophic expenditure, particularly for cancers and for emergency treatment for kidney disease, but for some population groups (rural) and for chronic care needs (especially for drugs), there were many gaps. Employee funded insurance was less commonly mentioned, but was also associated with these gaps. Private insurance did not show evidence of risk protection. There was a marked distinction between the availability of subsidised public insurance programmes, with wider availability in some contexts (predominantly HICs) and a lack of such programmes more commonly observed in LMICs.

Three studies from Review 1 provided some insight on the role of insurance (77,86,87), with one indicating that insurance may have saved 24% of cancer patients from incurring catastrophic health expenditure (86). Medicare in the US\* had reported benefits in reducing financial burden; however, studies reported major access barriers for indigenous and rural populations (29,90). Other insurance programmes covering hospitalisation (88) were reported, as well as waivers, food and accommodation support (68). In LMICs, access to insurance was a challenge. This was raised by a Kenyan Diarist living with asthma:

**“Today I manage my condition out of my pocket since I cannot afford insurance. Public hospitals cost less than private hospitals, but the main challenge is availability of medicines.”**

A Diarist in Uganda noted:

**“I was given intravenous insulin to stabilise my blood sugar and since the cost of treatment was high, I had to wait for my father to pay the full out-of-pocket amount, having no health insurance at the time.”**

Conversely, a Zambian Diarist with hypertension, obesity and arthritis expressed relief:

**“I’ve been living on medication for over 20 years, and now finally Zambia has implemented the National Health Insurance Management Authority (NHIMA), where my age qualifies me to be a beneficiary for all my NCD treatments.”**

\* Medicare is a national health insurance programme offered to all Americans aged 65 and older as well as some younger persons living with disabilities.

A Diarist in Malaysia underscored the need for increasing insurance coverage, saying,

**“For those with insurance, healthcare is manageable. Unfortunately, only one person in five Malaysians have medical insurance. Yes, there are limitations but overall, I am a beneficiary of the healthcare system that has taken care of me through my hypertension, high cholesterol, my heart disease, my type-2 diabetes and finally, my cancer.”**

Other Diarists shed light on gaps in coverage of government insurance schemes and other initiatives. A Diarist living with sickle cell disease in Kenya, for example, lamented that,

**“As an adult with national health insurance for which my employer pays the subscription, I am still not able to apply this to any outpatient services. Therefore, I had to spend 20 US dollars out-of-pocket per day buying medicine, because one capsule was 5 US dollars and I had to take 4 capsules a day.”**

This finding was seen also in a review exploring the use of telemedicine for chronic disease conditions, which included studies from the US, Italy, Australia, the UK, South Korea, Norway and Belgium. Here too, lack of insurance coverage of certain services and care-seeking meant these were foregone by patients, despite need (99). A Diarist in Vietnam living with multiple sclerosis also noted gaps in coverage:

**“The challenges I face include lack of access to treatment (because my condition is a rare disease) and economic burden (expenses for this illness are higher than my income). Unfortunately, multiple sclerosis is not covered by insurance in Vietnam, so I must pay for my care out-of-pocket, with financial support from my relatives.”**

One of the studies included in the systematic review by Maimaris reported a gap in coverage of medicines in the insurance programme so that 100% of the cost had to be borne by the patients, which cost more than US\$ 2,250 per year (108).

Studies in the US related to cancer described **widening the benefit package in insurance** (Medicare) as a potential strategy to avert economic burden, albeit noting gaps in coverage for drug costs and for particular populations (95,97). Viswanathan (2012) found that in the US, **improved prescription drug coverage** was associated with a reduction in patient spending (100).

The impact of insurance coverage for medications was critical, as a Jordanian Diarist with lived experience of cancer noted:

**“I was lucky enough to get my treatment expenses covered, the thing that made me stronger to continue grinding for my dreams.”**

Reduced co-payments were associated with lower morbidity, although Moss et al (2020) did note that “insufficient evidence is available to conclude that expansion has had a statistically significant effect on the costs and affordability of cancer care” (p. 789) (95).

Dodd (2018) and Maimaris (2013) found that patient co-payments reduced adherence to CKD and hypertension medication, respectively (29,37). However, one review reported a study from Nigeria that found that those with private insurance were less likely to need to take grants, gifts or loans, sell assets or decrease consumption (15).

It must be noted that even with health insurance coverage, people living with NCDs can face constraints in accessing care – a Diarist with an obesity diagnosis noted:

**“Where I live in Canada, you don’t have to pay to see a doctor or a specialist. While this is fantastic because everyone has access to treatment, it doesn’t always mean that you get treated well. I’ve had interactions with specialists that would make your toes curl, including a statement made by a cardiologist in an emergency room setting. He had no background information on me, didn’t ask questions, and based his “diagnosis” off what he saw in front of him: ‘She’s just fat and lazy and doesn’t want to put the work into being healthy’”**

Two studies explored the role of health insurance on a range of clinical and economic outcomes. A study in the US (98) concluded that evidence is **inconclusive on the role that regulation of private insurance** can play in reducing costs. A 2019 review of 51 studies from Africa, Asia and South America reported **insufficient or negative effects of social health insurance and community-based health insurance**, such as micro-health insurance and other schemes that target “left behind” population groups, or financial protection for groups facing disadvantage, including chronically ill persons (93). Authors concluded that “we found that health insurance schemes could prevent catastrophic health expenditure, however (the) chronically ill experienced insufficient financial protection and reimbursement rates for both social

health and community-based health insurance were generally very low” (p. 9) (93). Noting also that rates of utilisation – and thus spending – would be greater for chronically ill populations than others, authors conclude that “the impact of health insurance on poverty remains insufficiently clear for vulnerable subpopulations” (p. 12) (93).

## Models of care

Enrolment in accountable or planned care network arrangements (where networks of health providers share cost, quality and coordination of care) in the US was associated with 10% lower costs after the first year of treatment in a small sample of those living with cancer, although “the overall efficacy of alternative payment and delivery models in cancer remains unclear.” (p. 3305) (97). Interventions implemented under the US “health disparity collaboratives” programme (to improve quality in health facilities primarily serving populations facing economic and social disadvantage) were associated with 92% lower costs compared to usual care for diabetes, due to lower hospitalisation rates and lengths of stay, in 2000-2001 (101). This suggests that for chronic needs, enrolment in such programmes can avert heightened morbidity and help reduce costs. Evidence on models of care was not commonly found in literature from LMICs. Diary data suggests that free or subsidised acute care treatment has had an impact. As noted by a Malawian Diarist with kidney disease, access to free, life-saving treatment in a government hospital made a big difference for multiple individuals for whom dialysis care was **“hassle-free and without charge.”**

In our umbrella review we found no evidence regarding government interventions outside the health sector that helped reduce economic burden. This may have been because studies on general social protection may not report impact on NCDs specifically and also because literature describing such programmes (there are many in South America, for example), may not be in English. However, our Diaries data seemed to suggest that such programmes hold promise. A Diarist from Malaysia had this to say:

**“The income assistance programme is helping many and I cannot sing enough praises about it. My only wish is that the current age limitation may be lifted to include children and the elderly living with cancer.”**

# 06

## Conclusions and recommendations

Our review adds to existing literature on the economic burden incurred by people living with NCDs and their households as a result of paying for NCD care, although metrics and measures to characterise this burden were far from standardised. While the approaches and terminology used varied widely across studies, making it difficult to standardise findings and make inferences, several key conclusions can be drawn; for instance, the economic burden of NCDs is substantial and falls heaviest on those populations already at risk of being left behind by UHC.



In most cases, the costs of treatment were the highest expense and most often associated with catastrophic expenditure, defined as health spending that exceeds 40% of income

The impact of the economic burden of NCDs was uneven and affected populations already known to be left behind (not just in the NCD context but broader development context also): those at extremes of age, from lower socio-economic backgrounds, living in rural areas and men (even as we know that women tend to forego NCD care). We also noted that both NCDs with highly acute manifestations, like cancer, and ones with high chronicity, such as renal disease, had impacts like major or longstanding expenditure – both of which were difficult for households and likely have inter-generational impacts on poverty.

The impact of these economic burdens was also substantial – affecting incomes and livelihoods, and resulting in stigma and mental health challenges. Economic burdens were associated with changed or delayed treatment, foregone spending, use of savings and reliance on distress financing mechanisms. These characteristics of care-seeking have resulted in severe financial strain, decline in economic status, with gross inequalities in economic status across population groups that in some cases traverse generations.

Governments have made voluntary commitments to end poverty (SDG 1), achieve UHC (SDG 3.8) and reduce the burden of NCDs (SDG 3.4). It is therefore governments who have the responsibility to provide adequate health

services for people living with NCDs, by integrating essential NCD services across the continuum of care, as contained in Appendix 3 of the WHO Global NCD Action Plan, into UHC benefits packages. We did not see specific mention or analysis of this in our review and it is a crucial area of further study. Governments can ensure that their populations are protected from financial hardship in the course of seeking and attaining the necessary range of services required to attend to chronic illnesses. While existing mechanisms such as health insurance may play a role in reaching those who already face economic burdens, evidence is inconclusive on whether these are adequate to fully address the economic burdens of chronic illness.

This year and the next two offer a pathway of key milestones that could help reduce the household economic burden faced by people living with NCDs and their households. In 2023, governments and international institutions will meet for the UN High Level Meeting (UN HLM) on Universal Health Coverage, while the following two years will bring high level focus to global financing and action on NCDs. Our analysis points towards a set of recommended actions for governments, researchers and civil society to ensure we truly embody the letter and spirit of UHC for people living with NCDs while leaving no one behind.

## All actors

- **Refer to people living with NCDs and their care-givers as subject matter experts on NCDs**, demonstrated by meaningfully involving them in decision-making processes, including those related to UHC, to ensure that their needs, knowledge and calls to action are central to NCD programmes and policies.
- Use as their frame of **reference essential NCD services across a continuum of care and life course**, as contained in Appendix 3 of the WHO Global NCD Action Plan, **in UHC health benefits packages**.

## Governments

- Increase national health budgets to **expand the fiscal space for NCDs**, with a commitment to reaching globally recommended spending targets and, preferably, emphasise reaching marginalised and disadvantaged groups.
- Extend or create **financial risk protection** and social security schemes that are directed towards achieving UHC and therefore focus on covering populations currently left behind (like those in poor and remote locations), and also address more causes of financial distress over time, including but not limited to costs related to medication, transport and care for children and older persons.
- Ensure that **decisions are driven by data disaggregated by region, age, disease, socio-economic status, sex and gender, as well as other critical dimensions of inequality**, and that **monitoring mechanisms for existing and new programmes** and schemes are sensitive to context, to important differences and inter-sectionality within and across population subgroups and with respect to various conditions (and co-morbidities). This would require funding for, and partnerships with, institutions that generate actionable evidence through research and data analysis.
- Enhance **outreach and awareness** of government-sponsored NCD prevention and control programmes, where relevant, and link it to awareness-raising on UHC wherever possible.

## Researchers

- Develop a **standardised and comparable data collection approach** (including tools, definitions, and common outcome sets/measures) in researching the household economic burden of NCDs as well as the impact of interventions that aim to prevent and minimise it.
- Report **data that is disaggregated by region, age, disease, socio-economic status, sex and gender** when monitoring practice and generating evidence. This can help to identify the groups most at risk for poor health, eliminate biases in service delivery and enable the creation of targeted interventions.
- Prioritise **LMIC contexts as well as understudied populations and NCDs** in prospective research on UHC – using subjective and objective measures to investigate:
  - The role of various types of insurance, care models and other interventions at scale that are intended to reduce household economic burden among people living with NCDs.
  - Barriers that intersect with financial constraints in seeking care – which may include aspects like stigma, provider behaviour and social security – and how these may vary for specific conditions and populations, in particular groups experiencing marginalisation.
  - The long-term impact of economic burden and coping strategies, and how they may vary across different population sub-groups across generations, and in different contexts.

## Civil society

- Advocate for the dissemination of **accurate and comparable information on the costs of care across NCDs and their associated continuum of care** to increase transparency about out-of-pocket expenses for people living with NCDs and their households.
- Establish and maintain **accountability mechanisms that directly draw from the experiences of communities and people living with NCDs**. This will aid the effective implementation of financial risk protection and social security schemes that considers the end user and beneficiary experiences.
- Lead advocacy efforts with governments at the highest political level (including ministries of finance) to establish and monitor **commitments on NCDs across the continuum of care as part of efforts to achieve UHC**, and enable the scaling-up of financial risk protection and social security schemes for people living with NCDs and their households.

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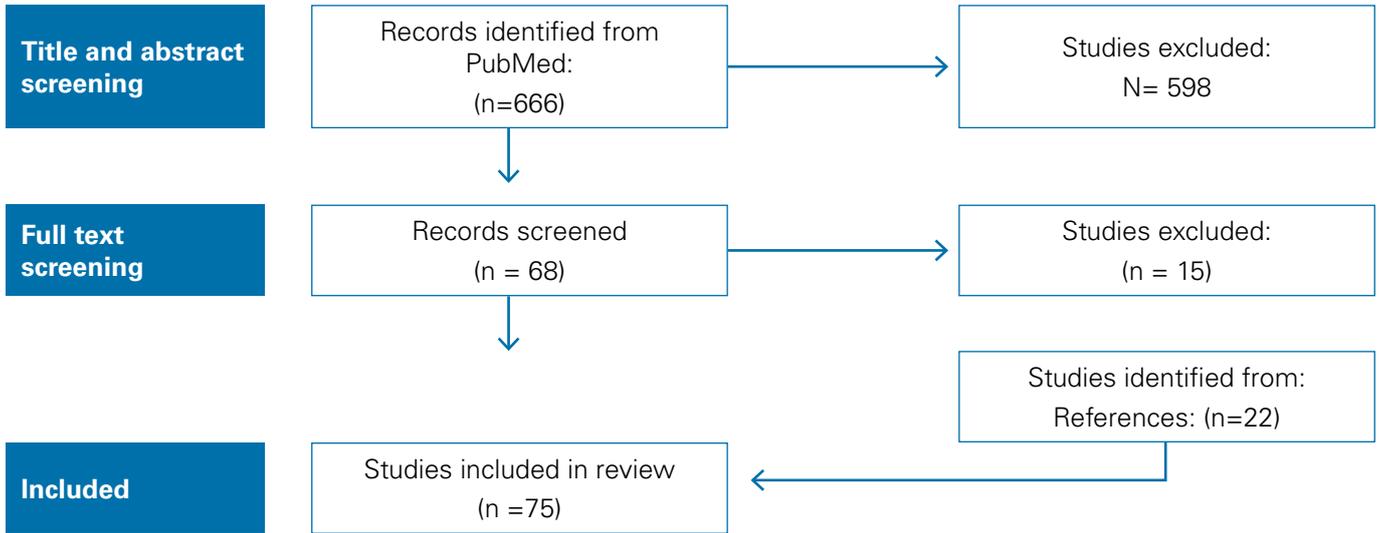
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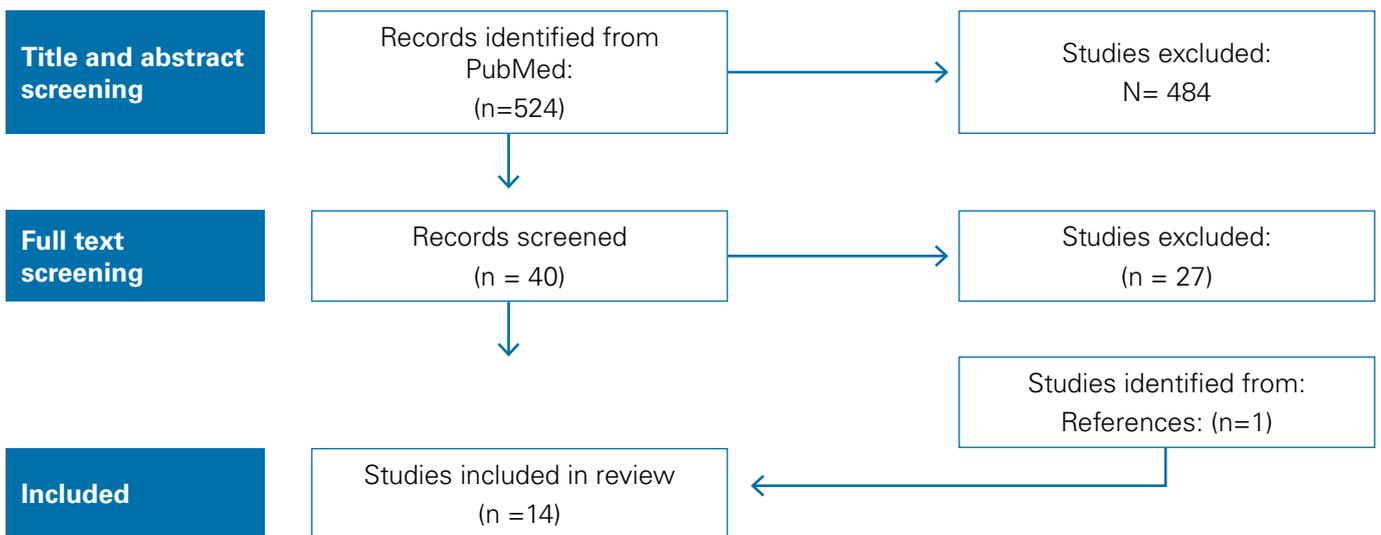
# ANNEX

## PRISMA of umbrella reviews

### UMBRELLA REVIEW 1 Household economic burden of NCDs



### UMBRELLA REVIEW 2 Strategies to reduce out-of-pocket expenses for people living with NCDs and their impact





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