



A REPORT BY
NATIONAL ENERGY ACTION AND MARIE CURIE

TAKING THE TEMPERATURE OF NG6



A review of how the NICE Guideline NG6 is delivering warm and safe homes, and what more can be done for vulnerable and terminally ill people

OCTOBER 2023

CONTENTS

03: Executive summary

Overview
Key findings and recommendations

06: Introduction

The research approach

08: Establishing the prominence of NG6 in existing research - a rapid evidence review

What is fuel poverty?
Fuel poverty, health and terminal illness
The NICE NG6 guideline
NG6 and terminal illness
Discussion
Selection of NG6 guidelines for this research

16: Utilisation of NG6 for those at the end of life and terminal illness in England and Wales: A document analysis

Local authorities in England
Local authorities in Wales
Recommendation 7 - Safe discharge for vulnerable patients
Recommendation 11 - Raising awareness among practitioners and the public

28: Conclusions and recommendations

Our recommendations

32: Annexes

Annexe 1: The NICE NG6 Guidance
Annexe 2: FOI Questions

CITATION

Butler, D., Steadman, L., Jackson, M., Stockton, H., and Smith, P. (2023). Taking the Temperature of NG6: A review of how NG6 is delivering warm and safe homes, and what more can be done for vulnerable and terminally ill people. National Energy Action.

For any queries, please contact research@nea.org.uk.

EXECUTIVE SUMMARY

Overview

Since its publication in 2015, the National Institute for Health and Care Excellence's (NICE) NG6 guideline has been recognised as a landmark resource for understanding and deploying appropriate action to support those at risk of worsening health because of cold homes and fuel poverty.

Despite it being recognised as a key resource for tackling the health impacts of cold homes, there is limited understanding of the extent to which the recommendations have been or are being implemented, and it is difficult to identify examples of best practice or examine related challenges that national, regional, and local services have faced.

Further, no analysis has been carried out to assess the specific delivery and impact of the recommendations with a consideration of key vulnerable groups, for example those at the end of life – a group we know can experience a vicious cycle of fuel poverty and are among the most vulnerable to the health and wellbeing consequences of poverty and cold and poor housing.

Deteriorating health often means higher costs to heat and power the home sufficiently, and for some households with a terminal or serious health diagnosis this can result in more than a doubling of energy costs. For those on the lowest incomes, these financial impacts are felt even harder.

The consequences of struggling to meet increased costs can be severe: it can lead to new infections, make existing symptoms flare up or become worse, and affect mental wellbeing. In the worst cases, enduring life in a cold, poor quality home may even hasten death.

This report takes steps to close an evidence gap. It details collaborative research undertaken by National Energy Action and Marie Curie to examine how the recommendations in NG6 are being delivered, with specific consideration of what this means for people at the end of life in England and Wales.

Through an evidence review of academic and policy research, as well as a document analysis of publicly available resources and additional reports and resources shared in response to Freedom of Information (FOI) requests, the research has aimed to provide a snapshot of what is happening in relation to five out of the 12 NG6 recommendations. The five selected NG6 recommendations – which focus on the

importance of a strategy, single point of contact, safe discharge, and public awareness - have been identified as more or most pertinent to those at the end of life or with a terminal illness.

While positive examples of how NG6 is being implemented were identified, our analysis shows that more action is needed. The research highlights that progress to date has been patchy and inconsistent. In many cases there is little to no data or detail on the implementation of NG6, which are a mandatory set of guidelines in England, and this means that either there are gaps in existing activity, or that work is happening but is not known about, making scaling up or learning from examples of best practice extremely difficult.

It is clear from the current climate and extensive evidence between health and cold homes, that focused and urgent action is needed to tackle fuel poverty among people with a terminal illness. It is unacceptable that any dying person should spend the end of their life in cold, damp, and uncomfortable conditions – deprived of the best possible quality of life because of unaffordable heating costs.

Our analysis shows that there is still much work to be done to deliver universal action on the recommendations set out in NG6. This new research hopes to take steps towards this, setting out crucial evidence of the extent to which relevant authorities and bodies are implementing the guidance.

Key findings and recommendations

Focusing on the five NG6 recommendations considered most or more pertinent to the experiences and needs of those with a terminal illness, our analysis sets out the following key findings in relation to each:

NG6 Recommendation 1 – Develop a Strategy

- The role of Health and Wellbeing Boards (HWBs) in the implementation of the NICE NG6 guideline in addressing the issue of cold homes and poor health was deemed critical. However, there is a recognition of





the need for sufficient funding to ensure HWBs can adopt the position of local leadership on this issue, as was intended with the publication of NG6.

- Many Joint Strategic Needs Assessments (JSNAs) and Health and Wellbeing Board Strategies (HWBS) published by local authorities in England mention 'excess winter deaths', however, typically only to highlight the number of winter deaths in the locality. These documents do not typically outline solutions to minimise winter deaths or use of NG6 guidance as part of strategy development in this area.
- Many resources from local authorities in England provide details of links to strategies and plans at local and national levels (for example, Affordable Warmth Strategies, Fuel Poverty Strategies or Cold Weather Plans) that set out support for vulnerable people living in cold homes. Some resources highlight the importance of, and make links to, energy efficiency schemes, though there was limited discussion of this in relation to reducing health inequalities and reducing the risk for health. There is also a need to explore where NG6 could be embedded within other existing strategies and plans, such as palliative care plans.
- Much of the evidence from the FOI responses focused on effective provision in terms of supporting vulnerable people during the winter and provide little or no detail relating to year-round preventative measures or whether there is adequate provision for 'normal' winter temperatures, not just extreme cold.

- Within the review, there was limited mention from local authorities of training for frontline professionals, and this forms a key part of delivery of NG6.
- No evidence was identified of the ways in which strategies and plans are evaluated or monitored. Some detail was shared regarding how and when strategies were updated and this varied: some were updated annually with recent figures or policy changes, while others were in place for 2-5 years with short-, medium- and long-term outputs.

NG6 Recommendation 2 – A single point of Contact

- Many local authorities provided details of external bodies who deliver support services such as community hubs, phone lines, and drop-in services for the public with the cost-of-living crisis and, more specifically, advice and guidance on reducing energy bills and keeping warm during the winter. Several went further and detailed Single Point of Contact (SPOC) services. These were typically based within local housing-related teams where the remit is to support residents with a variety of issues, including cold homes.
- The review adds further evidence to the position that effective cross-sectoral partnership working is critical for the delivery of NG6, and best practice is often found where well-trusted, well-established, and diverse organisations able to offer a wide range of forms of support are brought together.
- There is a need for a wide range of different forms of support and it must include in-person and in-home options – particularly in terms of supporting those with

serious health issues and vulnerabilities. For people who are terminally ill, support provided in-home is of particular importance.

- The role of advice, support, and information provision is critical. Effective energy-related advice and support should be seen as an essential not complementary component of efforts to tackle fuel poverty, including the implementation of NG6. What provision looks like for those experiencing terminal illness is likely an aspect of NG6 implementation that needs further attention.

NG6 Recommendation 3 - Tailored solutions

- Cross-partnership working, bringing together organisations working across different areas and forms of support, is regarded as a critical factor in providing support that is effective and can be tailored to different household, vulnerable, and demographic groups.
- Much of the evidence around tailored support detailed advice and information services. Many of these included elements such as the introduction of warm hubs (an initiative that was implemented widely during the winter of 2022-2023 during the energy price crisis).

NG6 Recommendation 7 – Safe discharge for vulnerable patients

- Thirty-six of the 39 Integrated Care Boards (ICBs) in England responded to our FOI requests. The responses received by ICBs were by far the most detailed and provided valuable insight into various activities, schemes, and programmes that have been implemented to support vulnerable people living in or at risk of cold homes.
- ICBs are supporting a wide range of schemes and services across the country to put an end to the discharge of vulnerable patients into cold homes. This includes the provision of bespoke hospital after-care services to ensure that, in line with NG6, people leaving hospital, including those with terminal illness, are able to return home to heating, hot water, and in some cases shopping.
- Discharge planning, as outlined in NG6, should coordinate a range of relevant professionals, not just those working in health and social care. Several ICBs shared details of how they are doing this at present. Evidence of effective partnership working between ICBs and other local partners was found, particularly with referrals to Singly Point of Contact (SPOC) services.
- ICBs shared details of funding, noting the Better Care Fund as a valuable resource, and also shared details of funding innovative projects and schemes focused on discharge to a warm and safe home.

NG6 Recommendation 11 – Raising awareness among practitioners and the public

- Awareness raising was noted throughout the review as essential, and an area where further efforts are needed. With an ever-changing and complex landscape of support, there is a constant need to increase awareness-raising activities and campaigns. It is also likely that lack of awareness, and potentially stigma and shame, are stopping people with terminal illness from accessing support.

Our recommendations

From these findings, we make the following recommendations for policy and practice:

- Further analysis is needed to understand the extent to which fuel poverty is having health consequences for people living with terminal illness, especially considering the impacts that the cost-of-living and energy price crisis is likely to have had.
- People with a terminal illness need to be explicitly identified as a category of 'vulnerable group' by NICE.
- Further research is critically needed to better understand the finer details of specific successes and challenges of schemes and services that are delivered under NG6.
- A review of work aligned with NG6 recommendations across the UK nations is needed, particularly to better understand and highlight that which is happening in Wales.
- JSNAs and HWBs need to go further and outline solutions and strategic activity to minimise winter deaths.
- NG6 implementation should complement existing strategies and plans, specifically in the context of terminal illness, for example, in end of life or palliative care plans.
- Opportunities to modify or expand training for frontline professionals should be identified to ensure the needs of people living with terminal illness and their families are factored into wider energy and fuel poverty training offers.
- To reach the most vulnerable people, energy-related advice and support must be available in multiple formats and settings, therefore in-person and in-home support must be protected and expanded and the value of this recognised in policy.
- There is a clear need to better understand barriers in accessing support that people with a terminal illness face and implement awareness-raising campaigns and targeted support for this vulnerable group specifically.

INTRODUCTION

People who are terminally ill, or reaching the end of life, can experience a vicious cycle of fuel poverty (1) - a situation in which a household cannot adequately afford or access sufficient energy for good health, wellbeing, and comfort. Those at the end of life are among the most vulnerable to the health and wellbeing consequences of poverty and cold and poor housing.

In 2021 Marie Curie commissioned the Centre for Research in Social Policy at Loughborough University to examine the number of people who die in poverty in the UK each year, and how the risk of being in poverty at the end of life varies for different groups of the population (2). This research reveals, for the first time, the extent of poverty and financial insecurity among people living with terminal illness and at the end of life in the UK.

The facts are striking:

- 90,000 people die in poverty every year in the UK,
- 1 in 4 people who die in working age are in poverty in their last year of life,
- 2 in 3 working-age parents who die experience poverty in the last five years of life,
- Women and people from minority ethnic groups are more likely to die in poverty.

Deteriorating health often means higher costs to heat and power the home sufficiently. Some may struggle to afford these increased costs due to depleted incomes as well as the other significant costs associated with terminal illness. Additionally, the consequences of living in a cold home can be severe for those experiencing severe ill health: it can lead to new infections, make existing symptoms flare up or become worse, and affect mental wellbeing. In the worst cases, enduring life in a cold, poor quality home may even hasten death.

Since its publication in 2015, the

National Institute for Health and Care Excellence's (NICE) NG6 guideline has been recognised as a landmark resource for understanding and deploying appropriate action to support those at risk of worsening health because of cold homes and fuel poverty (3). The guidance, which the UK Government is committed to supporting practitioners in a wide range of sectors to follow (4), sets out twelve recommendations that are focused on: *...reducing the health risks (including preventable deaths) associated with living in a cold home. It aims to improve the health and wellbeing of people vulnerable to the cold. Improving the temperature in homes, by improving energy efficiency, may also help reduce unnecessary fuel consumption.*(5)

Within this, people with a terminal illness are identified as a specific at-risk group:

...living in a cold home may have a greater effect on people who have to spend longer than an average amount of time at home. This could include those with chronic health conditions (including terminal illnesses) or disabilities.

There is, however, limited understanding of the extent to which the recommendations have been implemented, and no analysis has been carried out to assess the specific delivery and impact of the recommendations on those with terminal illness or at the end of life. Previous research has highlighted that delivery of NG6 broadly is 'patchy' with a recognised absence of cold homes strategies in place and that assessments of patients' needs are 'far from universal' (6).

This report takes steps to close this evidence gap. It details collaborative research undertaken by National Energy Action and Marie Curie to examine how the recommendations in NG6 are being delivered, with specific consideration of what this means for people at the end of life in England and Wales.

Completed over two stages, the first part of the research involved a rapid



RESEARCH APPROACH

Stage 1: Selecting Recommendations
A rapid evidence review of academic and grey literature to identify which NG6 recommendations have received focus or are considered more/most prominent in relation to end of life experiences and terminal illness.

Stage 2a: Scoping Review of Existing Strategies and Plans
Initial scoping and analysis of relevant publicly available resources collected via literature/online searches
Stage 2b: Freedom of Information (FOI)
Over two rounds, a total of 368 FOI requests collected were submitted to local authorities in England and Wales, English Integrated Care Boards (ICBs), the Office for Health Improvement and Disparities (OHID) and the Department for Energy Security and Net Zero (DESNZ).

evidence review of academic and grey literature to identify which of the 12 recommendations are of more or most significance in the context of end of life and terminal illness.

The second stage involved a document analysis of (1) readily and publicly available resources identified through online searches and (2) resources shared in response to two rounds of Freedom of Information (FOI) requests. Drawing on existing literature and publicly available resources identified from the document analysis, we aimed to build a better understanding of:

- The extent to which local authorities, Health and Wellbeing Boards and other relevant stakeholders in England and Wales are considering the impact of fuel poverty and cold housing among people who are living with terminal and life-limiting illnesses and those at the end of life.
- How different localities have implemented select recommendations from the NICE guideline NG6 for

people who are at the end of life, and the successes, challenges, and gaps in approaches.

- Assess the potential benefits of the successful delivery of the recommendations in NICE guideline NG6 for people who are terminally ill or at the end of life.

Within this research, we follow the definition set out in the Local Government Association's End of Life Care Guide, which states that:

End of life care is loosely defined as the last year of life, but accurate predictions are difficult, which makes planning, preparation and embedding good practice important. (7)

We extend this to also consider the various forms of terminal illness that a person may experience (for example, cancer, dementia, Parkinson's disease), and recognise that this is also an experience which children and young people in the home also go through.

ESTABLISHING THE PROMINENCE OF NG6 IN EXISTING RESEARCH: A RAPID EVIDENCE REVIEW

A rapid evidence review was undertaken to gather an initial understanding of which, if any, recommendations within NG6 have received focus or been considered more prominent within the context of the end-of-life experience and terminal illness. This section details the findings of that review.

What is Fuel Poverty?

Fuel poverty can be broadly understood as a situation in which a household is unable to afford or access adequate energy to maintain a safe, healthy, and comfortable life at home. The experience of fuel poverty is not solely about the struggle to stay comfortably warm (or cool) enough; it impacts upon many aspects of everyday life such as the capacity to cook, sufficiently light the home, fulfil domestic chores, meet personal hygiene needs, power, and charge essential devices such as mobile phones and medical equipment, as well as benefit from the enjoyment of socialising, hobbies, leisure, and entertainment.

In the UK context, fuel poverty has long been recognised as a social

policy issue with the first Fuel Poverty Strategy in England introduced in 2001. Across the four UK nations, fuel poverty is defined and measured differently. In Scotland, Wales, and Northern Ireland variations of the 10% indicator (in which a household needs to spend 10% of income on energy costs) are used. In England, the current measure, introduced in the latest strategy in 2021, is the Low Income Low Energy Efficiency (LILEE) indicator that defines a household as living in fuel poverty if it has a residual income below the poverty line (after accounting for required fuel costs) and lives in a home that has an energy efficiency rating below B and C.

While more than four million UK households are officially estimated to be living in fuel poverty, the scale of the issue varies greatly across the four nations. According to Government figures (8), fuel poverty affects:

- 3.26 million (13.4%) households in England
- 613,000 (24.6%) households in Scotland
- 196,000 (14%) households in Wales
- 179,000 (24%) households in Northern Ireland

Since 2021, the UK has been in the midst of an energy crisis. Rapid increases in gas market prices caused more than 30 energy suppliers to go out of business in 2021 and triggered some of the sharpest household energy price rises in history. In the UK, energy bills have more than doubled in the two years up to 2023 and National Energy Action estimates that from October 2023 the number of households in fuel poverty will be 6.5 million (9).

Fuel poverty disproportionately impacts certain groups, such as single person households, those on low incomes, people living in the private rented sector, families with children and households where someone is living with a disability or an illness that is long-term, chronic, or terminal. More than 40% of households in fuel poverty include someone living with ill health or a disability, and for these households, energy costs can be much higher due to longer periods of time in the home and greater energy needs

Fuel Poverty, Health, and Terminal Illness

A wealth of evidence has demonstrated the significant impact that fuel poverty and cold housing can have on health and wellbeing. In 2011, the Marmot Review Team published their still widely cited and comprehensive study of cold homes, fuel poverty and health (10). This focused attention on key areas of health risks, such as respiratory and cardiovascular conditions, dementia, worsening asthma and rheumatism, and mental ill health, as well as higher rates of colds and flus. In addition to detailing a review of the evidence

to date, the research argued for better alignment of environmental and health agendas, highlighting the manifold health benefits of reducing fuel poverty.

For dying people in particular, deteriorating health often means higher expenditure on heating the home sufficiently, due to increased time in the home, depleted incomes from a possible reduction in and ultimate end to employment, as well as often significant costs associated with managing and coping with terminal illness. For those with a cancer diagnosis, for example, the cost of that illness is estimated to be around an additional £570 a month, with increased fuel bills a contributing factor (11). The financial impact of a cancer diagnosis can be twice as high for those on the lowest incomes, those also more likely to be living in fuel poverty, compared to those with higher incomes.

Research by Marie Curie has shown that a terminally ill person's energy bill can rise by 75% after their diagnosis. As part of this rise in costs, Marie Curie found in their recent report (12) on the impact of rising energy costs on people at the end of life, 'One Charge Too Many', that the cost of running an oxygen concentrator can be £65 per month, a dialysis machine £27 per month and a ventilator £35 per month. Unsurprisingly, this leaves more than half of disabled adults worrying about paying energy bills. Evidence from research examining the experiences of those with cancer has found similar issues, noting "...the importance of financial wellbeing in maintaining and improving health" (13).

The cost-of-living crisis has added even greater strain on the lives of those with ill health and the lowest incomes. In 2023, Marie Curie (14) reported that in the preceding 12 months, 89% of Marie Curie healthcare staff have cared for patients who were struggling financially. Breaking these financial strains down even further, the survey reported that:

- 84% said that they had observed patients struggling to afford their energy bills,
- 31% also observing patients struggling to meet their housing costs,
- 28% reporting patients struggling to afford running at-home medical devices,
- 21% even reporting seeing patients struggling to afford suitable food.

Marie Curie healthcare staff were asked how concerned they were that their patients would be able to keep their homes warm over the winter. More than four in five Marie Curie staff (81%) reported that they were concerned or very concerned about this, with more than half (56%) reporting that they were 'very concerned' for their patients. Just 4% of staff reported that they had no concerns about their patients' ability to keep their homes warm over the winter.

Whilst official fuel poverty data shows that a high proportion of those in fuel poverty (>40%) are living with a disability or ill health, the exact number of households affected by terminal illness

in fuel poverty is unknown. As other research has highlighted, it is likely that the levels of fuel poverty among specific vulnerable groups, including those with terminal illness, are much higher than may be estimated. This can be linked to stigma associated with disclosing problems with paying energy costs, debts, as well as the potential for other issues and needs that might be experienced at the end of life to be prioritised by a householder and the services that support them. In other words, what constitutes sufficient energy use and problems with paying for energy may not be picked up on or disclosed in interactions around how best to manage the end-of-life experience. The opportunity to capture this data presents a clear opportunity to better understand the scale of the problem.

Expectedly then, fuel poverty can be seen to have a major detrimental impact on the end-of-life experience – leading to new infections, exacerbating existing symptoms like pain, and increasing the risk of mental ill health, including anxiety, depression, and stress. In the worst cases, fuel poverty may even hasten a terminally ill person's death. This is particularly important in the UK context which has the second highest level of excess winter mortality compared to similarly cold countries across Europe (15). Thousands of these deaths are, as NICE declare, entirely avoidable. And, as the Marmot Review in 2011 highlighted, countries with more energy efficient housing (and lower levels of fuel poverty) have fewer excess winter deaths.



THE NICE NG6 GUIDELINES

In 2015, the NICE NG6 guidance (16) - Excess winter deaths and illness and the health risks associated with cold homes - was introduced. Targeted towards Health and Wellbeing Boards (HWBs), and those working in health and social care, energy, housing, and other relevant sectors (across England and Wales only), the guideline encompasses 12 recommendations which are set out below (Table 2).

	ACTION TAKEN	WHO SHOULD TAKE IT
1	Develop a strategy to address the health-related consequences of cold homes	Health and Wellbeing Boards
2	Ensure there is a single-point-of-contact health and housing referral service for people living in cold homes	Health and Wellbeing Boards
3	Provide tailored solutions via the single-point-of-contact health and housing referral service for people living in cold homes	Health and Wellbeing Boards local authorities; housing providers; energy utility and distribution companies; faith
4	Identify people at risk of ill health from living in a cold home	Primary health and home care practitioners
5	Make every contact count by assessing the heating needs of people who use primary health and home care services	Primary health and home care practitioners
6	Non-health and social care workers who visit people at home should assess their heating needs	People who do not work in health and social care services but who visit people at home (e.g., meter installers, faith and voluntary sector workers, housing professionals etc.) Primary health and home care practitioners
7	Discharge vulnerable people from health or social care settings to a warm home	Those responsible for arranging and helping with someone's discharge from a health or social care setting
8	Train health and social care practitioners to help people whose homes may be too cold	Training providers for housing professionals and for people working in the faith and voluntary sector
9	Train housing professionals and faith and voluntary sector workers to help people whose homes may be too cold for their health and wellbeing	Training providers for housing professionals and for people working in the faith and voluntary sector
10	Train heating engineers, meter installers and those providing building insulation to help vulnerable people at home	Employers who install and maintain heating systems, electricity and gas meters and building insulation and those involved in employee training
11	Raise awareness among practitioners and the public about how to keep warm at home	Health and Wellbeing Boards, Public Health England and the UK Government (DESNEZ)
12	Ensure buildings meet ventilation and other building and trading standards	Building control officers, housing officers, environmental health officers and trading standards officers

NG6 is specifically focused on ways in which mortality and morbidity associated with living in cold homes can be reduced. With public health and related goals in mind, it aims to support cross-sectoral efforts to:

- Reduce preventable excess winter death rates,
- Improve health and wellbeing among vulnerable groups,
- Reduce pressure on health and social care services,
- Reduce fuel poverty and the risk of fuel debt or being disconnected from gas and electricity supplies (including self-disconnection),
- Improve the energy efficiency of homes.

NG6 and terminal illness

Within the NG6 recommendations, those with a terminal illness are identified as a particular at-risk group. In Recommendation 5, which outlines a need to 'Make every contact count by assessing the heating needs of people who use primary health and home care services', primary health and home care practitioners should, among other actions:

Be aware that living in a cold home may have a greater effect on people who have to spend longer than an average amount of time at home. This could include those with chronic health conditions (including terminal illnesses) or disabilities.

While this is the only instance in which there is explicit reference to terminal illness, there are several areas in which the recommendations have significant relevance in the context of terminal illness and end of life care (17).

The role of HWBs is deemed particularly important in the implementation of the NICE guideline in addressing the issue of cold homes and poor health (as outlined in Table 2 above). Established in 2012, HWBs were introduced as a mechanism for better integrating health and social care, drawing together the NHS, public health, adult social care and children's services, among others, to meet local population needs and address health inequalities at the local level.

Several studies have focused on the critical role of HWBs as a way of better understanding the extent to which NG6 is being implemented. For example, research by Marie Curie drew on insights from 109 of the 152 HWBs to explore the extent to which action had been taken and where gaps remained. The research concluded with a call for specific consideration of action against key aspects of NG6 such as the development of local strategies and the provision of a single point of contact and housing referral services for people living in cold homes, the first two recommendations – both of which are regarded as the primary responsibility of HWBs. Other NG6 recommendations positioned as critical in the context of terminal illness and fuel poverty included those focused on the role

of primary health and home care practitioners, for example, in assessing heating needs through contact points such as home visits and safe discharge to warm homes. Marie Curie's analysis of action to implement NG6 concludes that while some progress has been made this is patchy and inconsistent.

Similar findings can be found in research that predates the introduction of the NICE guideline on cold homes and health. In 2014, for example, Hospice UK developed a traffic light ('RAG') system to examine to what extent HWBs, in the first two years of existence, had considered the needs of dying people (18). Reviewing Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs) – both strategic documents that HWBs are responsible for producing – the study found that 43% had explicitly considered the needs of dying people ('green'), 26% had considered related issues ('amber') but without mentioning dying people, and 24% failed to mention either directly or indirectly people approaching the end of life. Ten HWBs had not published or made publicly available their strategies.

While the evidence would suggest that some progress has been made since 2014, common challenges persist. This includes, as Hospice UK's recommendations in 2014 set out, a need for more effective alignment of health, social care, and public health systems; utilisation of public health data; co-production of strategies between HWBs, palliative care providers and hospices, as well as other support services; and, for all documents to be made publicly available for accountability and transparency. This highlights the urgent need for work to better understand the barriers encountered by HWBs and other actors, and how best to develop strategies to overcome such challenges.

A 2016 study by NEA provides valuable insights on the extent to which HWBs have acted in accordance with the NICE NG6 guidelines in the first year (19). The study again centred on the assessment of JSNAs and JHWSs as critical data sources, this time with a focus on the consideration of fuel poverty and excess winter deaths. Findings revealed a mixed picture of progress: while 40% of HWBs failed to address the issue of fuel poverty, more than a third were prioritising it in their plans and this was noted as demonstrating a 17% increase from related research three years earlier. This could be perceived as evidence of the impact of the NG6 guideline in strategic planning at regional and local levels. Of major concern from the findings was that only 7% of HWBs referred to discharge protocols to ensure that ill people were returned to warm, safe homes. This was regarded as disappointing in the context of potential healthcare cost savings and the positive health impacts that could result from proper discharge planning.

While research is still limited, the issues of fuel poverty, cold homes, and poor-quality housing, among those with terminal illness has received some notable attention in policy in recent years. In 2021, for example, the topic was the focus of an

inquiry by the APPG for Terminal Illness (20). Bringing together the voices of experts, professionals and those with lived experience, a set of recommendations was developed from insights gathered as part of a call for evidence and three oral evidence sessions. The overarching aim guiding the inquiry was to identify ways to improve the end-of-life experience, with a focus on alleviating the impacts of fuel poverty, improving poor housing, addressing difficulties in affording housing and energy costs, as well as support for those experiencing homelessness at the end of life. Echoing earlier findings from research by Hospice UK, NEA, and Marie Curie, it was noted how, despite some positive examples, the implementation of NG6 on the whole needs improving. For example, the research noted that 43% of local authorities do not have a single point of contact referral service and 40% do not have a cold homes strategy. This situation is set against a shifting landscape where the role and function of HWBs alongside Integrated Care Systems are yet to be clearly defined.

A review of the academic literature found no studies to date that have explicitly focused on fuel poverty and cold homes in the context of terminal illness and end-of-life experiences. While the health implications of living in fuel poverty have been extensively examined across a range of disciplinary standpoints, most notably in the health and social sciences, this specific area of focus – fuel poverty and terminal illness - represents a significant gap in the literature to date.

Several studies, though not explicitly focused on terminal illness, have highlighted the experiences and challenges associated with managing chronic and life-limiting health conditions while living in fuel poverty. Useful insights from this body of work have relevance in understanding which mechanisms of support at the intersection of health and fuel poverty work well, and where significant gaps remain. For example, a review of a decade of large-scale studies which focused on human health and fuel poverty found significant positive health impacts on respiratory health, especially among children, from fuel poverty interventions (21). Beyond physical health, the review noted the significant impact that fuel poverty has on mental health and called for greater attention in this area, with a need for measures that better assess related aspects such as quality of life and social relations, as well as diagnosable mental health conditions.

A growing body of academic work has examined the role of 'place' in the context of terminal illness and death. Evidence suggests that for nearly two-thirds of people the preferred place to die is in the home and in UK policy, to die at home is described as a marker of a 'quality death' (22). However, for those living in the most socioeconomically deprived areas, dying at home is less likely to be the case than for those from higher socioeconomic areas (23). This inequality in health and death is even more stark for those from minority groups (24).

Further, a systematic review of more than 200 international studies highlighted that not only is poverty

and lower socioeconomic status an indicator of earlier onset of disease and reduced life expectancy it is also a risk factor for worse end of life care and a lower likelihood to access specialist palliative care. This demonstrates, as Davis et al (2019) point out, that there is "socioeconomic inequality in the care received by people towards the end of life", highlighting the criticality of universal implementation and delivery of policy mechanisms such as NG6.

The role of social relations and the capacity for family and friends to provide support has also been noted as critically important to consider in the context of end-of-life care for those living in poverty, including fuel poverty. It is not only the physical infrastructure (of poor quality, damp, cold housing, for example) that shapes the experience of death, but also the social relations embedded within that experience, and "...for people experiencing poverty, there is a high chance that their family members, and other potential support people in their life, are also experiencing poverty." (25) This points towards a lack of understanding as to the "added complexities of end-of-life caregiving within the context of poverty and deprivation", such as the additional financial burden faced by family and friends, particularly those supporting someone and likely themselves living in poverty. This emphasises the critical role that a wide range of actors play as set out in NG6, with particular focus to ways in which those who have regular contact and trusted relationships with dying people in their communities and homes.

While NG6 is predominantly concerned with action against the 12 recommendations, the guideline also provides suggested directions for research, highlighting key gaps such as a need to better understand the relationship between temperature and illness and death, coping strategies, the impact of energy efficiency, and barriers to support, as well as the cost effectiveness of interventions.

Embedded through several of the NG6 recommendations is the role of advice, support, and information provision. In research, it has been argued that effective energy-related advice and support should be seen as an essential not complementary component of efforts to tackling fuel poverty, including the implementation of NG6. For example, NEA's evaluation of the expansive £26.2 million Health and Innovation Program (26) highlighted the importance of advice and support in delivering NG6, with significant improvements to health and wellbeing reported as a result of physical measures to improve properties when delivered in combination with in-depth, meaningful advice and support.

There have, however, been evaluations of services such as the Macmillan Energy Advice Team (27) and the delivery of the npower Macmillan Fund, which have highlighted the value of collaborative working, effective signposting, and direct financial support alongside advice and support from trusted sources. Impacts of the latter included reduced fuel poverty risk, increased energy affordability, reduced energy rationing practices (i.e., turning off or going without the use of certain appliances for heating, cooking, cleaning, entertainment, etc.), and improvements to self-reported physical and mental health.

As with advice and support, training appears to receive less focus in the literature reviewed, although is often noted as a part of the design and delivery of services. However, Recommendations 9, 10 and 11 in NG6 focus explicitly on training. This is of health and social care practitioners; housing professionals and faith and voluntary sector workers; and, heating engineers, meter installers and those providing building insulation. The power of embedding training into the development of schemes and services working with frontline workers across health and social care sectors and beyond has been highlighted. Referred to as the 'cascade approach,' training is seen to have the greatest potential to reach people in need whereby every frontline worker trained to deliver energy-related advice and support is estimated to go on and support a minimum of 10-15 people experiencing energy-related vulnerability or fuel poverty. In other words, the potential reach in working with middle actors (who go on to support multiple service users) is much larger than working directly with the target audience. Understanding the experiences and modelling the scale of these impacts in a range of health-related contexts in relation to cold homes and fuel poverty would be extremely valuable, including that which focuses on terminal illness.

The 2021 "Better End of Life" report calls for a 'whole system' approach to ensure a positive end-of-life experience in the home and outlines that this will require input not just from those working in end-of-life care and the health sector, but that which extends into other sectors, too. As the report notes, "for people living with chronic life-limiting illnesses, the pandemic has had profound impacts." The role of informal sources of support – family, friends, and neighbours – is again highlighted as critical, with such actors positioned as important providers of palliative care and in need of good advice, information, and support. While not necessarily an essential part of

strategy at the local level, understanding how delivery of the different NG6 recommendations is shaped, enhanced, or constrained by these relations – within and beyond health and housing, as well as of informal sources of support is, therefore, critical to consider.

Discussion

Overall, the evidence review found limited attention in research focused specifically on the needs and experiences of and support mechanisms available to people with a terminal illness living in fuel poverty. The implementation of NG6 within this context is even less well understood. This represents a significant gap in existing policy and research, and an area that has the potential to drastically improve end of life experiences among some of the most vulnerable people with a terminal illness.

While academic research has extensively examined the relationship between health and fuel poverty, and common references to the NICE guidelines can be noted, no studies were found that have explicitly focused on fuel poverty or NG6 in relation to terminal illness. As discussed, however, several more policy-focused reports by national organisations (including National Energy Action and Marie Curie) that are working in this and closely related areas, have been published with greater and more explicit focus.

Within these reports, many of the wider research or policy recommendations set out are targeted specifically at, or have significant relevance to the implementation of, NG6. For example, there is a clear call across the evidence for the development, and where appropriate, review of strategies to address the consequences of cold homes (as per recommendation 1), an aspect considered a fundamental priority. Many of these recommendations align with those set out in this report (see the Executive Summary or Section 5).



Selection of NG6 guidelines for this research

From the evidence reviewed and consultation across project teams, five of the twelve NG6 recommendations were categorised as particularly pertinent to the needs and experiences of those with terminal illness and at the end of life, as well as the experiences of those supporting or providing care for such people. These recommendations were selected for specific focus within this research and are summarised (right) (Table 3):



14

R1 Develop a strategy

R2 Ensure there is a single-point-of-contact health and housing referral service for people living in cold homes.

R3 R3: Provide tailored solutions via the single-point-of-contact health and housing referral service for people living in cold homes

R7: Discharge vulnerable people from health or social care settings to a warm home. health from living in a cold home

R11: Raise awareness among practitioners and the public about how to keep warm at home.



Recommendation 1 of NG6 states that HWBs should include the health consequences of living in a cold home in the joint strategic needs assessment process. Any strategy developed to achieve this should identify those at risk, accounting for groups with particular problems, such as those in hard-to-heat homes or in need of more warmth. It should aim to prevent mental and physical health problems, including death from cold homes. Additionally, it should assess heating and insulation needs, set out year-round preventative measures, and ensure there is adequate provision for 'normal' winter temperatures, not just severe cold. Finally, the strategy should outline how other NG6 recommendations will be implemented and identify and meet training needs of other local practitioners. Recommendation 1 also states that planning should include identification of relevant cross-sectoral local providers and interventions; consider how NG6 is also reflected in other local strategies and plans; and ensure that the strategy is monitored, evaluated, and made publicly available.

Recommendation 2 of NG6 states that HWBs should ensure a local single-point-of-contact (SPOC) health and housing referral service is commissioned to help vulnerable people who live in cold homes. It outlines a wide range of groups that are considered vulnerable to the cold (not specifically those with a terminal illness) but does outline that vulnerability is due to: a medical condition; a disability that, for instance, stops people moving around to keep warm, or makes a person more likely to develop chest infections; or personal circumstances, such as being unable to afford to keep warm enough. The SPOC service should ensure that anyone who comes into contact with such groups is able to make referrals and that it has relevant national and local links to services providing a range of support. The service should provide face-to-face support, allow self-referrals and have a free phone number.

R3 of NG6 states that HWBs and relevant partner organisations and bodies should ensure that the local single-point-of-contact health and housing referral service provides access to tailored solutions. By this, such tailored solutions should focus on identified needs and not represent an 'off-the-shelf approach.' Examples of where tailored solutions are required include a need to account for language needs or support for those with hearing or visual problems. The package of possible solutions should include housing insulation and heating grants, energy-related advice and support, income maximisation, debt support, and benefit checks, support registering on priority service registers, access to home improvement agencies, and short-term emergency and crisis support.

R7 of NG6 focuses on the processes around discharging vulnerable people from health and social care settings to the home. It calls on those responsible for arranging and helping with a timely discharge, stating that such roles should include a responsibility for year-round assessments of whether a person is able to keep warm at home and/or is vulnerable to the cold. Planned discharge should involve a coordination of all practitioners to ensure discharge to a warm home is possible. Where needed, a referral to a single point of contact should be made for remedial works such as replacement or repair of heating system, for preventing or addressing fuel debts.

Recommendation 11 of NG6 focuses on raising awareness of the health impacts of cold homes on health among practitioners and the public. It outlines that Health and Wellbeing Boards, Public Health England (now the Office for Health and Income Disparities and the UK Health Security Agency), and the Department for Business, Energy, and Industrial Strategy (BEIS) (now the Department for Energy Security and Net Zero, DESNZ) should ensure up-to-date information is available, including details of national and local support. National-level advice should make clear the regional differences in support provided. This awareness raising should also work to address commonly held misconceptions about keeping warm and well, such as sleeping in a cold room being good for your health and that hypothermia is the main health problem caused by cold homes.

15

UTILISATION OF NG6 FOR THOSE AT THE END OF LIFE AND TERMINAL ILLNESS IN ENGLAND AND WALES: A DOCUMENT ANALYSIS

The document analysis used two approaches to maximise the number of relevant resources included:

1. Extensive online searches of publicly available resources and stakeholder contact/consultation,
2. Two rounds of Freedom of Information (FOI) requests.

Stage 1 involved a review of websites for the local authorities in England and Wales to search for NICE NG6 guidance in readily accessible and publicly available documents such as Joint Strategic Needs Assessments (JSNAs) or Health and Wellbeing Strategies (HWBS). For local authorities in England specifically, we identified that 8 out of 314 had available documents that mention NG6 guidance. We did not identify any Welsh local authorities that had noted NICE NG6 guidance in publicly available documents.

It is important to note the use of all NICE guidelines, not just NG6, differ between England and Wales. In Wales, while regarded as valuable, they are not mandatory, and Welsh Government state that:

The standards set out the priority areas for improving health and social care. They are not mandatory but should be used to plan and deliver services to provide the best possible care. (28)

Following the initial desk review, a total of 368 FOI requests were

submitted to local authorities in England and Wales, English Integrated Care Boards (ICBs), the Office for Health Improvement and Disparities (OHID) and the Department for Energy Security and Net Zero (DESNZ).

Given the focus on five of the twelve NG6 recommendations (see Section 3) that were considered most pertinent to the experience of people at the end of life or living with a terminal illness, FOI requests were targeted based on where significant responsibility for action lies. As such, FOI requests sent to English and Welsh local authorities related to recommendations 1 (develop a strategy), 2 (ensure single point of contact) and 3 (provide tailored solutions); those sent to ICBs related to recommendation 7 (discharge vulnerable people to a warm and safe home); and, for recommendation 11 (raise awareness among practitioners and the public), requests were sent to OHID and DESNZ.

Responses received:

- A total of 176 responses were received (out of 314 FOI requests submitted) from local authorities in England.
- There were 12 responses received (out of 22 FOI requests submitted) from Welsh local authorities.
- Of the 39 English ICBs that FOI requests were sent to, a total of 36 responses were received.
- Responses were received by OHID and DESNZ.

The following sections detail our findings from the review of publicly available resources, strategies, and documents as well as additional information and resources shared in the FOI responses. Within this, best practice is highlighted with the inclusion of several case studies.

Local authorities in England

NG6 Recommendation 1 – Develop a strategy

Recommendation 1 of NG6 states that HWBs should include the health consequences of living in a cold home in the joint strategic needs assessment process. Any strategy developed to achieve this should identify those at risk, accounting for groups with particular problems, such as those in hard-to-heat homes or in need of more warmth.

Our analysis includes approximately 143 JSNAs and HWBs. These were identified through online searches or shared in response to FOI requests.

Of the JSNAs and HWBs from local authorities in England, most mention 'excess winter deaths' – typically only highlighting the number of winter deaths in the locality, and not offering solutions to minimise winter deaths or use of NG6 guidance as part of strategy development in this area.

Some resources also noted details of or links to local Affordable Warmth Strategies, Fuel Poverty Strategies or Cold Weather Plans that were in place to provide support and guidance to vulnerable people living in cold homes. This included, for example, details on practical ways of reducing energy bills and links to support services or benefit entitlements.

With regards to how NG6 might be reflected in other existing strategies and plans, some HWBs pointed towards strategic priorities for reducing health inequalities across local areas. Within this work, local authorities were prioritising good quality homes, and noted efforts to maximise opportunities to 'level-up' by improving the energy efficiency of homes. For example, providing grants to residents for energy efficiency improvements to their home.

There may be other examples of where NG6 could complement other existing strategies and plans worth considering, specifically in the context of terminal illness, for example, in end of life or palliative care plans. The Local Government Association has produced an end-of-life guide for local councils (29) and while this refers to the broader NICE guidelines (specifically the guide on the final days of life), as well as the links between housing and health, there is no mention of NG6 and the impact of cold homes on terminal illness and end-of-life care.

In some cases, national plans and

strategies were utilised for shaping localised action. The Cold Weather Plan for England (30), for instance, was one example noted, and this was positioned as a resource that gives advice to help prevent the major avoidable effects on health during periods of cold weather.

Case study 1: Using national plans/guidance to shape local action

The London Boroughs of Richmond and Wandsworth Councils produce and implement a winter plan that is based on the Cold Weather Plan for England. This supports local authority directorates, NHS and voluntary and community sector partners, and residents to prepare for, respond to and recover from cold weather events, and outlines key initiatives that the local Health Protection Team has in place for the winter season, which includes Cold Weather Preparedness.

As part of the Cold Weather Preparedness plan, cold weather alerts are issued, and some resources are cascaded to all partners to raise awareness. The team also briefs and provides these resources to all stakeholders including community and voluntary sector organisations to promote the flu and COVID-19 vaccinations. Resources are available in different languages and briefings are through webinars focusing on Cold Weather Preparedness.

However, while this demonstrates effective provision in terms of supporting vulnerable people during the winter, it does not provide details of how consideration is being given to year-round preventative measures or whether there is adequate provision for 'normal' winter temperatures, not just extreme cold - as NG6 sets out.

We found limited evidence of how strategies were assessing heating and insulation needs, except for how this may fall under fuel poverty schemes or housing initiatives, but this was not typically clear within JSNAs and HWBs reviewed. There was one exception, however, which detailed a commissioned piece of work to undertake a housing condition review in the local area (see Case Study 2).

The work in Derbyshire also reflects similar work in several other local authorities in England where evidence was shared relating to the ways in which councils are identifying and building relevant cross-sectoral partnerships with local providers to deliver interventions.

Such strategic groups and bodies have been established to focus work on minimising the impacts of cold homes and fuel poverty.

In Rochdale, another example, this has seen the establishment of the whole-system Poverty Task and Finish Group to develop a partnership to create an Anti-Poverty Framework or Strategy. This seeks to connect the various strands of poverty work currently taking place and includes a workstream that is focused on warmth and shelter, covering support for fuel poverty, money maximisation, and accessing food and nutrition which in the longer-term would reduce overall poverty in the area.

Similarly, in Camden, the local authority has established neighbourhood hubs/networks to engage with the voluntary and community sector to provide support to residents via community and engagement meetings.

Case study 2: Assessing heating and insulation needs

Within the Derbyshire Health and Wellbeing strategy, there is detail of the Housing and Health Systems Group. One activity undertaken by the group involved commissioning a housing stock condition survey which has provided district and borough analysis in relation to: identifying people whose health is at risk from cold homes, groups that may face particular problems, such as those living in hard-to-heat homes or who need more warmth (for instance, because of limited mobility or specific health conditions) and assessing how heating and insulation needs to be improved to raise properties to an acceptable rating.

There was limited mention of training for frontline professionals, however, evidence of this can be found elsewhere. E.g. Northumberland County Council gave details of their work programme which aims to “build the warm homes literacy of frontline professionals” through the following:

- Citizens Advice deliver Warm Homes Training
- Rolling out Financial Wellbeing Making very Contact Count

Training

- Developed a Warm Homes Information resource for frontline staff.

No evidence was identified of the ways in which strategies and plans are evaluated or monitored. Some detail was shared regarding how and when strategies were updated and this varied: some were updated annually with recent figures or policy changes, while others were in place for 2-5 years with short-, medium- and long-term outputs

NG6 Recommendation 2 – A single-point-of-contact

Recommendation 2 of NG6 states that HWBs should ensure a local single-point-of-contact (SPOC) health and housing referral service is commissioned to help vulnerable people who live in cold homes.

Many local authorities provided details of external bodies who deliver support services such as community hubs, phone lines, and drop-in services for the public with the cost-of-living crisis and, more specifically, advice and guidance on reducing energy bills and keeping warm during the winter.

Several did go further, however, detailing dedicated single points of contact services which are typically based within local housing-related teams where the remit is to support

residents with a variety of issues, including cold homes.

In line with recommendation 2 of NG6, providing a single point of contact, North Lincolnshire Council, for example, has an Affordable Warmth Officer within the Environmental Health and Housing team. This role liaises with other service areas and partners to deliver assistance and help for those struggling in cold homes with supports the NG6 guidelines. The Affordable Warmth Officer works with colleagues across the region, along with managing fuel poverty

schemes, such as ECO4 funding and Green Homes Grants. Similarly, Bath and Northeast Somerset Council also have a SPOC, based within the environmental health team, which has a dedicated freephone number and email address for vulnerable households to access support and guidance around cold homes and practical ways of lowering the cost of energy bills.

In Hull, there is a well-established Warm Zone and Hull Hotspots team

that acts as a SPOC and whose work aims to reduce fuel poverty and address affordable warmth in the city. This service provides residents with energy efficiency advice and assistance to access a range of funding options for heating and insulation measures via local or national funding programmes.

Similarly, in Cornwall, there is a Winter Wellbeing Service. The Warm Homes Healthy People programme provides a single point of contact for residents. Householders in deprived Cornish communities are receiving one-to-one help to enjoy warmer, safer homes thanks to a pioneering project sponsored by the gas network provider Wales & West Utilities and co-managed by Warm Wales CIC. The Cornish project is working to replicate the success of Warm Wales’ award-winning projects in South and North Wales which have been running for almost three years. There is a full-time Community Energy Champion, who goes door-to-door in targeted communities to help householders save money and access a broad range of projects and services provided by Community Energy Plus together with other local and national organisations.

In Luton, the single point of contact role is referred to as the Domestic Energy Efficiency Manager. The local authority also details wider support via their Keeping Warm webpage which provides information on energy advice and grants, the winter fuel payment, and how to stay well in the winter.

Across Bristol and North Somerset, there is the well-established Warmer Homes, Advice and Money (WHAM) service. The project – comprising of five key organisations - helps to reduce financial poverty, food poverty and fuel poverty. It brings together a wide range of expertise, from energy efficiency advice to debt support, from the installation of small energy-

saving measures to a handy person service. The service ensures those in fuel poverty and whose health or circumstances make them vulnerable to a cold home can freely access support from leading organisations tackling all aspects of fuel poverty. The partnership also delivers workshops and outreach activities to train energy champions, and in-person, in-home support is available via SPOC caseworkers.



Recommendation 3 – tailored solutions

Recommendation 3 of NG6 states that HWBs and relevant partner organisations and bodies should ensure that the local single-point-of-contact health and housing referral service provides access to tailored solutions.

Evidence relating to how tailored solutions were in place was mostly found in detail linked to the ways in which local authorities in England are supporting residents through the energy and cost-of-living crisis. This was typically through crisis-focused support services, local housing teams, grants or funds, and innovative programmes, of which many examples were shared. Some of the approaches by local authorities are highlighted in this section.

Several local authorities have set up specific workstreams within wider programmes of work to explicitly focus on warm and safe homes.

Case study 3: Delivering tailored solutions from a SPOC

London Borough of Richmond and Wandsworth Council has established a jointly commissioned programme to respond to the cost-of-living crisis that includes a workstream specifically focused on Warm Homes. The aim of which has been to work with partners to improve energy efficiency and access to affordable warmth, specifically among those aged over 60 and with increased risk of excess winter mortality and therefore morbidity, too. There has also been the introduction of warm spaces in the local area, providing access to a network of safe, welcoming community spaces where residents can keep warm and access other services. The programme has allocated specific funding to increase tailored energy efficiency advice, support, and outreach, including home visits and minor efficiency improvements.

There was considerable emphasis on the importance of cross-partnership working, between HWBs and relevant partners, and how this formed a key part of delivery on NG6.

This has been at the centre of Camden's plan, for example. Through the Winter Health Protection Group, which aimed to respond to the health-related challenges during the winter months, teams from public health, communications, adult social care, environmental health, emergency planning, the NHS and UK Health Security Agency have all been working together. As with other schemes mentioned, the programme of support and initiative in Camden aims to provide support for vulnerable residents and a space to seek guidance on the cost of living, keeping warm in the winter, support with energy bills and access to local housing grants. The service includes a warm safe hub (as was evidence across many of the local authorities) as well as the Winter Wellness project to specifically support vulnerable older adults during the winter months.

In Northumberland, cross-partnership working has also been key. They have established the Warm Homes Group which provides an energy pathway involving Citizens Advice, Community Action Northumberland and local climate change and energy teams. These partners can collectively deliver interventions such as home visits (delivering also against recommendation 1 of NG6); support with energy costs and equipment via the Household Support Fund; money, debt, and energy advice; access to locally and nationally funded energy efficiency and retrofit schemes and grants; and support for the provision of holistic advice to enable individuals to take part in community life.

Aligned with the NG6 guidance, in September 2021, the government announced a national Household Support Fund for local councils to provide support for vulnerable households in England. The government stated that vulnerable households across the country would be able to access a new £500 million support fund to help them with essentials over the winter. This enables local authorities to use the

funding to provide tailored solutions to households living in fuel poverty and cold homes.

Additionally, NHS' 'Stay Well this Winter' fund can support those at risk of or living in fuel poverty through access to services, information, and potentially financial support to enable people to keep warm and well this winter, whilst reducing energy bills. There is also the Warm and Well free

advice line, which has all the up-to-date advice and access to grant funding and loans. Winterwatch, another example of a national programme, is an information service available to support vulnerable households stay safe and warm during challenging parts of the year. The scheme offers a bespoke, one-to-one session which has been designed to help low-income families get the most from energy usage.

Case study 4: Tailored solutions built into wider plans

The Borough of Richmond Upon Thames is working with Thinking Works to provide tailored solutions for its residents as part of a Winter Warmth Home Service and Cold Weather Preparedness Plan. Cold weather alerts are issued, and some resources are cascaded to a range of partners to raise awareness. The project works closely with the Public Health Protection team who brief and provides these resources to all stakeholders including voluntary and community sector organisations. Resources can be focused on vaccines, support services, advice and information, and are available in different languages and briefings are through webinars focusing on Cold Weather Preparedness.

There is also a forthcoming project delivered by Derbyshire Council, in partnership with National Energy Action, to deliver a £1m fuel poverty programme funded by the NHS and based on NG6 recommendations.

As evident from the review, local authorities are engaged in various initiatives and schemes to support vulnerable people living in cold homes. Many local authorities engage with external partners or programmes to provide support for the cost-of-living crisis and in particular guidance and advice on keeping warm during the winter period. There are grants and funds available from the NHS and Government to enable local authorities to provide housing renovations, insulation for housing and improve the energy efficiency of homes in the area. These practical solutions can make an impact on those nearing the end of their life, enabling them to reduce energy bills while still keeping warm during the cold months.

Local authorities in Wales

A total of 22 FOI requests were issued to local authorities in Wales and 12 responses were received. We did not identify reference to NG6 recommendations in existing strategies and resources via online searches. This was not necessarily surprising, however, as use of NICE guidelines differs between England and Wales, where in the latter use is not mandatory, and NG6 is instead used as a guide to plan and deliver the best possible care. (31)

In some cases, FOI responses from local authorities in Wales did not acknowledge the NG6 guidance or note if it was something that they were following. Other responses explicitly outlined that NG6 guidance was not a mandatory element of their work and that they therefore had no detail to share.

The analysis did, however, identify some examples of awareness and use of the NG6 guideline in Wales, though this was minimal compared to that which featured in the resources identified for bodies and local authorities in England.

The Welsh Government, for example, has developed the Warm Homes Programme which is based on the NICE guidance. The first iteration of this programme, delivered initially through Arbed and the NEST scheme, has funded energy efficiency improvements to eligible households, accompanied with free and impartial advice. The aim of the programme has been to reduce energy bills for those living in fuel poverty by installing energy efficiency measures. In Wales, an estimated 196,000 households are fuel poor, with a further 38,000 households estimated to be living in severe fuel poverty and 153,000 estimated households at risk of being in fuel poverty which is the equivalent to 11% of households (32). Between April 2018 and March 2021, 16,042 homes received free energy efficiency measures under the Warm Homes Programme. (33) Alongside eligibility criteria for people in receipt of a means-tested benefit, the NEST scheme includes special health eligibility criteria for households where someone in the home lives with a recognised chronic, circulatory or mental health conditions and has a low income

below the defined thresholds. There are no explicit provisions for people living with terminal illness.

The Welsh Government has recently set out its policy statement for the creation of a new Warm Homes Programme, which will be designed to respond to the cost-of-living crisis through a re-focusing of the eligibility criteria to better target support at the poorest in society (34). More recent modelled estimates of fuel poverty which account for surging fuel prices and the increased price cap suggest that as many as 45% of households could be in fuel poverty (35).

Case study 5: Regional partnerships

At a regional level, the Gwent Regional Partnership Board, which covers 5 of the 22 local authorities in Wales, has developed a regional Winter Plan and risk assessment setting out actions across health and social care. This is a wider strategic action plan to support people in the winter and sets out key actions to keep citizens well especially with strengthening community capacity and supporting hospital discharge (linking specifically to recommendation 7).

With regards to recommendation 2, 'Providing a single point of contact', the five local authorities within the Gwent Regional Partnership provide an Information, Advice and Assistance (IAA) Service established under the Social Services and Wellbeing (Wales) Act 2014. This provides a SPOC to access support and information and includes health and housing support. Vulnerable people living in cold homes can access support from the IAA team and are signposted to appropriate services.

In addition, Local Authority Housing Support teams are trained to support residents to access help if there are issues with unfit homes, for example if the heating was not working. The Housing Support teams can, if appropriate, link with landlords to repair under their obligations to the Housing Wales Act 2014 and their Rent Smart Wales licensing requirements and/or Environmental Health to enforce the landlord to carry out the repair.

While there was limited detail shared relating to the utilisation of NG6 in Wales, whether in the context of broader health or terminal illness specifically, many of the local authorities did provide details of specific information or webpages on the cost-of-living and support with energy bills, linking services to support and information helplines. As noted, this demonstrates that activity in line with NG6 is happening though it is

not necessarily clear to what extent and which areas are covered.

There is considerable acknowledgement of NG6 recommendations in the work of Public Health Wales (PHW) who advocate for a preventative approach in their report 'Improving winter health and well-being and reducing winter pressures in Wales'. The health impacts of winter weather and

actions required to reduce poor health during this period are examined, and the report highlights the need for action in this area, noting that 30% of excess winter deaths are due to cold homes. PHW explicitly refer to NG6 as a valuable mechanism for shaping their work in this area, that, while not explicitly mentioned, will include activity targeted towards those at the end of life and living with terminal illness.

Integrated care boards

NG6 Recommendation 7 – Safe discharge for vulnerable patients

Recommendation 7 focuses on the processes around discharging vulnerable people from health and social care settings to the home. It calls on those responsible for arranging and helping with a timely discharge, stating that such roles should include a responsibility for year-round assessments of whether a person is able to keep warm at home and/or is vulnerable to the cold.

Thirty-six of the 39 Integrated Care Boards (ICBs) in England responded to our FOI requests. Our requests were targeted towards ICBs, which replaced Clinical Commissioning Groups in 2022, due to their position as a statutory body responsible for planning and funding most NHS services, including discharge processes. The responses shared by the ICBs provide valuable insight into various activities, schemes, and programmes that have been implemented to support vulnerable people living in or at risk of cold homes.

Several of the responses detailed the provision of bespoke hospital after-care services to ensure that, in line with NG6, people leaving hospital, including those with terminal illness, were able to return home to heating, hot water, and in some cases shopping.

Discharge planning, as outlined in NG6, should coordinate a range of relevant professionals, not just those working in health and social care. Several ICBs shared details of how they are doing this at present

with a wide range of partners. NHS Bedfordshire, Luton and Milton Keynes ICB, for example, work closely with Age UK, Age Concern and Red Cross to deliver their bespoke discharge service. The service provides support to vulnerable people leaving hospital, ensuring that heating, hot water and shopping are in place. For those who need more support they provide this daily/weekly or as required for the intermediate period, until longer-term services can be put in place. With patients' permission, hospital staff are also able to enter homes in advance of discharge to make living spaces suitable, for example by switching on the heating.

Another example was the NHS Cornwall and the Isles of Scilly ICB, which operates a Discharge Grant Support Scheme where grants are used to purchase items directly on behalf of the individual to help improve the home environment. This can include buying blankets, clothes,

curtains, draught excluders, clothes airers and others.

Regarding referrals into SPOC and other cold homes services, evidence was again shared of effective partnership working between ICBs and relevant local partners to deliver safe discharge to warm homes. The Frimley ICB, for example, is engaging with Good Gym, an organisation that do work to support their communities, to enhance referrals to their hospital discharge service and integrate with the Wellbeing Circles project. Local multi-agency teams assess whether the patient is likely to be vulnerable to the cold and if action is needed to make their home warm enough for them to return to as per the NG6 guidance. The Good Gym staff note any faulty heating systems and report these to the local landlords or owners to ensure people are able to keep warm at home thus ensuring any heating issues are resolved in a timely manner, so as not to delay discharge from hospital.

Recommendation 7 of NG6

Case study 6: Timely support and avoiding discharge delays

NHS Herefordshire and Worcestershire Integrated Care Board has a range of support services, including the provision of energy-related advice and information that can be accessed by vulnerable people being discharged from hospital. This includes services such as Hospital Aftercare, delivered by Age UK, which supports people on the day that they are discharged with switching the heating on or getting warm food, as well as other support to settle back in at home.

The ICB has also implemented the Home First service, which involves home assessments by health and social care professionals for vulnerable people on the day they are discharged. In part, this is to ensure they return to a warm and safe home, as NG6 requires, and to assess any additional needs for immediate care and support.

outlines the need to take steps to ensure timely discharge, therefore requiring services to be in place that avoid a person needing to stay in a health or social care setting because they cannot return to a home that is not safe nor warm. This was evidenced by some of the ICBs, where the need for person and home assessments was recognised.

Regarding funding, the Better Care Fund was noted as one resource which has been used for delivering programmes of support to comply with NG6 guidance. For example, Leicester, Leicestershire, and Rutland Integrated Care Board (ICB) invests considerable Better Care Fund resource into their out of hospital services, also linked to the work of the local authority.

As well as funding sources, respondents to the FOI requests also shared details of where funding was going, and this included details of innovative projects and schemes focused on discharge to a warm and safe home. For example, NHS Hampshire and Isle of Wight ICB is funding two schemes which specifically support Recommendation 7 of the NG6; one project will see an additional 50 Advice First Aider/discharge volunteers trained, with these individuals set to be based in 'warm spaces', the second project is supporting carers with a weekly carers' session and carers' lounge.

One ICB (Northeast London ICB) highlighted that many people will not be

identified or self-identify as vulnerable and so may risk being discharged back to cold homes without additional services or assessments. This links closely with an awareness that those diagnosed with terminal illness may be experiencing health- or financial-related vulnerability for the first time and so could be unaware of support available or where to go for such support. Additionally, stigma and shame attached to seeking out support as a 'vulnerable' person, whether in terms of health or income, may play a critical role in poor levels of engagement. At present, the Northeast London ICB stated that they are undertaking work to consider what more can be done to identify this risk and to act on it.

The responses received by ICBs were by far the most detailed. Several examples of critical, and in some cases innovative programmes that are being funded to support vulnerable people in cold homes. There were several schemes or programmes that ICBs are supporting to put an end to the discharge of vulnerable patients into cold homes such as Warm Homes, Healthy People, Warm Spaces, Community Hubs – all of which aim to provide wraparound support to patients and demonstrate effective partnership working between charity organisations including British Red Cross, Age UK and Age Concern. One way to develop the work in this area could be to consider how the NG6 recommendation could be a part of ICBs' palliative and end of life care plans, providing wraparound support and ensuring that patients receive the best of life at home in a safe and comfortable environment.

Government and public health bodies

NG6 Recommendation 11 – Raising awareness among practitioners and public

Recommendation 11 of NG6 focuses on raising awareness of the health impacts of cold homes on health among practitioners and the public. It outlines that Health and Wellbeing Boards, Public Health England (now the Office for Health and Income Disparities and the UK Health Security Agency), and the Department for Business, Energy, and Industrial Strategy (BEIS) (now the Department for Energy Security and Net Zero, DESNZ) should ensure up-to-date information is available, including details of national and local support.

FOI requests were also issued to the Department for Energy Security and Net Zero (DESNZ), and to the Office for Health Improvement and Disparities (OHID) which is one part of what was formerly Public Health England. The FOIs issued to these two bodies asked specifically about how awareness of cold homes and health was being raised in line with the NG6 guidance.

For example, in 2020, Public Health England published the online resource: 'Health matters: cold weather and COVID-19' (36). The resource covers the impact of cold weather on health, how COVID-19 increased cold-related risks, as well as preventative actions particularly to those who are most vulnerable. Within the resource, 11 groups are set out as those that could be categorised as vulnerable. While this list does not explicitly refer to those with terminal illness, it does include groups that may include those at the end of life, for example, older people (those over 65 years), those who are frail and/or socially isolated, people with pre-existing chronic medical conditions such as cardiovascular and respiratory conditions, in particular chronic obstructive pulmonary disease (COPD) and asthma, and diabetes and people who are living in fuel poverty. The NICE guidance and specifically NG6 are mentioned and linked as supporting resources in this report. We would recommend that people with terminal illnesses are listed as part of these groups.

The Office for Health and Income

Disparities (OHID) is responsible for the building of scientific evidence, leading and developing policy and delivering core services. OHID supports the delivery of national and regional priorities for prevention of health inequalities, ensuring a joined-up approach to public health. OHID plays a key role in providing the statistics and data around excess mortality and palliative and end-of-life care profiles which are used by the ICBs and local authorities. OHID works with NICE to develop guidance and advice both at national and regional levels. OHID responded to our FOI request regarding recommendation 11, raising awareness of the impact of cold homes, highlighting how they were supporting regional teams with training to support practitioners with providing assistance to vulnerable patients.

In addition, details were shared of Public Health England's cold homes e-learning resource specifically aimed at supporting health and social care professionals to put NICE Guidance NG6: 'Excess winter deaths and illness and the health risks associated with cold homes' into practice. The training resource helps practitioners to direct vulnerable households to available support services. OHID has disseminated this training

module to practitioners, in addition to a range of other cold home resources. Regional OHID teams have also been supporting local systems on the cost of living and cold homes.

The Adverse Weather and Health Plan (37), a publication by the UK's Health Security Agency, the other arm of what was previously PHE, aims to make public and voluntary sector organisations and individuals aware of the risks of cold weather, enabling them to prepare and respond appropriately. The overarching goals for the strategy are to raise awareness and provide strategic direction, focusing on ways to prevent mortality, morbidity and to reduce the risk of healthcare services due to adverse weather events. While this publication provides detail on steps to be taken to prevent risks that adverse weather has to health, there is no specific mention of NG6 within the document itself (there is a single reference within the Appendices, however). Further, the document does not mention people with a terminal illness or those at the end of their life that require additional support in the Target populations section.

The Department for Energy Security and Net Zero (DESNZ) also responded to the FOI request enquiring about their activity in raising awareness of

NG6 guidance. DESNZ's role is to communicate and produce policy and strategy in this area and to raise awareness of government support. This includes financial support with energy bills and wider cost of living and energy efficiency which contributes to long-term reduction in energy bills at a national level.

The UK Government website provides information on the financial support available for people living in fuel poverty or struggling to pay their energy bills. For example, the Help for Households campaign (38) is a website sharing energy saving tips, help with energy bills, childcare costs and household costs. This campaign is directed at the public highlighting practical tips for reducing household bills and benefit entitlements; however, it does not provide information on the impacts that living in cold homes has for vulnerable people, particularly those at the end of their life or with a terminal illness and the requirement for these groups to

keep their homes warm or risk deterioration of their health.

In 2021, DESNZ published the revised fuel poverty strategy: 'Sustainable Warmth: Protecting Vulnerable Households in England' (39). This provides wider information on strategic approaches to helping low-income and vulnerable households heat their homes. NG6 is explicitly highlighted within strategy, forming part of the vision for delivering against fuel poverty targets and supporting healthcare professionals to follow the NICE guideline.

The Strategy states that: 'Transforming our housing stock so that homes are warm, healthy and fit for the future will help protect the health of those most vulnerable and reduce the strain on our NHS, whilst complementing the approach to more preventative healthcare.'

In addition, the Strategy raises awareness of local authority-delivered support and grants available to households and is complemented by additional support such as telephone advice lines and wider information provision. DESNZ also shared detail of how the Department is

supporting local authorities by raising awareness of schemes, such as the Energy Company Obligation, the Social Housing Decarbonisation Fund, the Local Authority Delivery Scheme and the Home Upgrade Grant. The Department states that these schemes and funds will help local authorities in targeting and delivering support to those most in need.

It is the role of OHID and DESNZ to raise awareness at national level of the NICE NG6 guidance, and evidence of this was shared in the FOI responses we received. OHID noted how they work closely with NICE in further developing guidance and recommendations at national and regional levels. DESNZ has noted how their Sustainable Warmth strategy raises awareness of NG6 and highlights the importance of the guidance in supporting vulnerable households living in cold homes or at risk of fuel poverty.

Neither OHID or DESNZ identify people with a terminal illness or people at the end of their life as a specific category with higher needs in their strategies which highlights the need to further integrate NG6 with palliative and end-of-life care at a national level.



Conclusions and recommendations

This research has aimed to provide a snapshot of what is happening in relation to five out of the 12 NG6 recommendations we consider to be more or most pertinent to those at the end of life or with a terminal illness.

Drawing on existing literature and publicly available resources identified from the document analysis, we aimed to move towards a better understanding of:

- The extent to which local authorities, Health and Wellbeing Boards and other relevant stakeholders in England and Wales are considering the impact of fuel poverty and cold housing among people who are living with terminal and life-limiting illnesses and those at the end of life.
- How different localities have implemented select recommendations from the NICE guideline NG6 for people who are at the end of life, and the successes, challenges, and gaps in approaches.
- Assess the potential benefits of the successful delivery of the recommendations in NICE guideline NG6 for people who are terminally ill or at the end of life.

In our review of publicly available information and resulting evidence from FOI requests, we identified no evidence of the explicit acknowledgement of how NG6 is understood or implemented in relation to the specific needs of those with terminal illness or at the end of life as a particular vulnerable group.

However, as this report has detailed, numerous relevant examples were identified where the recommendations are delivering on reducing health risks and improving health and wellbeing, and we recognise that this has relevance for all healthcare situations, including those involved people who are terminally ill, however it cannot

respond to the particular challenges faced by people living with a terminal illness.

We suspect that there is, and indeed the evidence strongly points towards, more activity happening at local and regional levels than that which is readily or publicly available in reports and online resources. Further scoping, mapping and wider research are needed to understand not just the current situation in terms of what is and is not available, but to go deeper to understand what works, where targeted provision exists and what challenges have been faced or refrained projects and schemes from being implemented.

FOI Responses

The analysis of the FOI response shows there is considerable work being done by local authorities and HWBs to ensure people in their communities, specifically vulnerable people, can stay warm and well in their homes. Via HWBs and JSNAs, this support is focused on mitigating the impacts of the cost-of-living crisis, energy prices, and cold homes, as well as providing ways of reducing energy bills, and other forms of targeted and tailored support.

Some fuel poverty strategies and housing plans provided actions and recommendations for improvements to housing in the area and local grants for refurbishments which would increase the energy rating of a house, however, the focus of this research did not extend to these strategies and there was limited attention on the specific needs of people with a terminal illness or people at the end of their life.

Our research identified 8 out of 314 local authorities had publicly available documents and resources that mention the delivery

of NG6 guidance. This shows that while there is a lot of work ongoing to support people, as noted above, it is not often or necessarily attributed to the NICE guidelines, or NG6 specifically.

In Wales, there was limited awareness of NG6 among local authorities. And while it was highlighted that for Welsh health bodies, NG6 is not mandatory, evidence was shared to demonstrate how its influence can be noted in the work being done to prevent ill health and reduce health risk and inequalities.

Responses from the ICBs were by far the most detailed and outlined numerous examples of how NG6 was being implemented across different strands of work, particularly in relation to discharge. These referred to a wide range of packages of bespoke hospital after-care services to ensure that, in line with NG6, people leaving hospital, including those with terminal illness, were able to return home to heating, hot water, and in some cases shopping.

It is important to note that while this research has highlighted many examples of good practice in relation to delivering against NG6 at the end of life, it did not review the success, availability or accessibility of the programmes or initiatives. Therefore, it does not seek to and cannot provide comment on the impact or validity of the FOI responses; it is instead hoping to provide a snapshot of how NG6 guidance is being implemented in England and Wales. Further research is critically needed, for example via more in-depth case studies, to better understand the finer detail of specific successes and challenges.

It is clear from the current climate and extensive evidence between health and cold homes, that focused and urgent action is needed to tackle fuel poverty among people with a

terminal illness. It is unacceptable that any dying person should spend the end of their life in cold, damp, and uncomfortable conditions – deprived of the best possible quality of life because of unaffordable heating costs.

Work to be done

Our analysis shows that, there is still much work to be done to deliver universal action on the recommendations set out in NG6. This new research hopes to take steps towards this, setting out crucial evidence of the extent to which relevant authorities and bodies are implementing the guidance, and of the steps needed to ensure compliance or action.



OUR RECOMMENDATIONS

- Further analysis is needed to understand the extent to which fuel poverty is having health consequences for people living with terminal illness, especially considering the impacts that the cost-of-living and energy price crises is likely to have had.
- People with a terminal illness need to be explicitly identified as a category of 'vulnerable group' by NICE.
- Further research is critically needed to better understand the finer details of specific successes and challenges of schemes and services that are delivered under NG6.
- A review of work aligned with NG6 recommendations across the UK nations is needed, particularly to better understand and highlight that which is already happening in Wales.
- JSNAs and HWBs need to go further and outline solutions and strategic activity to minimise winter deaths. NG6 implementation should complement existing strategies and plans, specifically in the context of terminal illness, for example, in end-of-life or palliative care plans.
- Opportunities to modify or expand training for frontline professionals should be identified to ensure that the needs of people living with terminal illness and their families are factored into wider energy and fuel poverty training offers.
- To reach the most vulnerable people, energy-related advice and support must be available in multiple formats and settings, therefore in-person and in-home support must be protected and expanded and the value of this recognised in policy.
- There is a clear need to better understand barriers in accessing support that people with a terminal illness face and implement awareness-raising campaigns and targeted support for this vulnerable group specifically.

ANNEXES

Annexe 1: The NICE NG6 Guidance

NG6 RECOMMENDATION 1: DEVELOP A STRATEGY

Recommendation 1 outlines that Health and Wellbeing Boards should:

- Include the health consequences of living in a cold home in the joint strategic needs assessment process.
- Develop a strategy to address the health consequences of cold homes. This should include:
 - Identifying people whose health is at risk from cold homes.
 - Groups that may face particular problems, such as those living in hard-to-heat homes or who need more warmth (for instance, because of limited mobility or specific health conditions).
- Assessing how heating and insulation needs to be improved to raise properties to an acceptable standard assessment procedure (SAP) rating. As a minimum, properties should be raised to a band C (69 to 80) and ideally, to a band B (81 to 91) rating.
- A tailored programme to make any necessary changes, including preventive measures, all year round – not just in the winter.
- Provision for 'normal' winter temperatures not just periods of severe cold. (Although lower temperatures have a more significant effect on health, the ill effects from cold homes are seen when outdoor temperatures drop to around 6°C. Because temperatures in this range are much more common, this is when the greatest number of health problems caused by the cold occur.)
- Preventing mental and physical health problems as well as deaths from cold homes.
- An outline of how the other recommendations in this guideline will be put into practice locally.
- Identifying and meeting the training needs of local practitioners involved in providing the services.
- Ensure planning includes identifying relevant local interventions and providers from all sectors (such as relevant local authority departments, the health sector, utilities, housing organisations and organisations in the voluntary sector).
- Consider how the issues and actions identified are reflected in health and wellbeing and other relevant local strategies or plans and ensure actions take account of other local and national strategies.
- Ensure the strategy includes monitoring and evaluation. Also ensure any evaluation is used to improve the strategy and is made publicly available.

NG6 RECOMMENDATION 2: ENSURE THERE IS A SINGLE-POINT-OF-CONTACT HEALTH AND HOUSING REFERRAL SERVICE FOR PEOPLE LIVING IN COLD HOMES

Recommendation 2 outlines that Health and Wellbeing Boards should:

- Ensure a local single-point-of-contact health and housing referral service is commissioned (see recommendation 3) to help vulnerable people who live in cold homes. A wide range of people are vulnerable to the cold. This is either because of: a medical condition, such as heart disease; a disability that, for instance, stops people moving around to keep warm, or makes them more likely to develop chest infections; or personal circumstances, such as being unable to afford to keep warm enough. In this guideline, the term vulnerable refers to a number of different groups including:
 - people with cardiovascular conditions
 - people with respiratory conditions (in particular, chronic obstructive pulmonary disease and childhood asthma)
 - people with mental health conditions
 - people with disabilities
 - older people (65 and older)
 - households with young children (from new-born to school age)
 - pregnant women
 - people on a low income.
- Ensure anyone who comes into contact with vulnerable groups is able to refer people to the referral service. This includes health and social care practitioners, fire prevention and safety services personnel and workers from charities and voluntary organisations, such as advice agencies.
- Ensure the referral service links with relevant national and local services that can provide a range of solutions. These are likely to include: health and social care providers, local housing providers, advice agencies (such as Citizens Advice and money advice organisations), health and social care charities, voluntary organisations, and home improvement agencies.
- Ensure the referral service:
 - Takes account of existing services.
 - Involves face-to-face contact, if necessary, with the person using the service, their families, and their carers.
 - Works with the person and their carers to identify problems caused by living in a cold home and the possible solutions.
 - Makes it clear to the person and their carer what actions are planned (or taking place) and coordinates activities to minimise disruption in the home.
 - Encourages self-referrals using a free phone number.
 - Monitors and evaluates the impact of actions taken and gives feedback to the practitioner or agency that originally referred the person.

ANNEXES

Annexe 1: The NICE NG6 Guidance

NG6 RECOMMENDATION 3: PROVIDE TAILORED SOLUTIONS VIA THE SINGLE-POINT-OF-CONTACT HEALTH AND HOUSING REFERRAL SERVICE FOR PEOPLE LIVING IN COLD HOMES

Recommendation 3 outlines that Health and Wellbeing Boards and their partners (see below) should ensure the local single-point-of-contact health and housing referral service provides access to tailored solutions to address identified needs, rather than an off-the-shelf approach. Solutions should take into account the language and reading ability of recipients, including any vision or hearing problems. Solutions should include:

- Housing insulation and heating improvement programmes and grants. Programmes should be led, or endorsed, by the local authority and include those available from energy suppliers.
- Advice on managing energy effectively in the home and securing the most appropriate fuel tariff and billing system (including collective purchasing schemes, if available). Note: the most appropriate fuel tariff may not be the cheapest if, for example, someone does not have a bank account or needs to budget on a weekly basis.
- Help to ensure all due benefits are being claimed, as people receiving certain benefits may be entitled to additional help with home improvements – and may get help to manage their fuel bills and any debt.
- Registration on priority services registers (for energy supply and distribution companies) to ensure vulnerable households get tailored support from these companies.
- Advice on how to avoid the health risks of living in a cold home. This includes information about what these health risks are (see Public Health England's cold weather plan for further information).
- Access to, and coordination of, services that address common barriers to tackling cold homes. For example, access to home improvement agencies that can fix a leaking roof, or to voluntary groups that can help clear a loft ready for insulation.
- Short-term emergency support in times of crisis (for instance, room heaters if the central heating breaks down or access to short-term credit).
- Who should take action? Health and wellbeing boards; local authorities; housing providers; energy utility and distribution companies; faith and voluntary sector organisations.

NG6 RECOMMENDATION 7: DISCHARGE VULNERABLE PEOPLE FROM HEALTH OR SOCIAL CARE SETTINGS TO A WARM HOME

Recommendation 7 outlines that those responsible for arranging and helping with someone's discharge from a health or social care setting should:

- Assess whether the person is likely to be vulnerable to the cold and if action is needed to make their home warm enough for them to return to. This assessment should take place at any time of the year, not just during colder weather, and well before they are due to be discharged to allow time for remedial action. For instance, it could take place soon after admission or when planning a booked admission.
- As part of the planned discharge, coordinate the efforts of all the practitioners involved to ensure the home is warm enough. This could include simple measures such as turning on the heating before discharge, providing advice on the ill effects of cold on health, or providing advice on how to use the heating system. (It could also involve more complex measures – see below.)
- If needed, refer the person to the local single-point-of-contact health and housing referral system (see recommendations 2 and 3). For example, refer them if the heating system needs replacing or the property needs insulating, or to prevent or address fuel debt. (The latter may accrue during someone's stay in health or social care accommodation.)
- Ensure any heating issues are resolved in a timely manner, so as not to delay discharge from hospital.
- Who should take action? Integrated Care Boards; secondary healthcare practitioners; social care practitioners.

NG6 RECOMMENDATION 11: DISCHARGE VULNERABLE PEOPLE FROM HEALTH OR SOCIAL CARE SETTINGS TO A WARM HOME

Recommendation 11 outlines that Health and Wellbeing Boards, the Office for Health and Income Disparities, the UK Health Security Agency, and the Department for Energy Security and Net Zero should:

- Ensure up-to-date information is available in appropriate formats for both practitioners and the public on how cold homes can affect people's health.
- Address commonly held misconceptions, for instance, that drinking alcohol can help keep someone warm, that hypothermia is the main health problem caused by the cold, or that sleeping in a cold bedroom is good for your health.
- Ensure up-to-date details of national and local support is available for both practitioners and the public. This support might include: help to improve the fabric of the housing or the heating system; help to make heating the home more affordable; or general advice on how to keep warm.
- Ensure national advice takes into account local and regional variations in the kind of support offered.
- Who should take action? Health and wellbeing boards; Office for Health and Income Disparities; UK Health Security Agency; the Department for Energy Security and Net Zero. If needed, refer the person to the local single-point-of-contact health and housing referral system (see recommendations 2 and 3). For example, refer them if the heating system needs replacing or the property needs insulating, or to prevent or address fuel debt. (The latter may accrue during someone's stay in health or social care accommodation.)
- Ensure any heating issues are resolved in a timely manner, so as not to delay discharge from hospital.
- Who should take action?
- Integrated Care Boards; secondary healthcare practitioners; social care practitioners.

ANNEXES

Annex 2: FOI Questions

FOI Questions

FOI Questions for Health and Wellbeing Boards

I am writing to you under the Freedom of Information Act 2000 to request information about the steps X local authority is taking to comply with the National Institute of Clinical Excellence's (NICE) Guideline NG6 on excess winter deaths and illness and the health risks associated with cold homes.

My questions are:

What steps are your local authority Health & Wellbeing Board taking to meet Recommendation 1:

Develop a strategy

What steps are your local authority Health & Wellbeing Board taking to meet Recommendation 2:

Identify a point of contact (health and housing referral service) for people living in cold homes.

Could you please provide a copy of your local authority Joint Strategic Needs Assessment?

FOI Questions for ICBs

I am writing to you under the Freedom of Information Act 2000 to request information about the steps X Integrated Care Board is taking to comply with the National Institute of Clinical Excellence's (NICE) Guideline NG6 on excess winter deaths and illness and the health risks associated with cold homes.

My question is:

What steps are your Integrated Care Board taking to meet Recommendation 7: Discharge vulnerable people from health or social care settings to a warm home.

FOI Questions for OHID and DESNZ

I am writing to you under the Freedom of Information Act 2000 to request information about the steps the X Office/Department is taking to comply with the National Institute of Clinical Excellence's (NICE) Guideline NG6 on Excess winter deaths and illness and the health risks associated with cold homes.

My question is:

1. What steps are your office taking to meet Recommendation 11: Raise awareness among practitioners and the public about how to keep warm at home.

Footnotes

1. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2020/fuel-poverty-and-terminal-illness.pdf>
2. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-5th-pp.pdf>
3. <https://www.nice.org.uk/guidance/ng6>
4. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/960200/CCS207_CCS0221018682-001_CP_391_Sustainable_Warmth_Print.pdf
5. <https://www.nice.org.uk/guidance/ng6/resources/excess-winter-deaths-and-illness-and-the-health-risks-associated-with-cold-homes-pdf-51043484869>
6. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/appg/h406-appg-report-4-interactive-single-pages.pdf>
7. <https://www.local.gov.uk/sites/default/files/documents/22.53%20End%20of%20life%20care%20guide%20for%20councils%20WEB.pdf>
8. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1139133/annual-fuel-poverty-statistics-lilee-report-2023-2022-data.pdf
9. <https://www.nea.org.uk/energy-crisis/energy-crisis-timeline/#:~:text=1%20April%202022%20%E2%80%93%20The%20Ofgem,are%20now%20in%20fuel%20poverty%20>
10. <https://www.instituteofhealthequity.org/resources-reports/the-health-impacts-of-cold-homes-and-fuel-poverty/the-health-impacts-of-cold-homes-and-fuel-poverty.pdf>
11. <https://ukhsa.blog.gov.uk/2016/11/01/understanding-the-costs-and-benefits-of-investing-in-cancer>
12. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/k406-povertyenergyreport-finalversion.pdf>
13. <https://www.scope.org.uk/campaigns/research-policy/cost-of-living-report/>
14. [report-on-key-findings-from-the-cost-of-living-survey-.pdf \(mariecurie.org.uk\)](https://www.mariecurie.org.uk/report-on-key-findings-from-the-cost-of-living-survey-.pdf)
15. <https://www.nea.org.uk/wp-content/uploads/2020/11/ACE-and-EBR-briefing-2015-10-Cold-man-of-Europe-update>
16. <https://www.nice.org.uk/guidance/ng6>
17. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2020/fuel-poverty-and-terminal-illness.pdf>
18. Hospice UK (2014). Mapping England's Health and Wellbeing Boards' vision for dying people.
19. <https://www.nea.org.uk/wp-content/uploads/2020/11/Get-Warm-Soon-Full-Report.pdf>
20. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/appg/h406-appg-report-4-interactive-single-pages.pdf>
21. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/appg/h406-appg-report-4-interactive-single-pages.pdf>
22. Health Improvement Scotland (2013). Palliative and End of Life Care: Indicators.
23. Davies JM, Sleeman KE, Leniz J, Wilson R, Higginson IJ, et al. (2019) Correction: Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLOS Medicine 16(7): e1002878. <https://doi.org/10.1371/journal.pmed.1002878>
24. Moreno-Leguizamon, C., Smith, D., & Spigner, C. (2017). Positive Aging, Positive Dying: Intersectional and daily communicational issues surrounding palliative and end-of-life care services in minority groups in the United Kingdom and the United States. In International handbook of positive aging (pp. 21-35). Routledge.
25. Rowley and Richards (2020). Structural inequalities and dying at home during COVID-19.
26. NEA (2018). Health & Innovation Programme: Social Evaluation Report (Executive Summary).
27. <https://www.nea.org.uk/who-we-are/policy-and-research/our-health-our-homes/>
28. <https://www.gov.wales/national-institute-health-and-care-excellence-nice-guidelines#:~:text=The%20standards%20set%20out%20the,provide%20the%20best%20possible%20care>
29. <https://www.local.gov.uk/sites/default/files/documents/22.53%20End%20of%20life%20care%20guide%20for%20councils%20WEB.pdf>
30. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1115873/2022-to-2023-cold-weather-plan-for-England.pdf
31. <https://www.gov.wales/national-institute-health-and-care-excellence-nice-guidelines#:~:text=The%20standards%20set%20out%20the,provide%20the%20best%20possible%20care>
32. Fuel poverty modelled estimates for Wales (headline results): as at October 2021 | GOV.WALES
33. <https://www.wao.gov.uk/news/welsh-governments-warm-homes-programme-needs-be-greener-clearer-and-more-tightly-managed#:~:text=The%20Welsh%20Government%E2%80%93%20Warm%20Homes%20Programme%2C%20comprised%20of,in%20fuel%20poverty%20by%20installing%20energy%20efficiency%20measures>
34. <https://www.gov.wales/fuel-poverty-modelled-estimates-wales-headline-results-october-2021-html>
35. <https://www.gov.wales/fuel-poverty-modelled-estimates-wales-headline-results-october-2021-html>
36. <https://www.gov.uk/government/publications/health-matters-cold-weather-and-covid-19/health-matters-cold-weather-and-covid-19>
37. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1155633/Adverse-weather-health-plan-2023-v2.pdf
38. https://helpforhouseholds.campaign.gov.uk/?utm_campaign=H4H_UK&utm_medium=Search&utm_source=Bing&utm_content=Brand&&&ads_rl=7726290658&gclid=0b3c0ecf3d541710b5a36aab9735392a&gclid=3p.ds&
39. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/960200/CCS207_CCS0221018682-001_CP_391_Sustainable_Warmth_Print.pdf

NATIONAL ENERGY ACTION

National Energy Action, the fuel poverty charity, campaigns so everyone can afford to live in a warm, safe and healthy home. This is something denied to millions because of poor housing, low incomes, and high bills.

Working across England, Wales and Northern Ireland, everything we do aims to improve the lives of people in fuel poverty. We directly support people with energy and income maximisation advice and we advocate on issues including improving the energy efficiency of our homes.

We do not work alone. Partnerships and collaboration have been at our heart for over 40 years, helping us drive better health and wellbeing outcomes for people struggling to heat their homes.

WHERE TO FIND US

Email: press@nea.org.uk

Web: www.nea.org.uk

NEA is an independent charity, Registration No. 290511. Company limited by guarantee. Registered in England, No. 1853927 Registered office: Level 6, West One, Forth Banks, Newcastle upon Tyne, NE1 3PA Tel: 0191 261 5677

JOIN THE CONVERSATION



Twitter [@NEA_UKCharity](https://twitter.com/NEA_UKCharity)



Instagram www.instagram.com/nea_ukcharity/



Linked In www.linkedin.com/company/national-energy-action



Facebook www.facebook.com/nationalenergyaction