

# Housing and Living Well with Dementia

## Executive Summary

from Policy to Practice in Greater Manchester

# Executive Summary

December 2021

**This report is a collaboration between the Greater Manchester Health and Social Care Partnership (GMHSCP) and the University of Manchester, Healthy Ageing Research Group (HARG) and the Manchester Institute for Collaborative Research On Ageing (MICRA).**

It presents evidence to inform the provision of innovative and inclusive housing across Greater Manchester (GM) for those living with dementia, carers and loved ones. It offers recommendations to policy and practice in GM through the forthcoming Integrated Care System, Housing Strategy and Provision, Combined Authority, and civil society across seven priority areas. The report consists of a rapid evidence overview of the literature, together with an analysis of housing provision

across the ten localities. It incorporates a series of consultations with key stakeholders including those living with dementia, carers and loved ones, frontline health and social care practitioners, planners, and commissioners. The report explicitly focuses on fit-for-purpose housing as an expression of human rights. It argues that attempts to address the housing needs, and intersecting health and social inequalities, of those living with dementia, carers and loved ones, should take account of, and reflect more strongly, the diversity that exists amongst citizens of GM. This requires new approaches to all stages of the commissioning process and represents a major challenge for policy-makers and practitioners, particularly in the current economic climate. The key findings that emerged from the literature review and the housing analysis are outlined below.

## Acknowledgments

Special thanks to everyone who generously contributed their time and expertise to this project: those who attended the various stakeholder engagement activities from across health and social care in Greater Manchester; people with lived experience of dementia, in particular John O'Doherty; members of the Dementia Carers Expert Reference Group, especially Kim Hughes; the Salford Institute of Dementia Lived Experience Group; the Greater Manchester Ageing Hub, Housing, Planning and Ageing Group; members of the project team,

specifically lead authors Dr Bernadette Bartlam and Jack Gould; as well as others who helped to shape the focus and design of the report. We also wish to thank the colleagues from Greater Manchester Health and Social Care Partnership for advice on accessing Greater Manchester Health and Social Care data.

This report was developed with support from Policy@Manchester within the University of Manchester, as part of the QR Strategic Priorities Fund grant monies allocation from UKRI Research England.



Please see full report for comprehensive list of references



# Dementia Prevalence and Greater Manchester

**Dementia is recognised as one of the most serious challenges we face, with individual and societal impacts outstripping cancer and cardiovascular disease.**

In 2015, dementia affected 47 million people worldwide (5% of the world's older population), a figure predicted to increase to 75 million in 2030 and 132 million by 2050. In the UK, the number of people living with dementia is predicted to rise to one million by 2025. Almost all those living with dementia (91.8%) also have another long-term health condition. The North-West region has the second highest number of deaths in England and Wales due to dementia and Alzheimer's Disease, and the second highest population rates. In 2019, at least 21,851 GM residents were living with dementia, 1 in 25 of this number diagnosed with Younger Onset Dementia.

When looking in more detail across the GM city region:

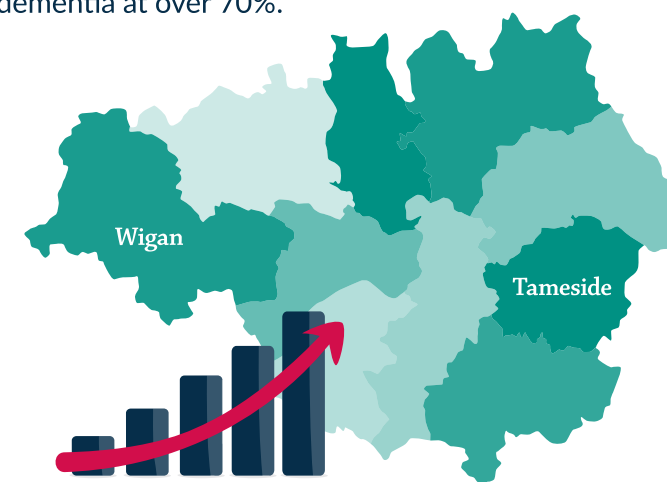
- Almost 8% of over 65s are predicted to have dementia in 2035, an increase of 63.3%.
- The districts of Wigan and Tameside are expected to experience the largest increase in the numbers of people with dementia at over 70%.
- By 2035 there will be a 43% rise in people aged over 65 living alone and those ageing without children will double.
- By 2035 there will be a 70% rise in people requiring accommodation with high level support

In 2015, dementia affected 47 million people worldwide (5% of the world's older population), a figure predicted to increase to 75 million in 2030 and 132 million by 2050.

There will be a  
**43% rise**  
in people aged over 65  
living alone.



The districts of Wigan and Tameside are expected to experience the largest increase in the numbers of people with dementia at over 70%.



Almost 8% of  
**over 65s**  
are predicted to have dementia  
in 2035,  
an increase of **63.3%.**



There will be  
**a 70% rise**  
in people requiring accommodation  
with high level support by 2035.



# The Social Context of Dementia

There is an increasing understanding of the crucial importance of the social dimensions to living well with dementia. This both at the level of personal relationships and social inclusion as well as through the interaction with natural environments and public spaces. These are central to creating and maintaining a nurturing and supportive home environment to enable ageing in place. Such a holistic framework aims to modify or remove the socio-political barriers so that individuals can have the opportunity of a flourishing life, rooted in empowerment, human rights and citizenship.

## The home in context

The surrounding community needs to provide an inclusive, accessible and enabling environment that optimizes opportunities for health, participation and security for everyone. An asset based approach that champions 'capabilities, capacities, and competencies' should be developed and delivered, one which allows people living with dementia, carers and loved ones to continue playing an active role in their neighbourhoods and communities.



# Inequality, Diversity and Belonging

In focusing on housing, as with any other aspect to living well with dementia, it is important that account is taken of the diversity that increasingly characterises the population. There are over 25,000 people with dementia from ethnic minority groups in England and Wales, and this is estimated to rise to 50,000 by 2026. People from ethnic minority groups living with dementia, carers and loved ones face difficulty in accessing services and often access services later, partly as a result of stereotyping by service providers, with services and information often not culturally appropriate.

Two-thirds of people with dementia are women and the condition is the leading cause of death in women in the UK. For lesbian, gay, bisexual, transgender plus people, living with dementia can be even more challenging than for heterosexual individuals. In GM, over a third of LGBTQ+ people in social housing do not feel safe in their neighbourhood, almost 50% do not feel a sense of belonging in their local community, and over 25% report felt lonely in the area they live.

People embody multiple characteristics (gender, age, ethnicity, health etc.), all of which are cumulatively shaped by experiences throughout the life-course. Intersecting as it does with such characteristics, living with dementia is unequal because of the many simultaneous and often overlapping dimensions of inequality people can experience, such as structural ageism, racism, stigma, disability and sensory loss, coupled with social, financial, and political exclusion. Inequalities deepened further by the current pandemic.

There are over

# 25,000

people with dementia from black and minority ethnic groups

in England

and Wales, and estimated to

# rise to 50,000

by 2026.





# Housing and Living Well with Dementia

Ageing in place, through healthy homes and neighbourhoods, enables us to build bonds between neighbours, reduce social isolation and loneliness, promote wellbeing, and prevent physical and mental ill health. Most of us would prefer to stay in our own homes, or move to new homes within our existing communities, as we age. Our homes can help us develop compensatory strategies in the face of physical and/or cognitive decline, including memory loss. In addition to promoting overall wellbeing, ageing in place is recognised as the most economical way of providing support for care needs, and can reduce pressure on public finances compared to residential or nursing homes. However, 'there is nothing homely' about poor housing conditions.

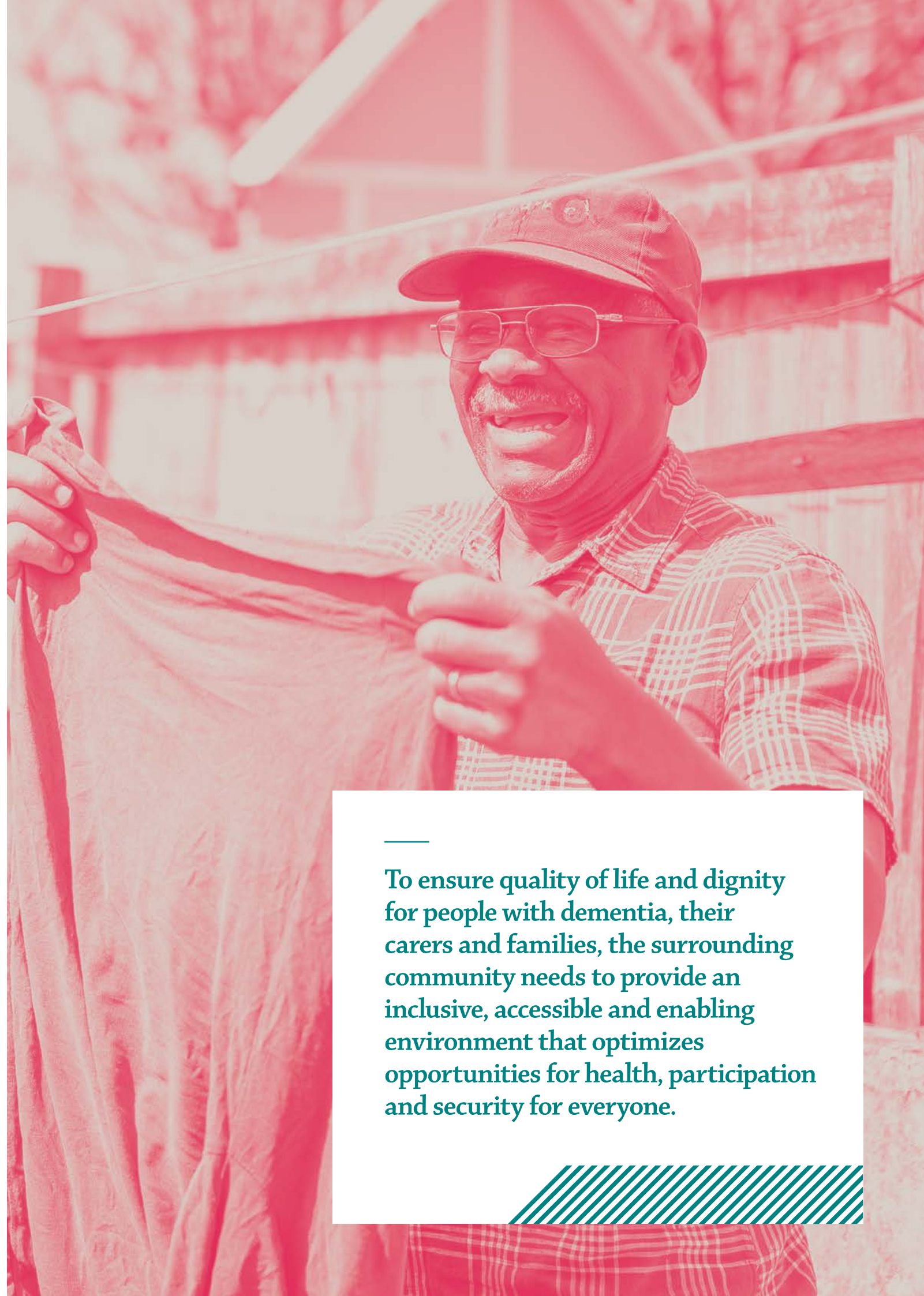

---

**Ageing in place is recognised as the most economical way of providing support for care needs, and can reduce pressure on public finances.**



---

**To ensure quality of life and dignity for people with dementia, their carers and families, the surrounding community needs to provide an inclusive, accessible and enabling environment that optimizes opportunities for health, participation and security for everyone.**



## Fit for purpose housing

Over two-thirds of the buildings and homes we will have by 2050 have already been built, yet current housing stock in the UK does not meet the needs of ageing populations and/or those living with dementia, carers and loved ones. 93% of homes lacking basic accessibility features, and sub-standard housing, particularly in the North of England, this is a major problem. Individuals exposed to poor housing conditions, such as mould, damp and cold, report worse mental and physical health, and experience an 11% increase in GP visits, increasing to 20% for age groups over 64, carrying considerable costs for the NHS and social care system. Furthermore, statistics for the financial year's 1995 to 2020 show 6% of social renters and 33% of private renters were living in poverty, compared to 12% of owner occupiers. Unsurprisingly then, many people struggle to maintain an acceptable quality of life in their own homes as their dementia advances. Ensuring homes are fit for purpose presents a major challenge in terms of both commissioning new builds and retrofitting existing stock.



# 93%

of homes lack basic accessibility features.

Individuals exposed to

### poor housing

conditions, experience an

### 11% increase

in GP visits, increasing

### to 20%

for age groups over 64.



## 67%

of the buildings and home we will have  
by 2050  
have already been built.

The financial years

### 1995 to 2020

show 6% of social renters and 33% of private renters were

### in poverty

compared to 12% of owner occupiers.



# The Impact of COVID-19

**Apart from increased mortality, the impact on existing inequalities of the pandemic (including the policy and practice responses to contain it) have been significant for those living with dementia, carers and loved ones.**

These include increased memory loss, difficulty concentrating, increased agitation/restless, anxiety and/or depression, and increased social isolation and loneliness. Such impacts are further exacerbated by socio-demographic factors, including age, gender, ethnicity, sexual orientation, disability, access to services and support, and housing. Disadvantage is evident, not least, in the ways that Covid-19 has disproportionately affected ethnic minority groups in the UK, with those of Black ethnicity having the highest diagnosis rates, a key determinant of which is overcrowded housing.

Although there is variation across groups, most minority ethnic populations live in the private rented sector. This is associated with poorer housing conditions and higher rents compared to the social rented sector, with high rates of multi-generational and overcrowding households a serious issue. The pandemic has intensified the challenges already evident across provision in the housing, health and social care sectors, including rising vacancies and precarious financial viability.





# Housing and Support in GM

**Spread over 10 different Local Authorities, home to over 2.8 million people, housing across GM is diverse in type, tenure and condition.**

However, there is a growing shortfall in supported housing designed for older people, estimated at only 8,500 units across the ten districts by 2035. For people aged over 65, there is considerable reliance on the social rented sector in GM when compared with national and regional averages, with over a quarter of residents relying on it. The private rented sector is growing, in part due to rising house prices, stagnating wages and the lack of availability in the social housing sector. Around 1 in 20 households live in overcrowded accommodation, disproportionately concentrated in the rented sector. There are widespread concerns about the quality of homes in the private rented sector, particularly within those parts of GM with concentrations of pre-war, low value properties, notably the terraced housing in and around the Pennine town centres. Over the past decade in GM, funding for Adult Social Care fell in real terms by about £300m, despite a 21% rise in the number of citizens aged over 65. However, reablement support aimed at improving independence and quality of life, and reducing the size of longer term packages of care, long term admissions to care homes and inappropriate readmissions to hospital has increased. Specifically £17.9m spent in 2017/18, compared to £19.3m spent in 2018/19, and an additional £3.1 and £4.8m spent on other short-term support in the same periods.

**We often make assumptions about where people want to live in their later life. Whether it's rightsizing to a more manageable property or moving into a retirement community, many of us paint a mental picture of 'housing for older people' without thinking. The reality, though, is very different: the vast majority of older people live in ordinary, mainstream homes, and they have absolutely no intention of changing that.**

Andy Burnham, Mayor of Greater Manchester, 2018

**In GM there is a growing shortfall in supported housing designed for older people, estimated at only 8,500 units across the ten districts by 2035. For people aged over 65, there is considerable reliance on the social rented sector in GM when compared with national and regional averages.**



Over the past decade in GM, funding for Adult Social Care fell in real terms by about

# £300m

There is a growing shortfall in supported housing designed for older people, estimated at

## 8,500

units across the ten districts by

## 2035.

Around

## 1 in 20

households live in overcrowded

## accommodation.



—

**There is growing recognition that dementia is not an inevitable feature of ageing and that, when it does occur - whether in younger or older people - early diagnosis and appropriate intervention can moderate both the impact and the progress of the disease.**

# Stakeholder Engagement

Following a response to the APPG on Housing for People Living with Dementia Call for Evidence, in June 2020 there has been an extensive period of stakeholder engagement across the city-region to enhance understanding of key issues affecting people living with dementia, carers and loved ones through lived experience groups.

Engagement and consultation activity has been steered by the GM Dementia Carers Expert Reference Group, the Dementia United Strategic Board and the GM Housing, Planning and Ageing Group. A series of focus groups with experts by experience including people living with dementia, carers and loved ones, frontline housing association staff, including operational managers, neighbourhood officers, maintenance workers and staff engaged in customer support from across Greater Manchester have been held throughout 2020/21. This was complimented by a series of in-depth meetings with GPs, Nurses, Local Authority Housing Leads, alongside national policy leads.

## Key issues for Stakeholders

In the light of their experiences, stakeholders identified a number of key issues which needed to be addressed in order to meet future housing needs:

- To be effective commissioning must be collaborative and joined-up to ensure it effectively shapes the market.
- The system needs to build on collaborative and integrated work across health and social care - so that people do not have to navigate complex systems, with multiple hand-offs.
- There is a need to identify plans to decommission housing options that constrain independence and re-invest in mainstream and supported housing options that focus and support ageing in place and asset-based solutions.
- Now is the time to invest in sustainable innovation that improves outcomes, including enhanced individual and community resilience, and better value for money.
- Care-givers are essential to recovery plans and need access to support for their own health and housing advice.
- Investment in enablers that help people live well and be socially connected and included, such as digital devices and skills, accessible design and assistive technology.
- Community mobilisation has been a positive feature during COVID-19, linking the voluntary and community sector (VCSE) and mutual aid groups to housing support, for example through navigators and social prescribing teams, is a significant opportunity.





# Recommendations

This report makes seven recommendations:

## Housing with Care

### 1. Accessible Guidance and Information:

Provide independent housing information and advice in a diverse range of accessible and culturally sensitive formats.

**2. Integrated Pathways:** Ensure housing is integral at every stage of the dementia care pathway. Ensure the support offer includes opportunities to explore housing options as well as financial and legal planning.



## Planning and Development



**3. Planning Ahead:** Identify clear standards for housing that meets the diverse needs of people living with dementia, including those from minority communities. Identify appropriate and acceptable sites specifically for age-friendly housing.

**4. Market-Shaping:** Recognise and respond to the growing demand for age-friendly and dementia-ready social and private rented housing, including those among ethnic minority and LGBTQ+ communities.

## Building a Community of Practice



**5. Combatting Stigma:** Encourage a wider public conversation to understand how healthy homes for people living with dementia, carers and loved ones are central to ambitions for COVID-19 recovery and delivering for an ageing population.

### 6. Knowledge Mobilisation and Implementation:

Establish a community of practice and learning and information networks among practitioners and those living with dementia, carers and loved ones emphasising an awareness of structural inequalities alongside an asset-based approach.

**7. Evidence-based Policy and Practice:** Further research is needed across a number of areas including how best to improve awareness and understanding of dementia, and the implications for housing and communities.



## Next Steps

This report and the seven recommendations offer the basis of a three-year Implementation Plan 2022-2025, to be developed through a series of workshops, aimed at developing collaborative conversations that emphasise an asset-based approach, and taking advantage of Integrated Care Systems (ICS) framework in GM. It links directly to the Framework for Creating Age-Friendly Homes in Greater Manchester. This sets an ambition for a permanent cultural shift in thinking around housing in later life, recognising that older people want a choice of different, affordable mainstream and specialist housing options, that meets both need and aspiration and in places where they can maintain or build social connections, achieve good health and independence. The GM Health and Social Care Partnership is in a unique position to lead the way in addressing the challenges identified here, and to build on the city-region's position as the first in the UK to join the WHO Global Network of Age Friendly Cities and Communities. To do so, consideration should be given as to how these findings may contribute to further refining the current strategic vision – Our People, Our Place.

In particular, whilst continuing to emphasise the positive and constructive aspects to ageing, thought should be given to acknowledging the reality of the discrimination and stigma faced by those living with dementia, carers and loved ones. Whilst acknowledging that this could be compounded by particular identity characteristics such as minority ethnicity, age and/or LGBTQ+, and to specifying strategies within the Implementation Plan to address these, including within its key milestones and performance indicators.



**The GM Health and Social Care Partnership is in a unique position to lead the way in addressing the challenges identified here, and to build on the city-region's position as the first in the UK to join the WHO Global Network of Age Friendly Cities and through the new Framework for Creating Age-Friendly Homes in GM.**





