Manchester City Council
Report for Information

Report to: Health Scrutiny Committee – 7 February 2024

Subject: Palliative and End of Life Care in Manchester

Report of: Manchester Deputy Place Lead and Marie Curie Lead

Summary

This report provides critical research from the *Better End of Life programme,* conducted in collaboration between Marie Curie*,* King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull and the University of Cambridge, in relation to experiences of palliative and end of life care, as well as identifying policies and resources that will help to make a positive difference to the lives of people affected by dying, death and bereavement. Marie Curie have asked all localities to respond to an audit questionnaire and the findings from this are discussed in the body of this report and will inform locality developments.

In order to give a rounded perspective of issues and challenges across Manchester as well as the GM Integrated Care Board, contributions have also been collected from the GM Quality Improvement Programme Manager, Palliative & End of Life Care, who describes the developments and ambitions of the GM Palliative and End of Life Care Programme, and the Manchester Locality Team, (Primary Care as well as Quality), where the issues and challenges in relation to transformation are discussed.

Recommendations

The Committee is asked to consider and comment on the report and in particular the findings from Marie Curie in section eight and the next steps for Manchester partners, which are set out in section nine.

Wards Affected: All

Environmental Impact Assessment -the impact of the issues addressed in this report on achieving the zero-carbon target for the city	Supporting people to die in their own homes and in their communities of choice, supports the zero-carbon agenda for the city. In addition, the provision of high-quality, targeted and accessible information to unpaid carers through a streamlined network ensures sustainability and support for carers of people who are in receipt of palliative and end of life care
Equality, Diversity and Inclusion - the impact of the issues addressed in this report in meeting our Public Sector	There is still unwarranted variation for people with life limiting illness in accessing coordinated and streamlined palliative and end of life care, and in

Equality Duty and broader equality commitments	many cases, much earlier in the progression of disease or illness. Additionally, there are variations in experience for those with protected characteristics. The ambitions of the GM Palliative and End of Life Care programme as well as the Manchester Palliative and End of Life Care Partnership is to reduce health inequalities through collaboration, system co-production, understanding the needs of all communities and promoting an inclusive approach. All locality partners aim to engage with and involve patients/the public on the commissioning of a service and design of pathways to ensure that services meet the needs of Manchester people and align with other programmes of work such as Making Manchester Fairer and the Anti-Poverty Strategy as well as Community Health Equity Manchester, Manchester’s Patient and Public Advisory Group and the Manchester Disability Collaborative.

Manchester Strategy outcomes	**Summary of how this report aligns to the Our Manchester Strategy/Contribution to the Strategy**
A thriving and sustainable city: supporting a diverse and distinctive economy that creates jobs and opportunities	Carers of people who are in palliative and end of life stage are often disadvantaged in employment opportunities, with many carers ending employment opportunities when their caring responsibilities increase. By supporting Carers to maintain employment through care and support interventions is positive for the city's economy and positive for Carers.
A highly skilled city: world class and home grown talent sustaining the city's economic success	
A progressive and equitable city: making a positive contribution by unlocking the potential of our communities	Access to co-ordinated, quality palliative and end of life care in a person's chosen environment should be a basic human right. This is a value of a progressive society and a key aspiration of the national Ambitions, and GM Commitments to establish a gold standard in ensuring that all people and their carers feel they are being listened to, and their views are taken into account at all points in their journey.
A liveable and low carbon city: a destination of choice to live, visit, work	
A connected city: world class infrastructure and connectivity to drive growth	

Full details are in the body of the report, along with any implications for:

- Equal Opportunities Policy
- Risk Management
- Legal Considerations

Financial Consequences – Revenue

There may be financial consequences for the revenue budget dependant on the acceptance of recommended changes.

Financial Consequences – Capital

There are no financial consequences for the capital budget.

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Background documents (available for public inspection):

The following documents disclose important facts on which the report is based and have been relied upon in preparing the report. Copies of the background documents are available up to 4 years after the date of the meeting. If you would like a copy, please contact one of the contact officers above.

End of Life Care Strategy (publishing.service.gov.uk)

CQC_A Different Ending_3.pdf

Palliative and End of Life Care in Integrated Care Systems – Marie Curie

Better End of Life - Marie Curie

Taking the Temperature of NG6 - Marie Curie & National Energy Action

Seventy years of end of life care in the community: how much has changed since 1952? - Marie Curie

Bereavement is everyone’s business – UK Commission on Bereavement

NHS England: Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026

Greater Manchester Commitments: Approach for Palliative and End of Life Care (gmintegratedcare.org.uk)

1.0 Introduction

1.1 Marie Curie is a national charity that works to support dying people and their families. The organisation offers expert care across the UK in people's own homes and in Marie Curie's nine hospices. During 2023, Marie Curie supported more than 50,000 people across the UK at the end of their lives. Currently in Manchester Marie Curie provides hospice care at home and offers free information and services which give guidance and support to families. Marie Curie is also the largest charitable funder of palliative and end of life care research in the UK and campaigns for the policy changes needed to deliver the best possible end of life experience for all.

1.2 The World Health Organisation defines palliative care as the 'prevention and relief of suffering of adult and paediatric patients and their families facing the problems associated with life-threatening illness. These problems include physical, psychological, social and spiritual suffering of patients and psychological, social and spiritual suffering of family members.

1.3 Using this definition quality palliative care should:

- ensure early identification, assessment and treatment.
- enhance quality of life, promote dignity and comfort, and may also positively influence the course of illness.
- be integrated with and complement prevention, early diagnosis and treatment of serious or life-limiting health conditions.
- support bereaved family members after the patient's death.
- seek to mitigate the pathogenic effects of poverty on patients and families and to protect them from suffering financial hardship due to illness or disability.
- not intentionally hasten death, but provide whatever treatment is necessary to achieve an adequate level of comfort for the patient in the context of the patient's own values and spiritual beliefs.
- be applied by health care workers at all levels of health care systems, including primary care providers, generalists and specialists in many disciplines and with various levels of palliative care training and skill, from basic to intermediate to specialist care
- encourage active involvement by communities and community members
- be accessible at all levels of health care systems and within patients' homes.
- improve continuity of care through strengthened health and social care systems.

2.0 Background

2.1 Individuals that experience a life limiting illness should be supported to live as well as possible before they die. They should be empowered to make decisions about their own care, with their wishes and preferences at the centre of all care planning and clinical decisions. All individuals should be treated with dignity and respect, with appropriate culturally sensitive care available for those who need it. The reality is that for too many people report experiences that fall short of what we all hope for and should expect at this stage of our lives. Currently there is significant unmet need for palliative and end of life care. The most recent estimates suggest that in England up to 25% of those who need palliative care are not receiving it. Applying national estimates this would equate to a minimum of around 830 people in Manchester going without the care they need each year.

2.2 The Health and Care Act 2022 directed that Integrated Care Boards (ICBs) have a legal responsibility to commission health services that meet their populations needs. The Act specifies all age palliative and end of life care services as a statutory responsibility of the ICB. The inclusion of palliative and end of life care is a welcome addition to the Health and Care Act given the rising numbers in the ageing population who are living longer, many with multiple co-morbidities and the advances in medicine supporting many adults and children to live longer with complex care needs.

2.3 In November 2023 Marie Curie published findings from a survey conducted with ICBs to see how they were responding to this new legal duty. The survey findings provide some grounds for optimism, as ICB respondents feel they are performing strongly in delivery of services, collaboration and engagement across providers, governance and accountability, and use of data to drive improvements.

2.4 However, the survey findings also point to areas requiring further work to ensure improved outcomes for people at the end of life. Only a minority of ICB respondents feel they have properly understood population need, and a majority report significant challenges in addressing inequalities in palliative and end of life care. Workforce and funding are seen as key barriers to improving services and ICBs also report significant gaps in some of the core components of commissioned palliative and end of life care services in the national Ambitions framework. Despite the legal duty being in place for over a year, current evidence indicates that nationally there is still an insufficient focus on palliative and end of life care both in needs analysis, commissioning and reduction of unwarranted variation.

2.5 The Covid-19 pandemic highlighted how hard it is for some groups of people with a terminal illness and their families to get the care and support they need, including people who are living in poverty, alone, or with dementia, or life limiting conditions not associated with malignancy (Cancer), as well as people with learning disabilities, those experiencing homelessness or who are in prison, ethnic minority groups, and LGBTQ+ people. The cost of living crisis is compounding this situation with poverty affecting more than 90,000 people each year at the end of their lives across the UK, including more than 1,100 in Manchester. 34% of people who die in Manchester are dying in poverty.

2.6 This is a key moment for action to improve palliative and end of life care. As a result of our ageing population, by 2043 it is estimated that 147,000 more people will require palliative care each year across the UK (a 25% increase). New models for delivering care in the community will be needed to reduce pressures on the NHS, local government and social care and, where it is the patient’s preference, for people to receive support to be cared for at home at the end of their lives. Larger numbers of families and carers will also require support through the process of dying, death and bereavement.

2.7 Integrated Care Systems and Councils have a critical role to play in helping people to die well. Many of the core services that local authorities provide, such as social care, are important components of a high-quality approach to end of life care. Councils are also an important source of information and advice for residents, and can help to play a convening role locally, working in partnership with Integrated Care Systems, healthcare providers, other agencies, and the wider voluntary and community sector.

3.0 Marie Curie- ‘Better End of Life Programme’

3.1 Health & Wellbeing

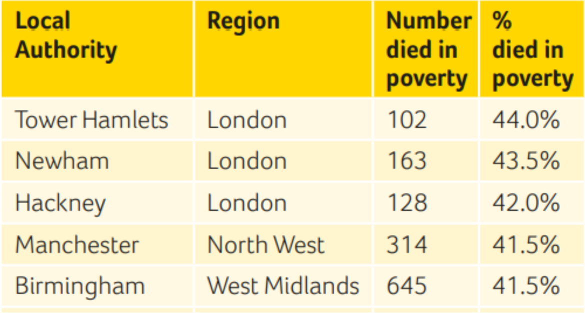
Good quality palliative and end of life care improves outcomes for individual patients, their carers and families however acute pressures on GPs and district nursing services, as well as workforce challenges in health and social care, within complex referral systems are making it extremely difficult for people to access the joined-up and local services they need. Research from Marie Curie’s ‘Better End of Life’ programme indicates significant current challenges for people in accessing palliative and end of life care services in community settings, particularly outside of traditional office hours. Many struggle to access community nursing services and find it very difficult to access the palliative care medication they urgently require during nights and weekends.
(Note: The Better End of Life programme is a collaboration between Marie Curie, King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull and the University of Cambridge)

3.2 Palliative care also delivers cost savings by reducing pressures on the wider health and care system. Emergency admissions to hospital for people in the last 12 months of life cost in excess of £1.2 billion in 2018/2019. In Manchester 7% of deaths are preceded by at least three emergency admissions in the last three months of life (in line with the national average). People who receive palliative care in community settings are less likely to be admitted to hospital, less likely to attend A&E, and spend less time in hospital if they are admitted.

3.3 Financial Security

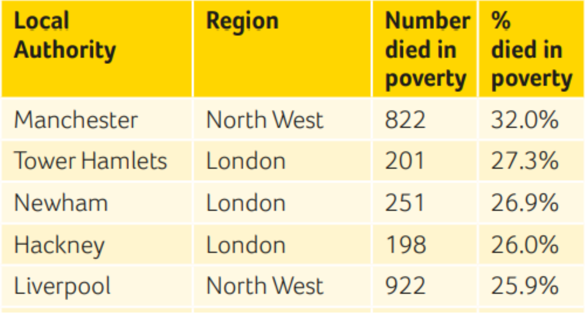
More than a third (34%) of people who die in Manchester do so in poverty. Many people experience poverty throughout their lives and continue to experience it as they reach the end of life. For many others however, the often devastating financial impact of terminal illness is what drives them into poverty even if they were previously financially stable as a result of a combination of income loss and additional costs after a terminal illness diagnosis. Working age parents with children are particularly vulnerable to moving into poverty after a diagnosis of terminal illness. In Manchester, 42% of working age people who die are below the poverty line in their last year of life.

Table 6. Number and proportion of working age people dying in poverty, 2019 (top 20 UK local authorities)



Local Authority	Region	Number died in poverty	% died in poverty
Tower Hamlets	London	102	44.0%
Newham	London	163	43.5%
Hackney	London	128	42.0%
Manchester	North West	314	41.5%
Birmingham	West Midlands	645	41.5%

Table 7. Number and proportion of pensioners dying in poverty, 2019 (top 20 UK local authorities)



Local Authority	Region	Number died in poverty	% died in poverty
Manchester	North West	822	32.0%
Tower Hamlets	London	201	27.3%
Newham	London	251	26.9%
Hackney	London	198	26.0%
Liverpool	North West	922	25.9%

The table above shows how Manchester ranks amongst other UK local authorities with regards to working age people and pensioners who die in poverty. Of all top-tier councils in England, Manchester currently ranks 4th highest for the proportion of working age people who die in poverty, and 1st for the proportion of pensioners who die in poverty.

3.4 Nobody should die in poverty. While much social security policy is outside the control of local government, there are important steps that local authorities can take to support local residents who are experiencing poverty or who are at risk of falling below the poverty line, including ensuring that people with a terminal illness are eligible for benefits that councils distribute. This is very much what the Manchester Anti-Poverty Strategy aims to address.

3.5 Inequality & Inequity

Profound and persistent inequalities exist in access to, and experiences of, care and support for people affected by dying, death and bereavement. Given the unique position and local insights they hold at place-level, local authorities have a key role to play in tackling inequity at the end of life. Groups and communities experiencing wider societal disadvantage, often at multiple intersections, are disproportionately represented among those without access to quality palliative and end of life care. These include, but are not limited to:

- People with conditions other than cancer
- The oldest old, i.e., people aged 85 years or over
- Racialised, minoritised ethnic communities
- People living in more deprived areas
- People with learning disabilities
- Imprisoned people
- LGBTQ+ communities

3.6 Support for carers

Around 38,200 people in Manchester care for a family member, friend or neighbour because they have long-term physical or mental health conditions, illnesses, or problems related to old age. Carers play a pivotal role in providing vital unpaid support to a family member or friend with a terminal illness, often doing so through to the end of that person’s life. This caring role is extensive, varied and in many cases around-the-clock.

3.7 Carers of people with a terminal illness are often older and have to manage the physical demands that caring places on their own health, at the same time as the impact of ageing. The demands of caring can have a significant impact on a carer's physical health, leaving them at increased risk of illness and injury. Looking after someone with a terminal illness can be a mental and emotional rollercoaster. Receiving news of a terminal illness diagnosis can be devastating and carers can experience feelings of fear, anxiety, and uncertainty about the future.

3.8 Despite the critical role that carers play and their huge contribution in supporting our social care system, the support available to them often falls short of what is needed. Under the Care Act 2014, carers are eligible for a formal assessment of their needs by their local authority, but only around a third of carers of a person with palliative care needs report having had an assessment done or reviewed in the past 12 months. The quality of assessments is also variable, with vital issues such as respite care and support with their own needs often not addressed.

3.9 Bereavement support

More than 18,000 people are bereaved in Manchester every year. Bereavement can be an exceptionally isolating and lonely experience, however almost everyone will experience a bereavement at some point in their life. While most people can be adequately supported by their friends, families and wider communities through a bereavement, some adults, children, and young people will also need more formal emotional support, whether from a peer support group, a volunteer, or a professional counsellor/therapist. But across the UK, over 40% of adults who want formal bereavement support don't receive any, while half of bereaved children said they didn't get the support they needed from their schools and colleges.

4.0 UK Commission on Bereavement

4.1 In 2022, the UK Commission on Bereavement carried out one of the largest ever consultations on bereavement support. It found that bereavement support needs to be more accessible; a lack of guidance and difficulty finding the right information about what to do after someone dies means that many bereaved people feel unsupported and lost. Furthermore, there is no legal right to take paid time off for bereavement, except parental bereavement leave for a person whose child has died, and many employers offer little or no additional bereavement support.

4.2 The Commission also highlighted that families can wait a long time for a funeral in some localities. Delays to funerals can be particularly upsetting for those bereaved families whose faith requires a swift burial. Out of hours systems to enable the rapid processing of death paperwork necessary for burials to happen quickly, which are available in some but not all local authority areas, can help.

4.3 The high cost of funerals, cremation and burials is another concern. The Commission also heard of difficulties some people experience in attempting to access public health funerals, in addition to some instances of stigma and hostility towards bereaved people seeking to access them. Public health funerals are provided by local authorities for people who have died when no one else is making the necessary arrangements for a funeral. There is a statutory duty on local authorities to arrange for a burial or cremation where no suitable alternative arrangements are being made, however, there is considerable variation in how these funerals are delivered across the country.

4.4 The Commission also found that for people living in social housing, a bereavement can also bring the profound worry and disruption of an immediate eviction notice. Some grieving people living in social housing receive an eviction notice and face the strain of having to find somewhere to live, or even the threat of homelessness, through no fault of their own. This is most common with adult children living with their parents. Having to leave the family home, with all its memories, can compound feelings of distress – especially so soon after the death.

4.5 Ensuring individuals and families are properly supported through bereavement also depends on tackling taboos and encouraging more open conversations about death and dying, helping to enable communities to adopt a compassionate approach to supporting bereaved people of all ages. Local Authorities can harness the resources and compassion of local people by embedding Compassionate Communities in their local areas. Compassionate Communities is a social movement where local people support others who are affected by dying, death and bereavement. They are networks of volunteers that work alongside formal services. (For example, a local person might volunteer to do food shopping for a neighbour who can’t leave the house, or provide companionship to someone living alone with a terminal illness.) This support can make a huge difference to the person who receives it, while complementing the work of formal palliative care services.

5.0 GM Developments

5.1 The Greater Manchester Palliative and End of Life Care Programme was established in 2013 as part of the Greater Manchester and Eastern Cheshire Strategic Clinical Networks and now embedded with NHS Greater Manchester ICB. The programme reports into the NHS GM ICB Medical Directorate under the SRO Chief Medical Officer and is clinically led by a Consultant in Palliative Medicine and a GP from the GM system, supported by a Programme and a Project Manager.

5.2 Following the 2008 national End of life Care Strategy there has been several national publications which have supported the development of the ‘Greater Manchester Commitments to Palliative Care individuals approaching or in the last year of life’. The GM Commitments outline a pledge to the citizens of GM and give clear direction of programme deliverables required, in preparation to meet a future need.

5.3 The Greater Manchester Commitments to palliative care individuals approaching or in the last year of life, align to the National Ambitions for Palliative and End of Life Care which were refreshed in 2021. In direct response to the outlined statutory requirement in the Health and Care Act NHS Greater Manchester ICB Board agreed to a Greater Manchester all age programme in September 2023 to address the unwarranted variation in palliative and end of life care across Greater Manchester.

5.4 **Table 1:** The 10 outlined deliverables were agreed as:

1) Increase the **identification** of individuals in the last year of life and understand the prevalence of palliative care for babies’ children and young people.
2) Increase the opportunity for personalised care conversations and **future care planning.**
3) Increase **digital sharing** of palliative and end of life care information for all ages through the GM Care Record.
4) Improve **data and intelligence** to support effective commissioning of palliative and end of life care across the system.
5) Address **workforce planning** to ensure an available workforce with the right skills to support the delivery of 24 hours 7-day services in palliative and end of life care for all ages
6) Grow **compassionate communities**.
7) **Address unwarranted variation** and inequalities in palliative and end of life care provision.
8) Professionals providing care for babies, children and adults with life-limiting illnesses should receive specific **training and education** in palliative and end of life care and in communication skills.
9) Every family shall have timely access to practical support, including clinical equipment, **financial grants, and benefits**.
10) To ensure **commissioning arrangements** to support palliative and end of life care provision are in place to are provide a seamless provision of care

5.5 The GM programme provides leadership, strategic direction and collaboration to support localities progressing against the GM commitments. The GM programme works across the GM Integrated partnership managing and supporting several groups to drive forward the work in relation to the 10 outlined deliverables. The GM programme has made significant progress in developing and supporting the implementation of an EARLY identification tool for primary care, which incorporates personalised approaches to advance care planning.

5.6 The programme is working with the GM system to support the use of the electronic palliative care coordination system (EPaCCS) as part of the Greater Manchester Care Record (GMCR) to enable the sharing of electronic records and advance timely decisions for people approaching end of life. The programme has undertaken scoping against the speciality palliative care nursing workforce and a service mapping to identify gaps in 24/7 provision and continue to work with the system to identify workforce solutions. The programme support discussion for all sectors in sustaining specialist palliative care services to support the population of Greater Manchester.

5.7 A number of dashboards are in development to support a population view and system wide map of activity including the hospice sector. Work is just beginning in one locality to address a joint strategic needs assessment (JSNA) and the programme team are exploring how this could be applied to provide a GM view.

5.8 The ICB and Partnership are committed to addressing unwarranted variation and inequalities in palliative and end of life care. The GM Programme have completed an Equality Quality impact assessment which will be monitored through the governance of the programme. The CQC report ‘A Different Ending (2016)’ highlighted 10 communities who receive less than adequate provision or services for palliative and end of life care.

a. People with conditions other than cancer
b. Older people
c. People with dementia
d. People from black, or minority ethnic (BME) groups
e. Lesbian, gay, bisexual, and transgender people (LGBT)
f. People with a learning disability
g. People with a mental health condition
h. People who are homeless
i. People who are in secure or detained settings
j. Gypsies or travellers

Since this report another emerging group of people who are dying in poverty and deprivation is also of concern to the programme.

5.9 In Table 1, deliverable number six (Grow compassionate communities) and deliverable number seven (address unwarranted variation and inequalities in palliative and end of life care provision) of the GM programme are a direct response to focus on the aspect of inclusion. The programme has delivered several quality improvement initiatives to support the outlined groups who have been identified as receiving less than adequate palliative and end of life care.

5.10 <u>Challenges</u>

The current financial constraints of the health and care system impact on the speed in which the programme can make whole system transformational change. The programme continues to work with the ICB and ICP to seek opportunities for funding and collaboration to support the palliative and end of life care programmme of work.

6.0 Manchester Developments

6.1 <u>Carers</u>

Manchester Local Care Organisation in 2023 published the Manchester Carers Commissioning Strategy 2023 -2025. This was developed in partnership with Carers Manchester Network in order to provide access to support for unpaid carers. The strategy sets out the vision and priorities of ‘Carers Manchester’, shared by Manchester Local Care Organisation and statutory services (Manchester City Council, NHS). Support for Carers is now embedded within the welfare benefits system and the health service through the NHS Commitment to Carers, whilst the Care Act 2014 makes explicit provision for the statutory assessment of Carer wellbeing and support needs, providing parity with the needs of the cared-for citizen.

6.1.1 Whilst the carers of those in receipt of palliative and end of life care are not explicitly referred to, the focus areas of the strategy will have a direct impact such as Carers Champions and Carers Registers in all GP practices, improved links with Mental Health Assessors and teams, access to learning and development opportunities and carer respite (break) offers.

6.1.2 MFT Carers Strategy 2023 - 2026 sets out five key commitments including identification and recognition of carers, communicating with carers, partnership with health, social care and third sector services to best coordinate care, developing carers awareness across all areas of the organisation and to develop training for staff and ensuring reasonable adjustments.

6.1.3 The strategy cross references to MFT’s Adult Supportive Palliative and End of Life Care Strategy 2021-2026. In the commitment entitled Identification and Recognition one of the key actions is “Ask carers ‘What Matters’ to them about the care of their significant other / loved one at all times, and particularly during Palliative Care of their loved one”. Quotes from carers appear throughout the strategy and against the five commitments which highlight the reality of carers experiences.

6.2 Primary Care

For most individuals, care in the last year of life will be provided in their usual place of care, led and/or coordinated by the GP. GPs aim to identify patients at the end of life early so that there is time for care planning conversations to take place with the individual and family/carers and advanced care plans can be developed.

6.2.1 The Enhanced Health in Care Homes (EHCH) Service is a primary care service that supports some of our most frail and complex individuals living in older people’s care homes. Within 7 days of moving into a care home an individual will receive a comprehensive geriatric assessment (CGA), which is a holistic physical/psychological/social assessment in partnership with the patient and family/carers. As part of this, advanced care planning discussions will be offered including priorities for future care and a focus on what matters to them.

6.2.2 This is an iterative process and plans are updated regularly as needed. GPs work closely with community teams, especially district nurses, to support patients to die in their preferred place of care. This includes prescription of anticipatory medications. For more complex patients GPs will contact the community palliative care team for advice and referral.

6.2.3 Challenges

Clinical leadership: Historically Manchester has had a GP Clinical Lead for Palliative and End of Life Care to work with locality clinical leads, colleagues and system partners in driving forward transformation programmes and improvements in outcomes for patients at the end of life. Manchester Locality is in the process of identifying clinical (Medical) leadership resource to sit on the Manchester Palliative and End of Life Care Partnership Group to support the locality nursing leadership in the delivery of the ambitions of the GM Palliative and End of Life Care Programme.

6.2.4 *Care pathways*: Available data clearly indicates that hospital is still the most common place of death. This occurs for a number of reasons including lack of support for individuals and families, lack of care planning, care plans not followed, lack of knowledge and training for staff, lack of information sharing, individuals with complex conditions, often with difficult to manage symptoms. A system approach is needed to provide better joined up care with information sharing across organisational boundaries and more information and support for individuals and family/carers.

6.2.5 *Early identification* of individuals in the last year of life enables planned and coordinated care planning conversations. Late recognition can affect the opportunity for patient centred decision making, choice of preferred place of care and lead to unnecessary admissions to hospital. This can be difficult especially in individuals with chronic illness where the disease trajectory can be uncertain. Alongside training and education, tools that sit within the clinical scope can support clinicians in identifying patients in the last year of life who would then be clinically validated and appropriate treatment and support action taken.

6.2.6 *Information sharing* is vital to ensure that professionals involved in the care of individuals at end of life can see advanced care plans and have the most up to date information to make decisions and recommendations. Multiple partners are often involved in the individuals care and use different clinical systems that do not integrate or enable information sharing. Without this mechanism, care is not coordinated, communication is impeded and there is a risk that the individuals wishes and preferences will not be understood or followed.

6.2.7 *The Electronic Palliative Care Coordination System (EPaCCS*) is a national system that supports the electronic transfer of information, there is an ambition to roll this out across GM. It will take a whole system approach to embed this and issues such as information governance, data sharing, consent, interoperability, digital maturity, engagement and system programme management will need to be addressed and overcome at locality level.

6.3 Manchester Palliative and End of Life Care Partnership

6.3.1 A number of tools and information sources have been used to gain a better understanding of areas of care in Manchester that work well, where pathways and approaches can be improved, where there are clear gaps and where patient experience indicates inequity. These include the Regional Ambitions Self-Assessment Tool (completed in 2021- summary of outputs of this exercise in Table 2 below) and the Macmillan Evaluation of the Implementation of a new City Wide Community Service Delivery Model (completed in 2022, focus on Manchester Macmillan Supportive and Palliative Care Service). All individual services work to a vision for their patient group however feedback from patients and carers over a period of time has made clear that for more patients to access palliative and end of life care and to reduce inequity, all parts of the system must work together in an aligned way to achieve those shared improvements.

Table 2:

Summary of outputs from Manchester's self- assessment		
What works well	**What could be improved**	**What is a gap**
Recognised approach to personalised care and support planning for children and adults	Training strategy for developing communications skills across all health and care staff and evidence of access by staff group and grade	Use of data sharing across all service providers e.g. Electronic Palliative care Co-ordinating Systems (EPaCCS)
Identification of those at end of life across all care settings	Implementation of patient focused outcomes tool (Integrated Palliative Care Outcome Scale) across Manchester and Palliative Care Registers	Multi-lateral contract arrangements that support integrated care.
Local Population Health based needs assessment for individual service planning (e.g., non-malignant conditions)	Central all age directory of services and clear statement about level of service that can be expected	Local Population Health based needs assessment to influence integrated EOLC pathways across the system
Use of Equality Impact assessments to measure and demonstrate equity	Routine use of performance indicators and data to inform system quality improvement	Access to training in simple procedures/processes as well as bereavement support for carers – anticipatory grief counselling as well as post-bereavement, and 24/7 helpline support
Skilled assessment and symptom management	Level of training access and competence for staff in nursing homes	Holding providers to account for person centred outcomes and fair access to care
Emergent integrated system education strategy	Responsive services addressing all forms of distress	Inclusion of a Palliative and End of Life Care system delivery strategy (integrated

		care) in the Manchester Target Operating Model
Help to support patients and carers in self-managing and improving quality of life	Levelling up and consistency of attainment of ambitions across North, South & Central	A named all age system Clinical (Medical) Lead with oversight of hospital, community and primary care pathways.
Community engagement representing different faith & cultural groups is embedded	Use of volunteers	Access to equipment out of hours and on weekends
Access to bereavement counselling	Understanding of impact of anticipatory grief on carers and families	Access to 24/7 helpline and counselling

6.3.2 As a result of informal discussions with a range of agencies and organisations, the Manchester Palliative and End of Life Care Partnership came into being as a *quality improvement programme* reporting into the Manchester System Quality Group. This multi-agency partnership group is made up of representatives from Primary Care, MLCO Community Services, MFT Palliative and End of Life Care leads, GMMH, Medicines Optimisation Team, Locality Quality Improvement, Cancer leads, service user representatives, Manchester Macmillan Palliative Care Supportive Service and St. Ann's Hospice (please see section 7.3. System Structure: Interdependencies across system elements)

6.3.3 The purpose of the partnership is two-fold, firstly, to become the strategic lever for the quality improvement of palliative and end of life care, ultimately by establishing an agreed, standards-based system model of care for Manchester. This is not intended to take the place of individual provider strategies but as a collective ambition for Manchester as a system, and to provide the ICB with assurance of a system-wide collaboration for improvement and quality in specialist and non-specialist palliative and end of life care for the Manchester population (Adults & Children)

6.3.4 The ambitions of the Partnership are to:

- Deliver the GM Palliative and End of Life Care programme in Manchester.
- Ensure that care is available to all those who need it, prioritising quality of life, living and dying well.
- Reduce inappropriate admissions to hospitals.
- Increase individuals dying in their preferred place of care.
- Increase identification of people with palliative and end of life care needs across the Manchester system regardless of diagnosis, condition, and disability.
- Increase use of the Electronic Palliative Care Coordinating System (EPaCCS) across Manchester.

6.4.5 Priorities identified by both Greater Manchester and Manchester locality to achieve these ambitions include:

a) *Improving earlier identification in Primary Care*: this is linked to improving registered patients being placed on GP Palliative Care Registers at the earliest point to signal they have specific needs now or in the future in this area. Being placed on this register will trigger advance care planning discussions with GPs, Social Care and other professionals involved.

b) *Improving Advance Care Planning:* Advance care planning' (ACP) is the term used to describe the conversation between people, their families and carers and those looking after them about their future wishes and priorities for care. Advance Care planning is key means of improving care for people nearing the end of life and of enabling better planning and provision of care, to help them live well and die well in the place and the manner of their choosing. It enables people to discuss and record their future health and care wishes and also to appoint someone as an advocate or surrogate, thus making the likelihood of these wishes being known and respected at the end of life.

c) *Improving Anticipatory Care:* Many people often equate Palliative and End of Life Care to cancer, however, there are many life limiting conditions and diagnoses where post-diagnostic planning and better monitoring could be initiated at a much earlier stage and consistently, but this is not always the case e.g dementia. Anticipatory care is often a consideration when a person is becoming visibly unwell or less mobile, whereas the actual purpose of this approach is to ensure that people are kept mobile and can enjoy their optimum independence for as long as possible. Good quality and pro-active care (system-wide and integrated) could avoid incidence of deconditioning, crisis management (crisis hospital admissions) as well as the opportunity to broaden offers of regular health checks for people with cancer as well as non-malignant diagnoses promoting a better quality of life.

d) *Improving access to anticipatory and post-bereavement support:* Many carers and families in the knowledge that their loved one is on a journey to end of life, experience anticipatory grief. For many, this can be as catastrophic as post bereavement grief. For some it provides a platform for preparation and planning, for others it can be a trigger for anxiety, loneliness and isolation. This phenomenon is often experienced as a "roller coaster" because feelings of distress can shift back and forth over a period of time. These experiences can apply both to the person dying as well as their carers and loved ones. Carers in particular have stated that access to counselling and support on a 24/7 basis would help to alleviate some of this distress.

e) *Improving the hospital to community discharge pathway:* Anecdotal feedback as well as incident reports tell us that the mechanisms for discharging patients from hospital back to their homes (or permanent setting) do not always operate efficiently, and communication is sometimes compromised. Work to improve this is already underway through various routes including the Resilient Discharge Programme, Primary/Secondary Care Interface meetings, Care Home Clinical

Subgroup. The Partnership brings together lead practitioners through which system issues can be addressed with a feedback loop into quality assurance mechanisms.

f) *General/Specialist skills:* While the Manchester Macmillan service provides excellent specialist support in managing plans for patients and carers, there is scope for further collaboration and integration with frontline services that deliver care to patients in-hours and out of hours. For example, where patients with a palliative diagnosis are flagged to North West Ambulance Service, Manchester Crisis Response and/or the IV service that have not previously been referred to the palliative care team (conditions including dementia, heart failure, respiratory disease). There is an opportunity to explore the confidence, competence and upskilling required for frontline services to provide reactive (generalist), palliative and end of life care/support, across disease groups and settings, for patients experiencing crisis, particularly late in the evening to avoid unwanted hospital admission. Investment in accredited training for appropriate staff and clinical supervision should be considered to strengthen and sustain good , consistent palliative and EOL care.

g) *The Electronic Palliative Care Coordination System (EPaCCS*) as stated in point 6.2.7, is a national as well as GM an ambition to roll this out across GM which will come under the oversight of the Partnership Group.

h) *Co-production/lived experience:* As part of the Manchester Macmillan Supportive and Palliative Care Service (MMSPCS) Programme a large and active service user group was in place for 3 years supported by a funded coordinator. This arrangement came to an end when the Macmillan service became embedded as part of MFT. The Partnership group has sought to maintain contact and involvement with a small number of service users and carers. Their voice and experiences are vital in ensuring quality of experience and in reducing inequalities. This will be further scoped by the group.

i) *Inequalities:* The Partnership is one of a number of points in the system where inequalities is a key focus. Reduction of unwarranted variation in patient experience should be a core activity. Various data sources indicates that there is an under representation of those identifying as ‘other than white’ on the Palliative Care Registers (PCRs) compared to the general population. Potentially people from minoritised communities may be coming to the attention of crisis services at very late stages of their conditions. In addition while cancer is the most prevalent long-term condition for those on both the Palliative Care Register and service users within the Manchester Macmillan Palliative Care service, it ranks 8th overall for the Manchester adult population with just 2.3% of the population on the GP Cancer Register. The recognition of the need for, and access to, palliative care for those living with non-malignant disease (e.g. Dementia, Heart Failure, etc) needs to be improved.

6.5 Challenges

6.5.1 *Programme coordination*: As a result of the ICB restructure, all ICB and Locality Teams are working in a much leaner way. System transformation requires overall programme management and coordination, at the present time these resources are unavailable. Consequently, all members of the Manchester Palliative and End of Life Care Partnership are working together within the parameters of their existing roles. This means that change will be slower and some resources (such as for the system roll out and implementation of EPaCCS) are not currently visible. This will directly impact on achievement of the ambitions overall.

6.5.2 *Locality priority*: Whilst Palliative Care is one of the nine health priorities as advised by NHS GM for Locality Delivery Portfolios, the definition “Inpatient palliative care related diagnosis and specialty admissions” narrows the perspective to Hospice care, and a relatively smaller population than those who die at home or in hospital. Commissioning of hospices is now within the remit of the GM Sustainable Services Programme Board. The definition above does not bring into focus community pathway redesign as this is not directly commissioned, as well as being a narrower reflection of the reality of many patients and families’ experiences. Locality Boards may opt not to include Palliative and End of Life Care as one of their commissioning priorities.

6.5.3 *Generalist Training*: Availability of recurrent resources to be able to work with the various sectors in establishing a meaningful anticipatory and post bereavement service for carers and their families, as well as establishing specifically skilled staff to provide competence based training to care homes, primary care, generalist staff across neighbourhood teams, community services, etc, This needs to be a system wide programme within an agreed model of training in order to ensure the required standards. Appropriate resources are not currently available within the system.

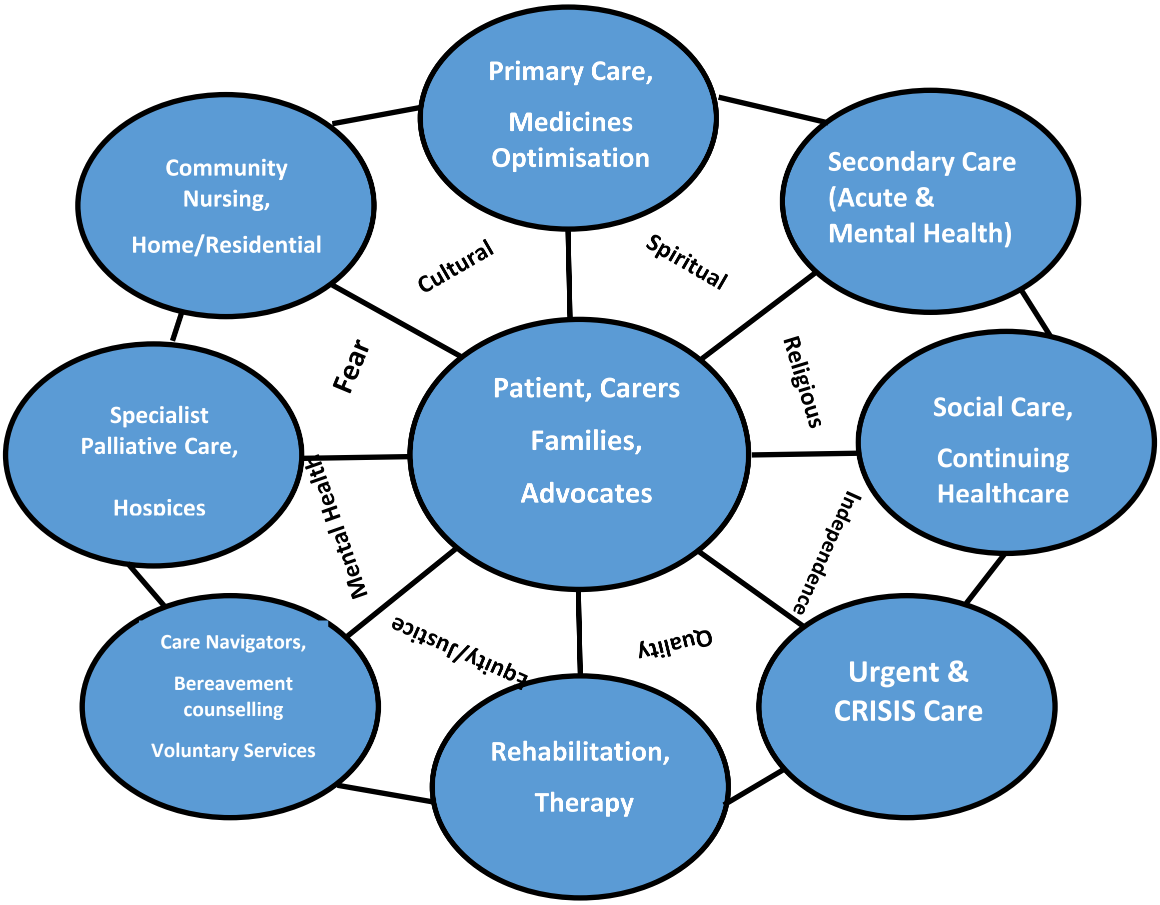
6.5.4 *Quality Standards*: Whilst there is commitment to achieving the standards laid out by the national ambitions demonstrated by Macmillan and “specialist” elements of MLCO and MFT (through its strategic statement), there is still significant work to be done to establish an agreed strategic approach that is owned by Manchester across the system. The involvement of all system stakeholders is critical in developing and agreeing a Manchester system model for palliative and end of life care that can be considered a seamless standards-based offer, providing early identification and timely intervention for all patients where appropriate, regardless of condition and symptomology as well as a full support offer for carers.

7.0 Summary

7.1 Personal experience of palliative and end of life care will only happen once in any person’s life, there are many touchpoints in the system that can work together in a more seamless way to ensure access, quality and as close to a positive experience as possible for patients, their carers and families.

7.2 This report has raised a number of issues regarding equitable access across conditions and minoritised communities. However, the needs of less visible communities such as people with learning disabilities, those who are homeless, people from travelling communities, those in prison, those with mental illness and detained under the Mental Health Act, and those with substance misuse problems with life limiting physical conditions also need consideration.

7.3 System Structure: Interdependencies across system elements



8.0 Marie Curie Findings

As a result of the *Better End of Life Programme* research, other policy/guidance as well as patient experience, Marie Curie is asking all Integrated Care Partnerships, Councils, providers and partners to discuss and consider the following:

8.1 To help improve the health and wellbeing of those living with a terminal illness:

- Ensure that all partners are meeting their statutory duties relating to palliative and end of life care and that services are culturally competent to meet the needs of our diverse communities. Services will need to address the inequalities of access and experience outlined in the Marie Curie report linked to protected characteristics and poverty.

- Ensure a fully accessible 24/7 palliative and end of life care advice line is in place so that local people, as well as health and care professionals, know where to turn for specialist palliative care advice when they need advice and support.
- Undertake and publish a Joint Strategic Needs Assessment specifically for palliative and end of life care to identify the current and future needs of the local population, which would give commissioners an accurate picture of local demand for services.

8.2 To help alleviate financial pressure on people living with a terminal illness:

- Review eligibility criteria for Council Tax Support to ensure that people living with a terminal illness and their family and carers are eligible, irrespective of age or savings.
- Prioritise people living with a terminal illness when allocating Discretionary Housing Payments.
- Consider the outgoings, as well as the income and assets, of applicants for Disabled Facilities Grants and fast-track the process and payment of grants.
- Use leadership roles on Health and Wellbeing Boards to ensure compliance with the National Institute for Health and Care Excellence's NG6 guidelines around excess winter deaths, illness and the health risks associated with cold homes.

8.3 To address health inequalities and inequities:

- Use their influence in supporting Integrated Care Boards to meet its new statutory duties relating to addressing and tackling health inequalities over the whole life course, including at the end of life.
- Ensure that an inequalities lens is embedded while conducting Joint Strategic Needs Assessments, providing commissioners with an understanding of the local unmet healthcare need for disadvantaged groups over the whole life course, including at the end of life.

8.4 In order to better help support carers:

- Ensure that every carer of someone with a terminal illness is offered a carer's assessment at least annually and that recommendations are acted upon promptly and fully.
- Ensures that Council's Carers' Strategies includes a specific focus on carers of people with a terminal illness and support through bereavement.

8.5 To help support all those who have experienced a bereavement:

- Reviews policies and procedures relating to public funerals to ensure that all people accessing such funerals are able to do so in a dignified manner.
- In its role of social landlord, allow a six-month grace period for evictions after a bereavement.

- Encourage schools and local employers to adopt a bereavement policy to ensure that people are supported through bereavement at school and at work.
- Embed a Compassionate Communities approach to complement the work of formal bereavement services.
- Ensure out of hours systems are in place to enable rapid processing of death paperwork and registrations so that quick burials can take place for people whose religion requires this.

9.0 Next steps for the Manchester system

9.1 It is proposed that Marie Curie and relevant officers from MCC and partners, meet again to discuss and consider the above findings and also the best approach for ongoing member engagement and involvement in this area of work.

9.2 The Manchester Palliative and End of Life Care Partnership will be supported to ensure that Palliative and End of life Care becomes a priority for system improvement through the new integrated arrangements relating to the Provider Collaborative Board (PCB) and Manchester Partnership Board (MPB).

9.3 The Manchester Palliative and End of Life Care Partnership will then be able to work through the PCB and MPB and bring back a report on progress to the Manchester Health Scrutiny Committee in the new municipal year.

9.4 Finally, Manchester partners have welcomed the excellent work of Marie Curie and their audit questionnaire has been completed by MCC officers and partners. This has helped to inform the content of this report and the next steps.

10.0 Recommendations

10.1 The Committee is asked to consider and comment on the report and in particular the findings from Marie Curie in section eight and the next steps for Manchester partners, which are set out in section nine.