Scottish
Partnership
for Palliative Care

Submission to Scottish Parliament Health and Sport Committee Inquiry into Health Inequalities (March 2022)

8[1]. What progress, if any, has been made towards tackling health inequalities in Scotland since 2015? Where have we been successful and which areas require more focus?

This submission will focus on inequalities experienced by people towards the end of life.

BACKGROUND ON PALLIATIVE CARE

"Palliative care" is often a misunderstood and misused term. One way of thinking about 'palliative care' is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close.

Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making.

However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Palliative care interventions are holistic and aim to modify the impact of illness/disease by addressing symptoms and should be delivered alongside treatments aimed at controlling or modifying the underlying condition(s). Palliative care can and should be provided alongside treatment aiming to cure or remove the underlying illness/disease where such treatments exist.

Bereavement support is part of palliative care.

In Scotland most of the care that people receive when their health is deteriorating could be termed generalist palliative care, being provided by

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[1] The first 7 questions in the consultation are administrative and have been omitted

health and social care professionals to people living in the community, in care homes and in hospitals.

It is palliative care regardless of whether someone has cancer, organ failure (including neurological conditions) or 'old age', or whether they are living at home, in a hospice, in a care home, in prison or in a medical ward, in ICU or a homeless shelter, or in a neonatal ward.

Specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital, but whose expertise should be accessible from any care setting and at any time. Services labelled 'palliative' are usually specialist palliative care.

Palliative care is provided by the NHS, the Third Sector, the Independent Sector and Local Authorities.

Organisations involved in delivering palliative care include primary care; care homes; care at home services; hospices; NHS 24; Scottish Ambulance Service; NHS specialist palliative care units; acute hospitals; community hospitals.

Legal responsibility for the strategic commissioning of adult palliative care lies with Integration Authorities (IAs). Children's palliative care is delivered by partnership working between Health Boards, Local Authorities, and CHAS (as the single national provider of children's hospice care), with Scottish Government funding for CHAS managed through NHS Lothian.

For more background on palliative and end of life care in Scotland please see *Every Story's Ending, proposals to improve people's experiences of living with serious illness, dying and bereavement.* This report published in September 2021 by SPPC presents a comprehensive overview and analysis, including a specific chapter on Inequalities, which this response draws on heavily.

AREAS REQUIRING MORE FOCUS:- GENERAL COMMENTS

People's experiences of death, dying and bereavement (including the palliative and end of life care they receive) is an area which requires more focus. Within this people with particular circumstances or characteristics have particularly poor experiences. It is important to remember that people can be disadvantaged in multiple ways at the same time. Whilst an improved understanding of the needs and experiences of specific groups is important, each person is an individual and within groups there will be heterogeneity.

Palliative and end of life care is frequently neglected in public health policy and thinking on health inequalities. Public health typically focuses on improving health outcomes (usually prevention and measurable improvement in someone's health status over time). However, towards the end of life most people experience an unpreventable and irreversible decline in their health status. It is easy to see how this doesn't fit neatly into existing health inequalities paradigms. However, good care and supportive environments can make a huge difference to someone's wellbeing even as their health declines. Over 60 000 people die each year in Scotland so this is a major issue, and also one with major resource implications for the health and care system – 1 in 3 hospital beds at any time are being used by people in the last year of life. Most residents of a care home for older people are in their last 18 months of life.

One way in which the lack of focus on this phase of life is exhibited is in the very limited data and analysis available relating to inequalities at the end of life. The Equalities Impact Assessment undertaken by Scottish Government at the time of the publication of their Strategic Framework for Action on Palliative and End of Life Care (2014) stated that 'There is a need for more data on all the protected characteristics groups and their use of and need for palliative care'. However, little progress has been made. Identifying, describing and understanding inequalities towards the end of life is a prerequisite for improving the situation, yet there remains a scarcity of good research and data analysis in Scotland or at UK level.

AREAS REQUIRING MORE FOCUS:- INEQUALITIES EXPERIENCED BY 12 DIFFERENT GROUPS AT THE END OF LIFE

1. People Who Are Socio-economically Deprived

Scottish Government's latest report on the Long Term Monitoring of Health Inequalities showed premature mortality rates are four times higher in deprived areas. Deaths from COVID-19 are higher in areas of socio-economic deprivation. Whilst not all people dying prematurely will have palliative care needs, levels of multi-morbidity increase with deprivation, and multi-morbidity and palliative care need are closely linked.

People living in deprived areas have different patterns of service use/ access. They are less likely to access specialist palliative care, they are more likely to spend time in hospital during the last 3 months of life, more likely to die in hospital and less likely to die at home or in a hospice. Even when people living in deprived areas access specialist palliative care they are less likely to die in a hospice and more likely to die in a hospital than those from affluent areas. People from the most deprived areas are less likely to report that they received sufficient support from health and social services to care for someone at home.

The Ritchie Report on Out of Hours (SG 2015) highlights how primary care resources are maldistributed by health care needs, according to socio-economic status and the fact that levels of multi-morbidity increase with increasing deprivation.

The impact of type of housing, material environment, and poverty on end of life experiences are not well understood. The Dying in the Margins project is exploring these issues in deprived communities in urban and rural areas in Scotland.

Serious illness and caring for someone with a serious illness are themselves causes of poverty. A decade of austerity has left an increasing number of people in Scotland facing funeral poverty.

2. Gender and Inequality

The experiences of different genders towards the end of life vary significantly. Women experience more years of ill health, report more pain, more fatigue, are less likely to die at home and provide more informal care than men. Women are less likely to express a preference for life extending treatments at end of life with this choice often seemingly linked to fears of being a burden. Research, policy and practice are heavily influenced by gendered assumptions, for example what may be expected of men and women as care givers. The inequalities experienced by women are so frequently viewed as objective norms that they are not considered as topics for research or as being relevant to the formulation of policy and practice. That the explicit and implicit policy emphasis on increasing dying at home is not accompanied by analysis of the impact on women as primary care givers is a good example of this blind spot. Similarly most economic analyses of palliative care fail to capture informal care costs which fall disproportionately on women (who are proportionately poorer in the first place, and who have been disproportionately impacted by a decade of austerity).

Gender stereotypes also impact negatively on men. Men are less likely to report stress, anxiety, depression and other emotional concerns, which probably reflects gender norms rather than levels of distress.

The experiences of trans men, trans women and people with non-binary gender identities towards the end of life are not well understood and not always considered in policy or needs accommodated in practice.

3. People Who Identify As LGBTQ+

LGBTQ+ people can feel anxious using health and social care services because of past discrimination, and this can lead people to delay or avoid accessing services. In turn this can increase pressure on LGBTQ+ carers who may be left isolated and unsupported. LGBTQ+ people approaching the end of life are often rightly worried that because of staff prejudice or unconscious bias their life partner may not be properly recognised as important and may be less included and supported both before and after death. Heteronormative assumptions by health and social care staff can make it hard for LGBTQ+ people to disclose their identity. LGBTQ+ people may experience greater isolation during bereavement and disenfranchised grief.

4. People of Ethnic Minority Background

Census data shows that the number and proportion of older people from ethnic minorities is set to increase rapidly and the need for palliative and end of life care in these groups will increase. In England there is some evidence that compared to White British people other ethnic minorities have less access to specialist palliative care services. Explanations for this include lack of referrals; lack of awareness of relevant services; previous bad experiences when accessing care; a lack of information in relevant languages or formats and family/religious values conflicting with the idea of hospice care. A study of the Scottish population dying of cancer found that rates of hospital death were similar regardless of ethnic group. Analysis of the VOICES survey in England found 'that people from BAME backgrounds were less likely to consider overall care in the last three months of life to be 'outstanding' or 'excellent'. They were also much less likely than people of White ethnicity to experience 'excellent' care (there is no 'outstanding category' for individual services) from care homes.' The Prince and Princess of Wales Hospice in Glasgow is an example of a specialist palliative care service which has taken steps to improve its understanding of and services to the multi-cultural communities in its catchment.

5. Inequalities linked to Type of Diagnosis

The type of condition someone has significantly influences where they are cared for, their referral pathways, who funds their support and accommodation (and the extent of charging), and therefore overall, the support they can access.

People whose 'main' diagnosis is organ failure (including neurological conditions), frailty and/or dementia are less likely to get the palliative care support they need and this applies both to specialist and generalist palliative care support. Paradoxically this position is reversed for children; those with cancer are less likely to access early palliative care.

Public and professional perceptions of palliative care as a specialist service for people dying with cancer persist. The uncertainty of prognosis in some conditions, for example chronic obstructive pulmonary disease (COPD) and dementia makes it harder for people with these conditions to access specialist palliative care services. Research suggests that care co-ordination for people with cancer is better than that for other conditions [though there is scope for improvement in all conditions]. Professionals find it harder to initiate discussions about end of life issues when prognosis seems less certain, and also where options for referral for support may be more limited. Research shows that people's experiences and expectations are different depending on whether they have cancer, organ failure (including neurological conditions), frailty and/or dementia .

6. Older People

People of all ages from neonates to centenarians may need palliative care. However, an estimated 85% of people who die with palliative care needs are aged 65 or older. Factors such as the prevalence of different conditions and household circumstance vary with age. For example, frailty and dementia become more common with age, people are more likely to live alone and this affects people's pathways of care. There is some evidence that people over 85 are less likely to receive specialist palliative care, and that older people with cancer may have less adequate pain relief. There is often uncertainty in prognosis for older people with frailty and dementia and this can lead to late or absent identification of palliative care needs. A recent study in England describes how dying without an 'end of life diagnosis' makes it harder for frail older people to access good community care. A study comparing the experiences of frail very old people with younger cohorts suggests that the very old are less likely to have had ACP discussions or, perhaps counterintuitively, to be aware that they may be reaching the end of life (or to have had this acknowledged). Older people are more likely to experience the death of a life partner and to have smaller networks of social support when bereaved. Because such bereavements are so common in this age group older people may be expected to 'just cope', and complicated grief and depression may not be identified or addressed. A recent review found that bereaved people over 65 are as likely as adults bereaved at a younger age to experience prolonged grief disorder, around 10% of those bereaved. Older people are less likely to seek help or to be referred for bereavement support.

7. Children with Life Shortening Conditions

Children with a life-shortening condition are 50% more likely to be living in the most deprived parts of Scotland compared with the least deprived, and are also more likely to be admitted to hospital with that condition.

There is also thought to be an association between the prevalence of life-shortening illness in children and some minority ethnic groups. The reasons for higher prevalence in these groups need to be better understood and the implications for service accessibility, design, and provision explored. Life with a child with complex medical needs can result in additional expenses – such as specialist equipment and adaptations – yet family members are also often less able to work due to their caring responsibilities.

8. People in Prison

The Scottish prison population is experiencing a rapid growth in the proportion of older prisoners. This is largely explained by long sentences associated with historic sexual abuse. Prisoners typically experience accelerated aging, with the onset of ill health 10 years earlier than the general population. An increasing number of prisoners have palliative care needs. Compassionate release at end of life is less likely to be an option for many of these older sex offenders due to breakdown of relationships in the community: prison may be their preferred location for end of life care. There are similar demographic trends and issues in Scotland’s high secure State Hospital.

Young prisoners are likely to have experienced parental, multiple and traumatic deaths than the general population and the rate of unresolved grief amongst prisoners is likely to be higher than in the general population.

The Scottish Prison Service and the health and care system faces major challenges in providing care (including end of life care) for growing numbers of prisoners with multi-morbidity and disability. Prisons are a difficult place to provide good palliative and end of life care for several reasons. The physical environment is not well suited to people with mobility issues and is difficult/expensive to adapt. There are difficulties accessing equipment and staffing levels are tight. There is a lack of overnight nursing cover. Maintaining necessary security is an obstacle to family contact, peer support and medicines availability.

9. People Experiencing Homelessness

Homelessness is often not just a housing issue but an indicator of multiple severe disadvantage and complex needs. There were 216 deaths in Scotland of people who were homeless in 2019. 70% of these deaths had external causes including drug-related deaths, accidents, suicides and assaults. People experiencing homelessness have complex palliative care needs and have worse symptoms at the end of life, yet they have worse access to good quality palliative care and often die without accessing care. People experiencing homelessness may be concerned about dying on the streets, dying alone, dying anonymously, losing control if admitted to hospital (and potentially having to deal with drug/alcohol withdrawal), and being forgotten about after death. They may also have pressing practical concerns. People who are homeless, like most people, have a preference to die somewhere comfortable where they know people.

People experiencing homelessness who have palliative care needs tend to be relatively young in comparison to the general population with such needs, and often have a particularly uncertain prognosis. Many have 'tri-morbidity – physical and mental health problems together with addictions. Many have also experienced trauma, which impacts their ability to access and benefit from services.

Mainstream services are not adequately configured to meet the needs of homeless people. Challenges for services include a lack of awareness; lack of flexibility; lack continuity of care (which is vital to establish trust); lack of 'assertive follow-up'; co-ordination between multiple agencies; lack of social support; hostels not designed to accommodate ill health.

Dying in the Cold, a recent report from Marie Curie Scotland, explores many of these issues in more depth.

10. Gypsy, Traveller and Roma People

A recent study identified key themes in the views, experiences and needs of gypsy, traveller and Roma people approaching the end of life:

"(1) Strong family and community values include a preference for healthcare to be provided from within the community, duty to demonstrate respect by attending the bedside and illness as a community problem with decision-making extending beyond the patient.

(2) Distinct health beliefs regarding superstitions around illness, personal care, death rituals and bereavement.

(3) Practical barriers to non-community healthcare provision include communication difficulties, limited awareness of and access to services, tensions between patients and healthcare professionals and lack of training in delivering culturally appropriate care."

11. People with Learning Disabilities

People with learning disabilities often die younger, are more likely to experience poor general health, have higher than average levels of unmet physical and mental health need and can be disadvantaged when accessing acute hospital. They often experience care which is unco-ordinated and have less access to specialist palliative care services and opioid analgesia. Staff often lack confidence in meeting the particular and individual needs of people with learning disabilities.

12. Forced Migrants

Forced migrants face a range of barriers to healthcare including palliative care. Language and communication issues are often an obstacle. Forced migrants may have a low baseline understanding of awareness of how the NHS works. They sometimes experience difficulties registering with a GP. Their entitlement to care is often questioned by frontline staff. Forced migrants may have been charged for care in the past and be concerned about being unable to pay for care. In some cases forced migrants may face no-choice dispersal and frequent moves from one location to the next. Forced migrants are often fearful of breaches of patient confidentiality and subsequent harassment by the Home Office.

9. What are the most effective approaches to tackling health inequalities and how successful is Scotland in pursuing such approaches?

The following approaches are important:

- Proactive engagement with disadvantaged groups and individuals to understand their experiences.
- Identifying and understanding disadvantage through quantitative and qualitative research.
- User involvement in service design, and the development of bespoke person-centred services for disadvantaged people.
- Joined up approaches which acknowledge the intersectional nature of disadvantage.
- Societal approaches which challenge stigma and prejudice.
- Redistributive fiscal policies which acknowledge that wider inequalities drive health inequalities.
- Political leadership, courage and investment in all of the above.

10. What actions would you prioritise to transform the structural inequalities that are the underlying cause of health inequalities?

Inequalities towards the end of life generally reflect patterns of inequality and discrimination within wider society. Societal approaches which tackle inequality, poverty and discrimination are fundamental to improving experiences and outcomes at the end of life. There is now good evidence for how governments can address poverty-related health inequalities by addressing the wider social determinants of health. Measures include redistribution of income and wealth. Social movements, properly enforced equalities legislation and society-wide campaigns are the basis for challenging discrimination and stigma at societal level.

11. What has been the impact of the pandemic both on health inequalities themselves and on action to address health inequalities in Scotland?

IMPACT OF COVID-19 ON PALLIATIVE CARE

The role of palliative care within a pandemic is to address suffering in all settings both for those who are dying and for those receiving disease modifying intervention. Good data and analysis on how inequalities in palliative care were created and exacerbated is not yet available. This section gives an overview. Negative effects of the pandemic are generally likely to have greater impact on people already disadvantaged.

Limited Knowledge Base

Prior to the first wave of the pandemic there was little published evidence about the trajectories of decline and symptoms to be expected amongst people dying with COVID-19. There was also limited evidence about how to adapt existing strategies for managing symptoms such as breathlessness amongst people with COVID-19.

Sudden Increased Need for Palliative and End of Life Care

By 28th March 2021 there had been 9,958 deaths registered in Scotland where COVID-19 was mentioned on the death certificate. During the calendar year 2020 there were 6,324 excess deaths, 11% higher than the five-year average.

Procurement and Supply Chains

The infectious nature of COVID-19 and the sudden increase in dying led to concerns and difficulties relating to the availability of PPE, equipment and medicines for palliative care.

Rapid Change in Place of Death

There has been a major shift in the place of death. From the beginning of 2020 until mid-March 2021 the total number of all deaths at home increased by 36% compared to the average number of people who died at home in the equivalent period in 2015-2019. The vast majority of these deaths at home (especially outwith the COVID-19 waves) were from causes other than COVID-19. There was also an increase in the complexity of needs of people dying at home creating challenges for GPs, district nurses and other community staff.

Loss of Human Contact

Measures to control infection have had a huge impact on the experiences of dying people and their loved ones, and on the provision of end of life care. Visitor restrictions meant many people died without desired contact with loved ones. Staff's ability to connect and communicate with dying people they are caring for has been made much more difficult by masks, visors and restrictions on touch. Families (and some staff) have experienced bereavement in traumatic circumstances, at a time when funerals and other usual sources of solace such as the support of friends, family and community have been restricted. Many individuals experienced multiple losses.

Staff Wellbeing

Caring for people who are dying can often be psychologically, spiritually and emotionally challenging. During the pandemic these challenges have been compounded by specific circumstances: dying has tended to be concentrated temporally during the waves of the pandemic; much dying with COVID has been concentrated within the care home sector where many staff experienced, at least initially, inadequate support from the wider healthcare system; some staff who previously had little experience of end of life care have been deployed in areas with high levels of dying; enforcing restrictions on visiting towards end of life can be traumatic for staff, as can facilitating final goodbyes via phone or video; relentless periods of intense and distressing work, when staff are already deeply fatigued; staff have had to deal with concern and fear about becoming infected and also infecting their own loved ones; usual coping strategies have been limited by restrictions on aspects such as social contacts and holidays.

Exacerbation of Existing Weaknesses

In addition to the challenges identified above which are specific to COVID-19 the pandemic has highlighted pre-existing weakness. Key deficiencies have included:

- Many people who would benefit from an anticipatory care plan were found not to have one.
- Anticipatory care planning and DNACPR are widely unknown, misunderstood and/or often negatively viewed by the public.
- Clinical decision making intended to avoid burdensome and non-beneficial treatments are sometimes perceived as denying access to life-saving treatment for old people, especially those in care homes.
- Care homes for older people are under-resourced and insufficiently supported by and integrated with health services.

12. Can you tell us about any local, regional or national initiatives throughout the pandemic, or prior to it, that have helped to alleviate health inequalities or address the needs of hard to reach groups? How can we sustain and embed such examples of good practice for the future?

There are many initiatives, often stemming from work or funding by Third sector organisations. Examples include:-

- A project funded by Macmillan Cancer Support to improve palliative care for people in prison. Partners included several hospices as well as NHS Boards and the Scottish Prison Service.
- Work by several hospices together with local NHS Boards to understand and improve palliative care for people who are homeless.
- Work by the Prince & Princess of Wales Hospice to make their services more accessible and appropriate for people with South Asian family origins.

More examples are in *Every Story's Ending, proposals to improve people's experiences of living with serious illness, dying and bereavement* published by SPPC in September 2021.

The learning from these sorts of projects should be sustained and embedded by means of a proper focus on end of life care experiences in commissioning processes. It is also important to develop data capture and analysis so that inequalities can be identified, and progress or regression identified.

13. How can action to tackle health inequalities be prioritised during COVID-19 recovery?

Palliative and end of life care should be at the centre of plans for NHS recovery. Unfortunately this is not the case. For example the Cancer Recovery plan makes no substantive reference to action on palliative care, which is a really startling omission – despite improvements in treatment around a half of people diagnosed with cancer die within 5 years. It is hard to see how the needs of particularly disadvantaged groups towards the end of life will be better addressed when this whole phase of life is omitted in key documents like this.

The establishment of the National Care Service should place emphasis on the palliative care needs of older people (who are the biggest single group needing support).

COVID has lead to an increase in bereavement and within that an even larger increase in people experiencing complex grief and associated mental health issues. There is a need for a more strategic approach to meeting people's bereavement support needs.

14. What should the Scottish Government and/or other decision-makers be focusing on in terms of tackling health inequalities? What actions should be treated as the most urgent priorities?

Measures which aim to make general services more accessible and person-centred will help to address inequalities in palliative and end of life care – for example work currently being done under the banner of health literacy. SPPC's report *Every Story's Ending, proposals to improve people's experiences of living with serious illness, dying and bereavement* identifies the following as actions to tackle inequalities. The first 5 actions would impact on all the groups identified under question 8)

1. Individual Personal Responsibility

Individuals engaged in delivering and/or improving care should all seek to become more aware of the multiple ways in which inequalities are created, expressed and experienced towards the end of life. Everyone has personal and/or professional domains, however large or small, within which they can contribute to challenging stigma, discrimination and promoting more equitable outcomes. Everyone can take personal responsibility for becoming aware of and challenging our own unconscious biases.

2. Research

There is a need to better understand current inequalities in service use and access, and the specific needs and experiences of different groups. The Scottish Palliative Care Research Forum should be resourced to progress a programme of work to identify and address priority gaps in knowledge. It may make sense to take a nationally co-ordinated programmatic approach to understanding and better meeting the needs of different groups. This could make best use of limited research capacity to inform and work with local service improvement pilots. Local learning should be shared with the Palliative Care Research Forum and disseminated through local palliative care leads.

3. Policy-making

All relevant Scottish Government policy making should include a more explicit and effective consideration of how to reduce inequalities experienced by people towards the end of life.

As more benefits are devolved to Scotland Scottish Government should continue to take account of the needs of people approaching the end of their lives and their carers, building on the recent introduction of BASRiS and the Funeral Support Payment.

4. Commissioning, Service Design and Resource Allocation

The most basic need is for strategic planning and commissioning processes which address outcomes for everyone at the end of life. Thereafter, during strategic planning and commissioning processes the needs of disadvantaged groups should be identified and explicitly addressed in plans, through culturally appropriate and accessible services. (see response to Q15 also)

Disadvantaged groups should be involved in service design to help planners and commissioners to understand and address barriers to access and deliver better outcomes.

Investing in approaches which address the needs of disadvantaged groups should, if necessary, be enabled by reallocating resources away from those who are currently best served.

5. Education and Training

In addition to standard equalities and health literacy training relevant staff should receive training specific to end of life issues. This could range from general awareness of inequalities at end of life to specific issues (for example the beliefs and practices around death of different ethnic groups).

6. Prisoners

The unpublished final report of the Macmillan Cancer Support Scotland funded project on palliative care in prisons will identify relevant actions. These are likely to encompass: creation of separate secure facilities for prisoners with palliative and end of life care needs; arrangements for families to maintain contact; improving staffing levels and skill mix; more education for healthcare and prison staff; robust guidance from senior management on how to manage prisoners; more flexible approaches to lockup of prisoners who are dying; incentivising and supporting those prison officers with an aptitude for providing care; careful development of ‘peer carer’ roles; knowledge-sharing by prisons and hospices which are already working collaboratively; improved access to controlled medications, whilst managing security and exploitation risks; greater co-ordination of services for prisoners released on compassionate grounds and support for their carers; clear guidance on roles, responsibilities and pathways when prisoners are to be cared for in hospices, either whilst remaining in custody or following compassionate release; further research to understand the perspectives of staff, prisoners and families.

7. People Who Are Homeless

Activity should be undertaken to improve awareness of the distinct needs of homeless people amongst relevant health, social care and housing/homelessness staff.

Specialist homeless GP practices, specialist palliative care services, homelessness services and other agencies should collaborate to identify and deliver pathways of care. The resourcing of CNS roles with a special interest can provide leadership and co-ordination for pathway development and delivery.

Pathways, with palliative care MDT involvement, should include outreach, in-reach to hospitals and bereavement support.

Specialist palliative care services should provide education and support to homelessness staff.

Community palliative care beds should be provided within hostels perhaps in conjunction with medical respite/intermediate care beds.

8. People with Learning Disabilities

Where appropriate, anticipatory care planning processes (including emergency care planning processes such as Respect) should be embedded within learning disability reviews.

15. What role should the statutory sector, third, independent and private sectors have in tackling health inequalities in the future?

The Third sector is a major provider of palliative and end of life care in Scotland (unusual/unique in terms of mainstream healthcare provision which is otherwise all provided by the NHS), and should continue to play a key role in innovation and the spread of improvements designed to address inequalities.

The statutory sector needs to improve its commissioning of palliative and end of life care, and within that develop a focus on addressing inequalities. More specifically:-

- Scottish Government guidance on strategic commissioning of palliative care should be revised and a clear expectation set that Integration Authorities develop whole system population-based plans and commissioning processes which identify, understand and invest to meet the palliative and end of life care needs of the local population and set out clear lines of accountability.

- Commissioning plans should address the specific needs and circumstances of disadvantaged groups including issues around service accessibility and inclusivity.
- Commissioning processes need to be complemented by financial mechanisms which cover the transitional risks/costs of transformational change and support the reallocation of funds across the system where this delivers better outcomes and better value.
- Commissioning processes should ensure that Third and Independent sector provision is financially sustainable, bearing in mind that such providers provide a large proportion of services (such as care at home and all varieties of hospice care including inpatient care, community nursing and other support), and often bring distinctive contributions of flexibility, innovation and reach to disadvantaged groups

HIS and CI scrutiny of Integration Authority strategic commissioning processes should examine the adequacy of commissioning arrangements for palliative and end of life care (including the extent to which inequalities are identified and addressed).

Data on inequalities at the end of life should be gathered as part of commissioning and delivering services, and regularly analysed to inform and provide accountability for improvement.