ANNEX 1(D)

**PROPOSALS FOR PRESCRIBED INFORMATION TO BE INCLUDED IN THE INTEGRATION SCHEME RELATING TO THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014**

**CONSULTATION QUESTIONS**

1. Do you agree with the prescribed matters to be included in the Integration Scheme?

   **Yes** [x]

   **No** [ ]

2. If no, please explain why:

   | |
   |---|
   | |

3. Are there any additional matters that should be included within the regulations?

   **Yes** [ ]

   **No** [X]

4. If yes, please suggest:

   | |
   |---|
   | |

5. Are there any further comments you would like to offer on these draft Regulations?

The regulations mostly focus on the statutory partners that will make up integration authorities and leaves other key integration partners, such as the third sector, largely out of their scope. The third sector and others, play a huge part in the delivery of health and social care services, providing staff and services. They must be seen on a more equal footing with the statutory partners or there is a risk that integration will not be as successful as all partners wish it to be.

This could potentially have a detrimental impact on the integration and delivery of services, for example, workforce planning.

Marie Curie nurses often provide end of life care in people's home alongside other health and social care staff. If the Plans for Workforce Development do not include other partners than there is a risk that this could impact on the quality, awareness and support delivered by staff throughout the journey of care. It could lead to a disjointed and inconsistent experience for the patient.

Workforce planning should also consider the role of volunteers and unpaid carers, as many of these people are integral part of delivering care to patients. Scotland's ageing population will lead to a greater demand for health and social care and this combined with a Scottish Government's vision to shift care to community settings and the home will lead to the role of volunteers and unpaid carers in delivering support and in some case services increasing.

The role of the third sector in the design, planning and delivery of social services will be crucial to achieving the Government's National Health and Wellbeing Outcomes.

We are pleased to see that there is a requirement for partnerships to consult with the third sector. However, we would like to see partnerships be required to demonstrate the impact and outcome of the consultations that they undertake with the third sector and others.

We would also like to re-iterate that consultation and engagement by integration authorities with the third sector must go beyond local Third Sector Interfaces and include, as far as possible, the broad spectrum of local and national charities operating in integration areas and localities.

We are concerned that the expertise of many third sector organisations both locally and nationally will not be captured by integration authorities. The third sector voice is not a generic voice. Third sector organisations represent many different specialities with an expert level of knowledge and understanding in those areas, which may greatly support different, and sometimes specialised, aspects of health and social care in an area. This could never be captured by one representative voice sitting round the table of an integration board/monitoring committee. It is imperative that integration authorities ensure that consultation with the third sector is wide reaching, on-going and where necessary broken down by specialty. It must also involve local and national organisations.

The issue of data sharing should also not be considered purely in terms of health boards and local authorities, as other partners may also be accessing key information, such as patient records. Marie Curie nurses and hospices come into regular contact with patient records and in we have arrangements with individual Boards around data sharing. It will be important for integration authorities to be aware of all these arrangements when developing processes and procedures.

We hope that if these concerns cannot be met through regulations that the guidance to accompany the regulations addresses them in detail.

ANNEX 2(D)

**PROPOSALS FOR PRESCRIBED FUNCTIONS THAT MUST BE DELEGATED BY LOCAL AUTHORITIES RELATING TO THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014**

**CONSULTATION QUESTIONS**

1. Do you agree with the list of Local Authority functions included here which must be delegated?

**Yes** [X]

**No** [ ]

2. If no, please explain why:

| |
|---|
| |

3. Are there any further comments you would like to offer on these draft regulations?

| |
|---|
| No further comments. |

ANNEX 3(D)

**PROPOSALS FOR REGULATIONS PRESCRIBING FUNCTIONS THAT MAY OR THAT MUST BE DELEGATED BY A HEALTH BOARD UNDER THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014**

**CONSULTATION QUESTIONS**

1. Do you agree with the list of functions (Schedule 1) that may be delegated?

**Yes** [X]

**No** [ ]

If no, please explain why:

| |
|---|
| |

2. Do you agree with the list of services (Schedule 2) that must be delegated as set out in regulations?

**Yes** ☐

**No** ☒

Marie Curie believes that the provision of hospice care, specialist palliative care and NHS Continuing Care should be listed within Schedule 2, as services that must be delegated to integration authorities.

Over 58,000 people die in Scotland every year.

The end of life care phase may last for weeks, months or years depending on someone's terminal illness. Care for those that are terminally ill can be delivered in a variety of health and social care settings including a person's home, acute hospitals, hospices, community hospitals and care homes.

End of life care enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and the provision of psychological, social, spiritual and practical support.

Integrated health and social care will help enable more of those that are terminally ill and at the end of life to receive greater person-centred care in a place of their choosing for as long as they are able.

Hospice care is an integral part of the care for terminally ill people and those that are at the end of life. As well as inpatient services, hospices are increasingly providing more day therapy and out-patient appointments, as well as hospice at home. In-patient stays can often be for short periods to manage pain and other symptoms before being discharged back into the community. It is therefore essential for hospice care to be considered in the strategic plans of integrated authorities and in locality plans, as part of this it will be important for those third sector and independent organisations responsible for running hospices to be involved in strategic planning and commissioning.

Currently, it is not clear within the draft regulations where hospice and palliative care will sit. There is certainly scope under the current proposals for very different arrangements according to each area. The regulations, as drafted currently states "all services already within the scope of CHP arrangements must be delegated to Integrated Authorities", which would mean in some areas hospice and palliative care would be delegated, such as in North and South Lanarkshire, but in others it would not necessarily be delegated, for example in Lothian authorities. However, there is no clear reference to palliative, specialist palliative or hospice care in the list of functions that may or must be delegated to integration authorities.

Specialist palliative care often takes place in the acute setting, but is part of a much wider palliative care package involving hospices, community hospitals, GPs and care at home. The nature of many terminal illnesses is that they follow a trajectory where they alternate between periods of stability and crisis leading to the need for hospital/hospice and specialist palliative care before being returned to a community care setting.

NHS Continuing Care can often be used as step-up or step-down facilities for terminally ill people and can be an important part of the care they receive. It is not clear if NHS Continuing Care comes under the listed care for older people, which is listed as a responsibility that must be delegated. In light of the recent review and traditional link between continuing care and health and social care we believe that this should be delegated to integrated arrangements.

Palliative care is holistic care, many aspects of which fall under the different services listed in the services that NHS Boards must and may delegate to integration authorities. Palliative care often works hand in hand with social care services delivering integrated care packages and support directly in people's homes.

With many of the other elements of end of life care and related issues being listed in schedule 2, such as, unplanned inpatients services, outpatients – accident & emergency, care for the older people, GP out-of-hours and general medical services it would make sense to add specialist palliative care, palliative care, hospice care and NHS Continuing Care to the list.

This would help ensure that those with a terminal illness and at the end of life can receive person-centred care in a setting as close to home as they would like, and that there would be a certain level of consistency in this across Scotland.

These issues and care at the end of life should also be explored in further detail in the guidelines.

3. Are you clear what is meant by the services listed in Schedule 2 (as described in Annex A)?

| | |
|---|---|
| **Yes** | |
| **No** | X |

If not, we would welcome your feedback below to ensure we can provide the best description possible of these services, where they may not be applied consistently in practice.

It is not clear exactly what will be included under each of the services listed in Schedule 2. The list is very open to assumption and we believe clarity to be essential for integration authorities to plan and deliver services.

We hope that the guidelines to follow will offer robust definitions of what is meant under each service heading.

4. Are there any further comments you would like to offer on these draft regulations?

ANNEX 4(D)

**PROPOSALS FOR NATIONAL HEALTH AND WELLBEING OUTCOMES RELATING TO THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014**

**CONSULTATION QUESTIONS**

1. Do you agree with the prescribed National Health and Wellbeing Outcomes?

**Yes** ☐

**No** ☒

If no, please explain why:

Marie Curie largely agrees with the National Health and Wellbeing Outcomes, however, we believe that Outcomes 2 and 3 could be specifically improved. We also believe, along with other third sector organisations that the outcomes could be strengthened with more rights-based language.

Specifically, we believe that outcome 2 should include a reference to those that are terminally ill. Terminally ill people have a very specific set of needs, many different to those currently listed in Outcome 2, but they are also determined to be as independent as possible and cared for at home or as close to home in as homely a setting as possible.

A terminal illness is a disease that will result in the death of the patient regardless of any treatment intervention. This draws a distinct separation between those with long term conditions and multi-morbidities who may continue to live with conditions for many years before or if they become terminal.

Ensuring those that are terminally ill receive the right care should be a high priority for society, the Scottish Government and integrated authorities.

At present, not all those that might benefit from palliative care are accessing it. This is particularly for those with a non-cancer diagnosis, where 80% of those that might benefit from accessing palliative care are not getting it. All those that are accessing palliative care are only getting it towards the very end of their lives typically in the last 2 months. The WHO recommends that people should be receiving palliative care in the last 12 months.

Members of the public, patients and healthcare practitioners have all stated in numerous studies that they struggle to talk about terminal illness, dying and care at the end of life. This can have a distinct impact on the care that people might receive in those final months. By making a direct and important reference to terminal illness in the national outcomes it makes it very difficult for those planning and delivering on health and social care to avoid and not make reference to it. It would be our hope that this would also result in local integration authorities reporting back and measuring success on delivering care for those with terminal illness.

We would like to see Outcome 2 amended to read:

- *People, including those with disabilities, long term conditions, **a terminal illness** or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.*

This reference will ensure that Integration Authorities must give the issue of terminal illness the attention it deserves and will need to show progress on this as part of reporting back on achieving these outcomes. This we believe will help integration authorities tackle some of the barriers and challenges of ensuring that everyone with a terminal illness, regardless of diagnosis, is accessing the care that they need at the time they need it.

Marie Curie also believes that in order to develop a truly person-centred health and social care service personal choice must be at the heart of it. None of the draft national health and wellbeing outcomes currently drafted make a reference to patient choice or participation.

The Scottish Government's Quality Strategy makes a direct reference to improving patient choice through the shared decision-making, which is one of the Government's Quality Ambitions listed in the strategy.

This would also reflect the Patient Rights Act 2011 with the Patient Rights charter introduced in 2012 which encourages patients "to take part in decisions about their health and wellbeing, and provide them with the information and support to do so".

These patient rights along with their general human rights should be encapsulated in the national health and wellbeing outcomes.

To this end we believe that Outcome 3 should be amended to read:

- *People who use health and social care services have positive experiences of those services, and have their **rights, choices** and dignity respected.*

We believe that these changes to the proposed National Health and Wellbeing Outcomes would greatly improve the outcomes of people with terminal illness.

2. Do you agree that they cover the right areas?

**Yes** [X]

**No** [ ]

3. If not, which additional areas do you think should be covered by the Outcomes?

**4.** Do you think that the National Health and Wellbeing Outcomes will be understood by users of services, as well as those planning and delivering them?

| | |
|---|---|
| **Yes** | X |
| **No** | |

5. If not , why not?

| |
|---|
| |

6. Are there any further comments you would like to offer on these draft Regulations?

| |
|---|
| |

ANNEX 5(D)

**PROPOSALS FOR INTERPRETATION OF WHAT IS MEANT BY THE TERMS HEALTH AND SOCIAL CARE PROFESSIONALS RELATING TO THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014**

**CONSULTATION QUESTIONS**

1. Do you agree that the groups listed in section 2 of the draft regulations prescribe what 'health professional' means for the purposes of the Act?

**Yes** ☐

**No** ☒

2. If you answered 'no', please explain why:

We believe that there are potentially professions missing from this list, as they are not obviously health and social care professionals yet can play a key role in health and social care.

For example, chefs at our hospices play an important part in ensuring patients receive the right diet and nutrition. Our chefs also speak regularly with patients regarding feedback on food and preferences, which can impact upon future food and menu choices.

There are also other staffing roles within the hospices and the organisation that might come into contact with patients and carers for a variety of reasons.

If the proposed list of health and social care professions is to provide the basis for plans for workforce development by integration schemes then there is a potential for some professions to be missed out in those plans, which we think would be a mistake.

We would like to see all those employed in health and social care services, regardless of profession and role, be recognised in some way to ensure effective workforce development and improved quality of service delivery and patient experience.

3. Do you agree that identifying Social Workers and Social Service Workers through registration with the Scottish Social Services Commission is the most appropriate way of defining Social Care Professionals, for the purposes of the Act?

**Yes** ☐

☐

**No**

4. If you answered ‘no’, what other methods of identifying professional would you see as appropriate?

| |
|---|
| See above |

5. Are there any further comments you would like to offer on these draft Regulations?

| |
|---|
| |

ANNEX 6(D)

## PRESCRIBED FUNCTIONS CONFERRED ON A LOCAL AUTHORITY OFFICER RELATING TO THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014

## CONSULTATION QUESTIONS

1. Do you believe that the draft Regulations will effectively achieve the policy intention of the Act?

**Yes** ☐

**No** ☐

2. If not, which part of the draft Regulations do you believe may not effectively achieve the policy intention of the Act, and why?

| |
|---|
| |

3. Are there any further comments you would like to offer on these draft Regulations?

| |
|---|
| Please see comments listed in previous sections. |