

Response ID [REDACTED]

Submitted to Review of access to palliative care services - Organisations/Health professionals  
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## Consent

1 The Committee for Health would like your permission to publish your response as part of the survey results. Please indicate your preference.

Consent:  
Publish response.

## Who are you?

2 What is your name?

Name:  
Professor Max Watson

3 What is your email address?

Email:  
[REDACTED]

4 Are you a healthcare professional? If yes, what is your role? If no, what is your interest in palliative care services:

Yes

1500 Characters:

Palliative Medicine Consultant Western Trust  
Director Project ECHO HospiceUK, London  
Adjunct Professor Palliative Medicine, St. John's Medical College, Bangalore, India  
Associate Professor, St. Margaret's Hospice, Taunton, Somerset  
Honorary Consultant, Princess Alice Hospice, Esher, Surrey  
Editor, and author Oxford University Press, (Published 12 books on Palliative Care)  
Instigator of Integrated Care Consultant Training Programme, Western Trust.  
Research in Palliative Care. Over 70 articles  
Previously worked in St. John's Hospice Newry, St Christopher's Hospice London, The Cancer Centre Belfast, and in Northern Ireland Hospice for 14 years.

5 What is your organisation?

Organisation:  
Western Trust, Hospice UK, and ECHO Institute

6 Do you currently work in palliative care services? If Yes, in what capacity?

Yes

1500 characters:

Western Trust Consultant in Palliative Medicine half time  
Hospice UK (UK wide organisation supporting and advocating on behalf of the UK Hospice sector)  
St. Johns, - Virtual teaching to International Fellows across the world twice monthly  
Princess Alice - Supervise the European Certificate of Essential Palliative Care since 2001  
Oxford University Press currently working on 4th Edition of the Oxford Handbook of Palliative Care  
The ECHO Institute, Albuquerque. Director in the UK responsible for rolling out the virtual communities of practice on-line in a range of palliative care and non palliative care clinical and social care settings. Since 2014.

## current state of palliative care services

7 In your view what is the current state of palliative care services in Northern Ireland?

Neither

8 Do you think there is an understanding by the public of what palliative care is? If no, what are the main barriers to the public understanding palliative care?

No

1500 Characters:

This question has been asked repeatedly throughout my very long career and it is disappointing to see that after years of asking it we are no further forward. If you asked each member of the Health committee what Palliative Care is I am sure you would get very different understandings. At the recent Assisted dying debate in Westminster it was clear that many MPs seem to regard Palliative Medicine as handholding with morphine. The reasons for this lack of clarity among the general public, health care professionals and public representatives include;

1. Unwillingness to engage in issues surrounding mortality, death and dying.
2. The multiplicity of services, service providers, training, and approaches all described as "Palliative Care".
3. There is no regional ownership or leadership to define and clarify Palliative Care services in Northern Ireland, rather the determination is left to the umpteen service providers to say what Palliative Care is.

## Access to services

9 Are palliative care services equally accessible to all who need them?

No

10 From your experience where are the gaps in the provision of service?

1500 characters:

The main gap in the provision of services is in regional leadership and accountability from Stormont and Castle Buildings to ensure that Palliative Care services are delivered in a joined up, equitable and easily accessible manner.

The lack of leadership and accountability has prevented the developments that have taken place in Ireland or the UK to happen here. With much Palliative Care in Northern Ireland being funded by cake sales the costs of making a Palliative service which is fully integrated with the NHS has been deemed too expensive. In the absence of MLA engagement we have been left with an ineffectual Palliative Care In Partnership Board lacking the power, resource or accountability to meet the dramatic demographic changes our region is facing. This is not meant as personal criticism. I have been a member of PCIP and share the failure that we are still trying to deliver on objectives that were first highlighted more than a decade ago.

Like England, Scotland, Wales, and the Republic of Ireland we need a Clinical Lead in Palliative Care who reports directly to the Minister and who can be held accountable for the development of the service. It is no longer good enough to say "Sorry we have no resources to do anything."

11 Do you believe barriers exist that prevent equitable access to these services? If yes, please provide examples in the box provided.

Yes

1500 characters:

Palliative Care Services are delivered in a fragmented and non integrated manner.

This fragmentation is due to the different palliative services of the Health Care Trusts, the reliance on the charitable hospices who deliver services in their own unique manner, and because of the inconsistency of service provision there is a failure in the NHS to refer patients to Palliative Care at a time when patients can be most helped.

Trying to access Palliative Care help frequently involves multiple phone calls to answering systems leaving patients and families feeling isolated and unsupported. For a population of 1.8 million this must be regarded as a terrible failure to patients and families. A failure to which we all should be held to account.

The failure of Northern Ireland to have electronic prescribing in place unlike the rest of the UK leaves families travelling across the country with loved ones very ill at home seeking medication that could be made readily available if electronic prescribing was in place. (Current estimate in 2030)

12 What additional services could/should be provided?

1500 Characters:

Primarily we do not need more services we need our existing services to be integrated, consistently funded and coordinated to provide a uniform level of support for patients and families across the region. Consistent funding allows services to be embedded and developed with dedicated staff.

3 suggestions

The establishment of a single regional call centre, with one phone number for all Palliative Care referrals, and requests for Palliative Care help 24/7 365/365, supported by ENCOMPASS, and connecting local services to patients and to health care professionals.

The region should fund the specialist anaesthetic nerve block service currently provided on an adhoc basis by the South Eastern Trust in Dundonald. This highly specialist service which provides spinal and regional nerve blocks under the supervision of both a Palliative Medicine and an Anaesthetic Consultant is invaluable for the very specific patients when pain cannot be managed by medication. Having the expertise of this service available for the whole region prevents patients having to be sent to Liverpool or Glasgow for the crucial intervention but it needs to be funded on a regional basis.

Electronic prescribing

## Integration of Services

13 How well are palliative care services integrated across the health system, through primary, secondary and specialist care?

1500 characters:

Very poorly integrated as mentioned above. Hospital Doctors and GPs are often unsure of when and how to use Palliative Care services and demonstrate this by repeatedly referring the wrong patients, with the wrong needs, at the wrong time to Palliative Care. This is because of the lack of clarity of what Palliative Care services provide and because of the continuing stigma associated with Palliative Care and the difficulties that some clinicians have in bringing up the topic of Palliative Care.

The multiplicity of different services and different referral criteria between different Trusts and different organisations make integration almost impossible in the current organisational heterogeneity.

14 Should palliative care be a regional service? Please outline your reasons in the box provided.

Yes

1500 characters:

We are only a population of 1.8 million yet we have countless organisations delivering different aspects of Palliative Care service in an ad hoc non joined-up way. Trying to do their best in a broken system.

With our small workforce our services are often paused or disrupted when staff are ill or on leave. The failure to fill gaps promptly can help Trusts save money but at the cost of disrupted services for patients. The lack of regional contracts for our senior staff prevents a consistent reliable service being provided. There is need beyond the Sprucefield roundabout and the inequity in recruitment for rural areas of senior clinicians is going to remain without regionalisation and fully embracing the virtual models of care delivery exemplified by Project ECHO.

A regional service with one point of access will also allow for the standardisation of service delivery, audit and quality improvement initiatives and ensure that trainees are exposed to Palliative Care services beyond Belfast.

15 What can be done to improve integration?

1500 characters:

1. All Hospices and Palliative Care services be integrated within the ENCOMPASS system ASAP so we can collectively share the same patient records together. Integration will not be possible without this.
2. The RESPECT form for DNACPR should be introduced across Northern Ireland ASAP as planned. We have multiple DNACPR forms, and a huge amount of work was done with Advance Care Planning preparing for the introduction of RESPECT, but then funding ran out. This work needs to be finished. The failure to deliver on a CMO lead project has sent a really negative message about the importance of Palliative Care.
3. Single point of access for all needing Palliative Care out of hours
4. Commitment to produce a Palliative Care Policy by 2028
5. Creation of a Medical Lead position (part time) to be accountable for the delivery of an equitable, integrated and affordable regional Palliative care service who reports directly to the Minister and the Health Committee.
6. Reintroduction of workforce planning for Palliative Care linking the growing need for services with the demographic changes that are coming
7. Health economist review of Palliative Care funding for Northern Ireland and how total costs can be reduced by full integration.
8. Introduction of electronic prescribing in Northern Ireland as in other parts of the UK would allow medication issues at the end of life to be dealt with promptly and reduce family and patient distress.

## Best Practice

16 Do you have any examples of good practice or pilots in palliative care that are meeting the needs of patients and families/carers? If so, is this best practice happening widely across Northern Ireland?

1500 Characters:

1. Integrated Care Fellowship Consultant Training Programme. This four year programme to train consultants able to work in both community geriatrics and palliative care was designed to meet the needs of the population in the Omagh and Fermanagh area where the over 80s will increase by 40% by 2028. This programme has been supported by Chris Whitty among others and is being considered in other Trust areas in Northern Ireland. By creating a workforce trained locally in both Palliative and Care of the elderly medicine we are safeguarding a medical workforce for the future who can lead the sort of integrated service that we need.
2. Co-Creating Hope. Early phase of this programme to link up the council, the Western Trust, voluntary sector and other community based assets to develop a population based approach to meeting the needs of the frail, elderly and dying across the Fermanagh and Omagh area.

17 Do you think that families receive sufficient support when accessing services? Please outline your reasons in the box provided.

Not sure

1500 Characters:

Sometimes they do sometimes they don't. It is frustrating that we are able to do this so well but consistently it does not happen.

As is the case with so much of Northern Irish Palliative Care services we are able to deliver world class care, but accessing the care is inconsistent.

## Funding and Strategy

18 Do you think the current funding for palliative care is sufficient? Please outline your reasons in the box provided.

Not sure

1500 characters:

With so many organisations involved it is impossible to answer this question with any certainty. In order to answer this question we need to define what Palliative Care service we want to deliver across Northern Ireland, and what services we need to dispense with. It should then be possible to begin to work out what services can be delivered on a regional level and what services need to be delivered locally and begin to assess how much such an integrated service should cost.

We need proper Economic modelling for our services.

19 Is the current model for the funding of hospices, including hospice at home/community care/rapid response support, sustainable and sufficient to meet needs now and in the future? Please outline your reasons in the box provided.

No

1500 characters:

The current funding model for hospices is unsustainable because it prevents long term planning, prevents the stability of workforce development that is needed and means that Hospice services are always under threat especially at times when community fund raising is reduced. The contrast with the Hospices in the Republic of Ireland who receive 100% funding which allows for the development of a fully integrated service is stark.

The decision that Hospices are no longer exempt from National Insurance increases and have needed to find the increased funding of the clinicians pay awards will lead to services reduced. We cannot have such an important part of an integral service subject to the vagaries of the charity sector.

20 Is there a need for a new Palliative Care Strategy for Northern Ireland? If yes, what should it include? If no, why not? Please outline your reasons in the box provided

Yes

1500 characters:

I think we need a new Palliative Care POLICY for Northern Ireland in preference to a strategy. A strategy remains aspirational. A policy brings with it responsibility and accountability.

Included

Regionalisation of Palliative Care services

Integration of services

Workforce planning for the next 20 years

Data collection of services to demonstrate impact

Funding strategy for charitable services delivering Palliative Care

Ease of access

Out of Hours services, clinician, pharmacy

Any other comments

21 Any other comments

1500 characters:

We have looked at these issues over the past twenty years and achieved relatively little of substantive improvement. It is hard not to be cynical and see this process of review as if it were another episode of "Yes Minister". Ultimately our Palliative Care service cannot be left in its broken state as it is a service that more and more families are going to need, including our own.