Regional Palliative Medicine Group Northern Ireland

The Regional Palliative Medicine Group is composed of Palliative Medicine Consultants from across Northern Ireland working to improve Palliative and End of Life services for our communities. We are involved in writing and reviewing regional guidance and policy. We provide multi-disciplinary education and training for undergraduate and postgraduate students. We provide representation to the Clinical Engagement Group within the Palliative Care in Partnership structure. We are also active nationally through our work with the Association for Palliative Medicine in UK and Ireland and the National Clinical Leads Group for Palliative and End of Life Care.

Current state of palliative care services

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

Very Poor

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

There are many barriers that have not changed over many years. The public and indeed professional understanding of what palliative care is, remains very poor.

1) Lack of promotion of public understanding by the Public Health Agency.
2) Inadequate attempts to improve public death literacy by the Public Health Agency.
3) Regional variances in services and providers making a complex system that is difficult to understand.
4) Failure to change legislation to make access to Palliative Care a legal right.
5) Failure of leadership to produce a regional palliative care policy detailing a strategic direction and plan to achieve better understanding.
6) Inadequate funding.
7) Inadequate workforce planning to ensure staff can promote public understanding.
8) Failure to implement regional pieces of work that would improve public understanding e.g. Advance Care Planning, Regional DNACPR.
9) It is such a continual struggle to provide and sustain basic services, that promotion of public understanding is neglected.

Access to services

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

No

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

There are gaps across the system which have never been addressed over many years and have continually got worse.

From leadership to transparent fair commissioning.

From access to GPs and district nurses to access to packages of care and equipment.

From sustaining specialist palliative care services in the community to in-patient units through workforce planning, fair funding, strategic development and implementation of change.

As demand increasingly outstrips capacity there is a growing risk that limiting access e.g. waiting lists, will be the only way to manage the demand.

If Northern Ireland is serious about addressing these gaps, then there needs to be a Regional Palliative Care Policy, recognition of the legal right to Palliative Care, and regional leadership to produce long overdue change.

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

Yes

Generalist Palliative Care-

1) Inadequate resourcing of GPs to provide the necessary level of input. This has been a progressing problem over the last 10 years as GP services become more pressurised and fractured.
2) Inadequate District Nursing provision.
3) Difficulty for patients to access unscheduled secondary care except through emergency department attendance. Failure to provide access to direct admission by GPs to hospital. Some regions have direct assessment units which go some way to close this gap.
4) Challenging access to medications out of hours in the community. This usually necessitates loved ones leaving their dying relative to go to the out of hours GP for a script before then driving miles to find a pharmacy that is open and that hopefully has the medication in stock.
5) Slow access to necessary equipment and packages of care to allow patients to die at home.
6) Services vary across the regional and are not equitably accessible.

Specialist Palliative Care-

1) Inadequate workforce planning making it difficult to sustain services.
2) Inadequate funding for specialist services.
3) Failure to provide a multi-year budget to allow services to plan and develop.
4) Services vary across the region and are not equitably accessible (post code lottery).
5) No current Regional Palliative Care Policy to provide direction and planning to ensure better accessibility.

6) No leadership to identify and plan to mitigate regional variation in services and gaps in provision.
7) No ability to be able to implement regional change.
8) Failure to listen to clinicians and patients who know best where and how services need to be improved.
9) Inadequate use of technology to improve services e.g. electronic prescribing, charitable hospice services have not been included in Encompass!
10) Inadequate availability of regional data that can be used to identify gaps and plan services.

What additional services could/should be provided?

1) Review of primary care resources and responsibilities for providing generalist palliative care.
2) Review of access to unscheduled secondary care for palliative patients e.g. direct assessment units.
3) The Palliative Care in Partnership programme team require sustained statutory funding. However, 1st it urgently needs its structure, membership, authority, accountability and ability to implement change reviewed.
4) The regional service planning, commissioning and decision-making structures require urgent review.
5) Increased clinical regional leadership to co-ordinate and plan services rather than continuing with a disjointed, complex and potentially less efficient approach.

Integration of Services

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

Very poorly.

Generalist palliative care is provided by the health system through primary and secondary care.

Specialist palliative care is provided in our hospitals and is well integrated there, however unfortunately nowhere else.

Charitable hospices, being outside of the NHS, have always been poorly integrated. Commissioning, connectiveness to NHS information systems, access to stores and equipment, workforce planning, service development and co-ordination would be necessary.

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

Yes

Generalist Palliative Care –

Access to palliative care, as in England and Wales, should be a legal right with a regional approach to ensure equity, efficiency and effectiveness.

Leadership to implement key pieces of regional work e.g. electronic prescribing, advance care planning, regional DNACPR.

Specialist Palliative Care –

There should be regional commissioning, service specification, workforce planning, availability and use of transparent data and agreed clinical guidance documents.

Regional clinical leadership implementing an agreed regional palliative care policy.

Perhaps a regional approach is more likely to be able to implement change that has not been possible for the last decade or more.

What can be done to improve integration?

1) Make access to palliative care a legal right as it is in England and Wales.
2) Appropriate resourcing though workforce planning and transparent fair commissioning.
3) Increased clinical leadership.
4) Change the structure of the Palliative care in partnership programme. It struggles to make decisions and has no power to influence or make change. Indeed, it acts as a bottleneck/ gatekeeper to progress.
5) Develop a regional palliative care policy with the appropriate leadership and funding to implement it.

Best Practice

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?

There are many examples of dedicated, compassionate and highly professional staff who are performing despite the lack leadership, resourcing, development or policy.

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

No

Services and care in Northern Ireland is good, the problem is in accessing them. It has become increasingly complicated to access care and support.

Unnecessary hurdles and barriers to access services reflect the disjointed and under resourced nature of services.

Demand is ever increasingly outstripping capacity.

We have ever lengthening waits to see GPs, Consultant outpatient clinics, diagnostics and emergency departments.

Services have become disjointed, overly bureaucratic and unnecessarily complex to navigate, making access by families difficult.

The failure over many years to address the ongoing problems is a significant frustration.

With access to Palliative Care so challenging, Assisted Dying legislation would produce increased likelihood of unintended risk.

Funding and Strategy

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

No

Generalist Palliative care -

Fair funding should be reviewed for GPs. They require appropriate renumeration to resource themselves to be able to provide essential palliative services.

Specialist Palliative care -

The current funding for palliative care is not sufficient, nor transparent or evidenced based.

We look to our colleagues in the Republic of Ireland who recently have agreed 100% funding for specialist palliative care services to ensure their services are fit for purpose. How can Northern Ireland justify not following this example?

A multi-year budget is required to allow services to plan and develop into the future.

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

The vision for the NHS was to provide care from cradle to grave. However, in Northern Ireland we heavily rely on our charitable hospices to provide the

palliative and end of life care rather than the NHS. Necessary care is being funded through bake sales and sponsored walks.

These financial insecurities mean charitable hospices struggle to sustain services, attract a workforce, develop and grow. It also drives unnecessary competition between hospices. It means hospices are unable to develop a multi-year budget preventing meaningful service development. It increases the fractured nature of services across the provinces as a drive to start or develop a service may be more influenced by attracting money than meeting clinical need.

The Republic of Ireland, quite rightly, has chosen to address the funding of their hospices by providing 100% statutory funding.

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

An overarching Palliative Care Policy is vitally important to sustain, develop and plan.

It should include-

1) workforce planning,
2) transparent fair commissioning,
3) mechanisms to access and use regional data to service plan,
4) it should be regional,
5) It should clearly set out a new regional leadership structure that has power to make decisions and affect change. The current structure has neither.
6) It should be clinically lead. There should be clear accountability for implementation of the policy.
7) It must have access to necessary finances to implement and sustain the necessary changes.
8) It should include both generalist and specialist palliative care provision.

Any other comments

In Northern Ireland we have many good people trying to do their very best for patients.

It is a perceived lack of leadership, direction and inability to implement change that has increasingly let down both patients and staff. Thank you for the opportunity to feed into the inquiry and allowing us to share our frustrations, concerns and also suggestions. We would be happy to meet with the committee.