

Terms of Reference

Welsh Managed Clinical Network for Paediatric Palliative Care (WMCN)

Wales Palliative Care Strategy Implementation Board

The Prime focus of the Wales Palliative Care Strategy Implementation Board (now the End of Life Board, EOLB) is to achieve the recommendations outlined within the Palliative Care Planning Group Report (2008) on the basis of the Sugar Report.

To assist this process, the EOLB has been instructed to:

- To advise the Minister for Health and Social Services on the allocation of future funding for hospice and palliative care services throughout Wales.
- To advise the Minister on changing priorities during the implementation process, including those which may mean re-prioritising the short, medium and long term recommendations.

The work of the EOLB is underpinned by the following core principles agreed by the Board and Palliative Care providers across all sectors:

- Good end of life and palliative care should be all available, universally across Wales.
- Fairness of service provision is fundamental to raising the standards of End of Life Care. This needs to be achieved without jeopardising evaluated evidence-based service developments by the leading specialist paediatric palliative care service providers in Wales.
- Close integration of services in an area, whether provided by the NHS or by voluntary sector providers, is essential for high standards in care.

Welsh Managed Clinical Network for Paediatric Palliative Care (WMCN)

The Wales Welsh Managed Clinical Network for Paediatric Palliative Care (WMCN) was originally convened as a result of the Children and Young People's Specialist Services Project in 2008. Following the report of the Palliative Care Planning Group later that year, the network took on a role in children parallel to that of the Palliative Care Implementation Group in adults. Its aim will be to support the work of the Wales Palliative Care Strategy Implementation Board (now called the End of Life Board and here referred to as the EOLB) by leading and facilitating the ongoing implementation, maintenance and evaluation of a comprehensive, integrated and coordinated system of palliative/end-of-life care insofar as it relates to children. WMCN will provide expert knowledge and advice on Children's palliative care provision for the families of children of Wales with life-limiting conditions (LLC) to inform the EOLB processes.

To achieve this, the **Welsh Managed Clinical Network for Paediatric Palliative Care** (or subgroups thereof) will generate and carry out a Work Plan that will promote good practice and encourage innovative solutions in order to:

Establish clinical strategy:

- Ensure there are mechanisms that will enable LHBs in Wales to meet the recommendations of the EOLB in respect of children by establishing effective planning and delivery mechanisms for palliative care services for children that are holistic and child- and family-centred, and can deliver the core elements of a palliative care service to children as defined by national and international guidelines in Children's Palliative Care.
- Advise the EOLB on areas where achieving the recommendations will require further investment.
- Advise on establishing equity (between adults and children, between different regions within Wales and between Wales and other countries) of high quality care delivery to meet the needs of patients and their families / carers.

Establish teaching and research strategy:

- Advise on research and teaching priorities in paediatric palliative care.
- Advise on and support the delivery of education and training priorities and programmes across Wales.

Establish effective communications:

- Establish ways to support primary care and general paediatric services, enhanced by specialist PPC service providers
- Act as the formal conduit between the EOLB and Child Health and/or Palliative Care Executive Leads in LHBs across Wales.
- Agree a communication strategy with the EOLB, and with individual LHBs, local and national user representatives and all relevant third sector partners.
- Lead, through local secondary PPC teams, on increased coordination between all sectors, particularly the statutory NHS and the voluntary sector, in providing care of the dying.
- Advise on future funding opportunities.
- Ensure there is a structure in place that allows the views of all stakeholders to be considered.
- Approve all new service developments, clinical posts and capital expenditure before Health Boards commence recruitment and advise the EOLB of such developments

Monitor effectiveness:

- Agree verifiable standards of children's palliative care on the basis of work by researchers in the paediatric field in Wales and beyond, and where appropriate in conjunction with other standard setting bodies in Wales
- Provide evidence about progress throughout Wales on the EOLB's recommendations in respect of children's palliative care by the means of a regular progress report.
- Recommend mechanisms to ensure that each service implements the relevant evidence-based tools for improving services, such as the Sugar Report, the Children's and Young People's Specialist Services report and the All Wales End of Life Care Plan.

WMCN Membership

- The WMCN will continue to be chaired by the all-Wales Clinical Lead for Paediatric Palliative Medicine of the time, subject to ratification by the WMCN.
- The membership will comprise:
 - Members of the all-Wales tertiary PPC team
 - Medical and Nursing PPC and Transition Leads from each LHB
 - Paediatric oncology outreach nurse specialists
 - Representatives of third sector providers, particularly the children's hospices serving Wales.
 - Representatives from social care and education services.
 - A representative from Together for Short Lives will attend meetings as an observer.
- Other members will be approved by the Chair in discussion with the Group.
- The Chair of the EOLB and EOLB coordinator will receive papers and there will be a standing invitation for them to attend meetings in person.
- Meetings will continue to be held quarterly.
- Members who find themselves unable to attend a meeting can nominate a deputy with the agreement of the Chair. Deputies will be of equivalent status to the member.
- It is important that the Network is able to make decisions and that those decisions have authority, so members are expected to attend a minimum of 75% of Network meetings a year.