Association for Paediatric Palliative Medicine

Newsletter

• volume 1 • Jun 2010 •

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Executive Committee

APPM executive committee and current roles:

Dr Lynda Brook
(Chair)

Dr Mike Miller
(Secretary)

Dr Emma Leon
(Treasurer)

Dr Pat Carragher
(Treasurer)

Dr Susie Lapwood
(training)

Dr Richard Hain
(CSAC chair and training)

Dr Ann Wallace

Dr Anna-Karenia Anderson
(Editor of Newsletter)

Dr Nicky Harris

Dr Sat Jassal

Dr Angela Thompson

Report from our chair

Formation of the Association for Paediatric Palliative Medicine (APPM)

We are pleased to announce that the Association for Paediatric Palliative Medicine (APPM) was formed in November 2009 following a merger of the Children's Hospice UK (CHUK) doctors group and the British Society for Paediatric Palliative Medicine (BSPPM).

The APPM represents doctors working in paediatric palliative care across all care settings in the UK. The APPM therefore represents both paediatricians with an interest in paediatric medicine and other doctors particularly GPs with a specialist interest, many of whom are working in children's hospices.

The aims of the APPM are:

- To promote the practice of paediatric palliative medicine and the development of standards of good practice
- To ensure appropriate standards of education, training and practice of paediatric palliative medicine including through the work of the Royal Colleges of Paediatrics and Child Health, the Royal College of General Practice and other relevant institutions.
- To promote equity of access to appropriate and effective paediatric palliative care services
- To identify priorities for paediatric palliative care research, providing direction and facilitation for research as appropriate
- To promote co-operation and collaboration with other professionals, statutory and voluntary organizations involved in the care of children and young people with life threatening and life limiting conditions and their families
- To maintain formal links and effective communication between relevant medical colleges and other national and international bodies1

The APPM will have a website launched shortly and links will be provided via the RCPCH website (www.RCPCH.ac.uk) and also via ACT (www.ACT.org.uk). Contact details, the terms of reference of the organisation, minutes of meetings and other useful information will be available on the website.

The first Annual General Meeting of the APPM will be held at the International Conference in Paediatric Palliative Care in Cardiff (6th – 8th July 2001: PPC2010@cardiff.ac.uk) at 1pm on 8th July 2010. All members and prospective members are welcome.

Membership and subscriptions

Previous members of both organisations will be contacted shortly with an invitation to join the APPM. Subscriptions at the current time will remain at £25 per year. If you are interested in joining the APPM please complete the enclosed personal details form.

College Specialist Advisory Committee (CSAC)

Training in Paediatric Palliative Medicine will continue to be quality assured and validated by CSAC. The CSAC sits formally under the RCPCH and is affiliated to the APPM. The CSAC is chaired by Dr Richard Hain. More information is available via the college website

Lynda Brook, Chair of APPM

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Revalidation update for doctors working in Paediatric Palliative Medicine

As doctors we are gearing up to the reality of revalidation, looming ever closer. There are still many unanswered questions, little is definite, and things are likely to change quite rapidly as the national processes continue to develop and begin to be piloted. But here are some developments regarding the current state of play. What follows relates primarily to revalidation rather than to appraisal.

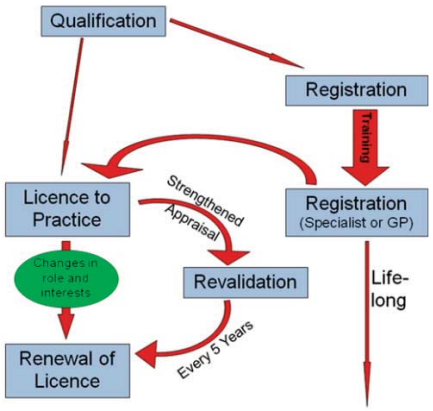
If you are a doctor working in paediatric palliative medicine, read on...

1. Role: for those of us who have diversified or changed our roles since initially qualifying as a GP or consultant, the very good news is that the currently proposed (but not yet agreed) model has our certification (as GP or consultant) as lifelong, and revalidation will just be about renewing our licence to practice as a doctor, based on continuing evaluation of our practice in the context of our everyday working environment(s). This is a shift from what was initially proposed, which was a 2 step process involving recertification as a specialist or generalist in addition to the basic relicensing as a doctor: that wouldn't easily have allowed for people developing unusual roles. (See diagram)

If you have several professional roles and employers, you would normally be revalidated through your main role and main employer, (but taking account of supporting information from all our roles), but see below re aiming for revalidation through NHS systems where possible.

2. Work setting: each employing organisation will need to ensure each of their doctors has a Responsible Officer (RO) who will make the final recommendation to the GMC about our revalidation. Very little seems to be decided about this as yet : the scope of the role, who might be eligible to be a Responsible Officer, how they will be resourced, and who those working mainly in non NHS settings would relate to. This is relevant for those of us who work mainly in charitable hospices: our Responsible Officer could theoretically be a PCO responsible officer, a hospital trust RO, an RO for the subspecialty, or an 'independent doctors' RO. All these might be possibilities, but I would argue strongly (and this is supported by the NHS Revalidation support team in my discussions with them) that it is worth building on our NHS links and pushing for NHS revalidation where possible (through PCT or hospital trusts) rather than setting up parallel systems for doctors in unusual fields or settings. If you are a GP by background, it is worth doing your best to stay on your local PCT 'Performers' List'.

Since revalidation may be a reality for some of us from 2011, the 2010-11 year (ie now!) is the first that will count 'for real' in terms of collecting our supporting information for annual appraisals. Although the precise requirements are still changing, we should use every opportunity both to engage in and to log (ideally electronically)



our involvement in significant event analysis, professional updating, audit, teaching, colleague feedback, patient / user feedback etc. As much as possible should be personalised and mapped to the new GMC 'domains and attributes'. Appraisal will be strengthened to support the new processes, and there are currently 10 Pathfinder Revalidation Pilot sites across the UK. One of my concerns is to ensure that appraisal remains as supportive and developmental as possible despite the increased emphasis on assessing supporting information.

My impression is that at local and regional level people are just beginning to think about the needs of doctors in atypical roles and settings, and seem to be welcoming input and ideas. You may find it a good time to engage positively with your local leads for appraisal and revalidation in order to influence how local procedures develop. I hope people also took the opportunity to respond to the GMC consultation on the proposals for Revalidation (consultation period closes 4 June). I have responded to the consultation on behalf of APPM, and we will continue to take these issues forwards to inform the development of processes where we have opportunity. Please let me know if there are points you would like us to raise, or services we should develop to support the revalidation of our members.

Susie Lapwood
Helen and Douglas House Hospices.
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Questions to consider and take action where appropriate:

- What is my main medical role?
- Who is my main employer?
- How will I (and my organisation) collect and personalise supporting information from all my work settings / roles to inform appraisal/ revalidation, and map it to the new GMC 'domains and attributes'.
- How will I document personal reflection and impact for any learning I undertake?
- How will I engage with local leads to inform development of appropriate systems locally?

Please keep me posted about any queries or concerns. Accompanying this is some relevant links to help us follow processes and requirements as they evolve.

GMC revalidation information : http://www.gmc-uk.org/doctors/licensing/revalidation.asp
GMC consultation (closes 4.6.10): Revalidation: The Way Ahead. GMC (March 2010) http://www.gmc-uk.org/static/documents/content/A4%20Consultation%20Doc_web_v2.pdf
RCGP Revalidation guide for GPs v 3 (Jan 2010): http://www.rcgp.org.uk/PDF/PDS_Guide_to_Revalidation_for_GPs.pdf

Development of the Children's Palliative Care Master Formulary (Q-Formulary)

Background

Paediatric palliative care is relatively new specialty worldwide. For example in the UK there are currently seven consultants in Paediatric Palliative Medicine and around 40 children's hospices.

Paediatric Palliative Medicine is characterised by use of medicines that are frequently off licence or off label due to

- Administration for conditions other than those listed in the product licence
- Administration at different doses to those listed in the product licence
- Administration via different routes to those listed in the product licence

There is a high risk of drug interactions and adverse effects due to

- Poly-pharmacy
- Use in a critically ill population with multiple pathologies

Scope for high quality pharmacological studies is limited because

- Most medicines used are not new drugs or new formulations
- The population is heterogeneous with a heterogeneous group of pathologies
- There are small numbers of patients
- Of ethical and practical issues in studies in palliative care

Most indications and doses of medicines used in paediatric palliative medicine are derived from anecdotal evidence and often involve scaled down adult doses.

Over the last 10 – 15 years, an increasing number of paediatric palliative care formularies have been published often with subtle differences in detail particularly regarding dose recommendations. This has led to increasing concern that advice given may be contradictory or confusing, particularly for those involved in care of the dying, but who do not practice paediatric palliative medicine on a regular basis.

Practical implications

There is an urgent need to

- Develop a process to achieve consensus on indications, route and dose recommendations based on available evidence and where this is insufficient expert opinion
- Standardise indications, routes and dose recommendations for use of medicines in paediatric palliative medicine
- Develop a system for routinely collecting and collating information on
- New and novel doses, routes and indications for medicines in paediatric palliative medicine
- Adverse drug reactions and interactions

Proposed solution

The Association for Paediatric Palliative Medicine, representing doctors with an interest in Paediatric Palliative Medicine in the UK, has recognised the need to develop a single master "Q" formulary for Paediatric Palliative Medicine. The aim is to produce a single standardised reference formulary from which all other formularies including the palliative care section of the British National Formulary for Children (BNFC) will be derived.

The "Q" Formulary for Paediatric Palliative Medicine will provide information on indications, routes and standardised doses for paediatric palliative medicine based on systematic literature review and appraisal of available research evidence together with expert consensus opinion where there is insufficient research evidence.

In order to do this the Q Formulary Group will

- Undertake an annual literature review for each drug in the formulary
- Prospectively collect information on novel uses routes, doses and adverse drug reactions using system similar to yellow card or RCPCH surveillance scheme
- Survey contentious areas
- Present clearly options where there is no current consensus or where different doses are recommended for different situations

The Q-Formulary Group comprises:

- Dr S Jassal, Medical Director Rainbows Children's Hospice, Loughborough
- Dr L Brook, Consultant in Paediatric Palliative Medicine, Alder Hey Children's Hospital
- Dr R Hain, Consultant in Paediatric Palliative Medicine, Cardiff
- Dr S Lapwood, Medical Director Helen House Children's Hospice, Oxford
- Dr F Craig, Consultant in Paediatric Palliative Medicine, Great Ormond Street Hospital, London
- Dr V Lidstone, Consultant in Palliative Medicine Velindre Hospital, Cardiff.
- Pharmacist to be appointed

The Q-Formulary will be based on the formats used within the British National Formulary. The foundation for the first version of the Q-Formulary will be based on the most recent formulary produced by Dr Richard Hain and Dr Sat Jassal for the Oxford Handbook of Paediatric Palliative Medicine which has in turn adopted indications, routes and dose recommendations from the BNFC unless research evidence or expert consensus suggested otherwise.

The process of developing the Q-Formulary has already begun. It is anticipated that the draft will be ready by July and final formulary would be submitted to the APPM by the end of 2010. Once this initial work has been done then the authors of the other related formularies for paediatric palliative medicine:

- The Oxford Textbook of Paediatric Palliative Care
- Rainbows Children's Hospice Symptom Control Manual
- The Oxford Handbook of Palliative Medicine in the Paediatric chapter
- Paediatric Palliative Care Guidelines. Second edition 2006, SW. London Surrey West Sussex and Hampshire and Sussex cancer networks
- Alder Hey Hospital local guidelines
- have agreed to update their pieces of work to be in line with the Q-Formulary.
- Publication of the Q-Forumulary
- The Q-formulary will be available to download online with links from key related websites
- The aim is also to set up a bulletin board function
- The Q-formulary will be published as part of standard textbooks as above
- The Q-formulary will also be published as part of the Palliative Care Formulary (Twycross)

We are asking the BNFC team to be prepared to adopt the Q-Formulary recommendations for Paediatric Palliative Medicine. It is not anticipated that the BNFC will necessarily adopt all medicines listed in the Q Formulary.

What this means for the wider national & international paediatric palliative care community

We are seeking to publicise the work on the Q-Formulary as widely as possible. We would like to know

- The potential relevance of the Q-Formulary to international children's palliative care
- Whether you would consider adopting
- Whether any similar work is ongoing elsewhere

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Dr Lynda Brook
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April 2010

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Current executive

The APPM executive currently comprises the following members

Dr Emma Leon – GP and Medical Director, Francis House, Manchester

Pat Carragher – GP and Medical Director, Children's Hospices Scotland (CHAS)

Susie Lapwood – GP and lead Doctor, Helen and Douglas House, Oxford

Richard Hain – Consultant in Paediatric Palliative Medicine, Cardiff

Ann Wallace – Community Paediatrician with an interest in Paediatric Palliative Medicine, Wessex

Lynda Brook – Consultant in Paediatric Palliative Medicine, Liverpool

Mike Miller – Consultant in Paediatric Medicine, Leeds and Martin House Hospice

AK Anderson – Consultant in Paediatric Palliative Medicine, the Marsden, London

Nicky Harris - Medical Director and Associate Specialist, Children's Hospice Southwest

Sat Jassal – GP and Medical Director, Rainbows Hospice, Loughborough

Angela Thompson –Associate Specialist in Community Paediatrics and Paediatric Palliative Medicine, Coventry and Warwickshire

Activities of APPM

The APPM has a number of proposed priority areas for the next few years.

1. Organising regular educational and scienttific meetings
See below for announcement

2. Support for appraisal and revalidation particularly for doctors working in paediatric palliative medicine outside the NHS.
Development of standards for education and training in paediatric palliative medicine for those not eligible for CCST via RCPCH.

3. Development of a master Q-Formulary for Paediatric Palliative Medicine.

Any thoughts on what you would like to see in your newsletter? All ideas, contributions and feedback welcome. Email: annakarenia.anderson@nhs.net. Thanks, ed.

STOP PRESS: APPM First Educational Study Day

The APPM is pleased to announce they will be hosting their 1st Paediatric Palliative Medicine APPM Educational meeting on the 12th November 2010 at BMA House in London. This will be an educational day with lectures from leading experts and working clinicians in their specialist fields on a range of clinically relevant topics for any medical professional (and senior nurse) wanting to update or gain knowledge in the area of paediatric palliative medicine. Our keynote speaker, Myra Bluebond-Langner will share her work about talking to dying children.

Other topics will include:

- Clinical ethics relating to best interests.
- Pain management: 'the basics', recent advances and chronic pain and sleep disorders.
- Neonatal palliative care.
- Other symptom management including seizures and gastrointestinal failure
- Emergency care planning and developing palliative care services

Scientific, educational and other relevant events for professionals working in Paediatric Palliative Medicine.

2010/2011 dates

March
ACT annual conference Birmingham
16th March 2011

April
RCPCH annual meeting Warwick April 2011
EAPC Lisbon 19th-21st May 2011
EAPC Research conference Glasgow
10th – 12th June 2010

July
International Cardiff Paediatric Palliative Care Conference Cardiff
'Face to Face with Interface'
7–9th July 2010

October
APPM Educational meeting London
12th Nov 2010

CHUK Hospice doctors and heads of care meeting 2011 (TBA)

RCPCH=Royal college of Paediatric and Child Health
APM= Association of Palliative Medicine
EAPC=European Association of Palliative Care
CHUK=Childrens' Hospices UK

Executive Committee (vacancies)

There will be three vacancies on the Executive committee from July 2010 one of whom should be a Paediatrician with an interest in paediatric palliative medicine. Nominations and self nominations are very welcome. Please email *Lynda.BrooK@alderhey.nhs.uk* before 5th July 2010. The new executive will be determined at the first Annual General Meeting (AGM) in early July.