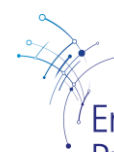




Summary of
Proceedings from the
Launch Symposium,
Discussion, and Proposed
Action Plan for the
England Centre for
Practice Development's

*International Community
of Practice for End of Life
Care*

Held at The Spitfire
Cricket Ground,
Canterbury,
7th October 2016.



England Centre for
Practice Development

Dr Stephen J. O'Connor

Version 1, December 2016.

INTRODUCTION...

- This report is an invitation to members, participants and stakeholders to participate in developing the aims, objectives and preliminary action plan of the England Centre for Practice Development's International Community of Practice for End of Life Care (ICoP).
- It provides a summary of proceedings from the international launch event held at The Spitfire Cricket Ground in Canterbury on Friday 7th October 2016 (Appendix 1).
- The launch event was attended by 85 academics, researchers, clinicians, practitioners, policy makers and service users from a diverse range of professional and organisational backgrounds (Appendix 2).
- The day began with participants sharing their hopes, fears and expectations for the future work of the community of practice.
- This was followed by presentations from invited speakers to demonstrate the challenges and gaps in current knowledge, policy and practice in the field of end of life care internationally; and provide context for subsequent discussion about the work of the ICOP (Appendix 3).
- In the afternoon, Professor Kim Manley CBE and Carrie Jackson, Director of the England Centre for Practice Development (ECPD) conducted a values clarification exercise and practice development workshop to start generating a shared sense of purpose for the ICoP as well as informing the development of a preliminary action plan to enable the ideas which were forthcoming to be progressed over an 18-month period.
- The resulting summary and framework presented below have been distilled from the comments collected (see colophon for examples) and are in draft format for consultation and review by participants and other stakeholders before disseminating for wider critique without the appendices.

WE WILL ACHIEVE THIS VISION THROUGH...

- Building foundations for action through a shared vision, transparent goals and a mutually agreed action plan that is delivered on.
- Connecting and learning from each other to promote good communication, partnership working and build collaborative networks for inquiry and action across disciplines for the benefit of patients, families, carers and practitioners.
- Drawing on ambassadors, strong leadership and role-modelling to challenge and revolutionise end-of-life policy and practice through sharing stories of impact in EoLC.
- Arranging focused events to promote exchange of ideas and sharing best practice to inspire, enable and educate others about the contribution, role and impact of EoLC research, innovation, education and practice development through conferences, webinars and workshops/symposia.
- Sharing best practice through social and other communication media.
- Providing access to learning resources, publications, reports, toolkits and creative materials to inform best practice in EoLC.

'The purpose of the ICoP is to transform and improve end of life care experiences for patients, families, and those who care for them through shared research, practice development and policy initiatives which are person and family centred, collaborative and mutually beneficial.

The aim is to help empower those who are dying, their families, and the staff who care for them to experience care which is effective, safe, dignified and above all; respectful of the expressed preferences of the dying person and those who matter to them'.

'The unique selling point or 'USP' of the ICoP is the commitment of its members who value the importance of kindness and compassion, and promote dignity and choice in order to facilitate good deaths'.

'They are also not afraid to challenge reified customs, policies or practices when necessary; and work together to co-create, gather, share and spread evidence from practice at scale to improve end of life care for all vulnerable groups'.

WHAT OUR COOPERATION WILL LOOK LIKE...

- Clear communication to enable us to articulate our collective values and beliefs
- Commitment to use and share online discussion fora, social media, blogs, Skype and Twitter to build a genuine community of practice.
- Promotion of attendance and participation in local, national and international conferences and symposia, workshops and meetings with each other to build consensus and promote action.
- Inspiring each other through mentorship and an Associate Fellow's network for students, service users, health and social care professionals.
- Development of Clinical Academic Fellows working between practice settings and academia to promote knowledge creation, growth and transfer to new settings.
- A deliberate effort to create inclusive, collaborative and innovative services which reach vulnerable and often disconnected groups and those for whom care and the availability of end of life services are less than optimum.
- The creation of sustainable partnerships capable of transforming practice through shared development goals and activities to promote the generation of practice based evidence and collaborative activities related to research, publication, policy development, reach and impact.
- Scaling up what we achieve individually through the development and dissemination of collegiate case studies demonstrating impact and sharing best practice.

AGREED PRIORITIES LOOKING AHEAD...

- Develop a clear purpose and action plan of priorities for the next 12 months.
- Clearly articulate the philosophy of the ICoP EoLC network linked to hashtag.
- Undertake a scoping exercise and publish a position paper to identify international challenges in research, policy and practice in EoLC currently and how this needs to be addressed.
- Share and disseminate impact stories, evaluation tools, best practice guidelines, toolkits, publications and reports, creative work and collaborative learning through the ICoP as a conduit for best practice.
- Develop a research priority action plan and target appropriate funding.
- Develop a strategy for involving creative practitioners and methods in the development of research and innovation.
- Develop a series of online blogs to share current gaps, challenges and best practice in EoLC with contributions from patients, families and practitioners.
- Identify how we can better work with patients and their families to identify what their end of life needs/concerns are.
- Identify opportunities to promote shared learning through workshops, conferences, symposia and other /events, e.g. newsletters etc. (Appendix 4).

'A multi-disciplinary collaboration and professional forum (both face to face and online) that builds relationships, and helps us learn from each other'.

'A constellation of local stakeholder groups working together with expert international input so as not to reinvent the wheel'.

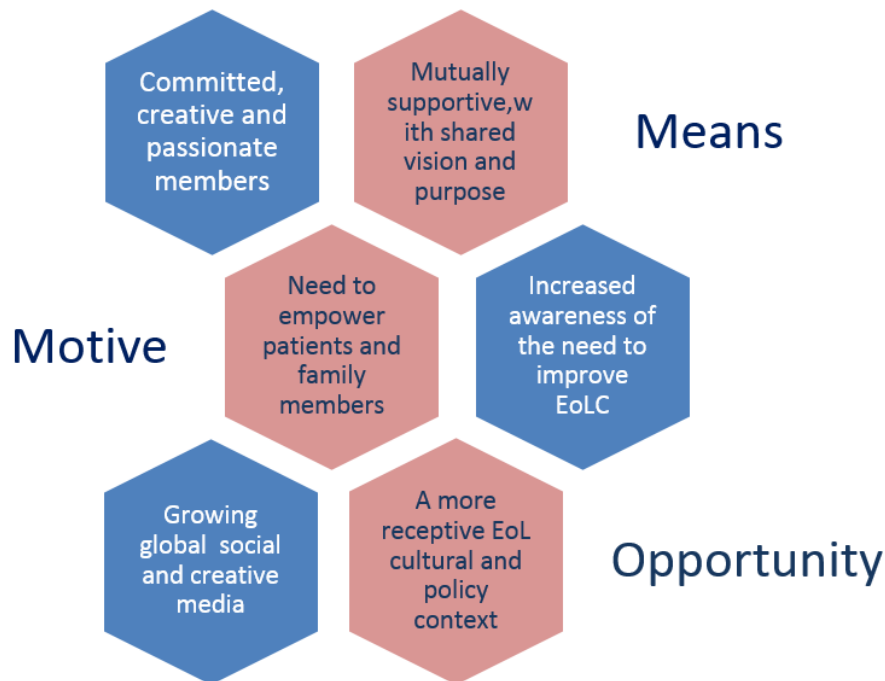
'Educating ourselves and others by sharing and learning from each other, breaking down social, cultural and professional barriers, and taking on board the experience of everyone'.

'Sharing expertise and experience with regular contact which is open, accessible and universal through conferences, annual symposia and use of social media'.

'We need to clarify our values and identify what the common end of life issues are, especially for vulnerable groups'.

'We need to partner and mentor each other to develop research and practice development projects which deliver seamless, person centred end of life care and gather that evidence to make that knowledge and experience available to others'.

ENABLERS...



'Having a clear strategy which includes a shared purpose, an explicit and unique selling point, a clear action plan with achievable goals, and a multi-disciplinary forum (both face to face and online) that builds relationships, and helps us learn from each other'.

'Access to international experts, policy makers and thought leaders- including meaningful involvement with patient and carer groups, fora and networks'.

'Connection to social media leaders in EoLC such as WeHospices, WeEoLC, WeNurses etc.'

'The co-creation of best evidence guidelines for person centred end of life care for use in all care settings, including those where death and dying are currently marginalised'.

'Anecdotal evidence that practitioners are more prepared to talk about death and dying with their patients, clients, and their families, and acting upon their wishes'.

'Evidence that policy makers and media organisations are taking up the work of the ICoP as part of the broader dialogue about EoLC.'

KEY INDICATORS OF SUCCESS...

- Influencing practice, shaping ideas and changing mind-sets through research and practice development initiatives, publications, reports, impact stories, conferences, events and workshops.
- Evidence of impact on the experience of patients, service users and their families.
- Recognition and endorsement by public, government and professional bodies nationally and internationally.
- Evidence that others are responding to the work of the ICoP through a wide range of media.
- Evidence of successful bids for funding and the initiation of collaborative projects.
- Positive feedback and people talking about the ICoP EoLC.
- Evidence of recognition by, and influence on, research bodies, educational curricula, social policy and thought leaders through, for example, research uptake, citation, publication, media coverage etc.

INHIBITORS...

- Inadequate time, resources and scope for secondments/joint appointments.
- Changing policy landscape and the fragmentation of services with regard to commissioning of care services.
- Reductions in professional education and training budgets.

STAKEHOLDERS REGARDED AS CRUCIAL TO THE PROJECT...

- Service user and advocacy groups (e.g. *Patient Opinion, National Voices, Involve, National Cancer Patient Collaborative, Dementia UK* etc.)
- Family service and advocacy groups (e.g. *Carers UK, National Carer Forum, Family Carers* etc.)
- Health and social care practitioners.
- Multi-disciplinary providers of healthcare (GPs, social care, community trusts, hospices, acute hospitals, corporate private businesses, residential and nursing home care providers etc.)
- Clinical Commissioning Groups, health insurance agencies, private industry.
- Higher and further education providers (Universities, Further and Technical Education Colleges, Schools, *Skills for Care* etc.)
- Policy makers both national (e.g. NHS England, Public Health England, Department of Health) and international (WHO, EU, EAPCC etc.)
- Charities and the voluntary sector.
- Research funding bodies.
- Professional regulatory bodies.
- Researchers working in EoLC – including those from non-medical fields (sociology, psychology, psychology, creative arts, media and sport etc.)
- Media (Newspapers, journalists, broadcasters, radio).
- Social Media platforms for EoLC.

EVALUATION OF THE LAUNCH EVENT

- The Launch event was evaluated by all the participants using two different strategies.
- The first was through inviting participants to co-construct Haiku's to capture their experiences and take home messages from the day. These can be seen in the colophon alongside this section and top of the page which follows.
- The second was to complete an online evaluation after the event using Bristol Online Surveys, although only 12 of the 63 people attending the event completed this in spite of several reminders.
- Statistical inferences have not been drawn from this data therefore, although some of the qualitative feedback is also contained in the colophon alongside and below this section.
- The only negative comments from the survey related to the lack of mention of the contribution which the arts can make to end of life care (although the ECPD is already involved separately in the delivery of art workshops in this area), the lack of time in a very busy schedule for informal dialogue and networking with other attendees, and mention that *Living Well Dying Well* provides good multi-professional training resources although not designed to empower carers to investigate questions of concern to them in the workplace.

'All members of the health and social care team, patients and their families'.

'The person first, the family second, the carers third, and everyone and anyone else thereafter'.

'All members of the healthcare professions and direct providers of social care'.

'The ability to deliver good deaths to all of its citizens is a sign of the cultural adequacy of any culture or society'.

'Death is the only medical condition which is going to affect all of us. As a consequence, we should all have a vested interest in getting it right!'

'Sharing compassion, Inspired global challenge - WOW!, Humbly loving life'.

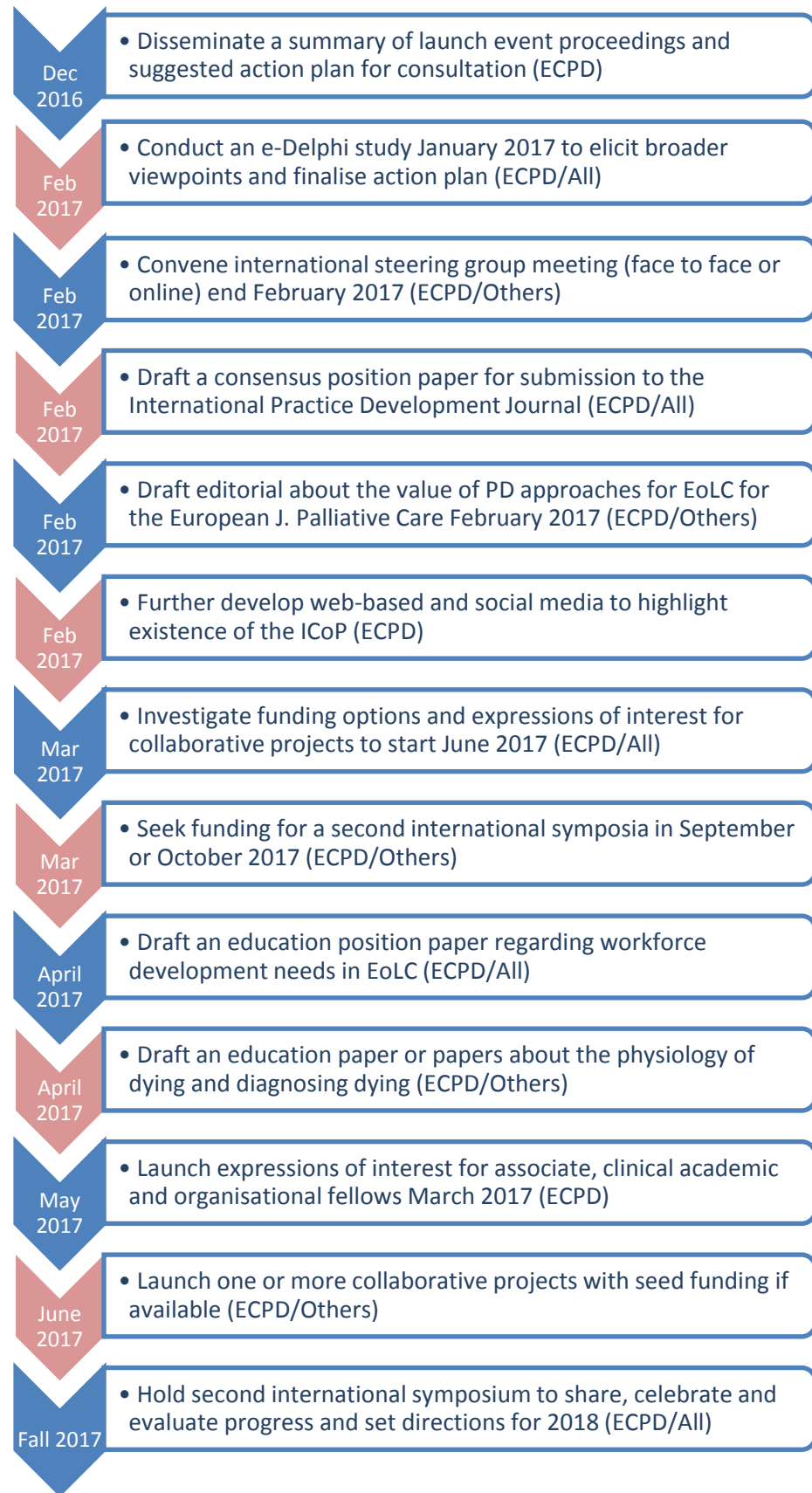
'Learn, tea, talk and share, Focused, person-centred care, Humbling, impact, LIFE!'

'Inspiring speakers, Sharing lemon tart, Coulis, Fun, friendly people'.

'Collaborating, Perplexing reality, Inspirational'.

'Daunting exciting, real feeling refreshing, Inspirational'.

SUGGESTED ACTION PLAN 2016/17



‘Daunting, informal, Real, exciting thought changing, Inspirational’.

‘Honest emotions, Necessary but too much? Educational’.

‘Disabilities, Not knowing when life is up, Happens to everyone’.

‘The whole day gave me greater insight into end of life care, and I have passed what knowledge I acquired to the rest of the team’.

‘I feel that the whole day made me reflect on my practice’.

‘The most useful parts of the day were in the afternoon when I got to meet peers and share ideas and experiences. I realised the wealth and diversity of experience we had’.

‘It was interesting to see the differences [in EoLC] in other parts of the world’.

‘The whole day was very interesting and raised awareness of difficulties in a variety of cultures and settings’.

‘After Friday I felt very empowered in end of life care, and further workshops would build on this’.

‘I enjoyed Professor Davina Porock’s work highlighting the lack of education and training within nursing and medical education’.

APPENDIX 1: SYMPOSIUM PROGRAMME

| Time | Session Title | Speaker/Facilitator |
|-------|---|---|
| 08.30 | Registration (<i>The Harris Room</i>) | |
| 09.20 | Official welcome: Hopes, fears and expectations exercise | Carrie Jackson |
| 09.40 | Horizon scanning and boundary crossing in end of life care | Professor Philip Larkin |
| 10.00 | Death in the elderly: a US perspective | Professor Davina Porock |
| 10.20 | Developing end of life care in India | Professor Devakirubai Jebaseelan |
| 10.40 | Refreshment and comfort break (<i>The Harris Room</i>) | |
| 11.00 | Negotiating end of life outcomes in children and young adults with cystic fibrosis | Professor Hephzibah Samuel |
| 11.20 | End of life care in learning disability: the 4 C's Reasonable Adjustments Framework | Tracey Rose and Daniel Marsden |
| 11.40 | Pressure ulcer prevention programme for palliative community patients: an innovation project | Nicola le Prevost and Debra Boots |
| 12.00 | Collaborative development of an open access, online advance care planning educational programme | Mary Kirk |
| 13.00 | Lunch (<i>The Cornwallis Room</i>) | |
| 13.20 | Recognising dying in the curriculum | Professor Davina Porock |
| 13.50 | Panel discussion: where are the gaps in end of life care? | Dr Stephen O'Connor |
| 14.20 | What is practice development and what can it offer? | Professor Kim Manley |
| 15.00 | Values clarification exercise and shared purpose for the ICOP | Professor Kim Manley and Carrie Jackson |
| 15.30 | Refreshment and comfort break (<i>The Harris Room</i>) | |
| 16.00 | Developing a shared ICOP purpose and action plan | Carrie Jackson |
| 16.10 | Future directions and final discussion | Dr Stephen O'Connor |
| 16.30 | Close of meeting | |



#EOLC4ALL

@EC4PD

@EcpdCarolyn

@Kimmanley8

@Soconn62

@ECPD6

@ECPD7

@TraceyPockett

@dmarsden49



*International
Community of Practice
for End of Life Care*

<https://www.facebook.com/groups/847962498650164/>

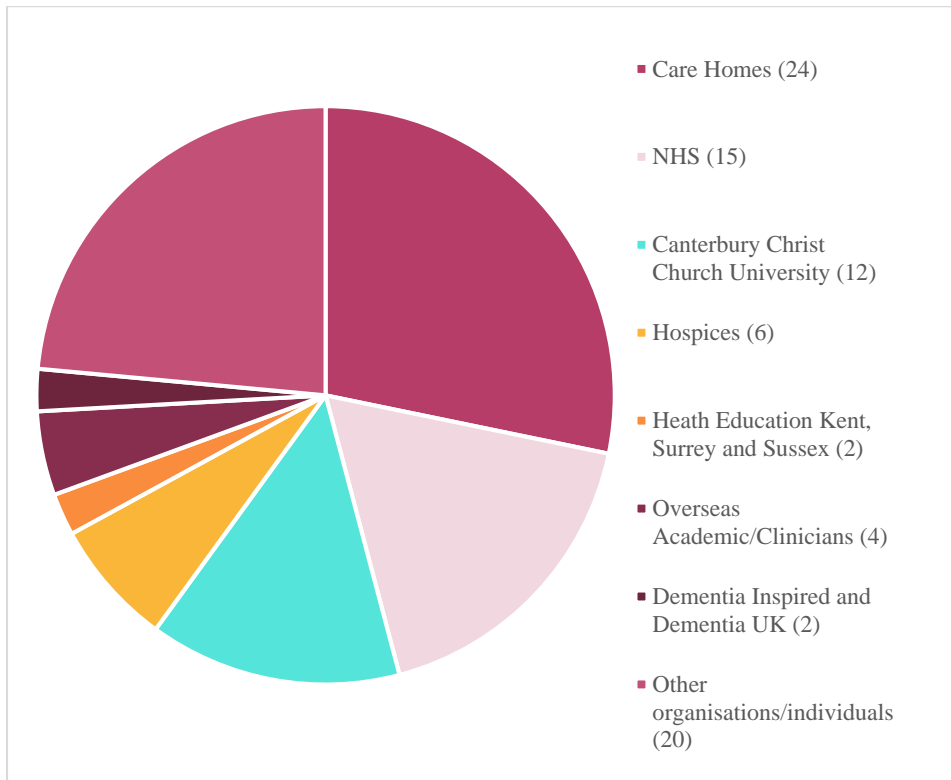
*England Centre for
Practice Development*

<https://www.facebook.com/groups/ecpd1/>

*International Fellows of
the England Centre for
Practice Development*

<https://www.facebook.com/groups/308585532836101/>

APPENDIX 2: ATTENDEES BY ORGANISATION/SECTOR (N=85)



APPENDIX 3: KEYNOTE SPEAKERS

Carolyn Jackson: Director of the England Centre for Practice Development, Canterbury Christ Church University.

Professor Philip Larkin: President of the European Association of Palliative Care and Chair of the All-Ireland Institute of Hospice and Palliative Care; Professor of Palliative Nursing University College Dublin and Our Lady's Hospice Dublin.

Professor Davina Porock: Vice Provost and Professor of End of Life Care, Lehman College, New York, USA.

Professor Kim Manley CBE: Professor of Practice Development, Research, and Innovation; Co-Director of the England Centre for Practice Development, Canterbury Christ Church University.

Professor Devakirubai Jebaseelan: Professor of Nursing at The Sacred Heart Nursing College, Madurai, India.

Hephzibah Samuel: Senior Lecturer, Paediatric Nursing, Faculty of Health, Social Care and Education, Anglia Ruskin University.

Mary Kirk: Consultant Nurse (Palliative Care), Kent Community Health Foundation Trust.

Tracey Rose: Community Learning Disabilities Nurse at Kent Community Health Foundation Trust.

Daniel Marsden: Practice Development Nurse for People with learning disabilities at East Kent Hospitals University NHS Foundation Trust.

Dr Stephen O'Connor: Reader in Cancer, Palliative and end of Life Care, ECPD.



England Centre for Practice Development

Successful launch of the International Community of Practice in End of Life Care Research and Innovation



Over 80 delegates from the USA, India, Germany, the Republic of Ireland, and the four home countries of the UK attended the launch symposium of the International Community of Practice for End of Life Care at Kent County Cricket Ground on the 7 October 2016. The symposium was opened by Professor Philip Larkin (Eire), President of the European Association of Palliative Care (EAPC), who reminded delegates that the way in which a society cares for its dying members is a sign of its cultural adequacy, and that poor end of life care impoverishes the spirit not only of those who are dying, but those who care for them too. His session was followed by Professor Davina Porock (USA) who provided analysis of end of life care provision in different states across the

USA and the paucity of end of life policy commitments by all of the main political parties engaged in the current US election. She also demonstrated how referrals for end of life care are significantly lower in 'for profit' medical systems than others and discussed the ethical imperative to put the needs of dying patients before profit. Professor Devakirubai Jebaseelan (India) provided delegates with an update on the development of palliative care in India which is currently ranked below Uganda in international comparisons: in spite of its greater size and wealth; and of the need to progress the proposed end of life care strategy more quickly through the Indian Parliament where it has been subject to endless delays. She reminded participants that compassion in policy making was as

important as that delivered at the patient's bedside, a theme which was taken up by the next speaker, Hephzibah Samuel who, using the death of a young person with cystic fibrosis as an example, reminded everyone of the need to extend end of life research and care provision for children and young adults dying of non-malignant conditions.

The event enabled local clinicians engaged in practice development projects to share their innovations including Pilgrims' Hospices award winning project on the early detection and prevention of pressure ulcers in patients cared for at home; another outlining the development of the four C's Reasonable Adjustment Framework for End of Life Care in Learning Disability at East Kent University Hospitals Foundation Trust; and the collaborative development of an open access, online learning programme on advance care planning developed by Canterbury Christ Church University, Kent Community Health Foundation Trust and local hospices (see <https://www.canterbury.ac.uk/health-and-wellbeing/advance-care-planning/home.aspx> to access the modules). A thought provoking talk by Professor Porock on the lack of end of life care content in undergraduate curricula for health and social care professionals was followed by activities facilitated by Professor Kim Manley CBE and Carrie Jackson to develop a shared purpose framework and action plan for the International Community of Practice. The initiative is being led by Dr Stephen J. O'Connor, Reader in Cancer, Palliative and End of Life Care at the University. The event was widely covered through social media making over 1.5 million impressions on the day of the launch (Twitter #EOLC4ALL).

Speakers from the event pose for pictures during a break in proceedings



SAVE THE DATE!



**20-21 July 2017 International Health Innovation Summit
Augustine House, Canterbury Christ Church University.**