There is potentially something to be gained for everyone by increasing palliative care research collaboration. In a recent editorial in BMJ Palliative and Supportive Care (1), Irene Higginson reviews current challenges for palliative care research, both in terms of the UK’s research agenda responsiveness to national policy and through key messages to funding agencies to ensure that research effectively translates into better patient and family care at end-of-life. A specific call for greater collaboration (both nationally and internationally) is made. She is not the first. An editorial by Stein Kaasa in 2008 at the advent of the European Palliative Care Research Collaborative (EPCRC) called for ‘an international arena for palliative care research’ (2). Has this been achieved? Particularly at this time of confusion for the UK in light of the recent referendum decision to leave the European Union and the vacuum that leaves in terms of a clear understanding of its implications for future research partnership, it is critical to understand how robust international collaboration can be achieved and what practical steps are needed to foster success.

There are some good examples of where an international collaborative approach leads to a stronger evidence-base and better patient outcomes. The International Palliative Care Family Carer Research Collaboration (IPCFRC) led by the Centre for Palliative Care in Melbourne is one example (3). Projects such as the PRISMA project, led by Kings College London, have equally brought international expertise together to enhance the evidence base. A recent Delphi study involving 64 experts from 30 countries provided clarity on the core variables of a palliative care population (4). From the European Union, cross country collaborations have linked care providers, university partners, and voluntary and statutory agencies to address the complexity of palliative and end-of-life care (5-7). In all cases, the benefits of shared working are combined expertise, developing common tools and evidence-base, and broader reach and impact of findings. Collaborations such as these enable sharing of methodological expertise, greater conceptual clarity, and cohesive wide-reaching dissemination of relevant and timely information. Overall, a case for international collaboration and its benefits for palliative care would seem to be made.
However, effective collaboration requires a careful consideration of the factors which influence its success or failure and, most importantly, what messages that has for current and future palliative care research.

Collaborations come in many kinds; we should not look simply to international collaboration. Research in palliative care is not unique in terms of method and application. Many disciplines (mental health, paediatrics, older person care) experience similar challenges in research with complex populations. Public health, social sciences, and health economics offer a range of expertise highly relevant for palliative research. Collaborative sharing of experience and method enhances and strengthens both process and outcome of palliative care research. This also challenges a misplaced disease-orientated research agenda suggesting palliative care as only relevant to specific groups at specific times (i.e. end-of-life). The argument for earlier intervention of palliative and rehabilitation models warrants a lifespan approach to research endeavour widening the potential vista of national and international research collaboration and opportunity. Paediatric palliative care offers a good example here, where collaboration opens the possibility to innovative studies reflective of the changing pattern of disease and treatment in childhood life-limiting and life-threatening illness (8, 9).

A further critical question relates to the development of research capacity and there is an urgent need to consider how we prepare the next generation of researchers. The lack of senior academic appointments in palliative care both in the UK and across the EU, particularly at Professorial level, means that we risk losing the benefits that academic scholarship brings; an opportunity to embed palliative care into curricula, access to a diverse range of funding streams, support for research development, and of course, inter- and cross-sectional collaboration. To be competitive in EU and International programme grants, cross-speciality collaboration is essential to meet the breadth of expertise these calls increasingly seek. As a discipline we now need greater strategic academic leadership, one which extols palliative care research as a career trajectory in its own right, rather than an addendum to clinical practice roles and functions. Developing strong models of international mentorship in research is essential and there are some examples to consider (www.aahpm.org/career/mentoring). In an ever-ageing workforce, this is a matter of some urgency.
So, reflecting back on Higginson’s editorial in BMJ, we welcome the points raised and acknowledge the inherent risks to the discipline and quality of research if those issues identified are not addressed. We strongly recommend collaborative action in a number of different ways: working nationally and internationally with other researchers (to deliver better collaborative studies); working together with researchers outside of palliative care (to improve our science and extend our whole pathway research); and exerting research leadership to build future capacity and strengthen academic career pathways in palliative care research.

Collaboration fosters growth. Research in palliative care is about making a difference in the lives of patients and families. Doing that in partnership with others who hold the same aspirations, values and ideals will translate theory and method into real world change for professionals, patients and caregivers. As we ponder our collaborative future as nations together, these things do and will matter.

References


4. Sigurdadottir KS, Kaasa S, Rosland JH, Bausewein C, Radbruch L, Haugen D on behalf of PRISMA. The European Association for Palliative Care basic dataset to describe a palliative cancer population: Results from an international Delphi process. Palliative Medicine, 28(6), 463-473.


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