AIIHPC
All Ireland Institute of Hospice and Palliative Care

All Ireland Research Active Hospice and Specialist Palliative Care Providers Event - 12 June 2024

Open Session Discussion Results – Post Consultation

Table 1: Lack of protected time

Barriers

- Ethics process – time constraining endeavour
- Funding
- Time - fitting research around normal clinical duties; nurses doing ward rounds, then having research duties to do after clinical duties
- No obvious remuneration for research work and no incentives

Solutions

- Streamlining ethics process
- Changes in culture around research with more sympathetic management/leadership; prioritising involvement in research /place value on research; top down in organisation e.g., include in mission statement – importance of research culture
- Collaboration to share knowledge and resources
- Pre-set up projects for Masters Research to make it attractive and benefit from university collaboration
- More group research projects as this is better than individual research
- Creating a research centre
- Efficient allocation of research staff hours with protected time for research contracted into roles (e.g., 80/20 split)
- Funding for protected allocation of staff time for research
- Building trust between stakeholders

Table 2: Research Infrastructure

Barriers

- Funding
- Not having a lead researcher/research officer
- Limited experience, people feeling they don't have enough experience to carry out research
- Lack of knowledge about the governance structures required for research
- People are so busy clinically and it is difficult to generate interest in research; lack of lead person for bringing it along
- Lack of guidance in accessing expertise, e.g., research policies in place that exist in some organisations in Northern Ireland
- No clear pathways for ethics and number of organisations are involved at the moment; you need to fill out different forms etc., it is very cumbersome and takes a lot of time

Solutions

- Identifying a Research Lead who is going to lead within the organisation
- Developing a business case for a research officer and how to fund that the role
- Access to expertise through universities, other hospices, the HSE, etc., to build a collaborative approach
- Identifying research priorities and working together, e.g., identify two or three big projects where hospices could work together rather than smaller projects
- All Ireland Institute of Hospice and Palliative Care (AIIHPC) have groups and committees already in place that can be used in different ways for a joined-up approach, and we can use AIIHPC's formal networks where there's a repository of expertise and central data
- Incentivising interest in research, sharing what we have, some hospices may have librarians and others don't
- Disseminate knowledge
- Protect time
- Learn from international examples of research
- Develop more clinical academic posts

Table 3: Funding Access

Barriers

- Limited resources and what seems like quite a small pot for funding
- Lots of people with very good ideas but applying with competing interests for funding/resources
- Funding - can seem daunting; the amount of work involved in funding applications; complexity of application process; knowledge required; estimating costing and timing in budgets for complex interventions; administrative task of it, regardless of the outcome
- Trying to keep your head up after failed applications
- Lack of collaborators for a particular project at the time you have an interest in it
- Need to be trend with a research idea, or need to have a project that is popular at that time, to be successful with certain funding calls

Solutions

- Collaborators and seeking external collaboration – being in the right network infrastructure to support a funding application
- Collaboration within our own organisations
- Strategic partnerships - looking potentially outside the traditional palliative care researchers, looking outside own multi -disciplinary team into the oncology sector, the organ failure sector; seek out opportunity and experience within their sectors that some people would say are more advanced and more consistently applying for calls
- Dedicated personnel, e.g., research nurse role, learning from established research nurse roles (full or joint academic); developing networks
- Developing networks within the palliative care sector, but also within the private sector, keeping abreast of trends

- Attending events like AIIHPC's event on Research Active Hospice and Specialist Palliative Care Providers event, building relationships and strategies
- Strategy to demonstrate research impact – we are great at sharing the human side/clinical side of the story, for example in palliative care week. We can learn to do the same for research - that could be very impactful for the research that we are doing. This then builds into funding applications.

Table 4: Funding and research strategy

Barriers

- Awareness of where to access funding; funding often goes to the academics
- Funding application process is difficult, our approach is often splintered and we need to be more collective in that approach
- Research question can be difficult, there's a competitive process
- Carrying out research that is likely to impact patient care and not just something that somebody has thought is a good idea, but that it's actually going to make a difference to the care that we're delivering
- Other specialties have established research, and we tend to have to align with them, such as oncology
- Lack of infrastructure in hospices to support our research
- Perceived policy and political agenda behind funding
- A lack of top-down support, and it's felt that we're in a bottom-up approach

Solutions

- More collaborative approach between policy, research and clinical staff
- Influence our leaders in hospices, our chief executives, our policy makers, and put forward a very strong voice about dedicated research positions and the importance of having them
- Need strategy for clinical research
- Academic mentorship is very important
- Job plans should include protected time for research
- Monitoring process in place through KPIs for research to make sure that everybody is participating in it
- Need for proper investment
- Learn from other organisations to see why they have been so successful
- Encourage all staff to have a critical mind to bring research, to bring their question into research
- HRB applied partnership funding as a model
- Meaningful research which adds value, which is directed by knowledgeable users / PPI involvement

Table 5: Funding and Research Strategy

Barriers

- Identifying funding sources
- Northern Ireland - health service is experiencing financial constraints whereas in the Republic of Ireland hospices and palliative care services are moving towards 100% core funding, therefore there may be potential funding opportunities

Solutions

- Highlighted potential funders including philanthropic funding sources; competitive grant calls: national or international; calls unique to the island of Ireland: cross-border or Ireland US calls; industry, infrastructure awards and core service provision, universities, academic pathways etc.
- Philanthropic funding sources - in Republic of Ireland, 100% of core services is now being funded by the state, which frees up philanthropy fundraising by the hospices for research and innovation. However fundraising should not assume full responsibility for funding research and innovation. In other areas of healthcare core academic practice/ research is funded through exchequer funding and isn't maintained through philanthropy alone. As such, core recurring revenue should come from the State and fundraising should be reserved for the really blue skies thinking/ proof of concepts areas of research development
- Opportunities to support each other across the island of Ireland
- Financial constraints NI health service is currently experiencing - instead of that being a point of difference, it could be a point of support and mutual assistance, both in terms of the comparative approach, where we can show what's working in the south and extrapolating to the north, but also then the resonance that if you're thinking about trying to build research in a very resource constrained environment, you want to focus on clinically meaningful research to get the engagement
- Current lack of research infrastructure could be addressed by coming together collectively from across the island of Ireland to look at research themes and ideas. The Palliative Care Research Network could broker this agreement
- Learn from the UK NIHR experience, instead of being passive recipients of grant calls/ awards, could move towards being active influencers of an infrastructure call
- Come together with a common agreement across the island of Ireland, about what a research infrastructure would look like. A collective agreement regarding multi-site research, this moves toward both research infrastructure and a commitment to a certain amount of throughput through studies, the All-Ireland Cooperative Oncology Research Group and other models
- Strength and numbers and collaboration, which both would grow commonality but also allow for individualisation, the bottom line being in service to patients and the communities

Table 6: Collaboration

Barriers:

- Time commitment – clinical side lack of time for research
- Lack of awareness at a local level from the ground up, do people really understand research and how to engage in it and the process but also looking at the differences and the lack of awareness of each of the different cultures
- Clinicians understanding of the academic side and academics understanding the clinicians' side
- Funding – unsure how to apply for the funding and where it goes; understanding funders priorities and where they feel the money should go within the services
- Competition amongst particular organisations for funding, some have funding and some have less funding etc.
- Ethics

Solutions

- Networking, working together as opposed to against
- One large research study rather than smaller studies
- Understanding different cultures, different areas and perspectives
- Time – more people involved and collaborating together means the less time an individual will need to spend working full time on that piece of research. Beneficial from a financial perspective as well
- Creation of new roles – involve clinical academic role with regards to teaching and supporting research
- Strategic objectives – research part of strategic plans; leadership support
- Partnership arrangement -academic mentorship
- Sustainability
- Enabling partnership arrangements
- Academic mentorship role