All Ireland Hospice and Specialist Palliative Care Providers

Research Active and Research Interested

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AIIHPC
Palliative Care Research Network

Aim

- To improve care for people with palliative care needs
- To bring together hospice and specialist palliative care providers, researchers, policymakers, funders, charities, and public and patient involvement contributors
- To learn from each other about hospice and specialist palliative provider involvement or interest in research, the barriers and enablers
- To develop a position paper with outcomes of today's event

All Ireland Research Hospice and Specialist Palliative Care Provider Survey

- Developed by AIIHPC to understand current research activity or future interest in research, and the barriers and enablers to involvement

- Survey shared with hospice and specialist palliative care providers across the island of Ireland

- 18 organisations completed survey with some organisations having more than one response

Organisations Participated

Northern Ireland

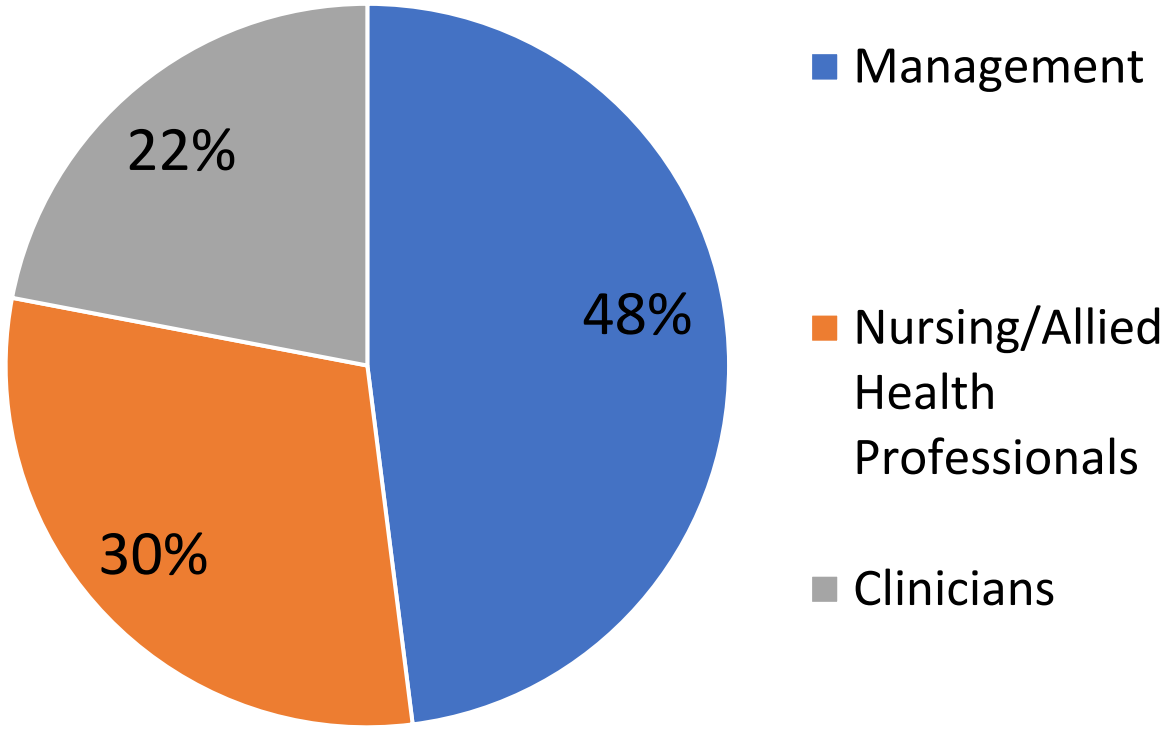
- Belfast Health and Social Care Trust
- Foyle Hospice Derry
- Marie Curie NI
- Northern Health and Social Care Trust
- NI Hospice
- Southern Area Health and Social Care Trust
- Southern Area Hospice
- South Eastern Health and Social Care Trust
- Western Health and Social Care Trust

Republic of Ireland

- Galway Hospice
- Laois/Offaly Specialist Palliative Care Provider
- LauraLynn's – Ireland' Children's Hospice
- Marymount University Hospital and Hospice
- Milford Care Centre
- North West Hospice, Sligo
- Our Lady's Hospice and Care Services
- St Francis Hospice
- South East Palliative Care Centre Waterford

27 participants from 18 organisations completed the survey

Participant Roles



Research Active (12 Organisations)

Developing and/or Leading and Recruiting Participants

- Belfast Health and Social Care Trust
- LauraLynn – Ireland's Children's Hospice
- Marie Curie NI
- Marymount University Hospital and Hospice
- Milford Care Centre
- North West Hospice Sligo
- Our Lady's Hospice and Care Services
- St Francis Hospice
- Western Health and Social Care Trust

Recruiting Participants

- Foyle Hospice Derry
- NI Hospice
- Northern Health and Social Care Trust

6 NI and 6 ROI

Not Active (6 Organisations*)

Interested in Being Involved

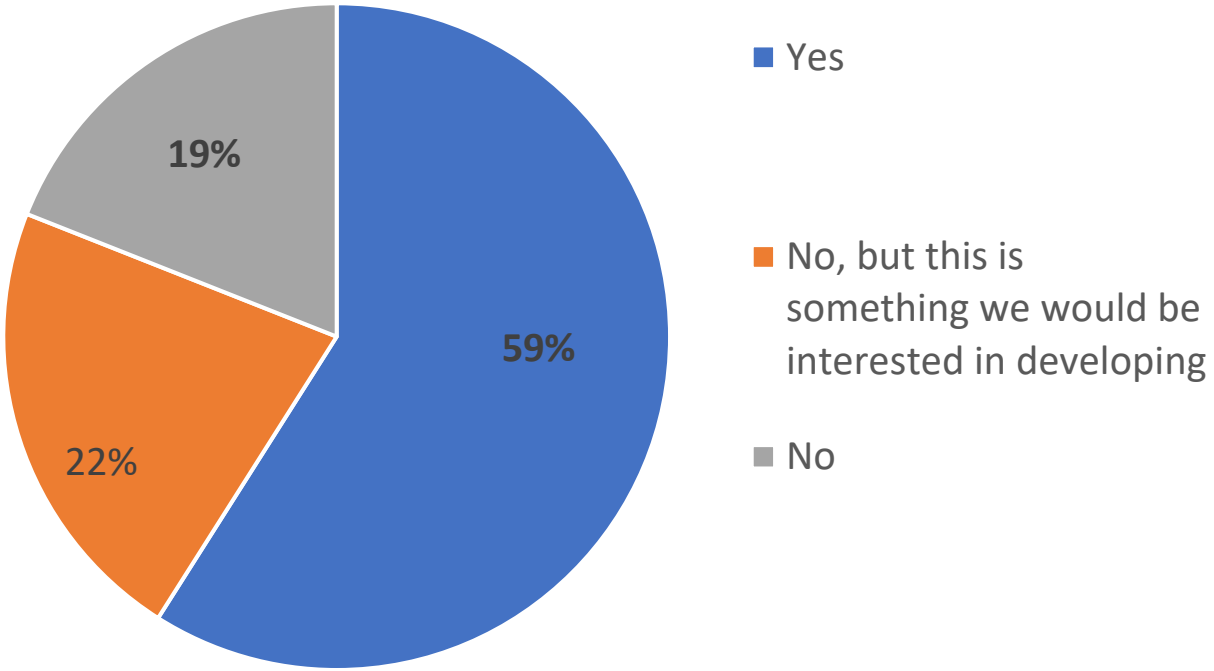
- Galway Hospice
- South Eastern Health and Social Care Trust
- Southern Health and Social Care Trust
- Southern Area Hospice Services
- South Eastern Palliative Care Centre Waterford and Care Services

Not Interested

- Laois/Offaly Palliative Care Services

* Two organisations had mixed responses from participants

Research in Strategic/Business Plan



Top Ranked Barriers Conducting Research

1. Lack of protected time and competing priorities
2. Access to research support, expertise, infrastructure
3. Understanding how to apply for research funding
3. Understanding what research is and what is needed to conduct research
4. No formal palliative care training
5. Leadership to support palliative care research
6. Perception of research not part of routine care
6. Patient and public perception of palliative care

Ranked Barriers Categorised

1. **Resourcing**
   - Lack of protected time and competing priorities

2. **Research Knowledge**
   - Access to research support, expertise, infrastructure
   - Understanding how to apply for research funding
   - Understanding what research is and what is needed to conduct research
   - No formal palliative care training

3. **Organisational Culture**
   - Leadership to support palliative care research
   - Perception of research not part of routine care

4. **Patient and Public Perceptions**
   - Patient and public perception of palliative care

Ranked Barriers Research Active

Developing and/or Leading and Recruiting Participants

1. **Resourcing**
   - Lack of protected time/competing demands
2. **Research Knowledge**
   - Understanding how to apply for research funding
   - Access to research support, expertise, and infrastructure
   - Understanding what research is and what is needed to conduct research
3. **Organisational Culture**
   - Leadership to support palliative care research

Recruiting Participants

1. **Resourcing**
   - Lack of protected time/competing demands
2. **Research Knowledge**
   - No formal palliative care research training
   - Understanding how to apply for research funding
   - Access to research support, expertise, and infrastructure
   - Understanding what research is and what is needed to conduct research

Ranked Barriers Not Active

Interested in Being Involved

1. **Resourcing**
   - Lack of protected time/competing demands

2. **Research Knowledge**

   - Understanding what research is and what is needed to conduct research
   - Understanding how to apply for research funding
   - No formal palliative care research training
   - Access to research support, expertise, and infrastructure

Individual Comments on Barriers

*"Building **strong relationships with universities** can be a barrier."*

*"Lack of understanding as to the benefits of research and **how it relates to clinical care** on the ground."*

*"**Accessing funding** and building strong relationships with universities can be a barrier."*

*"**Funding clinical staff**, especially medical staff to allow research to be led is the key. Dedicated research nurses are very helpful but ultimately if **senior clinical are not given time and space** to support this research, it will be impossible to conduct"*

Top Ranked Enablers Conducting Research

1. Allocation of staff time for research involvement
1. Dedicated staff (e.g. research nurses)
1. Funding
2. Collaboration with universities, charities, and policymakers
3. Knowing what other organisations are doing
3. Research guides, support and training
4. Supportive clinical lead
5. Ethics application support
5. Access to public and patient involvement contributions

Ranked Enablers Categorised

1. **Resourcing**
   - Allocation of staff time for research involvement
   - Dedicated staff (e.g. research nurses)
   - Funding
   - Ethics application support (ranked 5)
2. **Collaboration and Knowledge**
   - Collaboration with universities, charities, and policymakers
   - Knowing what other organisations are doing
   - Research guides, support and training
3. **Leadership**
   - Supportive Clinical Lead
4. **Patient and Public Engagement**
   - Access to patient and public contributions

Individual Comments on Enablers

*"We try to give **protected time** for our care staff to be involved in research but this can be challenge due to **competing demands**."*

*"**Bite-size education sessions** linked with clinical scenarios. **Promotion of Masters and PhD programmes** with supports."*

*"**Collaborative opportunities** such as those facilitated through meeting platforms by AIIHPC."*

*"**MDT working on research** ensuring novice researchers work alongside experienced researchers and across disciplines"*

Other Needs Identified

*"Better **opportunities for Health and Social Care Professionals including Non Consultant Hospital Doctors (NCHDs), on repeated cyclical rotations** from one setting to another, to collaborate cross site/ institution- follow up on research initiated by colleagues after handover at term end"*

*"Good input to posters/conference but **increased all discipline publication** would be beneficial, medics very strong with publications."*

*"Research in the **community setting**"*

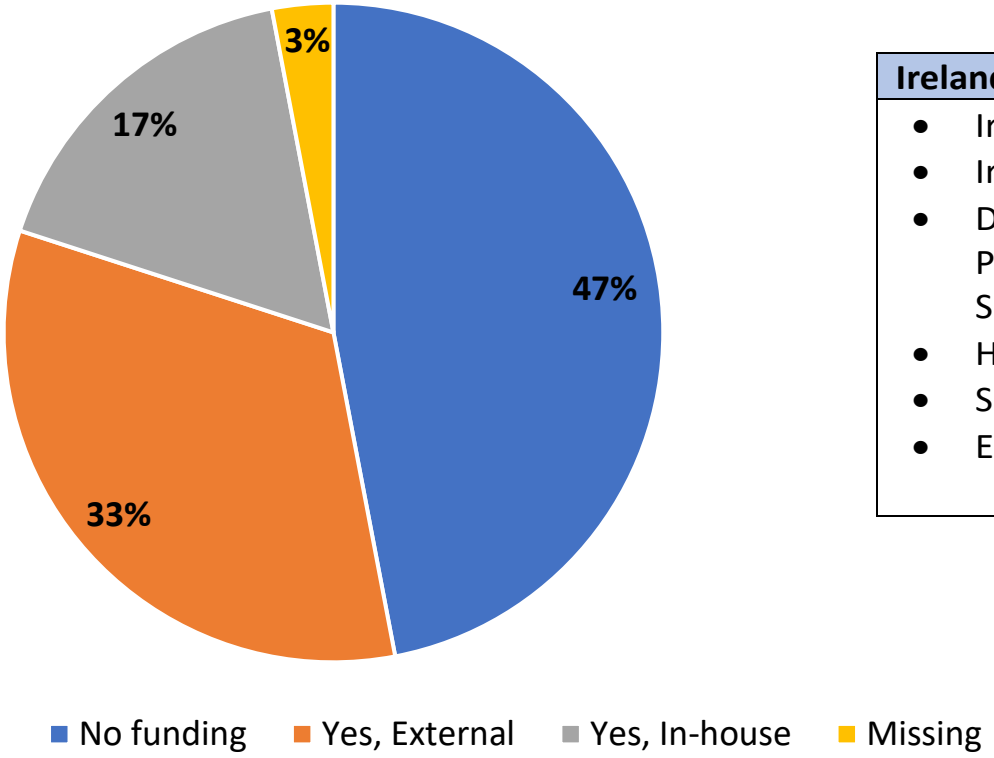
*"We **don't know what our needs are**!"*

Ongoing Projects

Ongoing Projects

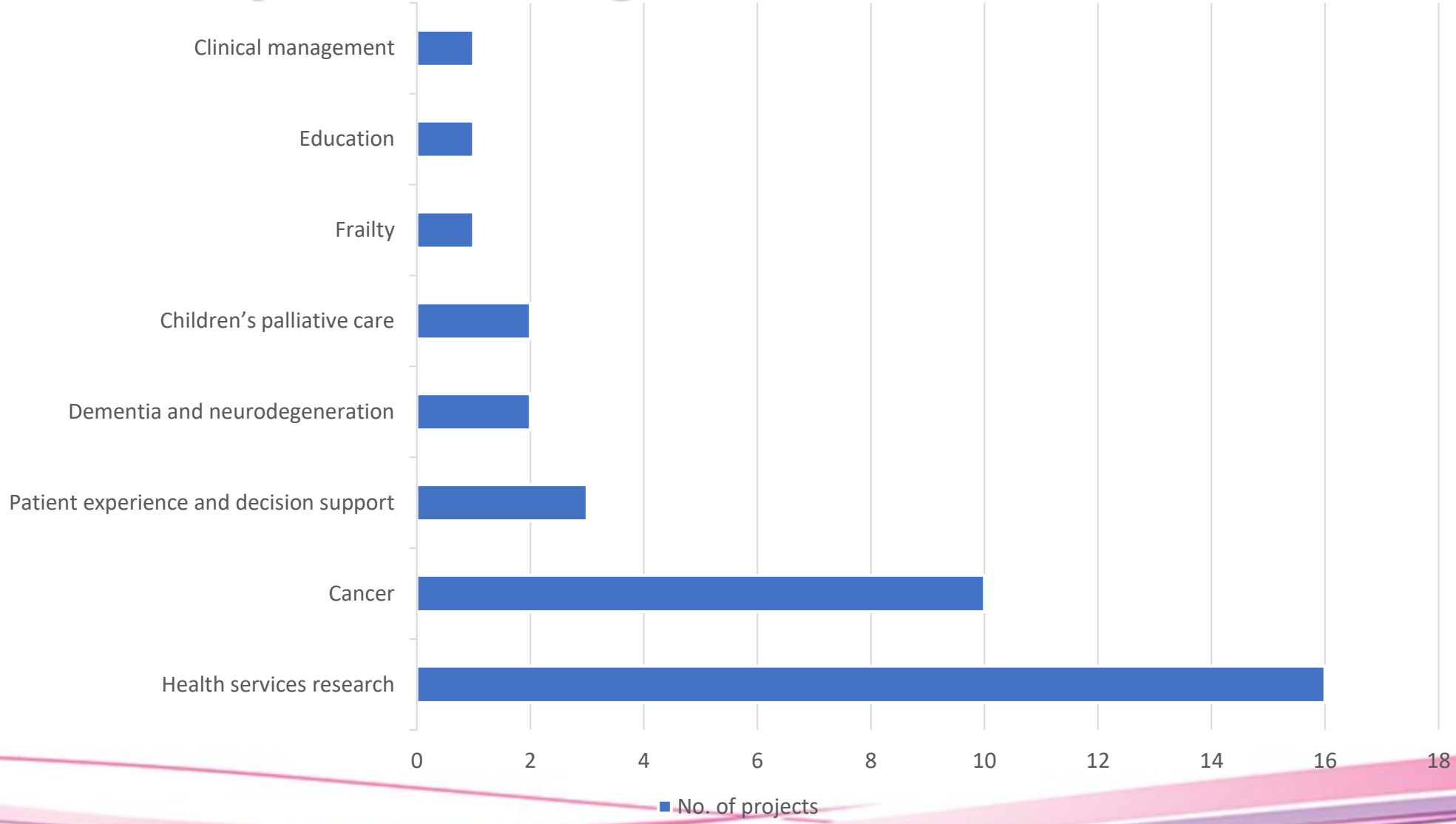
Organisation	No of Projects
Republic of Ireland	
Milford Care Centre	9
St Francis Hospice	9
Our Lady's Hospice & Care Services	8
Marymount University Hospital & Hospice, Cork University Hospital Group	6
LauraLynn – Ireland's Children's Hospice	2
Northern Ireland	
Belfast Health and Social Care Trust	1
NI Hospice	1
TOTAL	**36**

Project Funding



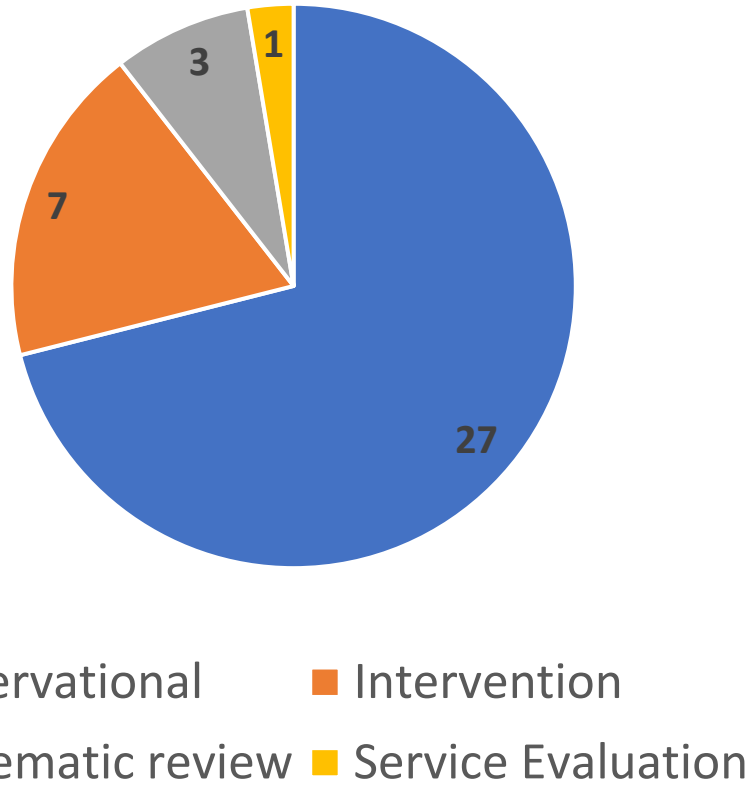
Ireland	UK	International
• Irish Health Research Board • Irish Cancer Society • Dublin City University Postgraduate Research Scholarship • HRB APA award • Science Foundation Ireland • Enterprise Ireland	• Northwest Cancer Research Grant	• Global Oncology Programme MSD • Horizon Europe • Princess Margaret Collaborative Research Grant

Project Categories

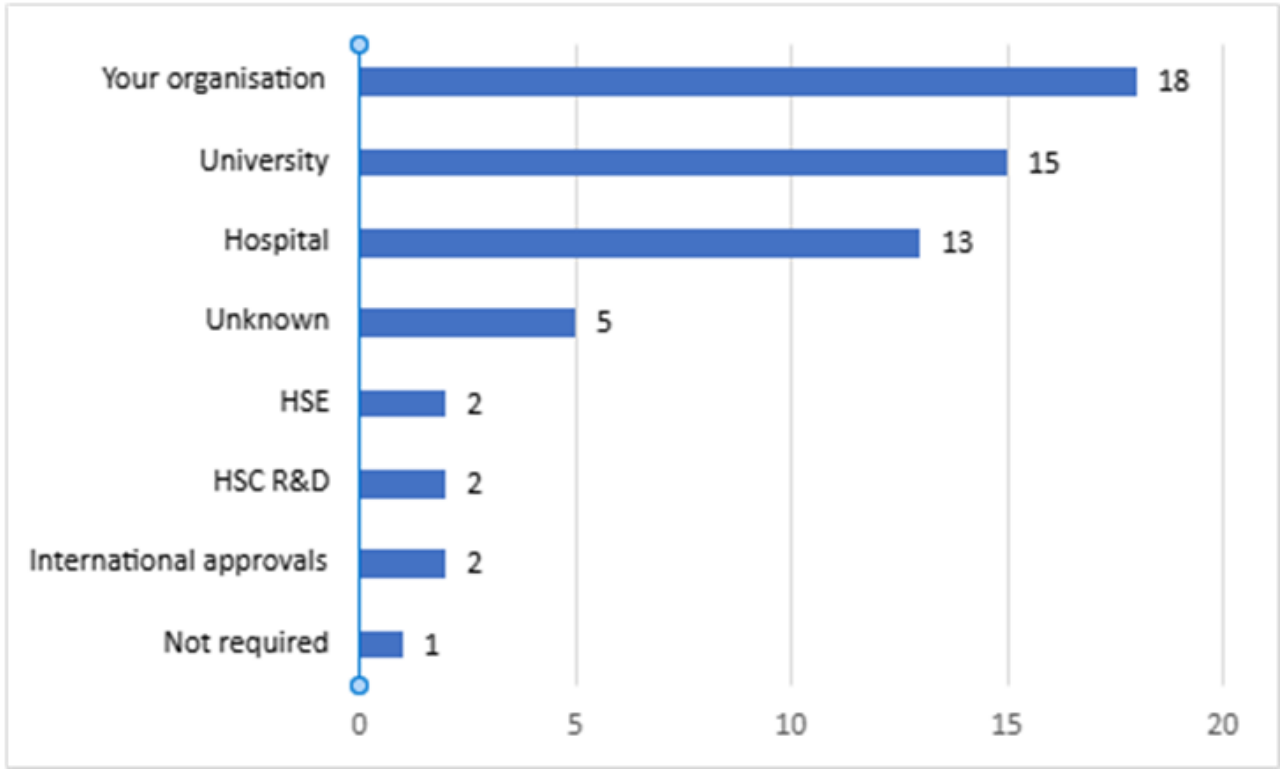


Participants Type and Methods

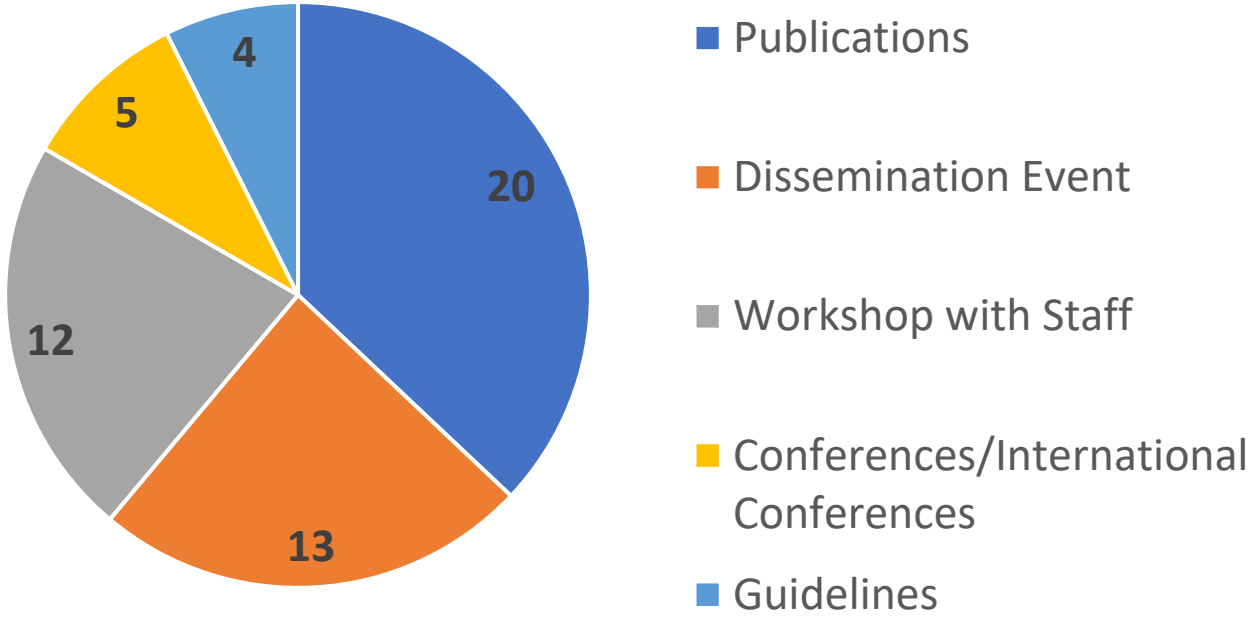
Participants/Type of study	N
Staff	12
Patients	10
Data analysis/chart review	6
Staff, patients, family, carers, general population	5
Systematic review	3
Patients, family	2



Project Ethical Approvals



Outputs / Expected outputs



Other less reported: further service development, patient information, improvements in resource allocation and patient prioritisation, national policy, approaches to care

Conclusion

- 12 organisations research active and 5 interested in being involved in research
- 59% have research in strategic/business planning and 22% like to include
- Main barriers to involvement are resourcing and research knowledge; and organisational culture (additional for those leading on research)
- Main enablers are resourcing, collaboration and knowledge, and leadership

Conclusion

- 36 ongoing projects across 7 organisations with 47% of projects not funded, 17% funded inhouse and 33% funded externally
- Projects mainly focusing on health services research, cancer, and patient experience and decision making and recruiting mainly staff and patients
- Studies mainly observational and intervention based with ethical approvals across mix of organisations
- Outputs focus on publications, dissemination events and workshop with staff