Research Engagement

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Why is it important to engage in research?



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Rate the reasons for engaging in research from high to low

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Rate the reasons for engaging in research from high to low:

1. To provide evidence based treatment and care.



2. To best understand the changing needs of the community that hospices serve



3. To create a culture of inquiry



4. To involve service users and the public in addressing research questions and defining the research agenda which may be different from professionals and managers.



5. To test and improve complex interventions.

6. To provide evidence of cost-effectiveness of hospice care

7. To build practitioners' expertise in critical appraisal of research and informed analysis of policy recommendations.

8. To provide the best evidence to support negotiations with commissioners and purchasers of hospice services.

9. To attract the best quality staff who wish to undertake research and advance knowledge

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Barriers to research engagement



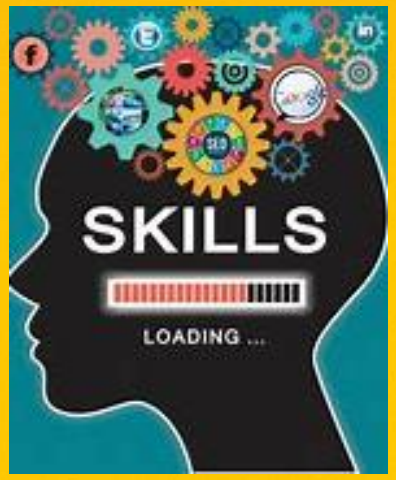
Gatekeeping



Lack of research culture



Lack of research awareness



Lack of research skills

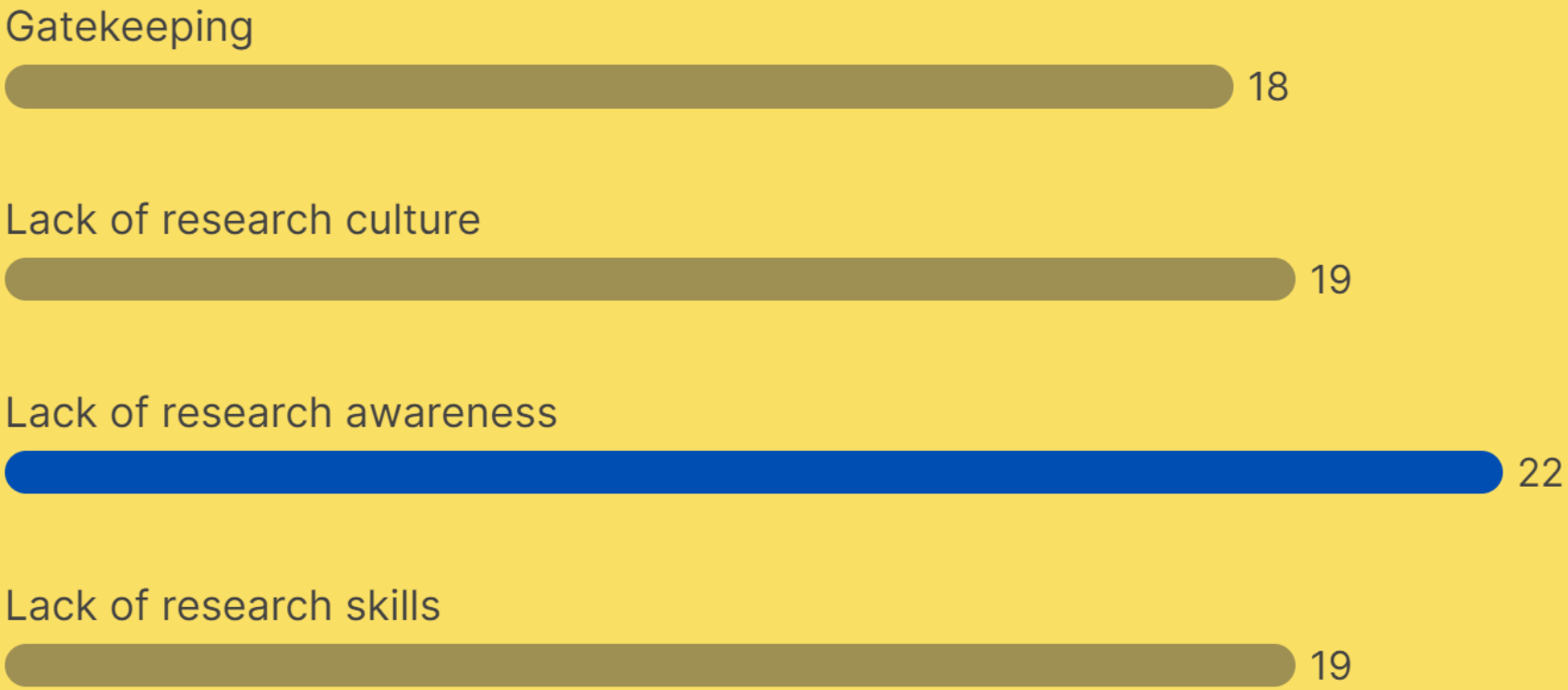
Have you experienced any of these barriers to research engagement?

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Have you experienced any of these barriers to research engagement?



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Have you found any other barriers to engaging patients, caregivers or staff in research?

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Have you found any other barriers to engaging patients, caregivers or staff in research?

Time 12 | Funding 7 | Research 5 | Manager 4

Anonymous
Nah

Anonymous
Research too focused on instituitions needs rather than community needs

Anonymous
Sometimes research is seen as an optional extra, so it can be challenging to convince of it's importance

Anonymous
Funding, allocated time

Anonymous
Appropriate payment for time Inc travel time

Anonymous
Time. Not understanding the necessity

Anonymous
Carers cannot find the time

Anonymous
GDPR

Anonymous
Too many competing priorities

Anonymous
lack of networking opportunities with researchers

Anonymous
Time
Support from management

Anonymous
Time and expertise - also not prioritised

Anonymous
Too much effort getting things off the ground

Anonymous
Ethics - dalays

Anonymous
Research goals focused on funding

Anonymous
Time
Guilt at spending time away from patients
Fear

Anonymous
Governance issues. As most hospices are outside the NHS and university, the indemnity and sponsorship can be challenging

Anonymous
Time

Anonymous
Patients become too unwell

Anonymous
Funding

Anonymous
Not prioritised by management / organisation etc who ultimately set the agenda

Anonymous
Language

Anonymous
Data protection issues

Anonymous
Not oart of usual care

Anonymous
Lack of staff therefore lack of time

Anonymous
Support from management

Anonymous
Poor collaboration between primary and secondary care

Anonymous
Funding for their time

Anonymous
Staffing shortages

Anonymous
Time

Anonymous
Finding research we can get involved with

Anonymous
Funding

Anonymous
Time, work clinically

Anonymous
Time, work clinically

Anonymous
Funding

Anonymous
Ethics

Anonymous
Funding/time for resesrch

Let’s talk about this journal club style…

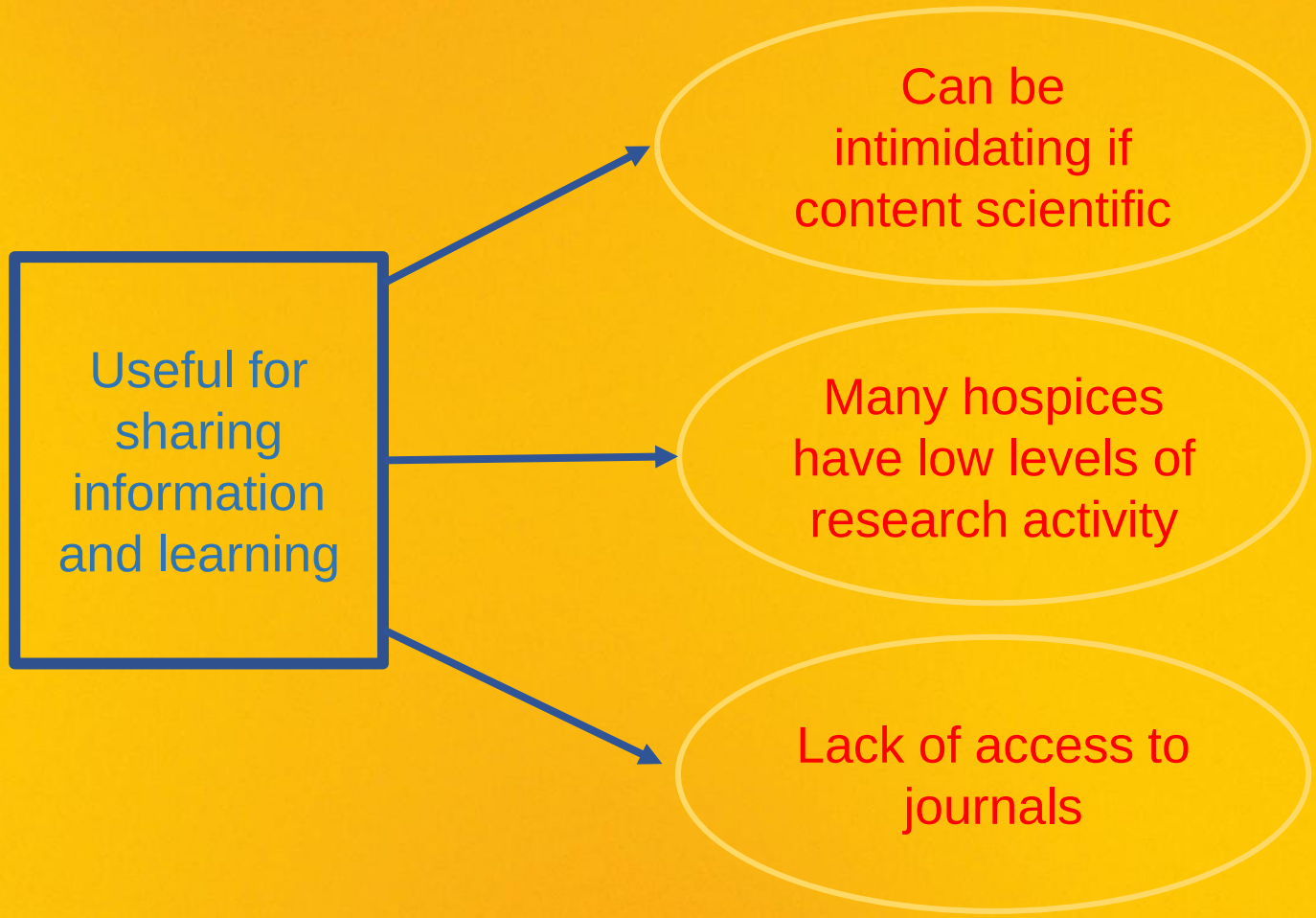


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What is a journal club?



Can this help with staff engagement in research?



Source: Payne and Turner, 2012

What are the main findings?

Should this change practice?

What are the research questions?

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The paper…





Development of a hospice research culture through staff development, education and collaboration

Palliative care research is essential for evidence-based models of care that improve terminal illness outcomes.[1] Investment in hospice research is essential for the projected increases in palliative needs.[2] Hospices are crucial to practice and policy development, but there are many hospice research barriers.[3] Well-documented problems include lack of research funding, governance challenges, methodological issues and absence of research culture.[1 4] Hospices require strategic infrastructure and processes to progress from 'research aware' to full participation and research leadership.[3] Over 2 years, Marie Curie Hospice Liverpool developed a series of quality improvement initiatives to establish a UK hospice research culture and improve research opportunities.

First, a governance process was established to facilitate the appropriate sponsorship and indemnity arrangements. This involved partnership with a local National Health Service Trust and University research teams. Patient and public engagement activities for research were established through our day therapy services. Patients met with researchers to provide perspectives for proposed research (from idea conception to research delivery). Second, a new morning board-round handover system provided focused clinical handover to hospice staff. As part of that, potential research participation eligibility was routinely discussed for all hospice inpatients. Third, Liverpool Clinical Commissioning Group funds provided a doctor (AMcD) and nurse (SS) with protected research time over 6 months to support National Institute for Health Research (NIHR) portfolio research studies. Initial duties involved training in hospice research processes. This included relevant training completion, data record management, ethical review facilitation and research promotion in the hospice. Our staff established contacts with the NIHR North West Clinical Research Network nurses in the local Trust. We focused on recruitment (patients and family caregivers) and data collection for the NIHR studies.

The process has led to several positive outcomes. Notably, patients were eager to participate in studies and showed great desire to improve future care, consistent with previous work.[5] The process improved research opportunities for hospice patients, increased recruitment and created new research collaborations. Both staff members (AMcD and SS) developed research skill and knowledge, with one (SS) in receipt of a national award. Challenges encountered were time-related due to research governance process delays. Ongoing issues exist with funding for further work. We have recently appointed a research lead (ACN) to further support research delivery. In summary, the process demonstrated research improvement potential through steps to develop and engage hospice staff, secure funding and establish collaborative research partnerships. This activity has directly resulted in a growing research hospice culture and has potential as a model for other hospices.

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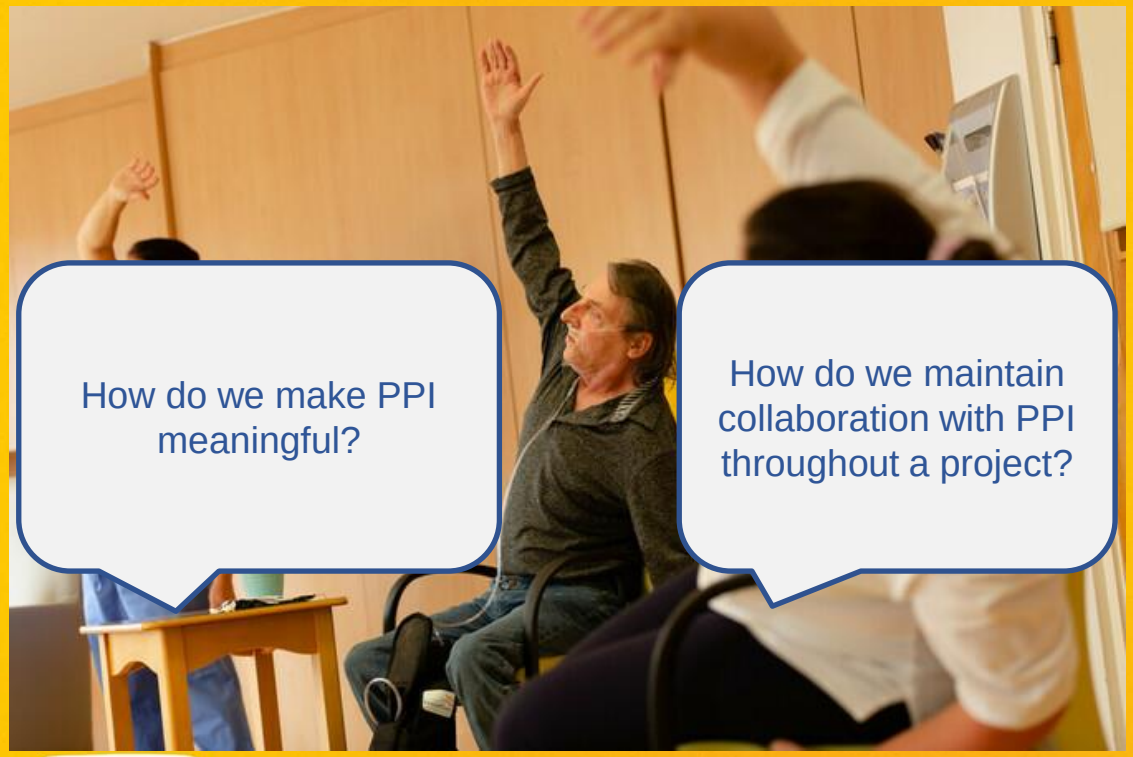
1 Higginson IJ. Research challenges in palliative and end of life care. *BMJ Support Palliat Care* 2016;6:2–4.
2 Etkind SN, Bone AE, Gomes B, *et al*. How many people will need palliative care in 2040? past trends, future projections and implications for services. *BMC Med* 2017;15.
3 Payne S, Preston N, Turner M, *et al*. *Research in palliative care - can hospices afford to not be involved?* International

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Engaging patients early

This paper describes early engagement of patients in research activity through day services



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How do we make PPI involvement meaningful and how do we maintain collaboration with PPI throughout a project?

Results 4 | Research 4 | People 4 | Outcomes 3

Anonymous
Not too time -onerous for public
Possible financial recompense
Providing support if triggered by lived experience

Anonymous
involving them in creating and running an (interactive?) exhibition or other form of disseminating the research and its findings

Anonymous
Recognising that professionals can also be patients or relatives

Anonymous
Involving from the off, don’t bring in at late stage. Make them aware of the process (how long things can take!) and give timelines

Anonymous
Observe the research ethics

Anonymous
Engagement with public to share results and assess the impact of actions

Anonymous
Clear expectations

Anonymous
Ensure they are involved at each step of the reasearxhh process, setting up and reviewing draft protocol steering groups etc

Anonymous
I think starting with the end in mind and thinking of the potential outcomes from a project first, and then using the PPI from the start so they can help guide how the outcomes can be realised.

Anonymous
involving people in the analysis of (their own) data, for example asking them for their view on the results/findings or involving them in data analysis (co-analysis)

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Anonymous
Look
Listen
Learn
Negotiate need for this with management

Anonymous
Use simple language

Anonymous
Transparency
Sharing results
Communication

Anonymous
Getting the right people involved, hearing their experiences and supporting people to stay for the duration

Anonymous
Research project to be genuinely participatory from the outset.Ask them what they want to participatebin rather than recruiting for specific projects

Anonymous
Co-design essential

Anonymous
updating them/family on study progress and study results

Anonymous
Need community engagement lead to collaborate with external agencies to find patients.

Anonymous
Presenting outcomes beyond showing a published journal or conference paper

Anonymous
Make sure it's about co-design rather than just collaboration. Making sure they have opportunity to feel listened to and not making involvement too onerous

Anonymous
I guess it's about being open about it, advertising the fact we are an establishment that is involved in research & what's on offer

Anonymous
People are visual creatures, graphs, and charts that are often confusing to the novice. Making clearer in simple term's the aims and outcomes will make the benefits more obvious.

Anonymous
Embedding in culture through creative activities

Anonymous
Relatable and person specific meaningful to them and clear information sharing

Anonymous
To keep people involved, even after the research.

Staff Development, education, collaboration







Staff development

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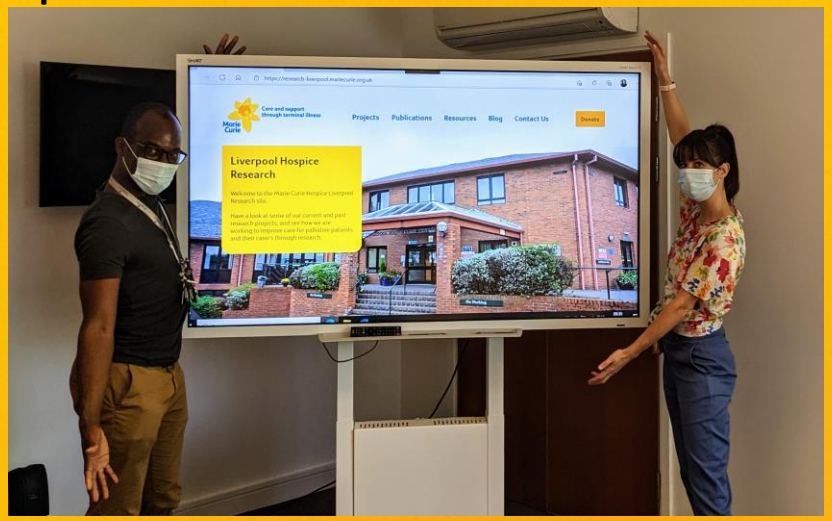
Staff Development, education, collaboration







opment Education



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Staff Development, education, collaboration



Think local



Make connections



Work together



Collaboration

Continue to offer research opportunities to patients, caregivers and staff



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Do palliative patients and their caregivers want to be involved in research?



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What are the main findings?

The paper describes a process to engage and develop staff in order to improve research activity and promote a hospice research culture

Should this change practice?

Provides a basis to consider how to engage staff, patients and caregivers in research

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What are the research questions?

- How do we all play a part in research?
- Do healthcare professional's recognise the important part they play in research engagement?
- Can some simple changes in your area raise the profile of research?



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