

The Sheffield experience of Patient & Public Involvement (PPI) in the INTEGRATE-HTA Project

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Background – Reflections on Patient & Public Involvement

More people living with life-limiting illnesses such as cancer and heart disease benefit from palliative care. Palliative care aims to enhance quality of life for both patients and families. However, palliative care services vary widely across Europe. An EU-funded project (INTEGRATE-HTA) is developing new Health Technology Assessment methods and testing these in palliative care. Patients and the public in seven European countries have been involved in several ways and will continue to be so throughout the project.

Aim & Involvement

To share reflections of the Sheffield academic team and lay representatives on PPI involvement in INTEGRATE-HTA. In Sheffield, twenty PPI representatives have been advisors in the INTEGRATE-HTA project to date, helping the researchers to focus on issues of importance to stakeholders. Two PPI representatives have extended their involvement, participating in the project management group in England and a range of project activities including helping to identify relevant literature and giving a talk about PPI to young researchers setting out on their careers.

Reflections

Opportunities

"Sharing perspectives, skills and expertise on palliative care topics from the academic to the real world."

"Engaging in this project has given me the understanding, knowledge and confidence to want to engage in more at this level."

*"Potential to influence policy at an EU level and ensure it is in line with actual needs and requirements of service users."
"The opportunity to disseminate best practice."*

Challenges

"Ensuring that the complexity of the project does not preclude the involvement of the lay representatives."

"Researchers are totally immersed in the project but lay representatives have only 2 hours a month to get up to speed with all the latest developments."

"Being uncertain of lay people's expectations of the project & what it can achieve."

"The mass of paperwork."

Benefits

"We have taken on board a number of PPI suggestions regarding project focus and dissemination."

"Lay involvement in the meetings is useful in terms of challenging the views of both PPI reps and researchers."

"PPI has been valuable, providing a view on palliative care & how it is seen/experienced by lay people."

Conclusion

Sheffield's experience in this European project indicates that PPI plays an important role in shaping the project. The opportunities for PPI and challenges of this need careful consideration to ensure that benefits are not lost.

For more information please contact Louise.brereton@sheffield.ac.uk or visit www.integrate-hta.eu

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