

# Changing the narrative: patients, those with lived experience, carers, families, as knowledge creators and knowledge users

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## Background and context

- HSE Research and Development Action Plan for Health Research 2019-29
- HSE Research and Development knowledge translation (KT), dissemination, and impact process.
- Patient and public involvement (PPI) in project development and implementation.
- Patients, those with lived experience, carers, families and the public as knowledge creators and knowledge users.

## Methodology

Initial consultation with the PPI Reference Group resulted in a nominated sub-group working with the project leads. The group were tasked with building PPI stories and narratives, developing guidance on communication and PPI, and PPI in research. The sub-group held monthly meetings involving shared exploratory conversations. This generated shared stories and narratives of the experience of PPI contributors sharing and using research.

## Results

The exploratory conversations built relationships, led to a shared understanding and narrative. The group were able to identify points of the KT process where meaningful PPI can be integrated. Barriers and challenges to meaningful PPI engagement in KT were recognised. To address the barriers and challenges guidance on the importance of communicating research to increase engagement and impact for patient organisations was developed. The group also produced guidance on PPI in research and were able to influence and impact on the development of resources and guidance.

## Implications

- PPI is a knowledge creation process
- Building a narrative develops relationships, a shared understanding, and co-creates knowledge
- Patients, those with lived experience, carers, and families are knowledge users
- PPI must be integrated into knowledge translation to increase the relevance of research

## Co-creating resources

Guides to knowledge translation:

<https://hseresearch.ie/research-dissemination-and-translation/>

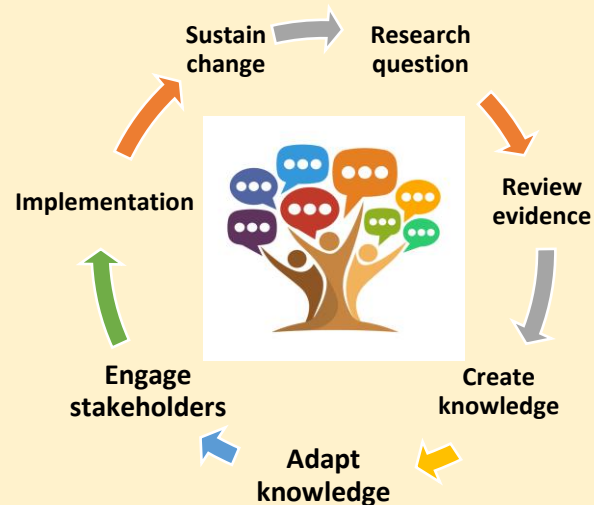
On-line learning portal:

<https://www.hseland.ie>

Knowledge translation and impact explainer video:

<https://www.youtube.com/watch?v=4lZzeEWzKME&t=1s>

## Elements of Knowledge Translation & Opportunities for PPI



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