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Using creative co-production to develop a treatment decision support tool for people with malignant pleural effusion

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Background

Malignant pleural effusion (MPE) is a common, serious problem predominantly seen in metastatic lung and breast cancer and malignant pleural mesothelioma (MPM). Recurrence of MPE is common, and symptoms significantly impact on people's daily lives.

No ideal treatment strategy for MPE currently exists. However, there are four main treatment options aimed at relieving symptoms and improving quality of life. These include aspiration, thoracoscopy with pleurodesis, bedside pleurodesis and indwelling pleural catheter. Choosing which option is best depends on many factors and making decisions can be challenging in pressured clinical environments. This project aimed to develop a support tool to help this decision making process for people with MPE.

Methods

Pleural teams from three sites in the UK undertook a creative co-production (CC-P) approach led by the translating knowledge into action (TK2A) team of the NIHR Research Collaboration and Leadership in Applied Health Research and Care Yorkshire and Humber.

The geographical distance between the three sites and the ill-health of service users meant a novel distributed model of CC-P was used. This comprised of three locally run workshops with clinicians, patients and carers that were designed and structured by the TK2A CC-P experts. This was followed by a joint national workshop with representatives from all stakeholder groups to consider findings and outputs from local meetings.

The design team worked with participants to develop outputs including patient timelines and personas. These were used as the basis to develop and test visible and tangible prototype ideas.

Results

Some key messages emerged that informed prototype development. Understanding and managing their pleural effusion was the priority for patients, not their overall cancer journey. Preferred methods for receiving information were varied but visual and graphic approaches were favoured. The main influences on people's decisions about their MPE treatment were personal aspects of their lives (e.g. how active they are, what support they have at home).

The design team developed a first prototype (i.e. a video representing a web-based support tool) to help people identify personal priorities and guide shared treatment decisions. This requires further development before implementation into practice.

Conclusion

The creative design methods and distributed model of co-production used in this project overcame many of the barriers to traditional co-production methods such as power, language and time. They allowed specialist pleural teams and service users to work together to create a patient-facing decision support tool owned by those who will use it.