

## Putting outcome measures into palliative care practice: what works?

### Background

Palliative care seeks to improve the wellbeing and quality of life of people with advanced illness. This is by taking a comprehensive approach to care that identifies and improves a person's symptoms, addresses their concerns, and increases their ability to do everyday tasks and take part in activities that give them pleasure.

It is important that we are able to demonstrate what works and what doesn't work in palliative care. An 'outcome measure' provides one way of doing this. Outcome measures are brief questionnaires completed by a patient or their carer. When used properly, they allow health professionals to assess a patient's symptoms, concerns, and ability to do everyday tasks and monitor how these change over time.

They also tell us whether or not the care and support received has improved a person's well-being and quality of life. This information enables us to demonstrate the value, and improve the quality of, palliative care by knowing and showing what interventions work well and why.

Outcome measures are widely used in other areas of healthcare. However, they are used inconsistently, if at all, by palliative care professionals. The aim of this study was to understand the best ways to ensure that outcome measures are used well in everyday practice within palliative care.

### What we did

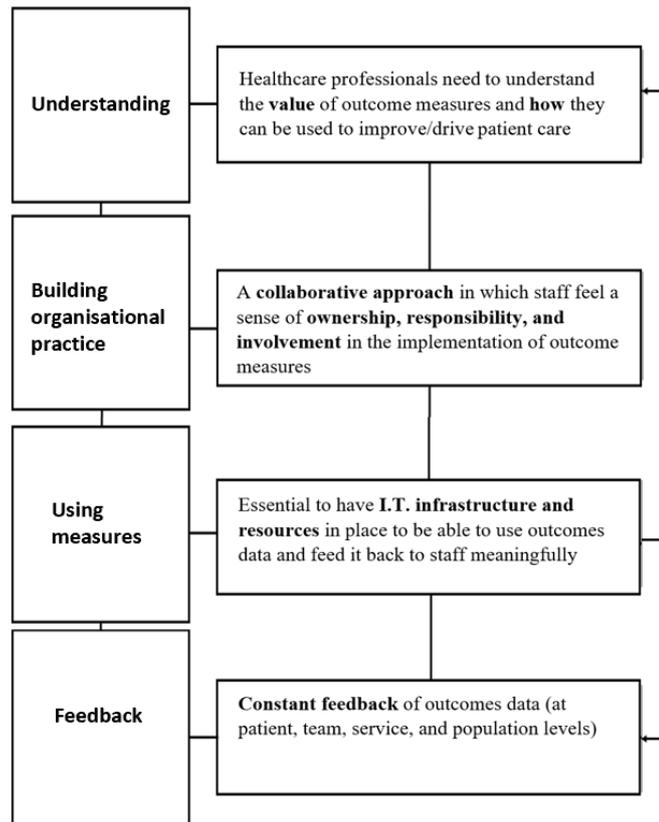
- We wanted to understand what works and why when implementing outcome measures in everyday palliative care practice.
- This work is part of the wider RESOLVE project which aims to directly improve the health status and symptom experience of Yorkshire patients living with advanced cancer. More information can be found here: <https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/resolve>

<p><b>How we did it</b></p>	<ul style="list-style-type: none"> <li>• We spoke with 63 healthcare professionals about how they used outcome measures in their everyday work and what they thought was important for using them in everyday practice.</li> <li>• These healthcare professionals were representative of varying roles (nurses, doctors, healthcare assistants, therapists) and experience.</li> <li>• We made sure to speak to people across the different settings where palliative care is commonly provided, including those who work within the hospice building itself and those who work in the community (visiting and delivering palliative care to patients in their own homes).</li> </ul>
<p><b>What we found</b></p>	<p>We found that the processes that impacted the everyday use of outcome measures fell into four categories:</p> <p><b>1. How people understood outcome measures</b> It was important that those who used outcome measures understood what they were and why they were using them in their everyday work. It was also important that people knew how to use outcome measures appropriately. However, professionals did not feel as though there was enough training, education, and support in place to help them with this.</p> <p><b>2. Building practice around outcome measures</b> A key process in helping to get people ‘on board’ with using outcome measures was to ensure that those who used them felt included in their implementation. It was also important that outcome measures were constantly used and ‘in view’ so that people did not forget to use them in their day-to-day work. However, in many cases, a ‘top-down’ approach to implementation made people feel disconnected and disengaged from their use.</p> <p><b>3. Using outcome measures</b> It was crucial that electronic systems existed that could be easily used by all, so that information from outcome measures could be put onto, used within, and then taken out of these systems for further analysis. When this was not the case, the implementation of outcome measures was severely disrupted and, in some cases, abandoned.</p> <p><b>4. Feedback</b> It was important that information collected from outcome measures was fed back to those who used them. This was because being able to see how outcome measures contributed to the care that health professionals were giving to patients and their families</p>

reinforced their use. When feedback was not given, many saw outcome measures as a ‘tick-box exercise’; something they were asked to do, but with no idea as to why.

A summary of important processes can be seen in Figure 1.

Figure 1: An overview of the processes important to the implementation of outcome measures into routine clinical practice



**Recommendations**

Based on the findings of this work, we created a list of recommendations to provide professionals who are leading the implementation of outcome measures, and those using them in everyday practice, with important things that they should consider before and during implementation.

These have been designed to ensure that outcome measures are used in everyday practice in ways that are able to benefit patients and their families/carers.

In summary, these recommendations are to make sure that:

- Health professionals understand what outcome measure are, why they are using them, and how to best use them to improve care of those with advanced illness and their families.

	<ul style="list-style-type: none"><li>• Teams and services are aware of the ways in which they can work together to ensure that outcome measures are a part of day-to-day practice.</li><li>• Services have electronic systems in place that are easy to use for outcome measures.</li><li>• Services ensure that important information regarding outcome measures is fed back to those who collected them in order to demonstrate how they inform and benefit patient care.</li><li>• Health professionals know how to use outcome measures to demonstrate the value, and improve the quality, of palliative care that people receive.</li></ul>
<p><b>In depth findings can be found in the paper attached entitled:</b></p> <p>Bradshaw, A., Santarelli, M., Mulderrig, M., Khamis, A., Sartain, K., Boland, J. W., Bennett, M. I., Johnson, M., Pearson, M., &amp; Murtagh, F. E. M. (2020). Implementing person-centred outcome measures in palliative care: An exploratory qualitative study using Normalisation Process Theory to understand processes and context. Palliative Medicine.</p> <p><a href="https://doi.org/10.1177/0269216320972049">https://doi.org/10.1177/0269216320972049</a></p>	

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