

**Symposium Description (250 words max.)****Symposium Lead (name and affiliation):**

Darshini Ayton

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**Rationale for Symposium:**

What truly matters to patients? Improving the measurement of patient reported outcomes in clinical quality registries

**Topic description:**

There is growing international momentum around using patient-reported outcome measures (PROMs) to drive improvements in quality of care, and to achieve better value for patients and funders. Routine use of PROMs in clinical quality registries can support clinical practice and the delivery of healthcare services. This symposium presents the steps involved in improving the measurement of patient-reported outcomes within a state-wide population-based cardiac registry—the Victorian Cardiac Outcomes Registry (VCOR). A mixed-methods project was undertaken in collaboration with industry partners to develop a PROM for patients undergoing percutaneous coronary interventions (PCI), which was integrated with objective clinical measures to provide a holistic assessment of care. Genuine patient-centred methods were used to ensure that the patient's perspective was included in the development of the PROM. This symposium includes four presentations. The first will explore the main outcomes patients consider to be important following their procedure. The second presents findings from a discrete-choice experiment to quantify patient perspectives about the outcomes they most value, and the third presentation will outline the use of Rasch analysis to identify the final set of items to be included in a PROM. The final presentation describes how the PROM was integrated with objective clinical measures to provide a more holistic measure of patient wellbeing following a PCI. The symposium will conclude by discussing how PROMs can be used in research and the healthcare setting to achieve a more person-centred approach to quality and safety improvement.

**Presentation one:** What truly matters to patients? Exploring patient-reported outcomes following percutaneous coronary intervention

**Authors and affiliations:** Darshini Ayton, Anna Barker, et al

**Overview: (99 words)**

Percutaneous coronary intervention (PCI) is a cardiac procedure used to treat

obstructive coronary artery disease. Patient-centred care is a priority in cardiovascular health and leads to increased patient satisfaction, engagement with rehabilitation activities and reduced anxiety. Routine collection of patient-reported outcomes (PROs) can inform patient-centred care. A systematic review undertaken by the authors demonstrated that existing cardiac patient-reported outcome measures (PROMs) have limited patient involvement in their development. This presentation will summarise qualitative research undertaken with patients who had undergone PCI in the previous 6 months to identify and explore outcomes that patients perceive as important following the procedure.

**Presentation two:** What truly matters to patients? Symptoms and feelings valued by patients after a percutaneous coronary intervention: a discrete-choice experiment to inform development of a new patient-reported outcome

**Authors and affiliations:** Renata Morello, Anna Barker et al

**Overview: (92 words)**

This presentation summarises findings from a discrete-choice experiment (DCE) to identify which symptoms and feelings following PCI are most important to patients. The DCE consisted of two hypothetical scenarios of 10 symptoms and feelings experienced after PCI, described by three levels. Of the 138 individuals recruited, 129 (93%) completed all 16 choice sets. Preference weights were estimated using a conditional logit model. Eight symptoms and feelings were identified as being important to patients following a PCI, with the most important being *feeling unhappy*, followed by *physically being able to do usual activities*.

**Presentation three:** What truly matters to patients? Developing a new patient-reported outcome measure using Rasch analysis

**Authors and affiliations:** Sze-Ee Soh, Anna Barker, Darshini Ayton et al

**Overview: (98 words)**

This presentation summarises the use of Rasch analysis to select the best set of items to form a concise and psychometrically sound PROM, using a consecutive sample of 200 patients registered in the Victorian Cardiac Outcomes Registry (VCOR) 30 days following their percutaneous cardiac procedure. Five items were identified that can be included a PROM for patients following PCI: pain or discomfort, shortness of breath, confidence in performing usual activities, feeling unhappy and having trouble sleeping. Whilst further psychometric evaluations of the PROM are recommended, the items identified capture the patient's perspective of the recovering following the procedure.

**Presentation four:** What truly matters to patients? Development of a percutaneous coronary intervention patient level composite measure for a clinical quality registry

**Authors and affiliations:** Susannah Ahern, Darshini Ayton, et al

**Overview: (103 words)**

In healthcare, composite measures combine data to provide a comprehensive view of patient outcomes. Despite composite measures being a valuable tool, the patient-centred perspective is often missing. This presentation summarises a study aimed to develop a composite measure for an established cardiac outcome registry. Both patients and clinical experts participated in this study. The final composite measure included five clinical outcomes with a total weighting of 90%, and the overall PROM score that comprised 10% of the total weighting. This composite score provides a more holistic reported measure of individual patient wellbeing at 30 days post their PCI-procedure.