

Consumer Involvement in Clinical Trials: A Scoping Review and Australian Perspective

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Background

The involvement of patients and the public (consumer involvement) in all aspects of research provides significant value and, in some countries, consumer involvement is a fundamental component of the research process. In Australia, clinical trial networks (CTN), are particularly effective at conducting high-impact, public-good clinical trials. However, little is known about the extent to which CTNs undertake consumer involvement or the types of involvement that add most value.

Objectives

The Australian Clinical Trials Alliance (ACTA) formed an expert working group to strengthen consumer involvement across the research continuum. To address these aims two activities were conducted: 1) scoping review of national and international initiatives and best practice 2) sector-wide consultation of CTNs, to map current practice and identify future initiatives that may be effective in increasing levels of meaningful consumer involvement within Australian clinical trials.

Method

Based on a literature search using terms; 'patient and public', 'consumer', 'involvement', 'engagement' 'research' and 'clinical trial', we analysed international best practice activities from several geographical locations (e.g. Australia, United Kingdom, United States, Europe) to provide an executive summary. We also conducted a national survey of consumer-involvement; both at clinical trial network-level across multiple healthcare disciplines, and in relation to specific engagement at an individual clinical trial-level.

Results

We aim to compare international best practice alongside national initiatives surrounding consumer involvement. Congruently a sector-wide consultation across clinical trial networks within Australia, will hopefully inform future strategies required to ensure patients and the public, become active partners across the breadth of national research endeavors.