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Title: How to Create an ICT System for Palliative Care: Methods for User Involvement during Design and Development

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Background: Information and communication technology (ICT) is emerging as a mode for delivering new and enhanced models of palliative care. Different ICT interventions are being developed, but methods for involving palliative care patients and health professionals are not well reported. Increased reporting of methods for user involvement across all stages of development can encourage ICT systems that target needs and requirements of patients and clinicians. We present the user involvement approach taken for an ICT system to support routine pain monitoring in community-based palliative care patients.

Method: The ICT system was designed to facilitate two-way communication between patients and health professionals; consideration of both users' perspectives was essential. Qualitative interviews and web surveys provided rich data to inform early, exploratory work, which was paired with a usability method called think-aloud protocol taken from the research field of human-computer interaction.

Results: Early qualitative work with patients (n = 20) and health professionals (n=105) provided key information on i) how patients interact with palliative care services, ii) how health professionals assess pain, and iii) the acceptability of ICT interventions for both groups. This led to the generation of a list of system specifications, written in lay language, which supported discussions and decision making around system requirements between social scientists, health professionals and developers. Following prototype development, the think-aloud protocol generated data on system usability issues.

Conclusion: A structured approach to user involvement in ICT system development in palliative care can generate rich and meaningful data to drive design. Consideration of how to communicate findings with developers is an essential component of this process. Methods available from other research disciplines can be utilised to supply valuable information to inform system development.