

Title: Development of a cancer pain self-management resource to address patient, provider and health system barriers to care

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Abstract

Objectives: The majority of self-management interventions are designed with a narrow focus on patient skills and fail to consider their potential as ‘catalysts’ for also improving care delivery. A project was undertaken to develop a patient self-management resource to support evidence-based, person-centred care for cancer pain and overcome barriers at the levels of the patient, provider and health system.

Methods: The project used a mixed method design with concurrent triangulation, including the following methods: a national online survey of current practice; two systematic reviews of cancer pain needs and education; a desktop review of online patient pain diaries and other related resources; consultation with stakeholders; and interviews with patients regarding acceptability and usefulness of a draft resource.

Results: Findings suggested that an optimal self-management resource should encourage pain reporting, build patients’ sense of control, and support communication with providers and coordination between services. Each of these characteristics was identified as important in overcoming established barriers to cancer pain care. A pain self-management resource was developed to include: 1) a template for setting specific, measurable, achievable, relevant and time-bound (SMART) goals of care, as well as identifying potential obstacles and ways to overcome these; and 2) a pain management plan detailing exacerbating and alleviating factors, current strategies for management and contacts for support.

Significance of results: Self-management resources have potential for addressing barriers not only at the patient level but also the levels of the provider and health system. A cluster randomised controlled trial is underway to test effectiveness of the resource designed in this project in combination with pain screening, audit and feedback, and provider education. More research of this kind is needed to understand how interventions at different levels can be optimally combined to overcome barriers and improve care.

Keywords: cancer pain, self-management, patient education, self-efficacy

Introduction

The problem of cancer pain

Pain is experienced by 30-75% of people with cancer (van den Beuken-van Everdingen et al., 2007; van den Beuken-van Everdingen et al., 2016) and is under-treated worldwide (Deandrea et al., 2008; Foley, 2011). Successful management of cancer pain is a complex undertaking dependent on a range of patient, provider and systems factors and the interactions between these (Jacobsen et al., 2009; Oldenmenger et al., 2009). Patient-level barriers have been documented in the form of reluctance to report pain and disproportionate fears of opioid addictiveness and tolerance. Provider-level barriers include a lack of priority accorded to pain management and poor communication with patients. Health system barriers include insufficient routine pain screening and poor coordination of care across providers. Clinical guidelines can improve quality of care and outcomes for cancer pain, but need targeted strategies to support implementation (Brink-Huis et al., 2008; Davies et al., 2010).

Continuing developments in cancer treatment mean that people can live with advanced cancer for many years, often alongside other co-morbidities (Phillips & Currow, 2010; Wong et al., 2018). Cancer symptoms such as pain therefore require management within a chronic disease framework focused on enabling patients to self-manage their condition, its impacts on their everyday life, and their emotional response to it (Bodenheimer et al., 2002; World Health Organization (WHO), 2002; Lorig & Holman, 2003; McCorkle et al., 2011). Health care aimed at supporting patient self-management needs to: be aimed at increasing patients' control over their condition within the context of their overall priorities and preferences; include information and training to enable patients to administer pharmacological and non-pharmacological treatments; leverage strategies to support and monitor patient behaviour change and coping; and enable ongoing partnerships between patients and providers and coordination of care to ensure appropriate advice and support is available as needed. This means that, to successfully improve patient self-management, interventions should ideally effect change not only at the patient level but also at the levels of the provider and the health system.

The current authors set out to design a cancer pain self-management resource with potential for addressing barriers across all three levels as part of a suite of strategies for implementing clinical guidelines for cancer pain we adapted for Australia from international precedents

(Lovell et al., 2015). Guideline implementation constitutes a ‘complex intervention’ as defined by the UK’s Medical Research Council (MRC) (Medical Research Council, 2006; Craig et al., 2008). The MRC’s Framework for Complex Interventions was therefore used as a guide, using the four phases of *development, feasibility and piloting, evaluation, and implementation*. This paper reports *development and feasibility and piloting* phases for the patient self-management resource. The *feasibility and piloting* phase for two other implementation strategies (pain screening and audit) has been reported elsewhere (Lovell et al., In press). A cluster randomised controlled trial (RCT) is underway to *evaluate* these strategies in combination with provider education on cancer pain care .

Method

A mixed methods approach was taken using a concurrent triangulation design (Cresswell, 2003). Our overarching research questions were: what are the barriers and facilitators to assessment and management of cancer pain, and how can we leverage these in a theoretically informed self-management resource? . Our starting assumption that a patient self-management resource could also address patient-, provider- and system-level barriers meant we needed to review evidence and canvass perspectives in relation to providers as well as patients.

The research was carried out over a 3 year period from mid-2011 to mid-2014. While many of the same methods also informed development of the clinical guidelines and the implementation suite as a whole, the current paper reports previously unpublished results focused on the development of the pain self-management resource.

The patient self-management resource was intended to have broad applicability across tumour types/stages and care settings and to complement a widely-used, evidence-based Australian patient education booklet and DVD called “*Overcoming Cancer Pain*”. This education resource is published by the Cancer Council New South Wales (NSW) and has been found to reduce mean average pain and worst pain scores versus usual care in a RCT (Lovell et al., 2010; Cancer Council Australia, 2013). “*Overcoming Cancer Pain*” includes information on cancer pain itself (causes, types, potentially exacerbating and alleviating factors), general advice on non-pharmacological and pharmacological management (including side-effects and misconceptions about opioids), the need for multi-disciplinary team input, and a question prompt list to support communication with providers.

Data sources included the following.

1. A review of existing evidence-based guidelines, including sections on patient and caregiver resources (see our online guidelines (Improving Palliative Care through Clinical Trials (ImpaCCT), 2013) for more details).
2. A systematic review and synthesis of qualitative studies investigating barriers and facilitators to patient care (Lockett et al., 2012).
3. A national online survey of current practice (Lovell et al., 2013; Lockett et al., 2013; Phillips et al., 2015), which included questions on providers' perceptions of barriers and facilitators to cancer pain assessment and management as well as the priority accorded to the following patient/caregiver level strategies to improving care: patient and caregiver education and resources; guidance on assessing patient-identified priorities; and inclusion of patient 'action plans' to aid self-management.
4. A systematic review and theory-driven meta-analysis of the evidence for different approaches to patient education (Marie et al., 2013). The theory in question was Michie et al's (2011) framework of behaviour change interventions developed via a comprehensive systematic review (Michie et al., 2011). Michie et al classified interventions according to their behaviour change 'functions' as these impact capability, opportunity and/or motivation - the 'COM-B model'. Educational interventions were independently coded for COM functions, and sub-group analyses were used to test whether these functions explained the heterogeneity in effects on pain intensity reported by previous reviews.
5. A desktop review of online, free-to-use pain diaries and other pain-related patient resources conducted in March 2013. Google searches were undertaken using search terms relating to pain diaries and pain self-management. Resources needed to be free-for-use in English language and go beyond information to provide tools to fulfil an 'enablement' function for assessment and management of pain as defined by Michie et al (2011) after the American Psychological Association as 'encouraging or enabling people to meet their own needs and ends' (Michie et al., 2011). Enablement became the focus of interest after our systematic review highlighted this as a potentially useful behaviour change function (see Results).
6. Consultation with stakeholders at local, national and international conferences and other fora (Agar M, 2012; Clayton J, 2012; Liauw W, 2012; Lovell M, 2012; Lovell M, 2012; Phillips J, 2012; Phillips J, 2012; Lovell M, 2013; Lovell M, 2013; Lovell

M, 2013; M., 2013; M., 2013; Lockett T, 2014). Fora were attended by pain specialists, cancer nurses, palliative care providers from different disciplines, pharmacists and consumers. Topics discussed included perceptions of patient-level barriers and the need for education and support for self-management.

An Advisory Committee met at regular intervals throughout the project to discuss emergent findings and develop iterative drafts of the self-management resource. The Committee consisted of two palliative care specialists (ML and MA) and a senior nurse (PMD), with coordination and support from social science researchers TL and AG. Input was sought at intervals from the other authors listed on this article, some of whom (FB, JS, JP) also served on the Working Party convened to develop the clinical practice guidelines.

The findings from the above methods were used to inform development of a draft self-management resource that was assessed for acceptability and perceived usefulness in semi-structured interviews with patients with cancer pain at two sites in Sydney: a public palliative care inpatient and outpatient unit and a private oncology outpatient service. Patients were purposively sampled to include a range of cancer diagnoses and experiences of pain assessment and management. Interview questions focused on participants' experience of pain management and education preferences in general, as well as specific experience of using the draft self-management resource, "*Overcoming cancer pain*" booklet and any other resources they may have accessed. Patients were given brief training in using the materials by the study nurse (MRB). Analysis was undertaken deductively by MRB to identify perceived benefits and problems associated with each resource feature, with emerging themes reviewed by two other members from the team (TL and ML).

Results

The above methods provided the following results informative to development of the self-management resource.

1. A review of guidelines identified support for patient education and involvement of patients in self-management in those published by the Scottish Intercollegiate Network (SIGN), National Health Service (NHS), National Comprehensive Cancer Network (NCCN), European Society of Medical Oncology (ESMO) and National Institute for Health and Care Excellence (NICE) (NHS Quality Improvement Scotland, 2004; Scottish Intercollegiate Network (SIGN), 2008; National

Comprehensive Cancer Network (NCCN), 2011; Ripamonti et al., 2011). Information topics recommended for inclusion in patient education concerned the causes and nature of cancer pain, pharmacological and non-pharmacological management, medication side-effects and safety, common misconceptions presenting a barrier to use of opioids (e.g. addictiveness and tolerance), and the importance of reporting pain in a way optimally informative to management, sometimes with resources to support this (e.g. pain diary). NICE, in particular, was found to provide online information for patients and families about opioids together with a question prompt list for discussing concerns and garnering information from the medical team (National Institute for Health and Care Excellence (NICE), 2012).

2. Results from our qualitative synthesis (reported in detail elsewhere (Lockett et al., 2012)) highlighted the need to integrate patient/family education within person-centred communication more generally and improve capacity to self-manage pain. The most pervasive finding was the need to individualise assessment and management and engage the patient as expert on his/her own pain. Lack of care coordination was identified as the most important health system barrier, often influencing the quality and timeliness of pain management and access to medications.
3. The survey of current practice was completed by 527 providers from different disciplines and settings across Australia. Results suggested further support for the need for patient/caregiver education. Of 425 providers who answered questions relevant to the self-management resource, 62% reported that they routinely provided education to patients with cancer pain and 51% considered more education important to improving care. Ninety-one percent of 416 respondents said they would welcome guidance on identifying patient priorities, 93% wanted patient 'action plans' to aid self-management, and 83% supported provision of a patient version of a clinician clinical pathway.
4. Results from our systematic review and meta-analysis indicated that educational interventions combining strategies for improving capability, opportunity and motivation tended to be effective in reducing pain intensity whereas those that did not contain all three functions were less so ([Marie et al., 2013](#)). In practice, COM versus less comprehensive interventions were distinguished by strategies for boosting patients' sense of control such as communication aids (e.g. question prompt lists) and guidance on tailoring management to individual needs. No evidence was found that greater resource-intensivity *per se* resulted in higher efficacy.

5. Our desktop review found free-to-use pain-related patient resources on 24 websites worldwide, including 23 pain diaries, three question prompt lists, one pain management plan and one motivational ‘toolkit’. See Lovell et al (2014) (Lovell et al., 2014) for a selection of these resources.
6. Consultation with providers confirmed the need for patient strategies aimed at encouraging reporting of pain and addressing opioid-related misconceptions. Potential solutions highlighted included use of a self-management record (hard copy or electronic), use of pain diaries, use of a question prompt list and advocacy from patients and consumer groups to tackle provider and systems-related barriers, as well as materials readily available on the website and media strategies aimed at educating the general public. Providers reported patient feedback to be a potent trigger for change. Involvement of the caregiver as well as patient was seen as important. Translation of resources into a range of languages was considered essential to benefit patients most at risk for low health literacy due to language barriers.

Based on the results above, the Advisory Committee concluded that “*Overcoming Cancer Pain*” contained necessary and sufficient information for patient education, and that sufficient pain diaries were available online to suit a range of preferences. However, therapeutic potential was identified for an innovative self-management resource aimed at ‘enabling’ proactive patient involvement in assessment and self-management of pain by: boosting patients’ sense of control and self-efficacy; helping them to communicate with providers and advocate for evidence-based, person-centred care; and supporting their role in coordinating care between different care providers in response to their individual needs. To this end, the team drafted a self-management resource that included: 1) a template for setting specific, measurable, achievable, relevant and time-bound (SMART) care goals for pain management, as well as identifying potential obstacles and ways to overcome them; 2) a pain management plan detailing exacerbating and alleviating factors, current strategies for management and contacts for support in the event of new or poorly controlled pain; and 3) a tool for self-evaluating capacity to self-manage pain and adequacy of support against the COM-B model (Michie et al., 2011). The rationale for each of the resource’s design features is summarised in Table 1.

Table 1 about here

Eighteen patients agreed to be interviewed for acceptability testing of the draft resource. Illustrative participant quotes on the goal setting tool, management plan and “*Overcoming Cancer Pain*” booklet are presented in Table 2.

Table 2 about here

Participants reported that the materials increased their confidence in communicating about their pain with providers and helped them to better understand management goals and options. However, several patients struggled with using a numerical rating scale to rate their pain severity, which they felt did not sufficiently capture the quality of their experience. The goal setting tool was perceived to be useful for informing anticipatory analgesia ahead of planned events as well as for prompting patients to reflect more generally on their current status and prioritise for the future. One negative case was a woman with breast cancer who felt her goals had not changed for at least a year. Participants found the pain management plan helped them to better understand breakthrough pain and drew comfort from information on where to get help, especially outside normal business hours. They also commented on the potential for the resource to facilitate communication and coordination between different healthcare professionals involved in their care across settings (e.g. GP, oncologist, pain specialist). However, they were less supportive of the tool for self-evaluating their capacity to self-manage pain, which they found difficult to understand and use. This tool was therefore removed from the next iteration of the resource, which is presented in Figure 1. This resource folds into an A5 size for portability.

Figure 1 about here

Discussion

The project described in this paper developed a self-management resource for cancer pain with theoretical potential not only to support patients’ administration of pharmacological and non-pharmacological therapies but also to address provider and health system barriers to care by improving patient-provider communication and facilitating coordination between different providers.

A RCT is underway to test whether this resource, alongside other strategies for overcoming barriers to cancer pain care, can improve patient pain and quality of life (Luckett et al., 2018). This research will test the hypothesis that patients’ sense of control may be an important

mediator in enabling self-management interventions to influence pain-related outcomes. People with cancer pain often report loss of control to be an important dimension of their experiences in relation to both pain and cancer itself (Flemming, 2010; Luckett et al., 2013). Interventions targeting sense of control and the related construct of self-efficacy have been found to lead to improvements in the ability to self-manage pain, functional status and, less frequently, pain itself in people with chronic non-cancer pain (Marks et al., 2005). Studies focusing on cancer pain to date have been largely descriptive, but have found consistent associations between self-efficacy for pain management and pain intensity/interference (Porter et al., 2008; Jerant et al., 2011; Kravitz et al., 2011; Kowal et al., 2012; Edmond et al., 2013; Baker et al., 2014). Evidence for a relationship between self-efficacy in communication and cancer pain experience has been more mixed, with the single intervention study to date finding coaching aimed at improving communication self-efficacy to lead to only temporary improvements in pain interference and no change in pain severity (Jerant et al., 2011; Kravitz et al., 2011). More evaluative research of the kind underway by the current researchers is needed to understand whether self-efficacy can play a therapeutic role in improving pain in and of its own right, or whether correlations to date merely reflect that self-efficacy is a surrogate for ability to self-manage, in turn responsible for better pain control.

Unfortunately, acceptability testing of the new resource found that patients found it difficult to appraise their capability, opportunity and motivation (COM) to self-manage pain. A systematic review by Michie et al (2011) suggests that COM may be prerequisites for behaviour change across health conditions (Michie et al., 2011), and further research is needed to understand how best these components can be assessed in a clinical context. In the meantime, the patient self-management resource designed in the current project may offer some utility for less formal assessment of COM during provider-patient discussion of goals and the pain plan.

Results from acceptability testing also indicated that a range of pain rating scales and diaries should be made available to cater for varying preferences. This is consistent with findings from our meta-synthesis that many patients find it difficult to rate pain using numerical or visual analogue scales (Luckett et al., 2012). Fortunately, there is now a variety of scales and diaries available to suit many patient needs. Training patients to use pain scales effectively is associated with improved uptake and adherence (Morren et al., 2009). Whilst recording pain patterns over time is informative to management, providers also need to consider the

possibility that rating pain could increase the perception of morbidity, potentially increasing fatalistic perceptions and negatively affecting a patient emotionally (Luckett et al., 2012).

Limitations

While use of discrete and diverse methods yielded rich data for triangulation, we lacked a formal approach for integrating results. Also, some of the functions we designed the resource's content and features to fulfil remain largely hypothetical. For example, whilst patient-held records have theoretical potential to improve care coordination, evidence for effectiveness is limited, and implementation faces its own set of barriers (Ko et al., 2010; Aubin et al., 2012; Price et al., 2015). One study found patient-held records to improve patients' self-monitoring and sense of control but failed to generate substantial engagement by providers (Williams et al., 2001).

Conclusion

Self-management resources have potential for addressing barriers not only at the patient level but also the levels of the provider and health system. A cluster randomised controlled trial is underway to test effectiveness of the resource designed in this project in combination with pain screening, audit and feedback, and provider education. More research of this kind is needed to understand how interventions at different levels can be optimally combined to overcome barriers and improve care.

References

- Agar M, L.T., Davidson PM, Boyle F, Liauw W, Green A, Lovell M. (2012). Australian survey of current practice and guideline use in adult cancer pain assessment and management: Perspectives of oncologists and haematologists. Poster presented at the MASCC/ISOO International Symposium on Supportive Care in Cancer. New York, United States.
- Aubin, M., Giguere, A., Martin, M., Verreault, R., Fitch, M.I., Kazanjian, A. & Carmichael, P.H. (2012). Interventions to improve continuity of care in the follow-up of patients with cancer. *Cochrane Database of Systematic Reviews*, 7, CD007672.
- Baker, T.A., O'Connor, M.L. & Krok, J.L. (2014). Experience and knowledge of pain management in patients receiving outpatient cancer treatment: what do older adults really know about their cancer pain? *Pain Medicine*, 15(1), 52-60.
- Bodenheimer, T., Lorig, K., Holman, H. & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *JAMA*, 288(19), 2469-2475.
- Brink-Huis, A., van Achterberg, T., Schoonhoven, L., Brink-Huis, A., van Achterberg, T. & Schoonhoven, L. (2008). Pain management: a review of organisation models with integrated processes for the management of pain in adult cancer patients. *Journal of Clinical Nursing*, 17(15), 1986-2000.
- Cancer Council Australia. (2013). "Overcoming cancer pain: A guide for people with cancer, their families and friends." Retrieved 18th February, 2014, from <http://www.cancercouncil.com.au/wp-content/uploads/2014/01/Can487-Overcoming-Pain-NSW-Lores2.pdf>.
- Clayton J, D.P., Phillips J, Luckett T, Green A, Agar M, Broadbent A, Lovell M on behalf of the STOP Pain Project Team, ImPaCCT (Improving Palliative Care through Clinical Trials) and HammondCare. (2012). STOP Pain Project: a collaborative, interdisciplinary project to improve the person-centredness of assessment and management of cancer pain. Poster presentation at the International Psycho-Oncology Society (IPOS) 14th World Congress. Brisbane, Australia.

- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M. & Medical Research Council, G. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, 337, a1655. Also available open-source online at www.mrc.ac.uk/complexinterventionsguidance.
- Cresswell, J. (2003). Research design: qualitative, quantitative, and mixed methods approaches. Thousand Oaks, CA, Sage.
- Davies, P., Walker, A.E. & Grimshaw, J.M. (2010). A systematic review of the use of theory in the design of guideline dissemination and implementation strategies and interpretation of the results of rigorous evaluations. *Implementation Science*, 5, 14.
- Deandrea, S., Montanari, M., Moja, L. & Apolone, G. (2008). Prevalence of undertreatment in cancer pain. A review of published literature. *Annals of Oncology*, 19(12), 1985-1991.
- Edmond, S.N., Shelby, R.A., Kimmick, G.G., Marcom, P.K., Peppercorn, J.M. & Keefe, F.J. (2013). Symptom communication in breast cancer: relationships of holding back and self-efficacy for communication to symptoms and adjustment. *Journal of Psychosocial Oncology*, 31(6), 698-711.
- Flemming, K. (2010). The use of morphine to treat cancer-related pain: a synthesis of quantitative and qualitative research. *Journal of Pain & Symptom Management*, 39(1), 139-154.
- Foley, K.M. (2011). How well is cancer pain treated? *Palliative Medicine*, 25, 398-401.
- Improving Palliative Care through Clinical Trials (ImpaCCT). (2013). "Cancer pain management in adults: Evidence-based clinical practice guidelines adapted for use in Australia." from http://wiki.cancer.org.au/australia/Guidelines:Cancer_pain_management.
- Jacobsen, R., Liubarskiene, Z., Moldrup, C., Christrup, L., Sjogren, P. & Samsanaviciene, J. (2009). Barriers to cancer pain management: a review of empirical research. *Medicina (Kaunas, Lithuania)*, 45, 427-433.

- Jerant, A., Franks, P. & Kravitz, R.L. (2011). Associations between pain control self-efficacy, self-efficacy for communicating with physicians, and subsequent pain severity among cancer patients. *Patient Education And Counseling*, 85(2), 275-280.
- Ko, H., Turner, T., Jones, C. & Hill, C. (2010). Patient-held medical records for patients with chronic disease: a systematic review. *Quality & Safety in Health Care*, 19(5), e41.
- Kowal, J., Wilson, K.G., McWilliams, L.A., Peloquin, K. & Duong, D. (2012). Self-perceived burden in chronic pain: relevance, prevalence, and predictors. *Pain*, 153(8), 1735-1741.
- Kravitz, R.L., Tancredi, D.J., Grennan, T., Kalauokalani, D., Street, R.L., Slee, C.K., Wun, T., Oliver, J.W., Lorig, K. & Franks, P. (2011). Cancer Health Empowerment for Living without Pain (Ca-HELP): effects of a tailored education and coaching intervention on pain and impairment. *Pain*(7), 1572-1582.
- Liau W, L.T., Davidson PM, Boyle F, Agar M, Green A, Lovell M. (2012). Improving assessment and management of adult cancer pain: A nationwide survey of oncologists and haematologists. Poster presented at the National Prescribing Service's National Medicines Symposium. Sydney, Australia.
- Lorig, K.R. & Holman, H. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*, 26(1), 1-7.
- Lovell, M., Agar, M., Lockett, T., Davidson, P.M., Green, A. & Clayton, J. (2013). Australian Survey of Current Practice and Guideline Use in Adult Cancer Pain Assessment and Management: Perspectives of Palliative Care Physicians. *Journal of Palliative Medicine*, 16(11), 1403-1409.
- Lovell M, B.F., Agar M, Lockett T, Phillips J, Clayton J, Green A, Birch MR, Davidson PM. (2013). (Accepted) Implementation forum for cancer pain assessment and management guidelines. Breakfast session presented at the 40th Annual Scientific Meeting of the Clinical Oncological Society of Australia (COSA). Adelaide, Australia.
- Lovell, M., Birch, M., Lockett, T., Phillips, J., Davidson, P., Agar, M. & Boyle, F. (In press). Screening and audit as service-level strategies to support implementation of

Australian guidelines for cancer pain management in adults: a feasibility study. *Pain Management Nursing*, Accepted May 13th 2018.

Lovell M, L.T., Davidson PM, Green A. (2012). Assessment & management of adult cancer pain: Lessons from a systematic review & synthesis of qualitative studies. Poster presented at the Australian Pain Society 32nd Annual Scientific Meeting. Melbourne, Australia.

Lovell M, L.T., Davidson PM, Green A. (2012). Assessment & management of adult cancer pain: Lessons from a systematic review & synthesis of qualitative studies. Poster presented at the 7th World Research Congress of the European Association of Palliative Care. Trondheim, Norway.

Lovell M, L.T., Phillips J, Stubbs J. (2013). Patient-Centred Approaches to Cancer Pain. Topical session presented at the Australian Pain Society's 33rd Annual Scientific Meeting. Canberra, Australia.

Lovell, M., Lockett, T., Boyle, F., Phillips, J., Agar, M. & Davidson, P.M. (2014). Patient education, coaching and self-management for cancer pain. *Journal of Clinical Oncology* doi: 10.1200/JCO.2013.1252.4850.

Lovell, M., Lockett, T., Boyle, F., Stubbs, J., Phillips, J., Davidson, P.M., Olver, I., von Dincklage, J. & Agar, M. (2015). Adaptation of international guidelines on assessment and management of cancer pain for the Australian context. *ASIA-PACIFIC JOURNAL OF CLINICAL ONCOLOGY*, 11(2), 170-177.

Lovell M, P.J., Agar M, Lockett T, Boyle F, Green A, Stubbs J and Davidson PM. (2013). What will it take to improve cancer pain outcomes? : Developing a dissemination and implementation strategy to promote a person-centred clinical pathway for cancer pain. Workshop presented at the Cancer Nurses Society of Australia, 16th Winter Congress. Brisbane, Australia.

Lovell, M.R., Forder, P., Stockler, M., Butow, P.N., Briganti, E., Chye, R., Goldstein, D. & Boyle, F.M. (2010). A randomised controlled trial of a standardised educational intervention for patients with cancer pain. *Journal of Pain and Symptom Management*, 40(1), 49-59.

- Luckett, T., Davidson, P.M., Boyle, F., Liauw, W., Agar, M., Green, A.R. & Lovell, M. (2013). Australian survey of current practice and guideline use in adult cancer pain assessment and management: Perspectives of palliative care physicians. *Journal of Palliative Medicine*, 16(11), 1403-1409.
- Luckett, T., Davidson, P.M., Green, A., Boyle, F., Stubbs, J. & Lovell, M. (2012). Assessment and management of adult cancer pain: a systematic review and synthesis of recent qualitative studies aimed at developing insights for managing barriers and optimizing facilitators within a comprehensive framework of patient care. *Journal of Pain and Symptom Management*, doi: 10.1016/j.jpainsymman.2012.1007.1021.
- Luckett, T., Davidson, P.M., Green, A., Boyle, F., Stubbs, J. & Lovell, M. (2013). Assessment and management of adult cancer pain: a systematic review and synthesis of recent qualitative studies aimed at developing insights for managing barriers and optimizing facilitators within a comprehensive framework of patient care. *Journal of Pain and Symptom Management*, 46(2), 229-253.
- Luckett T, D.P., Agar M, Phillips J, Boyle F, Stubbs J, Green A, Marie N, Lovell M. (2014). Triangulation of methods as a resource-efficient approach to developing complex interventions to support implementation of evidence-based guidelines: the example of cancer pain. Poster presentation, International Forum on Quality and Safety in Healthcare Conference. Paris, France.
- Luckett, T., Phillips, J., Agar, M., Lam, L., Davidson, P.M., McCaffrey, N., Boyle, F., Shaw, T., Currow, D.C., Read, A., Hosie, A. & Lovell, M. (2018). Protocol for a phase III pragmatic stepped wedge cluster randomised controlled trial comparing the effectiveness and cost-effectiveness of screening and guidelines with, versus without, implementation strategies for improving pain in adults with cancer attending outpatient oncology and palliative care services: the Stop Cancer PAIN trial. *BMC Health Services Research*, 18(1), 558.
- M., L. (2013). Implementation forum for cancer pain assessment and management guidelines. Oral presentation at the 12th Australian Palliative Care Conference. Canberra, Australia.

- M., L. (2013). Palliative cancer care. Oral presentation at the Pharmaceutical Society of Australia Clinical and Practice Expo. Sydney, Australia.
- Marie, N., Lockett, T., Davidson, P.M., Lovell, M. & Lal, S. (2013). Optimal patient education for cancer pain: a systematic review and theory-based meta-analysis. *Supportive Care in Cancer*, 21(12), 3529-3537.
- Marks, R., Allegrante, J.P. & Lorig, K. (2005). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: implications for health education practice (part II). *Health Promot Pract*, 6(2), 148-156.
- McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L.S., Lorig, K. & Wagner, E.H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: a Cancer Journal for Clinicians*, 61(1), 50-62.
- Medical Research Council (2006). Developing and evaluating complex interventions: new guidance. London, MRC.
- Michie, S., van Stralen, M.M. & West, R. (2011). The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implementation Science*, 6, 42.
- Michie, S., van Stralen, M.M. & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implement Sci*, 6, 42.
- Morren, M., van Dulmen, S., Ouwerkerk, J. & Bensing, J. (2009). Compliance with momentary pain measurement using electronic diaries: a systematic review. *Eur J Pain*, 13(4), 354-365.
- National Comprehensive Cancer Network (NCCN) (2011). NCCN Clinical Practice Guidelines in Oncology: Adult cancer pain. New York, NCCN.
- National Institute for Health and Care Excellence (NICE). (2012). "Managing pain with strong opioids in people with advanced, progressive disease." 1st August 2013, from <http://publications.nice.org.uk/managing-pain-with-strong-opioids-in-people-with-advanced-progressive-disease-ifp140/about-this-information>.

NHS Quality Improvement Scotland (2004). Best practice statement: The management of pain in patients with cancer. Edinburgh, NHS Quality Improvement Scotland.

Oldenmenger, W.H., Sillevius Smitt, P.A.E., van Dooren, S., Stoter, G. & van der Rijt, C.C.D. (2009). A systematic review on barriers hindering adequate cancer pain management and interventions to reduce them: a critical appraisal. *European Journal of Cancer*, 45(8), 1370-1380.

Phillips J, A.K., Keall R, Luckett T, Davidson PM, Lovell M on behalf of the STOP Pain Investigators. (2012). Nurses working in community, palliative and aged care settings perceive fewer barriers to cancer pain management than acute care setting: findings of a national survey. Poster presentation at the NSW State Palliative Care Conference. Dubbo, Australia.

Phillips J, L.T., Davidson PM, Lovell M, Green A. (2012). Stop Pain Project: A dual health professional and patient pathway to manage pain in individuals with cancer. Oral presentation at the Cancer Nurses Society of Australia's 15th Winter Congress. Hobart, Australia.

Phillips, J.L. & Currow, D.C. (2010). Cancer as a chronic disease. *Collegian*, 17, 47-50.

Phillips, J.L., Lovell, M., Luckett, T., Agar, M., Green, A.R. & Davidson, P.M. (2015). Australian survey of current practice and guideline use in adult cancer pain assessment and management: The community nurse perspective. *Collegian*, 22(1), 33-41.

Porter, L.S., Keefe, F.J., Garst, J., McBride, C.M. & Baucom, D. (2008). Self-efficacy for managing pain, symptoms, and function in patients with lung cancer and their informal caregivers: Associations with symptoms and distress. *PAIN®*, 137(2), 306-315.

Price, M., Bellwood, P., Kitson, N., Davies, I., Weber, J. & Lau, F. (2015). Conditions potentially sensitive to a personal health record (PHR) intervention, a systematic review. *BMC Med Inform Decis Mak*, 15, 32.

Ripamonti, C.I., Bandieri, E., Roila, F. & Group, E.G.W. (2011). Management of cancer pain: ESMO Clinical Practice Guidelines. *Annals of Oncology*, 22 Suppl 6, vi69-77.

- Scottish Intercollegiate Network (SIGN) (2008). Control of Pain in Patients with Cancer: A national clinical guideline. SIGN. Edinburgh.
- van den Beuken-van Everdingen, M.H., Hochstenbach, L.M., Joosten, E.A., Tjan-Heijnen, V.C. & Janssen, D.J. (2016). Update on Prevalence of Pain in Patients With Cancer: Systematic Review and Meta-Analysis. *J Pain Symptom Manage*, 51(6), 1070-1090.e1079.
- van den Beuken-van Everdingen, M.H.J., de Rijke, J.M., Kessels, A.G., Schouten, H.C., van Kleef, M. & Patijn, J. (2007). Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Annals of Oncology*, 18(9), 1437-1449.
- Williams, J.G., Cheung, W.Y., Chetwynd, N., Cohen, D.R., El-Sharkawi, S., Finlay, I., Lervy, B., Longo, M. & Malinovsky, K. (2001). Pragmatic randomised trial to evaluate the use of patient held records for the continuing care of patients with cancer. *Qual Health Care*, 10(3), 159-165.
- Wong, K.F., Charman, J., Round, T. & Henson, K.E. (2018). Cancer patients and primary care prescribed medications: offering insights into symptoms, polypharmacy and multimorbidity. *British Journal of General Practice*, 68(suppl 1).
- World Health Organization (WHO) (2002). Innovative Care for Chronic Conditions: Building Blocks for Action. Geneva, WHO.

Table 1. Pain self-management resource - objectives and associated content aimed at addressing barriers to care at the levels of the patient, provider and health system

Level of barrier	Objective	Associated content in the pain self-management resource
Patient	To increase patient's sense of control	Reassurance that most pain can be controlled, even if not completely relieved (cover page) Acknowledgement that patients are experts on their own pain and needs (cover page) Tool for identifying potential barriers in reaching goals and how to overcome these (goal-setting) Contact details for support, including after hours (management plan) Guidance on which situations warrant seeking medical attention
	To encourage reporting and monitoring of pain and alleviating/exacerbating factors	Highlights importance of pain reporting and monitoring, including triggers and alleviators (pain diary) Alternative pain diary formats highlighted to acknowledge varying preferences and enable choice aimed at improving face validity, interpretability and sustainability (pain diary)
	To support patient/caregiver adherence to agreed treatment regimen	Patient-held record of regular and breakthrough analgesia frequency/dose, laxatives, and non-pharmacological management (management plan)
Provider	To ensure management is person-centred and accords with patient priorities	Template for personalised SMART goals (goal-setting) 'Acceptable pain score' to give insight into patient's preferred balance between pain and pharmacological side-effects and inform interpretation of assessments (management plan)
	To foster patient/provider communication and teamwork	Highlights different expertise medical team and patient bring to co-managing pain Promotion of pain diary as a means of deepening provider understanding of pain patterns, triggers and alleviators (pain diary)
System	To facilitate coordination between different care providers	Encouragement to take goal setting tool, management plan and pain diary to every appointment ensure providers stay 'on the same page' (front cover)

SMART = specific, measureable, achievable, relevant, achievable and time-framed

Table 2. Examples of patient quotes on the use of a draft self-management resource and “*Overcoming Cancer Pain*” booklet (Cancer Council Australia, 2013)

Resource	Examples of patient and carer statements
Goal setting tool	<ul style="list-style-type: none"> <li data-bbox="584 400 1973 475">• [Goal setting was useful for] <i>recognition of when I need to take relief [pain] in advance.</i> Female, age 67, metastatic breast cancer <li data-bbox="584 512 1973 624">• <i>‘Nothing has really changed much in the last 12 months. I really haven’t needed to set new goals because what’s been done is working. I guess the goal is just to maintain it the way it is now.</i> Female, age 63, metastatic breast cancer
Pain management plan	<ul style="list-style-type: none"> <li data-bbox="584 667 1973 742">• <i>Just knowing that there was someone there who can help you if you need help.</i> Male carer of wife, age 77 years, metastatic breast cancer
“ <i>Overcoming Cancer Pain</i> ” booklet	<ul style="list-style-type: none"> <li data-bbox="584 778 1973 853">• <i>Gave me information about why a particular pain drug would be better than another one.</i> Female, age 63, metastatic breast cancer <li data-bbox="584 890 1973 1002">• <i>Probably understanding that the information that they [providers] would like to know [and] the whole concept of break-through and how to deal with it. It sets out a bit of a frame work which would indicate an expected trajectory for pain.</i> Female, age 60, metastatic colorectal cancer <li data-bbox="584 1038 1973 1150">• <i>The Cancer Council booklets are fantastic. Very applicable and particularly sharing that information with civilians because really we knew nothing about cancer, outside a lay persons experience of life.</i> Male carer of wife, age 67, metastatic breast cancer <li data-bbox="584 1187 1973 1230">• <i>Takes you from having no knowledge to having some.</i> Male, age 87 years, pancreatic cancer

Pain Management Plan

This plan includes the most important information you need to manage your pain.

- The plan should be made together with your healthcare team.
- Ask your doctor to sign and date the form on the inside page.
- Discuss any changes to the medication sections with your healthcare team first.

Other sections should be completed as follows.

Acceptable pain score

This helps others understand what you mean when you rate your pain on a scale of 0-10. Pain experiences is personal and ratings vary. While some people feel that '0' is the only acceptable level of pain, other people may accept higher pain scores if this means fewer medication side effects.

When to seek help

Situations when you need to seek help include sudden changes in pain severity, feeling or location. The plan may be to call someone in your healthcare team or, in other situations, to go to the Emergency department of the nearest hospital. Many people worry about bothering health professionals, so having a plan helps you make a confident decision if something unexpected happens.

Keeping a pain diary

Keeping a record of your pain, what you have tried for relief and how it has worked with and what has helped relieve it can help you and those caring for you to understand more about your pain and how it can be managed.

Your health professional may give you a diary to fill in. Some people use a mobile device, such as a smartphone, to keep track. Below is a sample pain diary, which can be found on the NPG Medication website, www.npg.org.au/_data/assets/pdf_file/0005/85338/My-pain-diary.pdf

DATE	TIME	TYPE OF PAIN	SEVERITY	LOCATION	CHARACTERISTICS	TRIGGER	RELIEF

Whichever diary you use, take it along to every appointment with your healthcare team. That way it can be used to guide discussions about your pain and its management. Notes you may find it useful to carry your pain diary at all times and to add notes as needed.

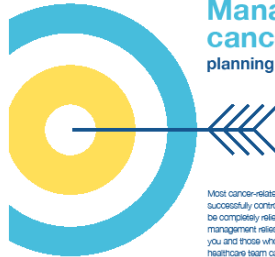
This resource was developed for the Stop Cancer Pain Project, which is funded by competitive research grant from the National Breast Cancer Foundation.



Keeping a diary will help you notice what makes your pain better or worse. Sometimes a specific event or situation can cause pain to occur. This is called a trigger. Knowing what triggers your pain might help you to prevent it or relieve it. For example, if sitting down for a long period of time makes your back ache, you can take pain relief before travelling or going to a movie.

On the other hand some activities may help your pain, like a warm bath, heat pack or massage.

Managing cancer pain planning for success



Most cancer-related pain can be successfully controlled even if it can't be completely relieved. Successful pain management relies on teamwork between you and those who care for you. While the healthcare team can offer expert advice, you are the expert on what your pain feels like, what makes it better or worse, and how it affects you day to day.

This booklet includes two tools to help you and your team better manage your pain and understand your needs and wishes.

- Pain-Goal Setting Tool
- Pain Management Plan

Take this booklet with you whenever you attend a healthcare appointment, so that the health professionals you see at different times and places stay 'on the same page'.

Pain Goal-Setting Tool

This tool will help you and your team set 'SMART' pain management goals.

Specific
Measurable
Achievable
Relevant to you
Time-based

Setting goals with your team will help them understand what you want from pain management. Having goals also helps you manage your pain.

This page is an example. The inside page is for you to set your own goals.

Goal	How will you measure it?	When will you achieve the goal?	
Goal 1	Find a balance between pain medication and its impact on my thinking	Pain less than 3 out of 10 and able to read a book	By discharge from hospital
Goal 2	Attend a family event interstate	Attending important family events	Meggie's wedding (3 October)
Goal 3	Feel in control of pain	Fewer episodes of pain over one week	Next appointment with doctor

Possible problem	How will I manage this problem?	
Goal 1	Pain level increases and I have to take extra medication that affects my thinking	Gradually reduce medication dose every 24 hours
Goal 2	Becoming more anxious as the event gets closer and I want to stay home	Have medication planned for the trip, and a plan to follow on the day
Goal 3	Feeling scared and out of control while waiting for pain medication to work	Relax and breathe slowly to stay calm and see how this affects my pain level and feelings

Pain Goal-Setting Tool

GOAL	How will you measure it?	When will you achieve the goal?
Goal 1		
Goal 2		
Goal 3		

Possible problem	How will I manage this problem?
Goal 1	
Goal 2	
Goal 3	

Name: _____

Date: _____

Regular pain relief		
Medication	Frequency	Dose
'Breakthrough' pain plan if regular relief insufficient		
Medication	Frequency	Dose
Laxative plan if taking opioids		
Medication	Frequency	Dose
Other adverse effect management		
Non-medicinal pain management (e.g. heat, massage, distraction)		

Acceptable pain score (0-10)										
0	1	2	3	4	5	6	7	8	9	10
← No pain									worst pain →	
When to seek help										
1	_____									
2	_____									
3	_____									
Contact										
Mon-Fri (Business hours)										
After hours										
Discussed with doctor										
Doctor's name										
Signature	Date									

Pain Management Plan

Figure 1. Pain self-management resource developed through a mixed method project