# BMJ Open Factors influencing the translation of shared cancer follow-up care into clinical practice: a systematic review

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#### **ABSTRACT**

**Background** The increasing incidence of cancer, coupled with improved survivorship, has increased demand for cancer follow-up care and the need to find alternative models of care. Shared cancer follow-up care in general practice is a safe option in terms of quality of life and cancer recurrence; however, there are barriers to translating this into practice. This review aimed to identify factors that influence the translation of shared cancer follow-up care into clinical practice.

Methods Systematic review. Seven electronic databases: MEDLINE, Science Citation Index, Academic Search Complete, CINAHL, APA Psychinfo, Health Source: Nursing/ Academic Edition and Psychology and Behavioural Sciences Collection, were searched for published papers between January 1999 and December 2021. The narrative review included papers if they were available in full-text, English, peer-reviewed and focused on shared cancer follow-up care.

**Results** Thirty-eight papers were included in the final review. Five main themes emerged: (1) reciprocal clinical information sharing is needed between oncologists and general practitioners, and needs to be timely and relevant; (2) responsibility of care should be shared with the oncologist overseeing care; (3) general practitioners skills and knowledge to provide cancer follow-up care; (4) need for clinical management guidelines and rapid referral to support general practitioners to provide shared follow-up care and (5) continuity of care and satisfaction of care is vital for shared care.

Conclusion The acceptability of shared cancer follow-up care is increasing. Several barriers still exist to translating this into practice. Work is required to develop a sharedcare model that can support general practitioners, while the oncologist can oversee the care and implement twoway communication between general and oncologists' clinics. The move towards integrating electronic healthcare records and web-based platforms for information exchange provides a promise to the timely exchange of information.

PROSPERO registration number CRD42020191538.

#### **BACKGROUND**

After active cancer treatment is complete, patients require ongoing follow-up care to treat late side effects, monitor recurrence and provide psychosocial care. 1-3 The duration and frequency of follow-up care

#### STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This review was undertaken with a rigorous systematic methodology and has identified some important enablers to translate shared cancer follow-up care into clinical practice.
- ⇒ It has some limitations. Only published peerreviewed literature was included, and it may therefore be subject to publication bias. Papers were limited to those in English, and there may be papers available in other languages that were not captured.
- ⇒ Given that healthcare practices vary internationally. this review may not reflect all practices. This review was limited to adult patients and excluded skin and blood cancers.

depend on the type and stage of cancer and the treatment. Cancer follow-up models of care fall into sequential, parallel or sharedcare models. 4 5 Sequential care is when one provider delivers all healthcare. Parallel care is when the specialist manages cancer-related issues (oncologist-led), and the general practitioner manages non-cancer-related health matters. Parallel care that is oncologist-led is the current most common model of care<sup>6</sup> and is usually provided in a hospital setting.<sup>8</sup> Shared-care is a partnership between health professionals that improves the quality of patient care by integrating the delivery within and across the health service and enhances communication between providers.<sup>9</sup>

The Institute of Medicine (IOM) states that 'cancer care is often not as patient-centred, accessible, coordinated or as evidencedbased as it should be'. 10 They emphasised the urgent need for new cancer models of care where health professionals work together to ensure that every patient receives care tailored to their particular situation. 10 The IOM developed a conceptual framework to address the identified deficiencies that aimed to place the patient at the centre of care in a system that supports patients in making informed medical decisions consistent with their needs, values and preferences. The



framework highlighted the need for adequately trained staff, a coordinated workforce, evidence-based cancer care and information technology to improve cancer care quality and patient outcomes.

Due to the growing number of cancer survivors and increased demand for follow-up consultations, the sustainability of oncologist-led parallel care has been questioned. <sup>11–14</sup> There has been limited progress in developing cancer follow-up models of care that address the person-centred care domains of respect for patients' preferences, coordination and integration of care, information and education, continuity and transition and access to care. <sup>15</sup>

The evidence for the benefits of shared cancer follow-up models of care is growing. <sup>16–20</sup> Randomised controlled trials have shown no difference in the recurrence rate or quality of life when a general practitioner provides cancer follow-up care compared with an oncologist. <sup>21–24</sup> Despite acknowledging the benefits of general practitioners' playing a greater role in cancer follow-up care, there are barriers to translating shared cancer follow-up care into practice. The specific research question for this systematic review was, 'What factors influence translating shared cancer follow-up care into clinical practice?'

#### **METHOD**

A protocol with defined objectives, study selection criteria and approaches to assess study quality was developed and registered with PROSPERO (online supplemental file 1). This systematic review followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses format<sup>25</sup> and statement (online supplemental file 2): (i) development of inclusion/exclusion criteria; (ii) extraction and coding of study characteristics and findings and (iii) data analysis and synthesis of findings. Both quantitative and qualitative papers were included in this narrative systematic review. This systematic review was part of a larger study on shared cancer follow-up care, approved by the Illawarra Shoalhaven Local Health District and University of Wollongong Human Research Ethics Committee (2020ETH00301).

# **Eligibility criteria**

Inclusion criteria: (a) general practitioner, patient and/or oncologist perceptions of shared cancer follow-up care; (b) general practitioner involvement in shared cancer follow-up care (not a substitute of care); (c) intervention with the general practitioner involved in shared cancer follow-up care; (d) adults patients in the follow-up period and (e) papers peer-reviewed, published in English between January 1999 and December 2021.

Exclusion criteria: (a) commentary, editorial, literature review, protocol; (b) patients on active treatment; (c) palliative care; (d) surgical only treatment; (e) paediatric and (f) skin cancer, melanoma or blood cancer (these were excluded as the follow-up regime varies to solid tumour follow-up).

# Information sources and search strategy

The search was conducted in the following seven electronic databases: MEDLINE, Science Citation Index, Academic Search Complete, CINAHL, APA Psycinfo, Source: Nursing/Academic Edition, Psychology and Behavioural Sciences Collection. To ensure relevant results were obtained, search terms were developed using a modified version of the PICO (Population, Interest, Comparison and Outcome) Framework.<sup>26</sup> The search terms were constructed and agreed on by both authors. The second author is a skilled academic who teaches literature searching and research methods at the postgraduate level and has experience in conducting systematic reviews, and a university librarian was also consulted. Alternative keywords for each search term (see table 1) were combined using the Boolean operator 'OR' to ensure all possible variations were captured; the search was then refined by combining the searches with 'AND'. The wildcard '\*' was used to allow for word truncations. The search string is attached as online supplemental file

#### **Study selection**

Papers were imported into Zotero reference management software, and duplicates were removed. Both authors independently used a stepwise procedure to identify relevant papers. Risk of bias was systematically assessed by two researchers using separate checklists. TS performed the

Table 1 Search terms			
PICO	Search terms		
Population	'general practitioner' OR 'primary care physician' OR 'family physician' OR 'family practitioner' OR GP OR doctor OR specialist OR oncologist		
	AND		
Interest	'model of care' OR 'shared-care' OR 'shared care' OR 'follow-up care' OR 'follow-up care'		
	AND		
Outcome	Cancer OR oncolog* OR neoplasm		
GP, general practitioners.			



initial search and screened the titles and abstracts against the inclusion/exclusion criteria; the remaining texts were retrieved in full and screened against the inclusion/exclusion criteria. HS independently checked the results and compared her findings with the first author. The authors met with the final list of included/excluded papers and resolved any disagreement by discussion and consensus. A third reviewer from the broader research team was available in case consensus could not be reached between the first two reviewers. Reasons for exclusion were recorded.

### **Data collection and quality appraisal**

The following data were extracted into a Microsoft Excel spreadsheet: first author, year, country, study type, aim, sample, methods, results and conclusion. The rigour of each included study was assessed by both authors using the Joanne Briggs Institute (JBI) Critical Appraisal tools checklists<sup>27</sup> that use a three-point grading system: include, exclude and seek more information. These grades are based on desirable and undesirable effects, quality of evidence, values and preferences and costs.<sup>27</sup> The JBI suite was selected as it contains 13 checklists that provide consistency in reviewing the different types of papers without using different tools with different grading/scoring systems.

#### **Data synthesis**

TS summarised the results, discussion and conclusion of the included papers into one Microsoft Excel document. Both authors then synthesised the findings into themes using Braun and Clarke's six-step thematic analysis framework.<sup>28</sup> Disagreements regarding the allocation of themes were resolved by discussion and consensus; the thematic analysis results are presently narratively.

#### Patient and public involvement

Patients and members of the public were not involved in this study. We intend to engage the public in disseminating our results, including social media engagement, newsletters and conferences.

# **RESULTS**

#### **Study selection**

The initial search yielded 1145 papers after duplicates were removed. After reviewing the abstracts against the inclusion criteria, 1047 were removed as they did not meet the inclusion criteria. The full text of the remaining 98 papers was examined in full, and a further 59 were removed. The remaining papers' reference lists were scanned to capture any additional papers that may have been missed in the initial search. The resultant 39 papers were assessed for quality using the JBI critical appraisal tools, resulting in 1 paper being excluded due to poor methodological quality, bringing the final total to 38 papers (see figure 1).

#### **Study characteristics**

Of the 38 included papers, 11 were from the USA, nine from Australia, six from Canada; the remaining papers

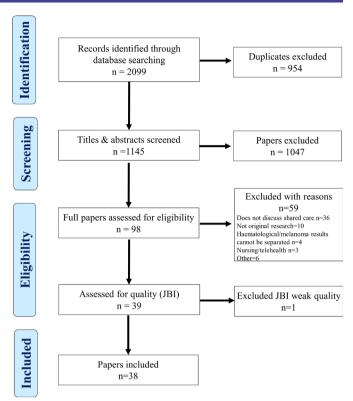


Figure 1 The Preferred Reporting Items for Systematic reviews and Meta-Analyses diagram representing the systematic literature search. JBI, Joanne Briggs Institute.

were from the UK, The Netherlands, Denmark, Norway, Italy, Singapore, Germany and France (see table 2). Half of the papers were published in the last 5 years, with the sample sizes ranging from 20 to 2159. There were 20 quantitative, 17 qualitative and one mixed-methods papers (see table 2).

#### Thematic analysis

Five themes were identified and are discussed below. Themes are ordered from the highest number of instances of articles within each them; however, frequency does not necessarily equate to order of importance.<sup>28</sup>

# Reciprocal clinical information sharing

Twenty-three papers referred to the importance of timely and quality sharing of clinical information between health professionals. Information sharing within health-care is complex and fundamental for effective and efficient shared care. <sup>29–31</sup> The primary method to share clinical information between doctors and patients was face-to-face verbal communication; <sup>32</sup> between oncologists and general practitioners, it was written correspondence, followed by phone, integrated electronic health records and email. <sup>29 30</sup>

Despite written communication being the primary method for information sharing, general practitioners were not provided quality and timely clinical information from oncologists to manage cancer follow-up care. 31-35 One paper found that only half of the oncologists said that they directly shared clinical information about their

Table 2 Summary of	Table 2 Summary of included papers			
First author, year				
Anvik et al, 2006 <sup>61</sup> Norway	To explore patient, relatives and GP views of the GPs role during initial cancer follow-up. Qual.—Int., FG.	Patients have trust in the GP. GP require good access to specialists. Follow-up plans will improve the care and cooperation. Hospitals to initiate a stronger collaboration.	CC, G	
Aubin <i>et al</i> , 2010 <sup>46</sup> Canada	To describe the actual and expected role of a GP in the different phases of cancer. Quant.—Quest.	Patients prefer oncologists to maintain overall responsibility. Patients would like their GP to be more involved, requires better communication and collaboration.	Res	
Aubin <i>et al</i> , 2012 <sup>4</sup> Canada	To compare patient, GP and specialist expectations of GP involvement during cancer phases. Quant.—Quest.	Differing views of GP role. GPs perceived themselves as involved in shared care; GP responsibility to be clearly outlined, and effective communication implemented.	Res, Inf	
Berkowitz <i>et al</i> , 2018 <sup>47</sup> USA	To explore preferences and knowledge of GPs in the care of head and neck cancer survivors. Quant.—Quest.	32% of GPs felt confident they could manage late/ long-term side effects; 30% believed they were responsible for care after 1 year and 81% after 5 years.	Res, Sk	
Brennan <i>et al</i> , 2010 <sup>38</sup> Australia	To explore follow-up practices and attitudes to alternative models of cancer care. Quant. and Qual. — Quest.	Specialists are supportive of sharing follow-up care. Survivorship care plan would improve care. 96% of specialists felt GPS needed more training.	Inf, Res, Sk	
Brennan <i>et al</i> , 2011 <sup>33</sup> Australia	To explore experiences with follow- up care and attitudes to alternative models of cancer care. Qual.—Int.	Patients relied on their specialist, but open to their GP playing a role. Communication seen as a barrier. Positive view on care plans.	Inf, CC	
Cheung et al, 2013 <sup>48</sup> USA	To assess how physician attitudes and self-efficacy affect preferences for cancer models of care. Quant. — Quest.	51% GPs support shared care. 59% specialists preferred a specialist-led model. 57% GPs able to perform routing follow-up care. Prior involvement increases willingness.	Sk, Inf, Res	
Coschi <i>et al</i> , 2021 <sup>43</sup> Canada	To assess oncologists' attitudes and beliefs regarding sharing/ transitioning survivorship care. Quant.—Quest.	There is a current lack of routine sharing. Absence of formal policies and guidelines. Patient preference and loss of patient outcome data are barriers.	FG, Inf, Res	
Crabtree <i>et al</i> , 2020 <sup>49</sup> USA	To understand how GPs perceive their role to cancer survivors. 38 GPs. Qual.—Int.	The majority of GPs felt follow-up care was within their role. Some GPs did not feel adequately educated about the needs of cancer survivors.	Res, SK	
Dahlhaus <i>et al</i> , 2014 <sup>34</sup> Germany	To examine German GPs views on their involvement in the care of cancer patients. Qual.—Int.	GPs are well placed for follow-up care. GPs want to stay involved in cancer care. Slow or non-existent information sharing is a barrier to shared cancer care.	CC, Inf, Sk	
Del Giudice <i>et al</i> , 2009 <sup>62</sup> Canada	To determine GP willingness and timeframe for GP-led follow-up model. Quant. — Quest.	GPs willing to take over responsibility of routine follow-up care after 2–3 years. Require a letter, follow-up guidelines, rapid referrals.	G	
Dicicco-Bloom and Cunningham, 2013 <sup>32</sup> USA	To provide a better understanding among GPs, patients and oncologist through cancer care. Qual.—Int.	GPs want regular updates of their patients, and are well placed for care. GPs wanted guidance about follow-up screening and side-effects and better information sharing.	G, Inf	
Doose <i>et al</i> , 2019 <sup>78</sup> USA	To examine patient & health system factors in shared care and quality of cancer care. Quant.—Quest.	No significant relationships between shared care and quality indicators of cancer care. Survivorship care plans may improve the quality of cancer care.	Inf	
Fidjeland <i>et al</i> , 2015 <sup>50</sup> Norway	To explore GP experiences and view providing cancer follow-up and taking a greater role. Quant.—Quest.	78% GPs felt confident in their knowledge and skills to provide follow-up care. Some GPs (42%) were more willing to take on follow-up care after 3 years	G, Res Sk	
Fok <i>et al</i> , 2020 <sup>51</sup> Singapore	To explore GP perspectives of a shared-care programme with oncologists. Qual.—Int., FG.	GPs willing to share the care but recommended role definition, training, clinical protocols, resources and access to oncologist's consultation.	Res, Sk	
			Continue	

Continued



First author, year	Study aim, methodology and		
country	methods	Results/conclusion	Themes
Hall et al, 2011 <sup>52</sup> UK	To explore the opinions and experiences of patients and GPs involved in shared care. Qual.—Int.	Most patients support shared cancer care, if there is robust support from specialist. GPs and patients have concerns about the GP gaining and maintaining clinical skills.	G, Res, Sk
Hanks et al, 2008 <sup>41</sup> Australia	To identify and compare the roles of GPs and colorectal cancer management in Australia. Qual. — Int.	Shared cancer follow-up care is influenced relationships. Improvement in GP and specialist relationship and communication could lead to better shared care.	CC, G, Inf, Res
Haq <i>et al</i> , 2013 <sup>29</sup> Canada	To document information needs of breast cancer patients, GPs and oncology specialists. Qual.—FG, Int.	GPs feel ill-equipped and felt unsure of their role. The care plan made the GP feel more engaged. Guidelines gave GPs more confidence in cancer follow-up care.	G, Inf
Hudson <i>et al</i> , 2012 <sup>60</sup> USA	To examine patient perspectives and preferences on GP roles in their cancer follow-up care. Qual.—Int.	Most patients prefer follow-up care with the specialists. Barriers identified was GP lack of expertise, limited involvement during treatment, lack of continuity of care.	CC, Sk
Hudson <i>et al</i> , 2016 <sup>63</sup> USA	To explore cancer survivors' experiences of follow-up care provided by GPs and oncologists. Quant.—Ques.	Patients rated GPs higher for coordination of care and comprehensive care. Prostate patients rated GPs higher for all items, compared with breast patients.	CC
Klabunde <i>et al</i> , 2013 <sup>39</sup> USA	To assess GPs and oncologists' roles in providing cancer follow-up care. Quant.—Quest.	Over 50% of GPs reported comanaging with an oncologist. GPs had a preference for a shared model care, and receipt of treatment summaries from oncologists.	Res, Inf, Sk
Klabunde <i>et al</i> , 2017 <sup>30</sup> USA	To explore factors that affect cancer patients follow-up communication and coordination. Quant.—Quest.	Half the oncologists communicated with the GP. Oncologists' reliance on written correspondence to communicate with GPs may be a barrier to care coordination.	Inf
Lang <i>et al</i> , 2017 <sup>53</sup> Germany	To assess the role of GPs in German cancer care from patients' perspective. Quant.—Quest.	Patients want their GP to play an active role. A shared care model where the GPs are supported by the specialists and have extra training is recommended.	CC, Res
Laporte <i>et al</i> , 2017 <sup>54</sup> France	To examine how women experienced the post-treatment and perceived the role of the GP. Qual.—Int.	Patients felt abandoned at the end of treatment. Patients accepted follow-up care with their GP, provided there was a close working relationship with the specialist.	CC, Res
Lawn <i>et al</i> , 2017 <sup>37</sup> Australia	To explore cancer survivors' views on shared care: what cancer survivors need. Qual. — G.	Patients need to be at the centre of the care. Information sharing between health professionals is important. It was perceived the GPs lacked the skills for shared care.	Inf, Sk
Lizama <i>et al</i> , 2015 <sup>31</sup> Australia	To investigate GPs perceptions about communication when providing cancer care. Quant.—Quest.	GPs want to be kept in the loop and want follow-up information. Timely transfer of relevant information between primary care providers and specialists is essential.	CC, G, Inf
Nielsen, 2003 <sup>40</sup> Denmark	To determine the effect of shared care on the attitudes of cancer patients towards the healthcare system and their health-related quality of life. Quant.—RCT, Quest.	Young people rated GPs knowledge higher than the control group. No significant difference in quality of life between the intervention group and control group.	G, Inf
Potosky <i>et al</i> , 2011 <sup>55</sup> USA	To compare GPs and oncologists' knowledge, attitudes and practices for follow-up care. Quant.—Quest.	Specialists believe GPs lack the skills. Effective communication between GPs and specialists can increase GP confidence in their ability to perform follow-up care.	Res, Sk

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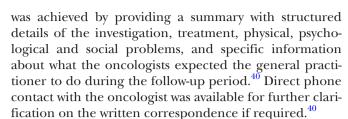
Table 2 Continued	Oharda elim madhada l		
First author, year country	Study aim, methodology and methods	Results/conclusion	Themes
Puglisi <i>et al</i> , 2017 <sup>42</sup> Italy	To investigate the views of oncologists, GPs and patients about surveillance strategies. Quant.—Quest.	Most GPs claim that cancer follow-up care should be shared with oncologists. Most GPs and oncologists have a poor relationship and patients report poor collaboration.	SK, Inf, Res
Roorda <i>et al</i> , 2013 <sup>35</sup> The Netherlands	To explore the discharge of breast cancer patients to GPs and the experiences and views of GPs. Quant.—Quest.	The barriers to shared care were communication, patient preference and GPs knowledge and skills. Development of guidelines would facilitate shared follow-up.	G, Inf, Res
Schütze <i>et al</i> , 2017 <sup>56</sup> Australia	To explore the views of cancer survivors, oncologist and GPs, about GPs involved in follow-up care. Qual.—Int.	It was important for GPs to have knowledge and an interest in cancer. It was important for the specialist to oversee the care and maintain overall responsibility.	G, Res, Sk, Inf,
Sisler <i>et al</i> , 2012 <sup>57</sup> Canada	To examine how patients evaluate the continuity and quality of their follow-up care with GP. Quant. — Quest.	Patients evaluate the GP favourably; patients with complex issues rated their specialist higher. Role clarification between providers is needed.	CC, Res
Tan <i>et al</i> , 2018 <sup>58</sup> Australia	To explore how non-English and English-speaking patients perceive care to be coordinated. Qual.—Int.	Both groups described similar barriers to care, but non-English-speaking participants described additional communication difficulties and perceived discrimination.	Res, Inf
Taylor et al, 2020 <sup>36</sup> UK	To examine the experiences of patients and healthcare professionals of follow-up in primary care. Qual.—Int.	There is a lack of clear policies and practices. Disparities in knowledge, understanding, processes and pathways. Unclear roles and responsibilities.	Res, Inf
Vuong <i>et al</i> , 2020 <sup>44</sup> Australia	To explore views on patient suitability for long-term colorectal cancer shared care. Qual.—Int.	Stronger systems such as cancer-specific training, survivorship care protocols, shared information systems, care coordination and navigational supports are needed.	Inf, G
Walter <i>et al</i> , 2015 <sup>59</sup> UK	To determine the current practice and views of GPs in England about cancer survivorship care. Quant. — Quest	GPs felt that cancer follow-up care can be shared, with the specialist maintaining overall responsibility. GPs felt confident in their ability to provide follow-up care.	G, Res
White <i>et al</i> , 2021 <sup>45</sup> Australia	To explore shared follow-up care model to understand information needs. Qual.—FG	Women need evidence for the effectiveness of shared follow-up care. Clear descriptions of GP and specialist roles is needed.	
Weaver <i>et al</i> , 2014 <sup>69</sup> USA	To describe survivors' perception of provider involvement in follow-up care. Quant.—Quest.	Care is more likely to be rated as high quality when one main provider is identified and an oncology specialist is involved.	Inf

patients with the general practitioner;<sup>30</sup> another reported that around half of general practitioners received the transfer of clinical information from the oncology clinic.<sup>35</sup> Not sharing clinical information with general practitioners results in many general practitioners not having clear instructions on follow-up and how to act in case of complications<sup>31</sup> 35 36 and leaves patients to be the conduit to transfer clinical information verbally between the oncologist and general practitioner.<sup>33</sup> 37

qualitative; Quant, quantitative; Quest, questionnaire; Res, responsibility; Sk, GP skills.

Due to inefficiencies with written correspondence, survivorship care plans (a record of cancer, treatment follow-up care plan) were developed to improve the transfer of information between the patient, general practitioner and oncologist.<sup>29 35 38</sup> Survivorship care plans may effectively address some of the information needs of both breast patients and their general practitioners,<sup>29</sup> and the provision of a plan from the oncologist to the general practitioners is associated with a higher likelihood of sharing follow-up care.<sup>39</sup> However, the use of electronic medical records between general practice and oncologists was identified as being more valuable than survivorship care plans.<sup>31 32</sup>

Using verbal and written correspondence for information sharing during shared care follow-up positively affected the patient evaluation of the cooperation between the general practitioners and oncologists.<sup>40</sup> This



Seven papers discussed issues with one-way information sharing: written information from the oncologist to the general practitioner. 29–32 34 41 42 Shared cancer follow-up care relies on the two-way transfer of information between all health professionals involved in patient care, <sup>32</sup> as oncologists need to receive important clinical outcome data about the patient from the general practitioner. 43 Five papers highlighted the need to further develop health information technology to assist the two-way information sharing process and improve the timeliness and quality of information between general practitioners and oncologists. 31 37 40 44 45 There is a need for shared information systems that are connected between the oncologist and the general practitioner to support care, and fast-track options to the hospital system when patients are unwell.<sup>44</sup> Additionally, it was important for patients to know that both care providers could see the results of a follow-up consultation so they could act on if needed. 45

#### Responsibility for follow-up care

Twenty-two papers discuss responsibility for follow-up care.  $^4$   $^{35}$   $^{36}$   $^{38}$   $^{41-43}$   $^{46-59}$  There was a preference from patients, general practitioners and oncologists, for oncologists to maintain overall responsibility for cancer follow-up care. 42 43 46 48 55 56 Oncologists were more likely to prefer an oncologist-led model instead of a shared-care or general practitioner-led model, as oncologists felt that they had the specialised knowledge for follow-up care, 48 and general practitioners did not. 42 48 55 However, oncologists were receptive to sharing care with general practitioners taking a greater role in the more standardised aspects of follow-up care.<sup>38</sup> Oncologists felt that improved collaboration between themselves and general practitioners was required for shared cancer follow-up care<sup>53</sup> and that defined roles would be needed for shared care to be feasible. 36 56 However, oncologists preferred that they maintain primary responsibility for the patient's care, even if they were sharing the care of the patient with the general practitioner. 42 48 55 56

General practitioners reported that they were already involved in the care of their cancer patients from the initial work-up of diagnostic tests and diagnosis, monitoring pathology results and coordinating long-term screening, 4 48 59 and welcomed a greater role in cancer follow-up care. 48 50 55 56 General practitioners viewed shared care positively 49 52 and preferred a shared model compared with the oncologist-led model.<sup>48 55</sup> General practitioners perceived that they could provide an important role in the follow-up phase for their patients and provide a more person-centred care approach<sup>34</sup> and help address unmet psychosocial needs.<sup>51</sup> However,

general practitioners felt that oncologists should maintain overall responsibility and provide overarching support to general practitioners and oversee the patient's results and progress. 52-54 56 59

Patients identified oncologists as having the primary responsibility in their current cancer journey, except when cancer progressed to an advanced phase and palliation (where the general practitioner became more involved in their partnership with a palliation team). 46 Many patients preferred the oncologist-led follow-up model and a parallel approach to follow-up care where the oncologist managed cancer-related issues and the general practitioner non-cancer-related health matters. 4 46 Despite the limited involvement of general practitioners in cancer follow-up care, patients indicated that they would appreciate their general practitioners taking a greater role in their long-term care if the oncologist remained involved. 46 53 56 Additionally, patients were more likely to accept a shared-care model if the general practitioner was directly supported by their oncologist, 53 as this reassured patients that they remained directly linked into the hospital system.<sup>56</sup>

#### General practitioners' knowledge and skills

Fifteen papers discussed the knowledge and skills of general practitioners for shared care. 34 37-39 42 45 47-52 55 56 60 Perceptions differed regarding general practitioners' skills and abilities to take a greater role in cancer follow-up care, and in some cases, limited acceptance for the general practitioners to be involved in cancer follow-up care. 45 49 60 Many general practitioners stated they felt confident in their skills to provide cancer follow-up care<sup>39 55</sup> and reported that they could provide routine cancer follow-up care by detecting and arranging diagnostic testing pathology and offer psychosocial support. 34 50 Some general practitioners highlighted their essential role in providing holistic care and how their involvement could generally improve overall cancer care.<sup>34</sup> General practitioners who agreed they had the skills to provide follow-up care were more likely to prefer a shared care model.<sup>39</sup> However, other general practitioners had concerns about gaining and maintaining the clinical skills needed to conduct cancer follow-up care. 47 48 51 52 Some oncologists and patients also felt that general practitioners did not have the specialised knowledge of specific treatment side effects and how to manage these and felt that general practitioners required upskilling to take on shared care. 42 55 56

Patients, general practitioners and oncologists confidence in shared cancer care increased if general practitioners received extra training on short-term and long-term side effects. 38 52 60 Another method identified to upskill general practitioners was integrating the general practitioner earlier in the patients' care. 50 60 General practitioners are usually involved in the initial screening and diagnosis, then again as cancer progresses to late-stage and palliative care. Earlier engagement of the general practitioner during active treatment would upskill them in managing acute side effects, which will

help in the long-term follow-up period.<sup>38</sup> Regardless of the extra training, general practitioners still wanted ongoing support from oncologists.<sup>56</sup>

#### Need for clinical management guidelines and rapid referrals

Fourteen papers discussed the need for clear clinical management follow-up guidelines to support general practitioners in shared follow-up care. <sup>2931323540414344505256596162</sup>

The lack of clear guidelines was a barrier to transitioning to a shared care follow-up model between oncologists and general practitioners. However, general practitioners were more willing to take a greater role in follow-up care if they were provided appropriate follow-up clinical management guidelines and more guidance about follow-up screening and side effects of cancer treatment. Specific follow-up guidelines, specifically templates, could be in the form of a printable checklist or using validated instruments and would reassure general practitioners that they were addressing aspects critical for the particular patients care. Having clear guidelines could help address perceptions that general practitioners did not have the adequate skills to be involved in shared care.

Clinical management guidelines that were best-practice or written by the oncologists would provide a safety net for recurrence or other serious events. Any clinical management guidelines that a general practitioner completed would need to be sent to the oncologist to oversee and continue to monitor the patient's progress and to be able to address any issues that arose quickly. Patients have shown positive results for not feeling 'left in the limbo' "(ref. 54, p267) when the oncologist has supplied specific follow-up details to the general practitioners.

Two papers<sup>41</sup> 62 highlighted that for general practitioners to play a greater role in cancer follow-up care, along with the provision of clinical management guidelines, they also need assurance of a rapid referral back to the oncologist if recurrence is detected.

#### Continuity of care and satisfaction of care

Ten papers referred to the importance of continuity of care, satisfaction of care and accessibility. \$\frac{31333441535457606163}{1333441535457606163}\$. Continuity of care for cancer patients refers to having the same health professional providing the care and having an ongoing doctor–patient relationship. \$\frac{33}{354}\$ Many patients reported having developed a relationship with their oncologist during the diagnosis and active treatment phase and subsequently felt 'dumped' (ref. \$\frac{53}{35}\$, p155) when experiencing a high turnover of oncologists due to registrar involvement. Some patients found this lack of continuity of care during the follow-up phase distressing. \$\frac{31}{354}\$ Additionally, some general practitioners felt disconnected from their patients during the follow-up care stage \$\frac{34}{4}\$ and felt excluded. \$\frac{33}{354}\$

A patient's relationship with their general practitioner and oncologist influences their acceptance and readiness for shared cancer follow-up care.<sup>63</sup> Patients had a stronger relationship with their general practitioner than their oncologist<sup>34</sup> and had stronger feelings of trust because of

their long-standing relationship.  $^{54}$  Breast cancer patients were the only tumour group that felt they had a stronger relationship with their oncologist and would prefer their oncologist to maintain follow-up.  $^{33 \, 63}$ 

Continuity of care is strongly associated with patients' satisfaction of care. <sup>57</sup> <sup>63</sup> Most patients are satisfied when their general practitioner becomes more involved in their cancer follow-up care. <sup>57</sup> Additionally, the distance a patient travels for their follow-up care influenced continuity of care and satisfaction. General practitioners in rural areas and some urban areas were found to provide improved continuity of care to their patients. <sup>41</sup> In a rural setting that provided cancer follow-up care, general practitioners reported that care was strengthened by a good working relationship with the oncologist. <sup>41</sup>

#### **DISCUSSION**

This systematic review analysed both qualitative and quantitative studies to provide a comprehensive picture of factors that influence the translation of shared cancer follow-up care into clinical practice for solid tumours (eg, breast, prostate, colorectal and lung). We found reciprocal clinical information sharing, responsibility for follow-up care, general practitioners' skills and knowledge, the need for clinical management guidelines and rapid referral, and continuity of care and satisfaction of care were important factors. While some themes we identified are similar to the findings of a recently published systematic review, 64 we add to the knowledge base by highlighting the need for reciprocal, two-way communication and establishing a mechanism for the oncologist to maintain overall responsibility for overseeing the follow-up care.

The need for reciprocal two-way communication is supported by a recent study that reviewed current e-care plans between cancer centres and general practices.<sup>65</sup> They did not identify a system that integrated general practice systems and hospital systems to address two-way communication.65 This highlights the need for infrastructure to support the transfer of information between general practitioners and oncologists for successful shared cancer care. While a current randomised controlled trial protocol exists to explore shared cancer care for colorectal patients, 66 this protocol does not specify how this transfer of information to the hospital oncologist will be achieved. The one study that has trialled and reported on the secure transfer of clinical information into the hospital with cancer patients to collect patient-reported outcomes, <sup>67</sup> used a web-based platform PROsaiq, <sup>68</sup> where the patient could complete a clinical assessment from home. The information subsequently transferred into the patients' hospital medical record and allowed the oncologist to monitor the patients' progress.<sup>67</sup> This web-based health technology has been evaluated as feasible and secure to use in the clinical setting<sup>69</sup> and offers promise for a technological platform for reciprocal information sharing.



We found that oncologists, patients and general practitioners want and need the oncologist to maintain responsibility and oversee the patient's cancer follow-up care. This is a challenging barrier to address due to medical legalities. The health professional who provides the consultation is legally responsible for the appointment outcome; therefore, a general practitioner who provides cancer follow-up care is responsible for that consultation. This issue is similar to cancer multidisciplinary team meetings with clinicians holding concerns about the legal framework, despite the known benefits of multidisciplinary care. 70 Consequently, it would be challenging to establish a shared care follow-up model, where the oncologist is responsible without establishing a legal framework. However, finding a mechanism for the oncologist to be involved and oversee the patient's follow-up care may be more feasible, provided there is a strong administrative and organisational infrastructure to support coordinated efforts.<sup>35</sup> This would depend on the successful transfer of information from general practice to the hospital.

The need for follow-up clinical management guidelines and rapid review also depends on the reciprocal transfer of information. General practitioners using follow-up guidelines developed by oncologists have shown positive results.<sup>29</sup> Patients believed the follow-up consultation was more detailed and comprehensive than oncologist-led follow-up. 71 72 Despite the efforts to develop and use follow-up guidelines, there needs to be health technology infrastructure or better integration for general practitioners to access any guidelines developed.

One notable finding was that despite the evidence that cancer follow-up care in general practice is safe, 73 74 perceptions still exist that general practitioners do not have the necessary skills and knowledge for cancer follow-up care. This may be in part due to medical hegemony and power differentials, 75 where the general practitioner is viewed as inferior in the medical hierarchy to the oncologist. Perception plays a powerful role in health psychology and is a determinant of behaviour <sup>76</sup> and can influence the patient's, general practitioners and oncologists preference for cancer follow-up care.

Another factor that will determine shared cancer follow-up is the relationship (either positive or negative) the patient has with their general practitioner and oncologist and if they have continuity of care. Higher levels of satisfaction of care with having their general practitioner involved have been reported for both breast cancer patients<sup>24</sup> and colorectal cancer patients.<sup>77</sup> A shared cancer follow-up model of care will not suit everyone, and any decision a patient makes about their follow-up care will be based on their own circumstances, perceptions, experience, values and needs.

This review was undertaken with a rigorous systematic methodology and has identified some important enablers for shared cancer follow-up care. The review included quantitative and qualitative studies and comprehensively captures the available evidence. This review has some limitations. The selected databases searched were chosen

as they contained the most relevant and up to date information on the topic. However, it is possible that some papers catalogued on other databases could have been missed. While two reviewers independently screened the results against the inclusion/exclusion, Cohen's Kappa value was not used to calculate the inter-rater agreement, so the precision of the inclusion criteria is unknown. There was limited data captured from oncologists which may make it difficult to define the extent of barriers to shared care from their perspective. Only published peerreviewed literature was included and may therefore be subject to publication bias. Papers were limited to those in English, and there may be papers available in other languages that were not captured. Given that healthcare practices vary internationally, this review may not reflect all practices. This review was limited to adult patients and excluded skin and blood cancers; therefore, the results may not be extrapolated to paediatrics and all cancer types.

#### CONCLUSION

Shared care is an alternative model to the oncologist-led cancer follow-up model of care. The model is dependent on the patients' personal preferences and relationship with their healthcare providers. A shared cancer follow-up model of care relies on the oncologist maintaining overall responsibility and overseeing the care, effective two-way information sharing between general practitioners and oncologists, and the provision of follow-up guidelines. Oncologists and general practitioners support a shared-care model of care; however, any model developed needs to be evaluated for feasibility and acceptability. The barriers to a shared cancer follow-up model of care between general practitioners and oncologists are complex and require a multifaceted approach. To improve the acceptability and feasibility of shared cancer follow-up care, researchers and health professionals in both primary and secondary care need to work collaboratively to address the barriers and translate the research into practice. Further research is required to better understand the use of health technology to bridge the information-sharing gap and explore the feasibility and acceptability of shared cancer follow-up care for oncologists, general practitioners and patients.

**Contributors** Both authors conducted the search, screening of articles and assessed their rigour. TS conducted the hand searching. TS summarised the findings from the studies into one document and both authors created the initial code frame. TS drafted the original manuscript, assisted by HS. Both authors reviewed revisions and approved the final manuscript. TS acts as guarantor for the overall data and content.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting or dissemination plans of this research.

Patient consent for publication Not required.

**Ethics approval** Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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#### International prospective register of systematic reviews

To enable PROSPERO to focus on COVID-19 submissions, this registration record has undergone basic automated checks for eligibility and is published exactly as submitted. PROSPERO has never provided peer review, and usual checking by the PROSPERO team does not endorse content. Therefore, automatically published records should be treated as any other PROSPERO registration. Further detail is provided here.

Review methods were amended after registration. Please see the revision notes and previous versions for detail.

#### Citation

Tiffany Sandell, Heike Schütze. Factors influencing the translation of shared cancer follow-up care into clinical practice: A systematic review. PROSPERO 2020 CRD42020191538 Available from: https://www.crd.york.ac.uk/prospero/display record.php?ID=CRD42020191538

# Review question [1 change]

What factors influence translating shared cancer follow-up care into clinical practice?

# Searches [1 change]

- MEDLINE, Science Citation Index, Academic Search Complete, CINAHL, APA PsycINFO, Health Source: Nursing/Academic edition and Psychology and Behavioural Sciences Collection
- -1999 to 2021
- -peer reviewed papers published in full
- -human subjects

Types of study to be included

All study designs will be included:observational, case controlled,

cohort, cross-sectional, randomised, pilot studies, mixed methods, and qualitative.

#### Condition or domain being studied [1 change]

This study aims to systematically review the literature that focuses on factors influencing the translation of shared cancer follow-up care into clinical practice.

# Participants/population [2 changes]

Inclusion criteria: (a) general practitioner, patient, and/or oncologist perceptions of shared cancer follow-up care; (b) general practitioner involvement in cancer follow-up care; (c) intervention with the general practitioner involved in cancer follow-up care; (d) adults patients in the follow-up period; and (e) papers peer-reviewed, published in English between 1990 and 2021.

Exclusion criteria: (a) commentary, editorial, literature review, protocol; (b) patients on active treatment; (c) palliative care; (d) surgical only treatment; (e) paediatric; (f) skin cancer, melanoma or blood cancer.

Intervention(s), exposure(s)

During the follow-up care period.



#### International prospective register of systematic reviews

# Comparator(s)/control

General practitioner and oncologist

#### Context

A study will be included if it addresses the communication and preferences between the general practitioner and oncologist.

Main outcome(s) [1 change]

By identifying factors that influence implementing shared cancer follow-up care, it will allow for the development of a model of care that addresses the issues.

- barriers
- enablers

Measures of effect

none

Additional outcome(s)

none

Measures of effect

none

#### Data extraction (selection and coding)

Two reviewers (TS and HS) will independently use a stepwise procedure to identify relevant articles.

TS will perform the initial search and screen the titles and abstracts against the inclusion/exclusion criteria, the remaining texts will be retrieved in full and screened against the inclusion/exclusion criteria.

HS will independently checked the results and compare her findings with the first author.

In case of disagreement, the reviewers will meet and reach consensus through discussion. Thematic analysis will be the method for research synthesis. The first step will be to develop descriptive themes based on the text, followed by generating analytical themes with a descriptive approach to present the findings.

Results will be exported from Zotera Reference Managing system to Microsoft Excel to create a database on: author, year, study type, cancer type, sample size, study aim, data collection and analysis; outcomes, barrier/enablers.

#### Risk of bias (quality) assessment

Two reviewers will independently assess risk of bias.

Joanne Briggs critical appraisal tools will be used to assess the quality.

A pre-designed Excel template will be used to collate these assessments.

Appraising reviewers will resolve disagreements about risk of bias by discussion.

### Strategy for data synthesis

A systematic narrative synthesis will be provided to analyse the relationships within and between the

included studies.



# International prospective register of systematic reviews

The synthesis will be developed using the narrative synthesis framework as described in CRD:

- 1. Develop theory around intervention
- 2. Preliminary synthesis grouping of populations, interventions and outcomes
- 3. Explore relationships within and between studies
- 4. Assess robustness of synthesis

Analysis of subgroups or subsets There is no planned investigation of subgroups

Contact details for further information Tiffany Sandell tem785@uowmail.edu.au

Organisational affiliation of the review Wollongong Hospital and University of Wollongong

Review team members and their organisational affiliations [1 change]

Mrs Tiffany Sandell. Wollongong Hospital and University of Wollongong Dr Heike Schütze. University of Wollongong

Type and method of review Narrative synthesis, Systematic review

Anticipated or actual start date 01 July 2020

Anticipated completion date [1 change]

22 July 2022

Funding sources/sponsors This review is unfunded.

Conflicts of interest None known

Language English

Country Australia

Stage of review [1 change]

Review Completed not published

Subject index terms status Subject indexing assigned by CRD

Subject index terms Humans; Neoplasms

Date of registration in PROSPERO 11 July 2020



# International prospective register of systematic reviews

Date of first submission 10 June 2020

Stage of review at time of this submission [1 change]

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes
Risk of bias (quality) assessment	Yes	Yes
Data analysis	Yes	Yes
Revision note updated date range as suggested by journal editor.		

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

### Versions

11 July 2020

16 June 2022

17 June 2022

21 July 2022

02 August 2022



# PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			LINE
Title	1	Identify the report as a systematic review.	1
ABSTRACT	-		
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	
INTRODUCTION	1		
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	39-48
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	48-49
METHODS	-		
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	54, 86
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	61
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Table1 Supplementary file 1
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	70
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	78
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	79-80
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	79-80
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	81
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	93 (Narrative)
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	91
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 2
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	72, 77
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	76



# PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	
RESULTS	1		
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	90 Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	NA
Study characteristics	17	Cite each included study and present its characteristics.	Table 2
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	85
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 2
Results of	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Table 2
syntheses	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Table 2
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	245
	23b	Discuss any limitations of the evidence included in the review.	293
	23c	Discuss any limitations of the review processes used.	293
	23d	Discuss implications of the results for practice, policy, and future research.	306
OTHER INFORMA	TION		
Registration and	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	53
protocol	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	53
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	321
Competing interests	26	Declare any competing interests of review authors.	318
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	325



# PRISMA 2020 Checklist

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: <a href="http://www.prisma-statement.org/">http://www.prisma-statement.org/</a>

# Supplementary File 3. Search String

Databases: MEDLINE, Science Citation Index, Academic Search Complete, CINAHL, APA Psycinfo, Health Source: Nursing/Academic Edition, and Psychology and Behavioural Sciences Collection

# Search String:

("general practitioner" OR "primary care physician" OR "family physician" OR "family practitioner" OR GP OR doctor OR specialist OR oncologist) AND ("model of care" OR "shared-care" OR "shared care" OR "follow-up care" OR "follow up care") AND (Cancer OR oncolog\* OR neoplasm)

Limits:

Date range: 01/01/1999 - 31/12/2021

Language: English

Available: online, full-text, peer-reviewed