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**Improving access to cancer information and supportive care services: A systematic review of mechanisms applied to link people with cancer to psychosocial supportive care services**

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## **Abstract**

**Objective:** Previous research has described the low uptake of psychosocial support services in people living with cancer. While characteristics of individuals using services have been examined, mechanisms applied to link individuals to support services are less frequently considered. This review aims to identify the mechanisms used to link people with cancer to support services and assess their impact.

**Methods:** Systematic searches of Pubmed, CINAHL, EMBASE and PsycINFO were conducted up to May 2020. Studies reporting service use associated with mechanisms to link adults with cancer to support services targeting emotional, informational, practical or social support needs were eligible. Eligible study designs included controlled trials, pre-post designs and observational studies. Study quality was assessed and a narrative synthesis of findings undertaken.

**Results:** Ten papers (from 8037 unique titles) were eligible. Testing the feasibility of the linkage mechanism was the primary aim in five (50%) studies. Three linkage mechanisms were identified: i) outreach from the support service; ii) clinician recommendation/referral; iii) mailed invitation. Outreach was the most successful in connecting people with cancer to services (52-90% use); clinician recommendation/referral was least successful (3-28%). The impact of different linkage mechanisms for different demographic groups was not assessed.

**Conclusions.** Outreach from services shows the most potential for increasing access to support services. However, the limited number of studies and limitations in the types of support services people with cancer were linked to, demonstrated the need for further work in this area. Identifying mechanisms that are effective for underserved, high-needs patient groups is also needed.

Registration number: PROSPERO (CRD42020150151).

**Key words:** cancer, supportive care services, referral, linkage mechanisms, systematic review, Psycho-Oncology.

**Running Header: Accessing support services: a review**

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## Introduction

Despite many countries adopting psycho-social supportive care guidelines outlining procedures for ensuring people affected by cancer have access to information and support, many people still report unmet supportive care needs relating to accessing information, managing care, and addressing psychological and emotional difficulties, finances, family, work and day-to-day living.<sup>1-6</sup> Higher levels of unmet supportive care needs have been shown to increase the risk of experiencing elevated symptoms of anxiety and depression.<sup>7-10</sup> With evidence suggesting up to 28% of people with cancer can experience depression<sup>11</sup> and up to 50% can experience elevated anxiety,<sup>12-14</sup> current strategies to manage these emotional and support needs are suboptimal.

Although information and support services for people affected by cancer are common in the community and treatment centre settings, uptake can be low even in those with identified need. A study in a single hospital in the United States found only 19 of the 195 cancer patients (10%) identified as having high levels of distress participated in a recommended supportive care service<sup>15</sup>. Another study from Australia found that 60-70% of cancer patients with elevated distress declined offers of assistance<sup>16</sup>. Although a trial in Belgium found that an enhanced distress screening program could increase referral acceptance from the 4% found in usual practice to 28%, similar to the Australian study, 70% of cancer patients with elevated distress were not connected to a support service<sup>17</sup>. The low take-up of referrals to psychosocial supportive care services suggests a disconnection between the level of unmet support needs in adults affected by cancer and their engagement with services that may help to address these needs. A systematic review of the literature published until March 2011 identified 25 studies exploring barriers to the provision of psychosocial supportive care for adults with cancer, with eight studies focusing on patient barriers, 13 reporting health professionals' barriers to referral, and four reporting barriers for both patients and health professionals<sup>18</sup>. For people with cancer, the most common reason for not taking up referrals was feeling that they had support from family or other sources (37%), followed then by lack of information about the service (19%), transport difficulties

(17%), lack of confidence in service (13%) and negative perceptions and stigma associated with psychological services (10%).<sup>18</sup>

A 2014 review concluded that, for health professionals, negative perceptions of some support services, including perceived lack of scientific validity of interventions, and fear of negative outcomes for patients, are key barriers preventing referral.<sup>18</sup> Papers published since this earlier review suggest there has been little change in both uptake of referrals by survivors and the reasons for not taking up referrals, even in those screened for elevated distress. For instance, a quantitative study from Australia<sup>19</sup> assessing the reasons those identified as having elevated distress did not take up a supportive care referral found preference for self-management (46%), and not viewing distress levels as severe (23%) were key barriers. A qualitative study,<sup>20</sup> also from Australia, found that the perception that accepting a supportive care referral was “admitting defeat” and indicated an inability to cope, was a barrier to take-up. A large, multi-centre study in Germany found that those with more negative attitudes towards psychological services were less likely to use supportive care or psychological services<sup>21</sup>. A longitudinal study following Swiss patients screened for distress, which assessed intention to use support services and their actual use, found greater use in patients with more positive attitudes towards psychological support, and those demonstrating more positive coping styles<sup>22</sup>. Based on these findings, the authors argued that mental health literacy, knowledge, and patient empowerment are important factors influencing the uptake of supportive care services<sup>22</sup>.

Another strategy for attempting to understand factors that influence use of psychosocial supportive care services by people with cancer may be to determine characteristics of interventions that are used and found successful. A systematic review of 53 studies suggested that interventions that were nurse-led, telephone-based rather than face-to-face, commenced before treatment started, and did not screen for distress, had better uptake and adherence<sup>23</sup>. However as most of the studies included in this review were RCTs testing a novel intervention, the authors noted that uptake and adherence levels may be influenced by participants’ desire to assist with research rather than interest in the

supportive care program. This interpretation gains some traction with findings showing that uptake was greatest in studies where participants could be randomised into a no intervention condition<sup>23</sup>. The review concluded that work was needed to identify specific factors that increase the likelihood of acceptance and use of support services.

One factor that may be important is how the referral is made, or how people are linked to the psychosocial supportive care service. While the previously mentioned systematic review<sup>23</sup> examined characteristics of interventions that may be related to patient uptake and adherence, they did not specifically look at the actual process or mechanism that connected patients to supportive care services. This may reflect that many studies conducted as trials of support services focus on the impact of the service and assign people to receive or not receive the service. As studies have repeatedly shown, a low uptake of support services by people affected by cancer, greater understanding is needed of the mechanisms being applied to connect people to these services, and to determine whether some mechanisms are more effective than others. This review begins this investigation and aims to identify the interventions or strategies (referred to as mechanisms in this paper) used to connect people affected by cancer with psychosocial supportive care services (referred to as support services and includes services providing informational, emotional, practical and social support), and assess the impact of these different mechanisms on use of these services. A secondary aim of the review is to identify the populations targeted in research conducted in this area and assess whether the efficacy of the different mechanisms vary between populations.

## **Method**

The protocol was registered in PROSPERO (CRD42020150151). The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist was used for reporting<sup>24</sup>.

## ***Search strategy***

We searched Pubmed, PsycINFO, CINAHL and EMBASE to identify studies meeting our eligibility criteria. Search terms combined index terms and text words relating to information, psychosocial support, cancer, referral and interventions. Search terms included: (Neoplasms OR Carcinoma OR cancer OR "medical oncology") AND (telephone OR "Psychosocial Support systems" OR "Social Support" OR "community support service\*" OR "helplines" OR "cancer nurse" OR hotline\* OR "mobile health unit\*" OR counselling OR "group support" OR "patient information" OR "peer support" OR "support group") AND ("health promotion" OR "consumer health information" OR "health information" OR "health education" OR referral OR consultation OR implementation). Trial runs of the search terms indicated we needed to include title, abstract and text in the search strategy to ensure all potentially relevant papers would be identified. Appendix A shows a search strategy for one database.

Database searches were supplemented by searching references of relevant published articles included in our review. Searches, including tests and trials, were conducted between March 2020 and April 2020.

### ***Eligibility criteria***

*Study Design:* Original research studies of any study design, published in the peer reviewed literature with no restrictions on publication year were included. Studies needed to be published in English.

*Participants:* Eligible studies focused on referral of adults (aged  $\geq 18$  years), affected by cancer (patients, family and carers) to supportive care services. Studies targeting children or adolescents (aged  $< 18$  years) were excluded. Studies involving health care professionals or patients were eligible.

*Intervention:* Eligible studies described a mechanism that aimed to link people affected by cancer to services providing some element of supportive psychosocial care.

*Programs/Services referred to:* Eligible studies needed to link patients to community or hospital-led programs or services that could target emotional, informational, practical or social support needs. Services or programs delivering mind-body practices such as meditation, mindfulness and/or yoga were included. The service could be delivered online, face-to-face or over the telephone.

*Outcomes:* Uptake (utilisation) of services as a result of the linkage mechanism was the primary outcome of interest. Data on referral rates, the involvement of health services and health professionals in the referral program, and the attitudes towards, and the perceptions of patients and health professionals of the referral mechanism were recorded where available.

*Exclusion criteria:* Studies were excluded if they only reported rates of recruitment and referral to a trial (randomised or other designs) testing a supportive care intervention. Studies were excluded if they did not specify the mechanism for linking patients to a support service (e.g., they mentioned 'referral' but the mechanism for referral was not described). Following Brebach et al<sup>23</sup> studies linking patients to allied health services, hospital social work departments, psychotherapeutic-based services and palliative care were excluded as these interventions can include elements of medical care (e.g. medication), physical therapy (physical rehabilitation) and social services (e.g. government payments). Research suggests that referral to these types of services after distress screening are more likely to be accepted than those to emotional or information-based support services<sup>25</sup> supporting the suggestions that these types of services are perceived differently from informational, emotional and integrative supportive care services<sup>23</sup>.

### ***Data extraction, management and analysis***

Authors VW and NP reviewed abstracts and full-text papers to assess eligibility against the inclusion criteria. Each abstract and paper was read by these two reviewers, with disagreements resolved by discussion or referral to a third reviewer, with subsequent discussion until consensus reached. For each eligible paper, the full text was read by two

reviewers independently, who extracted the following data: authors; publication year; country, setting, who delivered intervention to patients; sample size; completion rate; sample age and sex; type of cancer; research design; aims, type of supportive care service; referral or linkage mechanism description: theoretical approach, design (web-based, face-to-face, by personal invitation, social media etc.); outcome measure; key results.

A narrative synthesis approach was applied due to the heterogeneity of study designs and the inclusion of descriptive as well as intervention research.

### **Quality Assessment**

Three assessment tools provided a basis for assessing a range of study designs. Specifically, we used the quality assessment tool for: controlled intervention studies; cohort studies and before-after studies with no control group (<https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools>). These tools posed between 12-14 questions relating to study design, participant recruitment and analysis with questions requiring a yes, no or not clear response. Depending on responses to each question papers are assessed as good, fair or poor.

### **Results**

A total of 8037 unique citations were identified through the database searches, with six additional papers identified through reference lists of relevant systematic reviews or papers. The number of papers included/excluded at each stage are shown in Supplementary Figure 1. After reading the full text of 61 papers, 10 papers were eligible for inclusion in the review.

### **Included studies**

Types of studies: Table 1 provides a description of the design characteristics of included studies. Studies were from a limited range of countries with five (50%) from Australia<sup>26-30</sup>, three (30%) from the Netherlands<sup>31-34</sup>, one from Scotland<sup>35</sup> and one from the US<sup>36</sup>. Studies were published between 1997 and 2020. Study designs varied across papers with two

cluster RCTs<sup>27, 30</sup>, one RCT<sup>32</sup>, three single arm, post-test only studies<sup>29, 36, 37</sup>, two prospective designs<sup>31, 35</sup>, one cross-sectional design<sup>34</sup> and one mixed design involving pre-test post-test design for clinicians and a post-test design for patients<sup>28</sup>. Most studies were set in health services, with one set in the community<sup>35</sup> and another using the cancer registry to invite patients from specific hospitals into the study.<sup>32</sup> No study targeting carers or family members were assessed as eligible for the review. A mix of patient surveys, health professional surveys, and administrative data were used to assess impact of the referral mechanism on support service uptake. Overall quality ratings are shown in Table 1. One study<sup>35</sup> was rated poor, with four assessed as fair and five rated as good quality (see Table 1).

The primary aim of five studies<sup>28-31, 36</sup> was to assess the impact of the linkage mechanism on people's use of the supportive care service. Of the remaining studies, four<sup>26, 27, 32, 35</sup> aimed to assess the impact of the support service on patient psycho-social outcomes (e.g. anxiety) and one aimed to assess health service and health professional adoption of the intervention<sup>34</sup>.

Mechanisms for linking patients to support services could be grouped into three basic types: i) direct outreach from the support service with or without health professional referral (total 6 studies: 3 included health professional recommendation); ii) clinician recommendation/referral only (5 studies); and iii) mailed invitation from the health service (1 study). While, in the main, studies utilised only one of these basic mechanisms, two studies by Livingston et al<sup>27, 30</sup> included multiple study arms with one arm utilising direct outreach with clinician referral and the other utilising only clinician referral. Results from the two study arms in the two different studies are included in this review.

Although the most common target group in the studies were patients (n=7; 70%), one study targeted both health professionals and patients<sup>28</sup> and two studies<sup>34, 36</sup> targeted health professionals and/or hospitals (Table 1). Studies including health professionals in their target group, reported on the introduction of the linkage mechanism into hospitals/clinics, and the uptake and response of health professionals.

The health professionals involved in delivering the linkage mechanism to patients most commonly included specialist doctors (e.g. surgeons, urologists, medical oncologists) and nurses. The number of health professionals involved in the studies was variably reported and included the number of health professionals trained, the number taking part in surveys and number of clinics/health services involved (Table 1). The cancer diagnoses of participants in studies were mixed; five studies included any cancer type, two involved men with prostate cancer with one of these also including men with colorectal cancer, one study involved a mix of breast and melanoma patients; another involved women with breast or gynaecological cancers, and another involved breast cancer survivors (Table 1).

Support services: The support services referred to, or accessed, varied across studies. Five Australian studies aimed to link people to a community-based, telephone cancer support service staffed by oncology nurses<sup>26-30</sup>. Three studies aimed to link patients to an e-health information program ('Oncokompas')<sup>31, 32, 34</sup>, one study linked patients with a community-based patient navigator termed a 'Link officer', who assessed needs and referred participants to different practical, emotional and social support services,<sup>35</sup> and one study aimed to improve uptake of yoga for cancer patients<sup>36</sup>.

### **Effects of the linkage mechanism on usage rates**

The support service uptake rates achieved in the six studies reporting this information are shown in Figure 1, with results grouped according to the main type of linkage mechanism utilised. A linkage mechanism that involved an outreach telephone call from the support program achieved the greatest uptake rates, with the next most successful strategy involving an email that provided a direct link to the online support system. Of the four studies that did not report the uptake rates achieved, two<sup>28, 36</sup> compared the number of people using the service before and after the introduction of the linkage mechanism, rather than reporting uptake rates. Both studies found an increased number of service contacts after the linkage mechanism was introduced however only one study confirmed the statistical significance of this increase.<sup>28</sup> One study<sup>34</sup> assessing hospitals' adoption and implementation of the online resource 'Oncokompas' reported health care professionals' estimates of the number of

patients they referred to 'Oncokompas', the number of patients where 'Oncokompas' was discussed at follow-up visits and the number of patients bringing printouts from 'Oncokompas' to consultations.

i) Outreach from the support service (with or without clinician referral): Six studies utilised a system where patients were contacted directly by the support service. In three studies, contact was through an outreach phone call (referred to as an outcall),<sup>26, 27, 30</sup> whereas in the other three studies, patients received an email invitation that included a link to the online support service.<sup>31, 32, 34</sup> Two studies by Livingston and colleagues, used the same linkage mechanism with one a feasibility study<sup>30</sup> which lead to the larger RCT.<sup>27</sup> The linkage mechanism in both studies also involved a specialist referral that recommended contact with a telephone-based information and support service (Helpline) with patients receiving a referral slip (Table 2). Participants in the studies were men, newly diagnosed with prostate or colorectal cancer. In both studies, three groups were compared, with one study group receiving four outcalls from the Helpline, one group receiving one outcall, and one arm receiving the specialist referral and referral slip with Helpline contact at the participants' instigation. In the third study by Livingston et al., participants finishing chemotherapy were invited to receive one outcall from the support service.<sup>26</sup> Outcalls were effective at linking patients to the support service with over 85% of participants across the three studies receiving at least one outcall from the support service (Figure 1, Table 3). Patient assessment of the outcall program was positive<sup>30</sup> with respondents reporting the referral and outcall program as a 'good idea', describing the service as providing comfort and support. Clinician assessment was also positive, with clinicians reporting the referral could be readily incorporated into usual practice and did not compromise care.

Three studies implemented a strategy to link patients to the 'Oncokompas' e-health information platform. Two studies<sup>31, 32</sup> examined 'Oncokompas' reported patient uptake whereas the third<sup>34</sup> assessed hospital and health professional participation in the program, with health professionals estimating registration and patient use. Melissant et al<sup>31</sup> assessed uptake of 'Oncokompas' in women with breast cancer who had finished treatment. This

study reported an adoption rate for 'Oncokompas' of 75% based on number of people agreeing to take part in the study, with 56% of all those invited accessing the online program (Table 3). A large RCT of 'Oncokompas' reported similar rates of adoption and uptake, with 78% of those invited activating their account and 52% of those invited accessing 'Oncokompas' at least once.<sup>32</sup>

As patients needed to be registered with 'Oncokompas' to receive their invitation, Matthijs de Wit et al<sup>34</sup> studied hospitals' uptake of and health professionals' utilisation of 'Oncokompas' providing information on health professionals' registration of patients with the online program. Of 65 hospitals approached, 31% adopted 'Oncokompas'. At participating hospitals, health professionals were instructed in how to discuss 'Oncokompas' with patients, were given a script providing general information about the online tool and 'Oncokompas' business cards to give to patients. Data from health professional surveys suggested only 21% registered patients. Of those registering, the majority (59%) reported discussing 'Oncokompas' with patients at follow-up consultations, suggesting patient use of the online program at a level that can be seen as roughly similar to those found in studies targeting patients<sup>31, 32</sup> (Table 3).

ii) Clinician recommendation/referral: Five studies<sup>28, 29, 36 27, 30</sup>, examined the impact of patients receiving a health professional recommendation to a support service on patient-initiated contact with the recommended service. Four studies<sup>27-30</sup> referred patients to the same telephone-based information and support service to talk to a cancer nurse. In one study<sup>29</sup>, health professionals, usually the cancer specialist, provided newly referred patients with an information brochure for the support service, recommending use if needed. Although health professionals were briefed on study procedures, there was no training in relation to how the patient should be provided with the information. Only around 4% of patients who received the promotional pamphlet contacted the support service (Table 3). In the second study, health professionals used a referral slip to recommend patients contact the support service at the end of chemotherapy or radiotherapy<sup>28</sup>. Health professionals received a single 50-minute training session that covered information on the support service referred to and

the procedures for the referral. Results were reported in relation to the number of calls per month to the support service from patients at participating hospitals before and after the linkage mechanism was introduced. The paper reported that the support service's monthly call rates from participating hospitals increased by up to 100% during the study period (comparison numbers in metropolitan hospital were 12 to 24 a month; regionally from 2 to 3 a month). The proportion of people who responded to a clinician referral with referral slip can be assessed through the third study arms of Livingston et al's trials,<sup>27, 30</sup> which involved only the clinician referral (with referral slip) to the support service. Livingston et al reported uptake rates in this study arm of 28% in the pilot study<sup>30</sup> and 18% in their main trial.<sup>27</sup>

Marco et al<sup>28</sup> and Broadstock and Hill<sup>29</sup> reported experiences of health professionals with the linkage mechanism with all three studies reporting that health professionals found it simple. In Marco et al<sup>28</sup> 97% of health professionals surveyed indicated they would continue to refer patients to the support service after the study.

Koula et al<sup>36</sup> conducted a pre-post study to assess the impact of a single brief (5-10 minute) education session about the benefits of yoga and referral pathways into a cancer specific yoga session that was provided to health professionals managing women with breast or gynaecological cancer (Table 2). The intervention led to a doubling of participants at weekly yoga classes, with attendance increasing from under 10 a week to 10-20 patients attending weekly classes during the intervention period (Table 3). However, the number of referrals made by health professionals and participation rates (i.e., attendees as a proportion of number referred for attendance) were not reported. After the education session, clinicians were more likely to agree that yoga could be beneficial to patients and reported stronger intentions to refer patients to the yoga program.

iii) Mailed invitation: One study<sup>35</sup> invited newly diagnosed cancer patients to participate in the "Improving the Cancer Journey" program, which provided patients with a patient navigator (referred to as the 'Link Officer'). The 'Improving the Cancer Journey' program is a community-based service operated through a local authority (e.g. city council) and 'Link Officers' were non-health professional council workers trained in supporting and

referring cancer patients. Patients are invited to take part in the program by mail, with the letter of invitation sent to all newly diagnosed patients by a division of the National Health Service in the United Kingdom on behalf of the program. Interested participants were required to contact the program to arrange a meeting with the Link Officer. The paper reports that approximately 50% of those invited joined the program; however, information on the number of letters sent, the number contacting the program and the number meeting with the Link Officer is not reported.

### **Effectiveness with different populations**

No study reported on the comparative impact of the linkage mechanism for different patient groups including those distinguished by cancer type, gender, age, ethnic or language background. Due to the different referral mechanisms utilised in studies involving men only or women only it is not possible to determine whether referral rates or uptake differ across cancer type or by gender of patients. Similarly, the effect of time since diagnosis on uptake rates was difficult to assess because most studies were conducted while patients were in treatment or just finishing treatment. Both 'Oncokompas' studies involving patients,<sup>31, 32</sup> recruited people post-treatment completion. Qualitative findings from Melissant et al<sup>31</sup> suggested that many thought the information was not relevant to them because they had finished treatment, did not have symptoms, or believed the offer of the service was too late in their care trajectory.

### **Discussion**

Despite the low uptake of supportive care referrals being recognised as limiting the potential benefits of these services for people living with cancer<sup>18, 19</sup> we could identify only 10 studies that described, in sufficient detail, a method to link patients to supportive care services. This is because of the paucity of data on the impact of linking mechanisms on uptake of support services. Nonetheless, although several of the studies reviewed were not designed to specifically test their referral mechanism, the provision of uptake data allowed us to examine the success of strategies used.

The review identified three mechanisms for linking patients to support services: outreach from the services via outcalls or email (with or without clinician referral); clinician recommendation or referral; and postal invitation to take part in a support program. There is some evidence that uptake of support services was highest for those strategies that used an outreach procedure for connecting the support service to the cancer patient, with outcalls from a telephone-based information and support program achieving the highest rate of engagement with over 90% of those referred<sup>27</sup>. High uptake rates were also seen for mechanisms where a link to an online information platform was emailed to patients (52-75%) and where patients were linked to a lay, community-based, navigator via a mailed invitation letter (50%). Lowest rates of uptake were found when contact was at the instigation of the patient, although the addition of a specific clinician referral increased uptake rates. The type of support service linked to was limited with five of the 10 studies linking to a community-based telephone information and support service. Consequently, whether the effectiveness of a linkage mechanism is dependent on the type of support service targeted is not known.

Previous studies have suggested that lack of clinician referral to information and supportive care services is a barrier to their use.<sup>38</sup> Clinician referral was the strategy most utilised in studies reviewed here, although commonly it was not used in isolation. A review examining barriers to patient use of supportive care services noted that many clinicians have negative perceptions of psychological services, are unsure of their benefit, and fear referral could take too much time<sup>18</sup>. These results are consistent with those from a study of Australian oncology professionals<sup>39</sup>. Our findings are consistent with the notion that health professionals' perceptions of, and knowledge about, support services can be improved by education. As several of the studies reviewed found that the time taken to refer people to support services could be easily accommodated in their day-to-day workload,<sup>27-29</sup> providing health professionals with a standard mechanism for referral, consistent with their usual practice, would be a useful mechanism to be added to usual care.

Although clinician referral improved uptake of services, the greatest effect was when this strategy included the support service contacting patients directly. Mechanisms utilised

for direct patient contact involved an outcall service originating from a community-based cancer information and support service and an automated email for an online e-health program. Direct contact from support services to a patient after a clinician referral are relatively novel in the cancer support space, but this linkage strategy has parallels to mechanisms used in smoking cessation where GPs or other health professionals refer smokers to a Quitline for assistance with quitting smoking.<sup>40</sup> Recent work examining the success of this referral mechanism with smokers in the real world suggest engagement with Quitlines may be around 30%.<sup>41, 42</sup> The higher engagement of cancer patients in support programs using a proactive outreach linkage mechanism in the studies reviewed here, suggest this strategy may be more engaging for cancer patients. Qualitative findings from Livingston et al's<sup>30</sup> study suggested this mechanism was highly acceptable to patients, with many thinking it constituted normal practice. A proactive approach to inform newly diagnosed cancer patients about a community-based support program has been adopted by the 'Improving the Cancer Journey' program<sup>35</sup> although the need for patients to initiate the contact with the service limited uptake to 50%.

Patients' negative attitudes towards psychological/psychosocial services may be a barrier to accepting a supportive care referral, with work suggesting that some patients see accepting assistance as defeat.<sup>18, 21, 43</sup> No intervention reviewed here addressed patient attitudes directly, with most relying on clinician recommendations to provide the impetus for contact with the support service. A recent study assessing perceptions of supportive care in the general population suggests that prioritising treatment and physical health over psychological needs is pervasive.<sup>43</sup> Increasing awareness of the benefits of supportive care and its potential for reducing anxieties, concerns and depression that may arise over the course of cancer care may help to ensure this aspect of care is not neglected. Strategies to inform people of the benefits of services while reducing stigma regarding their use are needed.<sup>18</sup>

Strategies aimed at improving screening for anxiety and depression are most effective when they involve organisation or system level change.<sup>44</sup> Only one study included

in this review<sup>34</sup> reported on the uptake of an intervention at the organisational level, with this study reporting relatively low involvement rates from health services and the health professionals working in them<sup>34</sup>. Although several studies in the current review took an organisation-wide approach to intervention implementation, the impact of the approach used is unclear due to differences in reporting. For instance while Matthijs de Wit<sup>34</sup> reported on the number of health services that opted into their study and health professionals' estimates of the number of patients they discussed 'Oncokompas' with, this study did not report the actual number of people receiving the 'Oncokompas' email invitation or the number using this program. Similarly, Marco et al's<sup>28</sup> implementation process included enlisting local champions, local co-design of referral slips and staff training, but the number of calls from patients as a function of the number of referral-slips dispensed was not reported.

One study<sup>36</sup> utilised a brief education session (i.e., 5 minutes) with cancer clinicians and other health professionals to improve referral of women to a cancer specific yoga program. Although this study reported a positive impact of this brief training program, further studies are needed to confirm the effectiveness of brief interventions given limitation in the study design including lack of a control group. Longer education sessions for health professionals were utilised in the implementation of 'Oncokompas' program within hospitals and in Marco et al's study. The optimal length of time for health professional education sessions needs to be determined.

We aimed to explore whether mechanisms for linking people to support services were equally effective for different population groups. In two studies only men were the target of the linkage mechanism, and only women were the target of the linkage mechanism in another two studies. The lack of comparison population in these studies mean the relative effectiveness of the different linkage mechanisms for males and females cannot be determined. Unfortunately, findings were not reported for other demographic groups. The high rate of uptake of some interventions, particularly the outcall services, suggest these approaches may be effective for most population groups, although further data are required, including data on language of delivery. Further, despite people from non-English speaking

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cultures being less likely to utilise supportive care services,<sup>45</sup> no study specifically investigated the impact of strategies for these populations including for people from diverse cultural and language backgrounds. As informal carers can experience significant burden<sup>46</sup>,<sup>47</sup> and are less likely to use support services,<sup>48, 49</sup> and identifying strategies to successfully link carers to support services is critical. While no study focusing on carers met our eligibility criteria, we are aware of at least one trial testing the impact of contact with a cancer nurse from a community-based support service on caregiver burden.<sup>50</sup> This study was not included in the current review as it focused on reporting recruitment rates to the trial.

### ***Clinical Implications***

Cancer services in many countries have introduced distress screening as a gateway to providing services to reduce unmet needs and psychological morbidity among cancer patients. However, the effectiveness of these programs in reducing unmet needs will be limited if uptake of recommended services remains low. Identifying strategies that can improve effectiveness of linking people to support services will be important to increase the impact of distress screening programs. The current review suggests that to date there has been a lack of detail on the referral or linkage mechanism used to connect people to support services. While the current review suggests that an outreach program is most effective, the small number of studies in our review highlight a lack of evidence in this area limiting recommendations. Our study suggests that distress screening program should consider how patients can be most effectively linked into services they may need. Reporting the outcomes from different linkage mechanisms used may help to identify the most effective strategies.

### ***Study limitations***

Several limitations to our review need to be noted. It excluded studies that looked at mechanisms that linked people with cancer to hospital-based, allied health, psychotherapeutic and social work services. As many hospital-based distress screening programs refer to these services<sup>51</sup>, our decision to exclude these types of services limits the generalisability of our findings. However as 48% of Australian cancer centres include referral to community-based information and support services as part of their distress

screening management protocols, understanding strategies that can increase the uptake rate for these referrals is important.<sup>51</sup> Following Brebach et al's<sup>23</sup> suggestion that many cancer patients participate in supportive care research studies for reasons other than a need to access support services, we excluded studies that only reported participation rates for a supportive care trial or did not specify the mechanism for linking people to a support program. We did not include information on the effectiveness of interventions in addressing patients' needs or distress levels as this was outside the scope of our review. Evidence regarding the impact of psychological and other supportive care interventions on distress, unmet needs and other quality of life outcomes is mixed,<sup>52-55 56, 57</sup> and further work is needed to identify the most effective interventions for specific individuals. Despite identifying over 8000 titles in our initial search, we found only 10 papers that met our eligibility criteria. While we believe this indicates a lack of research activity in this area, we note that indexing these papers is not straightforward and therefore our search strategy may have missed some potentially eligible papers. Although we attempted to include all relevant papers by looking through references of included papers, it is possible that some papers were missed. Finally, we only included papers that were written in English and were peer reviewed.

### **Conclusions**

Despite these limitations we believe our review has identified an important yet relatively overlooked component in providing cancer patients with the supportive care they need. There is substantial body of research that identifies effective supportive care programs for people affected by cancer,<sup>57, 58</sup> but much less work has been undertaken to identify the strategies that can effectively link people to these services. Our study has identified three types of referral mechanisms that have been at least partially tested to date. Mechanisms that proactively link people to support services may have the most reach, but adoption at a population level may require substantial personnel and financial investment. Linking people to online support programs through an email invitation may be an alternative. Mechanisms that can effectively encourage patients themselves to engage in support programs are needed. To maximise use of support services, more studies are needed to test the impact of

different linkage mechanisms including studies to develop and test resources that might be utilised as part of the linkage mechanism. Similar to work undertaken to improve participation rates in screening programs,<sup>59, 60</sup> studies that test the impact of different types of messages, different communication channels and the impact of follow-up invitations, may help to ensure that people affected by cancer engage with support services when they are needed.

**Ethical Approval:** As this study involved only analysis of previously published research ethical approval was not required.

**Conflicts:** The authors report no conflicts of interest.

**Data availability:** Data sharing not applicable – no new data generated.

**Author Contributions:** Conceptualization, VW, EV, GS, CW, PL, AU, NP, EY; Search and literature review, VW, NP, EV; writing—original draft preparation, VW, NP; writing—review and editing, VW, NP, EV, GS, AU, EY, CW, PL funding acquisition, CW, GS, VW, PL. All authors have read and agreed to the published version of the manuscript.

## References

1. Fiszer C, Dolbeault S, Sultan S, Brédart A. Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. *Psychooncology*. 2014;23: 361-374.
2. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer*. 2009;17: 1117-1128.
3. Skandarajah AR, Lisy K, Ward A, et al. Patient-reported outcomes in survivors of breast cancer one, three, and five years post-diagnosis: a cancer registry-based feasibility study. *Qual Life Res*. 2020.
4. Wang T, Molassiotis A, Chung BPM, Tan JY. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliat Care*. 2018;17: 96.
5. Beesley VL, Alemayehu C, Webb PM. A systematic literature review of the prevalence of and risk factors for supportive care needs among women with gynaecological cancer and their caregivers. *Support Care Cancer*. 2018;26: 701-710.
6. Henry M, Alias A, Cherba M, et al. Immediate post-treatment supportive care needs of patients newly diagnosed with head and neck cancer. *Support Care Cancer*. 2020;28: 5557-5567.
7. Barr K, Hill D, Farrelly A, Pitcher M, White V. Unmet information needs predict anxiety in early survivorship in young women with breast cancer. *J Cancer Surviv*. 2020;14: 826-833.
8. Molassiotis A, Wilson B, Blair S, Howe T, Cavet J. Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. *Psychooncology*. 2011;20: 88-97.
9. Oberoi D, White VM, Seymour JF, et al. The influence of unmet supportive care needs on anxiety and depression during cancer treatment and beyond: a longitudinal study of survivors of haematological cancers. *Support Care Cancer*. 2017;25: 3447-3456.
10. Urbaniec OA, Collins K, Denson LA, Whitford HS. Gynecological cancer survivors: assessment of psychological distress and unmet supportive care needs. *J Psychosoc Oncol*. 2011;29: 534-551.
11. Ng CG, Boks MP, Zainal NZ, de Wit NJ. The prevalence and pharmacotherapy of depression in cancer patients. *J Affect Disord*. 2011;131: 1-7.
12. Peng YN, Huang ML, Kao CH. Prevalence of Depression and Anxiety in Colorectal Cancer Patients: A Literature Review. *Int J Environ Res Public Health*. 2019;16.
13. Hashemi SM, Rafiemanesh H, Aghamohammadi T, et al. Prevalence of anxiety among breast cancer patients: a systematic review and meta-analysis. *Breast Cancer*. 2020;27: 166-178.
14. Watts S, Prescott P, Mason J, McLeod N, Lewith G. Depression and anxiety in ovarian cancer: a systematic review and meta-analysis of prevalence rates. *BMJ Open*. 2015;5: e007618.
15. Funk R, Cisneros C, Williams RC, Kendall J, Hamann HA. What happens after distress screening? Patterns of supportive care service utilization among oncology patients identified through a systematic screening protocol. *Support Care Cancer*. 2016;24: 2861-2868.
16. Clover K, Kelly P, Rogers K, Britton B, Carter GL. Predictors of desire for help in oncology outpatients reporting pain or distress. *Psychooncology*. 2013;22: 1611-1617.
17. Bauwens S, Baillon C, Distelmans W, Theuns P. Systematic screening for distress in oncology practice using the Distress Barometer: the impact on referrals to psychosocial care. *Psychooncology*. 2014;23: 804-811.
18. Dilworth S, Higgins I, Parker V, Kelly B, Turner J. Patient and health professional's perceived barriers to the delivery of psychosocial care to adults with cancer: a systematic review. *Psychooncology*. 2014;23: 601-612.

19. Clover KA, Mitchell AJ, Britton B, Carter G. Why do oncology outpatients who report emotional distress decline help? *Psychooncology*. 2015;24: 812-818.
20. Lambert SD, Kelly B, Boyes A, et al. Insights into preferences for psycho-oncology services among women with gynecologic cancer following distress screening. *J Natl Compr Canc Netw*. 2014;12: 899-906.
21. Faller H, Weis J, Koch U, et al. Utilization of professional psychological care in a large German sample of cancer patients. *Psychooncology*. 2017;26: 537-543.
22. Tondorf T, Grossert A, Rothschild SI, et al. Focusing on cancer patients' intentions to use psychooncological support: A longitudinal, mixed-methods study. *Psychooncology*. 2018;27: 1656-1663.
23. Brebach R, Sharpe L, Costa DS, Rhodes P, Butow P. Psychological intervention targeting distress for cancer patients: a meta-analytic study investigating uptake and adherence. *Psychooncology*. 2016;25: 882-890.
24. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Int J Surg*. 2010;8: 336-341.
25. Skaczkowski G, Sanderson P, Shand M, Byrne A, Wilson C. Factors associated with referral offer and acceptance following supportive care problem identification in a comprehensive cancer service. *Eur J Cancer Care (Engl)*. 2018;27: e12869.
26. Livingston PM, Craike MJ, White VM, et al. A nurse-assisted screening and referral program for depression among survivors of colorectal cancer: feasibility study. *Med J Aust*. 2010;193: S83-87.
27. Livingston PM, White VM, Hayman J, Maunsell E, Dunn SM, Hill D. The psychological impact of a specialist referral and telephone intervention on male cancer patients: a randomised controlled trial. *Psychooncology*. 2010;19: 617-625.
28. Marco DJT, Boltong AG, Dabscheck A, Akers G, Pryce M, White VM. Integrating referral to community-based cancer information and support services in a hospital setting. *Support Care Cancer*. 2018;26: 787-795.
29. Broadstock MJ, Hill D. Evaluation and impact of promotion of a cancer helpline to cancer patients through their specialists. *Patient Educ Couns*. 1997;32: 141-146.
30. Livingston P, White V, Hayman J, Hill D. How acceptable is a referral and telephone-based outcall programme for men diagnosed with cancer? A feasibility study. *Eur J Cancer Care (Engl)*. 2006;15: 467-475.
31. Melissant HC, Verdonck-de Leeuw IM, Lissenberg-Witte BI, Konings IR, Cuijpers P, Van Uden-Kraan CF. 'Oncokompas', a web-based self-management application to support patient activation and optimal supportive care: a feasibility study among breast cancer survivors. *Acta Oncol*. 2018;57: 924-934.
32. van der Hout A, van Uden-Kraan CF, Holtmaat K, et al. Role of eHealth application Oncokompas in supporting self-management of symptoms and health-related quality of life in cancer survivors: a randomised, controlled trial. *Lancet Oncol*. 2020;21: 80-94.
33. Berezowska A, Passchier E, Bleiker E. Evaluating a professional patient navigation intervention in a supportive care setting. *Support Care Cancer*. 2019;27: 3281-3290.
34. Matthijs de Wit L, van Uden-Kraan CF, Lissenberg-Witte BI, et al. Adoption and implementation of a web-based self-management application "Oncokompas" in routine cancer care: a national pilot study. *Support Care Cancer*. 2019;27: 2911-2920.
35. Snowden A, Young J, Savinc J. Proactive community support tailored to holistic needs: A cohort study. *Cancer Med*. 2018;7: 4836-4845.
36. Koula MJ, Knight JM. Increasing provider awareness of and recommendations for yoga and meditation classes for cancer patients. *Support Care Cancer*. 2018;26: 3635-3640.
37. Passalacqua R, Annunziata MA, Borreani C, et al. Feasibility of a quality improvement strategy integrating psychosocial care into 28 medical cancer centers (HuCare project). *Support Care Cancer*. 2016;24: 147-155.
38. Frey Nascimento A, Tondorf T, Rothschild SI, et al. Oncologist recommendation matters!-Predictors of psycho-oncological service uptake in oncology outpatients. *Psychooncology*. 2019;28: 351-357.

39. Fennell KM, Bamford L, Olver I, Wilson CJ. Good training, systems and funding, not good luck: what hematologists and oncologists believe would make it easier for them to refer their cancer patients to psychosocial care. *Transl Behav Med.* 2019;9: 139-146.
40. Vidrine JI, Shete S, Cao Y, et al. Ask-Advise-Connect: a new approach to smoking treatment delivery in health care settings. *JAMA Intern Med.* 2013;173: 458-464.
41. Warlick C, Richter KP, Mussulman LM, Nazir N, Patel V. Prevalence and predictors of quitline enrollment following hospital referral in real-world clinical practice. *J Subst Abuse Treat.* 2019;101: 25-28.
42. Piñeiro B, Vidrine DJ, Wetter DW, et al. Implementation of Ask-Advise-Connect in a safety net healthcare system: quitline treatment engagement and smoking cessation outcomes. *Transl Behav Med.* 2020;10: 163-167.
43. Wilson C, Phyu WLL, Skaczkowski G. Influences on Public Perceptions of the Importance of, and Responsibility for, Supportive Care Following Cancer Diagnosis. *J Cancer Educ.* 2020.
44. McCarter K, Britton B, Baker AL, et al. Interventions to improve screening and appropriate referral of patients with cancer for psychosocial distress: systematic review. *BMJ Open.* 2018;8: e017959.
45. Costas-Muñoz R, Hunter-Hernández M, Garduño-Ortega O, Morales-Cruz J, Gany F. Ethnic differences in psychosocial service use among non-Latina white and Latina breast cancer survivors. *J Psychosoc Oncol.* 2017;35: 424-437.
46. Applebaum AJ, Breitbart W. Care for the cancer caregiver: a systematic review. *Palliat Support Care.* 2013;11: 231-252.
47. van Ryn M, Sanders S, Kahn K, et al. Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue? *Psychooncology.* 2011;20: 44-52.
48. Mosher CE, Champion VL, Hanna N, et al. Support service use and interest in support services among distressed family caregivers of lung cancer patients. *Psychooncology.* 2013;22: 1549-1556.
49. Mast ME. To use or not to use. A literature review of factors that influence family caregivers' use of support services. *J Gerontol Nurs.* 2013;39: 20-28; quiz 29.
50. Heckel L, Fennell KM, Reynolds J, et al. Efficacy of a telephone outcall program to reduce caregiver burden among caregivers of cancer patients [PROTECT]: a randomised controlled trial. *BMC Cancer.* 2018;18: 59.
51. Fradgley EA, Byrnes E, McCarter K, et al. A cross-sectional audit of current practices and areas for improvement of distress screening and management in Australian cancer services: is there a will and a way to improve? *Supportive Care in Cancer.* 2020;28: 249-259.
52. Duncan M, Moschopoulou E, Herrington E, et al. Review of systematic reviews of non-pharmacological interventions to improve quality of life in cancer survivors. *BMJ Open.* 2017;7: e015860.
53. Rueda JR, Solà I, Pascual A, Subirana Casacuberta M. Non-invasive interventions for improving well-being and quality of life in patients with lung cancer. *Cochrane Database Syst Rev.* 2011;2011: Cd004282.
54. Carey M, Lambert S, Smits R, Paul C, Sanson-Fisher R, Clinton-McHarg T. The unfulfilled promise: a systematic review of interventions to reduce the unmet supportive care needs of cancer patients. *Support Care Cancer.* 2012;20: 207-219.
55. Galway K, Black A, Cantwell M, Cardwell CR, Mills M, Donnelly M. Psychosocial interventions to improve quality of life and emotional wellbeing for recently diagnosed cancer patients. *Cochrane Database Syst Rev.* 2012;11: Cd007064.
56. Cramer H, Lauche R, Klose P, Lange S, Langhorst J, Dobos GJ. Yoga for improving health-related quality of life, mental health and cancer-related symptoms in women diagnosed with breast cancer. *Cochrane Database Syst Rev.* 2017;1: Cd010802.
57. Schell LK, Monsef I, Wöckel A, Skoetz N. Mindfulness-based stress reduction for women diagnosed with breast cancer. *Cochrane Database Syst Rev.* 2019;3: Cd011518.

58. Son H, Son YJ, Kim H, Lee Y. Effect of psychosocial interventions on the quality of life of patients with colorectal cancer: a systematic review and meta-analysis. *Health Qual Life Outcomes*. 2018;16: 119.
59. Musa J, Achenbach CJ, O'Dwyer LC, et al. Effect of cervical cancer education and provider recommendation for screening on screening rates: A systematic review and meta-analysis. *Plos One*. 2017;12: e0183924.
60. Mullins RM. Can older women be motivated to attend for their final Papanicolaou tests? The use of targeted and general personalised reminder letters. *Cancer Epidemiol*. 2009;33: 306-308.

## Appendix A

### Search strategy: Pubmed

#### All fields searched

*Population:* All cancers, all patients

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Neoplasm\* OR Carcinoma OR Cancer OR Melanoma OR Psycho-Oncology

*Outcome:* Supportive care service

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("support group" OR "support service\*" OR "community support service\*" OR "community participation" OR "patient education" OR "emotional support" OR "social support" OR "peer support" OR "patient info\*" OR "peer counsel\*" OR "consumer info\*" OR "self-help group" OR "hospital based support" OR "community based service\*" OR "online intervention" OR "telephone service\*" OR support OR "telephone intervention" OR counsel\* OR welfare OR "psycho\* support service\*" OR telephone OR "psychosocial support system\*" OR helpline\* OR "community nurse" OR hotlines OR "cancer nurse" OR "specialist nurse" OR "mobile health unit" )

AND

*Intervention:* linkage mechanism

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("health promotion" OR "consumer health information" OR "health literacy" OR "health information" OR "health education" OR "health knowledge" OR "public health" OR referral OR consultation OR implementation OR "health information")

Table 1: Study characteristics of the ten papers reviewed.

First Author; Publication year; Country	Aims	Design	Setting	Cancer types	Type of linkage mechanism (involvement health professionals)	Target for intervention		Outcome data	main conclusions	Quality
						Target group	Patient numbers and response to intervention/ evaluation			
<b>Broadstock<sup>29</sup>, 1997 Australia</b>	To investigate the impact of promotion on service demand to assess whether further promotion would require an expansion of the service, and to evaluate this method of promotion in terms of adherence to protocol and acceptability of procedures	Single arm, post study	Radiotherapy centre, four hospital oncology outpatient clinics (including one rural clinic), private consulting rooms	All cancers	Health professional recommendation With Helpline brochure  (24 health professionals, 17 admin staff involved)	Patients	Attended rooms; n=532 received brochure n=464	Patients: calls to the Helpline during the study period and the 6 weeks following  Health professionals and staff: attitude to intervention	A small number of patients called Helpline as a result of the promotion suggesting promotion of cancer helplines by these methods leads to a manageable increase in service demand. Cancer specialists were willing, to link patients with complementary information services.	Fair
<b>Koula<sup>36</sup>, 2018 USA</b>	To (1) assess healthcare providers' beliefs about and referral patterns to yoga and meditation services, and (2) evaluate the effectiveness of a brief yoga/meditation educational presentation to increase providers' intent to recommend these programs.	Single arm: post test	Hospital	Gynaecological, breast mixed	Health professional recommendation  (40 health care professionals trained)	Health professionals	Doctors: n=17; Nurses: n=16; Other: n=7	Weekly participation numbers for yoga program  Health professionals' attitude to intervention.	Brief provider-targeted educational intervention about yoga and meditation for cancer patients is effective at significantly increasing provider knowledge about the benefits of these therapeutic modalities, with a majority of participants indicating their increased likelihood to recommend these services in the future. Education session lead to increase in referrals and attendance at yoga by patients.	Fair

<b>Livingston<sup>30</sup>, 2006 Australia</b>	To test the feasibility and acceptability of a specialist referral combined with telephone outcalls from a cancer information support service for men diagnosed with colorectal or prostate cancer.	Cluster RCT	Doctor office	Prostate	Health professional referral +/- Outreach from program  (6 clinicians involved)	Patients	112 invited to participate 100 (89%) agreed to participate  Condition 1) Referral and outreach—4 calls: n=31;  Condition 2) Referral and outreach—1 call n=37  Condition 3) Referral only n=32.	Contact with support program.  Survey of participants assessing attitudes  Health professionals attitude to intervention	Telephone delivery of information and support to people with cancer is potentially a simple and cost-effective approach that offers great advantages in terms of ease of access, greater reach of the patient population and anonymity for people diagnosed with cancer.	Fair
<b>Livingston<sup>26</sup> 2010, Australia</b>	To test the feasibility and acceptability of screening for distress among patients with CRC who had completed active treatment. Patients identified as having elevated levels of distress were referred to psychological or social work services at their treating health service.	Single arm prospective	Chemotherapy units	Any cancer needing to have chemotherapy	Outreach from program  (6 public/private health services involved)	Patients;	68 patients approached; 59 consented; 54 received first call (4 did not complete);	Contact with support program.  Patient distress and need scores	The tested model of care has potential to change delivery of services to patients with cancer, showing that psychological needs do not cease on completion of active treatment.	Good
<b>Livingston<sup>27</sup> 2010a Australia</b>	To examine whether a specialist referral to a Cancer Helpline, with a telephone intervention, involving either four or one scheduled outcall(s) from trained cancer nurses, produced greater reductions in cancer-specific distress, anxiety and	Cluster RCT	Specialist clinics/rooms/hospital clinics/community based support system	Male colorectal, prostate	Health professional referral =/- Outreach from program  (42 health professionals and 7 clinics involved)	Patients	650 eligible patients; 571 (88%) participated:  Condition 1) Referral and outreach—4 calls: n=209;  Condition 2) Referral and outreach—1 call n=197;  Condition 3) Referral only n=165.	Contact with support program;  survey of patients	Referral was easy and acceptable way to introduce newly diagnosed cancer patients to cancer Helpline. Outcall program effective at linking people to Helpline with > 80% of people receiving outcall taking the opportunity to discuss psychological and emotional issues. Most participants reported that receiving Helpline calls was a positive experience; that helped them to think more	Good

	depression compared with usual care.								positively about their cancer diagnosis and reduce their worries.	
<b>Marco<sup>28</sup> 2018. Australia</b>	To implement and evaluate a hospital-based referral mechanism to increase patient uptake of community-based cancer information and support services in relation to feasibility, acceptability and impact of the intervention.	Mixed design: Pre - post test clinicians, post test patients	Hospital	Any cancer	Health professional referral	Health professionals and Patients	Clinicians: attended education session: 66 Completed post education session survey: 40 Completed post intervention survey: 40 (61%)  Patients: n= 430 patients received a referral slip.	Support service data tracking number of calls from people attending intervention hospitals  Health professional attitudes	The study provides preliminary evidence that the intervention increases awareness and uptake of community-based cancer information and support services Ongoing clinician education and improvements in patient-clinician communication are important for effective translation from referral to service uptake.	Good
<b>Matthijs de Wit<sup>34</sup>, 2019, Netherlands</b>	To investigate the adoption and implementation of 'Oncokompas' in clinical practice and to obtain insights in possible determinants of implementation.	Cross-sectional	Hospital	n/a	Health care professional referral	Hospitals and health professionals	65 Hospitals: HCPs participated  205 health professionals invited to complete survey; 72 returned survey, 61 provided information on 'Oncokompas' related work	Adoption rate by hospitals. Implementation rates within hospitals.  Clinician attitudes Estimated numbers registered and use	The results contribute to optimisation on interventions and strategies to adopt and implement (online) self-management applications in cancer care.	Fair
<b>Melissant<sup>31</sup>, 2018, Netherlands</b>	To investigate the feasibility of 'Oncokompas' by (1) investigating adoption, usage, and satisfaction; (2) exploring possible socio-demographic and clinical factors, and HRQOL that may influence user satisfaction; and (3) examining barriers and facilitators of	Mixed design: Prospective, with qualitative component	Hospital	Breast cancer	Outreach from program  (health professional involvement numbers not reported)	Patients	101 eligible; 76 completed the baseline survey and received invitation; 68 completed the second survey;	Registration with online program and use of program	'Oncokompas' was considered feasible among breast cancer survivors based on the definition of an adoption and usage rate of over 50%, However satisfaction only at 6.9/10 and most people wouldn't recommend it to others (Net Promoter Score: 36).	Good

	the feasibility of 'Oncokompas'.									
<b>van der Hout<sup>32</sup>, 2020, Netherlands</b>	To evaluate the reach, usage as intended, and efficacy of 'Oncokompas' to improve knowledge, skills, and confidence for self-management.	RCT	Community and letter from treating doctor	Colorectal cancer; breast cancer; Hodgkin lymphoma; or head and neck cancers	Outreach from program  (14 health services, health professional involvement numbers not reported)	Patients	2953 assessed for eligibility, 625 in RCT, 320 assigned to intervention group, 318 received intervention.	Registration with online program and use of program	'Oncokompas' did not improve the amount of knowledge, skills, and confidence for self-management in cancer survivors. This study contributes to the evidence for the development of tailored strategies for development and implementation of behavioural intervention technologies among cancer survivors.	Good
<b>Snowden<sup>35</sup> 2018 Scotland</b>	The primary aim was to determine whether significant difference between initial assessment of concern and follow-up scores in people using the Link Service	Pre-post cohort study	Community	Any cancer	Invitation letter from health service on behalf of support service  (health professional involvement numbers not reported)	Patients	In 2017, 2413 people had used the service.  Number approached not reported	Service record data.  Level of concern as assessed during program participation	Patient level of concern went from a level associated with specialist referral to a much more manageable level. All patients should be screened for financial problems to show that they can be helped with all their concerns.	Poor

Table 2: Within each of the four main types of linkage mechanisms, intervention descriptions for each study.

First Author Year	Intervention detailed description	Health professional involved	Training for health professionals	Distress screening part of intervention	Theory/ model used for intervention	when referred	what services offered 1
<b>Outreach from support service</b>							
<b>Livingston<sup>30</sup> 2006</b>	The specialist used a standardized script for referring patients and referred the patient using a referral pad with tear-off sheets containing the Cancer Information Service (CIS) telephone number and hours of operation. In conditions 1 (referral and 4 outcalls) and 2 (referral and one outcall) Helpline staff called patients, in Condition 3 (referral only), patients had to instigate contact with Helpline.	Doctor	Study procedures	No	No	newly diagnosed	Cancer Information Service (CIS) Helpline
<b>Livingston<sup>26</sup>, 2010</b>	At the second-last chemotherapy cycle, the oncology nurse asked eligible patients if they were willing to receive a call from the cancer nurse at the CIS helpline at end of treatment. Participant details were then passed on to the CIS staff who contacted patients following the standardised intervention protocol 7–10 days after recruitment (outcall one) and 4 weeks later (outcall two).	Nurse	No	Yes DT by Helpline staff	No	End of chemotherapy	CIS Helpline
<b>Livingston<sup>27</sup> 2010a</b>	At the end of the consultation in which patients received their diagnosis, specialists followed a standardised script and introduced patients to the concept of the CIS Helpline and stated that they would either arrange for the CIS Helpline to contact them to offer information and support if in conditions 1 or 2, or if in condition 3, recommended that the patients contact the Helpline for information and support. For conditions 1 and 2, the specialist provided a referral slip detailing the outcall(s) the patients would receive, the CIS Helpline toll-free telephone number, hours of operation and contact period. Patients assigned to condition 3 received a referral slip with the CIS Helpline toll-free telephone number and hours of operation.	Doctor	Study procedure instructions; regular meetings with specialist, quarterly newsletters	No	No	At diagnosis	CIS Helpline
<b>Melissant<sup>31</sup>, 2018</b>	People received an email invitation to use the 'Oncokompas' after they completed the baseline survey. In 'Oncokompas', survivors follow three steps: measuring HRQOL by means of patient reported outcome measures (PROMs) ('Measure'), obtaining insight into their cancer-	Breast Nurse register interest, email invitation	No	No	No	Finished treatment within previous 1-2 years	'Oncokompas' Online information program

	related symptoms through automatically generated tailored feedback ('Learn'), and taking action by selecting optimal supportive care services ('Act').						
<b>van der Hout<sup>32</sup>, 2020</b>	Cancer survivors obtain access to 'Oncokompas' through health-care provider who invites the survivor to use 'Oncokompas' by submitting an online form within 'Oncokompas' including name and email address. The 'Oncokompas' system automatically emails an activation link to the survivor.	e-mail invitation	No	No	No	3 months to 5 years after treatment with curative intent. Mean time since diagnosis in intervention group 25 months	'Oncokompas'—online information program
<b>Matthijs de Wit<sup>34</sup>, 2019</b>	Implementation of 'Oncokompas' consists of the following steps: 1) Health Care Professional (HCP) informs the patient about 'Oncokompas', 2) logs into 'Oncokompas' with HCP account, 3) submits an online form with personal information of the patient: name, e-mail address, date of birth, treatment phase (before/during/after treatment), and home address to register them with the system. 4) 'Oncokompas' sends a personal activation link to the e-mail address of the cancer survivor, who then completes the registration and starts the Measure component as described above.	Doctors and nurses	Instructional meetings with HCP and educational materials on 'Oncokompas' including a script containing general information about 'Oncokompas', goals of the implementation, manuals on working with 'Oncokompas', frequently asked questions information.	No	No	any time point	'Oncokompas'-Online information program
	<b>Health professional referral/recommendation</b>						
<b>Broadstock<sup>29</sup>, 1997</b>	Clinicians treating patients for cancer provided them with a four page promotional pamphlet describing CIS services and number to contact CIS. Pamphlet described CIS as offering: up-to-date, accurate cancer information; an experienced and understanding person to talk to; access to welfare and supportive services; practical advice on coping; print resources; and discussion of	Doctor	No	No	No	Newly referred patients or those having their first outpatient consultation with the specialist.	CIS Helpline

	options to complement personal information from one's doctor.						
<b>Koula<sup>36</sup>, 2018</b>	Brochure presenting the research supporting yoga and meditation as an effective intervention in the cancer setting developed for oncology health care providers. Brochure included a schedule for yoga and meditation classes at the cancer centre. 5 minute presentation outlining content of brochure delivered at regular breast, gynaecologic, radiation, and surgical oncology groups.	Health professionals	5 min in-person presentation about study brochure's components at regular meetings	No	No	Any time	Yoga program
<b>Marco<sup>28</sup>, 2018</b>	A prescription pad-style referral form comprising a checkbox list of CIS services. The programs and services listed were determined in consultation with site and priority given to those CIS services not available at the hospital. If, during their normal clinical interactions, clinicians identified patients who might benefit from a CIS service, they were asked to tick the corresponding service on the referral form, hand the referral to the patient and encourage them to call CIS to access the service. The message from the clinician to the patient was brief yet specific, with clinicians tailoring the referral to the need of the patient at that time. No formal script was provided to clinicians. Rather, they were asked to introduce the referral at an appropriate time, respecting the patient's current condition and level of understanding or comprehension of the information	Nurses/doctors	Participated in single 50 minute education session presenting information on the CIS Helpline service and procedures for referring patients	No	No	When finish chemo/radio or at outpatient clinic	CIS Helpline
	<b>Mailed invitation from health service</b>						
<b>Snowden<sup>35</sup> 2018</b>	A branch of the National Health Service sends all newly diagnosed cancer patients a letter inviting them to contact the Improving Cancer Journey service and arrange an appointment with a "Link officer" at a place of the patient's choosing. Patients must call service to arrange the meeting. At meeting, the link officer goes through a health needs assessment with patient discussing each of 57 concerns with patients rating a concern on a scale between 0-10. Results are recorded. A care plan is co-constructed between the patient and link worker. The plan can involve signposting to a particular agency, or referral to relevant services. 200 local agencies partner with program and all referrals are managed by the link officers. Referrals and uptake or not, are recorded centrally along with their assessment and care plan. After the initial visit, the patient receives a	None-letter mailed from Data branch of National Health Service on behalf of the support service.	Yes, 3 months training	Health Needs assessment	No	Soon after diagnosis	Lay Link Offices attached to the city council who can link patients to range of services including Information booklets/videos; Relaxation programs; financial support programs, housing programs etc.

	letter from detailing the agreed care plan and a summary of the discussion. At an agreed time, normally around 4-5 months later, the link officer telephones the patient to review plan, assess current needs and concerns and refer as needed.						
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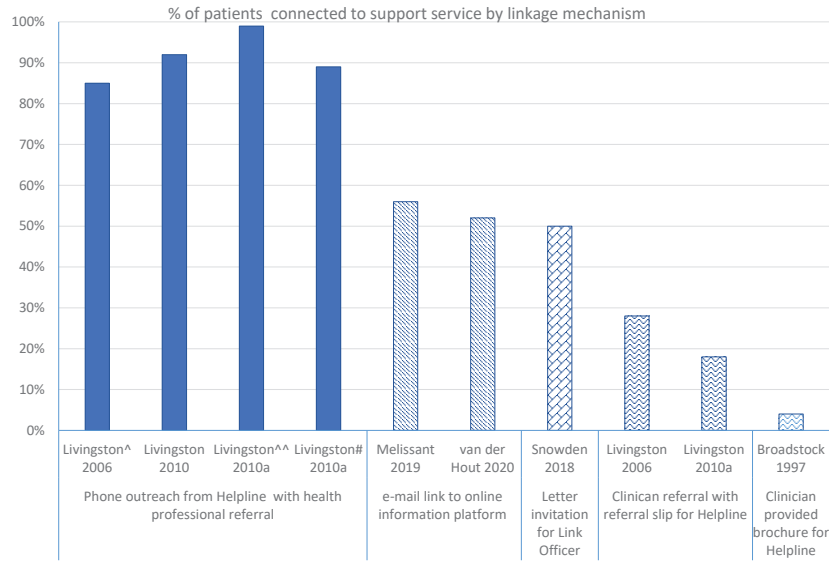
Abbreviations: CIS: Cancer Information Service; HCP: Health Care Professional

Table 3: Within each of the three linkage mechanisms, uptake rates for health professionals involved, patient referral rates, patient uptake rates and patient and health professionals' experiences for each study.

Author	Intervention	Results: Clinicians Health professional	Results: Patients	How were referral outcomes assessed
	<b>Outreach from support service</b>			
<b>Livingston<sup>30</sup> 2006</b>	Clinician standardized script and referral slip	No information on uptake. 6 specialists took part.  Specialists did not consider the referral compromised their consultation, in terms of time or content. Clinicians did not always remember to refer patients.	In Condition 1 (referral and 4 outcalls). Number of people having the four calls not reported directly. No reporting that calls did not take place. 29 of the 31 people in this condition (93%) took part in second interview and reported on their experiences of the outcall. Nine (29%) participants called into the service over the first 4 months, in addition to receiving their outcalls In Condition 2 (referral and 1 outcall): Number of people having the single outcall not reported directly. No reporting that calls did not take place. 29 of the 37 people in this condition (78%) took part in second interview and reported on their experiences of the outcall. Two (5%) people called in to the service.  In Condition 3 (referral only), nine (28%) participants called CISS.  93% of Condition 1 and 2 participants taking part in the 4 month interview reported a positive experience of receiving the outcall, they thought the referral was a good idea.	Number of scripts given out, contact with helpline--determined study logs and for call ins through use of a special number.
<b>Livingston<sup>26</sup>, 2010</b>	Outcall from cancer nurse at Helpline.	Six health services; number of staff not recorded	54 (92%) received the first outcall and 50 (85%) received the second outcall.  Satisfaction with the program was high, 82% reporting outcall 1 "quite or very helpful" and 79% reporting outcall 2 "quite or very helpful".  Participants reported that they "took comfort" in the support provided by the call, that it was "good to have someone to chat to" and also that it was helpful "to discuss issues that I was uncertain about".	Contact with the Helpline recorded by Nurse doing the calls
<b>Livingston<sup>27</sup> 2010a</b>	Clinician used standardized script and referral slip.	Urologists: 77% entry into study; referred: 40% of those approached. Colorectal: 85% entry into study, referred: 68% of those approached.	Condition 1 (referral and 4 outcalls) 89% received all four outcalls. Eight (4%) also called into the service Condition 2 (referral and 1 outcall) 99% received call. 10 (5%) also called into the service. Condition 3 (Referral only) 29 (18%) contacted the Helpline.	Number of scripts dispensed by doctors. Number of people contacting helpline via special number. Number of people that accepted the outcall

<b>Matthijs de Wit<sup>34</sup>, 2019</b>	Health care professionals sign up to 'Oncokompas', automatic email to patients	<p>Adoption rate by hospitals: 31% (20/65).</p> <p>Percent of 205 health professionals referring into 'Oncokompas': 21% overall (62% for those completing survey).</p> <p>Of those completing the survey (n=61): number of patients offered 'Oncokompas' to:</p> <ul style="list-style-type: none"> <li>None: 28%</li> <li>1-5 patients: 31%</li> <li>6-10 patients: 16%</li> <li>11-50 patients: 18%</li> <li>51+ patients: 7%</li> </ul> <p>Number of patients discussed 'Oncokompas' with next consult:</p> <ul style="list-style-type: none"> <li>None: 41%</li> <li>1-5 patients: 43%</li> <li>6-10 patients: 9%</li> <li>11-50 patients: 7%</li> </ul> <p>Number of patients with copy of 'Oncokompas' dossier</p> <ul style="list-style-type: none"> <li>None: 93%</li> <li>1-5 patients: 7%</li> </ul> <p>Reasons for not referring: forgot (n=24), done by somebody else (n=9), no time (n=6), patients in palliative care (n=5), do not endorse content (n=4), no access to internet (n=4), lack of 'Oncokompas' (n=4) too difficult (n=3).</p>	not reported	Look at number of hospitals that agree to implement the intervention. Look at referral to 'Oncokompas' reported by HP as part of a survey of HP
<b>Melissant<sup>31</sup>, 2018</b>	Email invitation to use the 'Oncokompas'.	not reported	<p>Adoption rate of 'Oncokompas' was 75% (76/101). Usage rate: 75% for study participants or 56% of all invited (57/101).</p> <p>Satisfaction with 'Oncokompas' was good with a mean score of 6.9 (range 0–10).</p>	Registration and login data
<b>van der Hout<sup>32</sup>, 2020</b>	Email invitation to use 'Oncokompas'	Unclear. 14 health services originally participating in survivorship outcomes register. Participation rates of clinicians not reported.	Within the intervention group, 248 (78%) activated their account. 167 (52%) used 'Oncokompas' at least once during the 6-month follow-up period.	Uptake determined by registration and login data for 'Oncokompas'
<b>Health professional recommendation/referral</b>				

<b>Broadstock<sup>29</sup>, 1997</b>	Clinicians provided pamphlet	Number of clinicians/clinics approached not clear. Eighteen of 19 (95%) specialists and 19/19 clinic staff completed post study questionnaires. Distribution of pamphlet by clinician/clinic not reported. Clinicians saw the distribution of pamphlet as simple (100%), worthwhile (61%); was not time consuming (78%) was not a nuisance (67%), 72% indicated that at least some patients were interested. Clinic staff though task was simple (100%), worthwhile (89%); was not time consuming (95%).	8 calls from patients and 10 calls from family members = 3.9% (95% CI: 2.1%–5.6%) uptake.	Number of pamphlets distributed across clinics as reported by clinic staff, number of calls to the helpline. Dedicated number for the Helpline
<b>Koula<sup>36</sup>, 2018</b>	clinician referral to yoga program	No direct information on number of clinicians referring. 40 health professionals completed pre and post surveys.  34/40 (85%) more likely to refer to yoga program post intervention  Increase in proportion of health professionals strongly agreeing that yoga has benefits from 67% to 85% post education session.	Baseline: < 10 patients attended weekly yoga classes. After study, approximate doubling in attendance with 10–20 patients attending weekly classes. From September of 2014 (research initiated) until March 2015, 240 yoga sessions were sold. From October 2015 until April 2016 (research concluded), 398 sessions were sold.	Yoga teacher attendance reports, number of yoga class tickets sold
<b>Marco<sup>28</sup>, 2018</b>	Health professional prescribe Helpline.	No information on number of staff that could potentially be trained. No information on number of staff that provided referral slip to patients. Post intervention survey completed by 40/65 staff. 29/40 (73%) thought it was easy to refer 37/40 (93%) thought easy incorporate into routine practice. Barriers: time (10/40), overlooking (19/40), patient condition (11/40). 37/40 indicated they would continue to refer patients.	A total of 430 patients referred to the cancer information and support service during study period. Calls from the participating health services increased by up to 100% per month from baseline after implementation of the referral mechanism. However baseline contact was low: approximately 12 calls per month from Metro hospital patients and 3 calls per month from regional hospital patients. However, increases in call rates were in contrast to an overall decrease in total number of calls to service over the entire study period (23 months). Interviews were conducted with 45 patients; most remembered receiving the referral and were positive towards the intervention. 9/45(20%) reported contacting the service.	Count of referrals from referral pads used in each site. Routine Helpline data collected on callers including hospital of patients. Survey of staff and interviews with people from participating health services.
		<b>Mailed invitation from health service</b>		
<b>Snowden<sup>35</sup>, 2018</b>	Invitation letter from health service; Link Officer	-	Approximately 50% accepted invitation into program Numbers that accepted invitation but did not meet Link Officer not reported. Numbers referred to different services and uptake not reported in this paper	Program records but reporting not clear.



<sup>^</sup> Average across two outcall conditions. Based on number participating in first follow-up interview; <sup>^^</sup> Condition 2 only (1 outcall); <sup>#</sup> Condition 1 (4 outcalls) received all calls.

Figure 1: Estimate of psychosocial supportive care services uptake rates achieved by different linkage mechanisms.