

**Evidence Check**

**Barriers and enablers  
for older people at  
risk of and/or living  
with cancer to  
accessing timely  
cancer screening,  
diagnosis and  
treatment**



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An Evidence Check rapid review brokered by the Sax Institute for the Cancer Institute NSW.  
July 2022.

This report was prepared by: Allison Boyes, Jamie Bryant, Alix Hall, Elise Mansfield.

doi:10.57022/ieoy3254

July 2022

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**Suggested Citation:**

Boyes A, Bryant J, Hall A, Mansfield E. Barriers and enablers for older people at risk of and/or living with cancer to accessing timely cancer screening, diagnosis and treatments: an Evidence Check rapid review brokered by the Sax Institute ([www.saxinstitute.org.au](http://www.saxinstitute.org.au)) for the CINSW, 2022. doi:10.57022/ieoy3254

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# Barriers and enablers for older people at risk of and/or living with cancer to accessing timely cancer screening, diagnosis and treatment

**An Evidence Check rapid review brokered by the Sax Institute for the Cancer Institute NSW. July 2022.**

This report was prepared by Allison Boyes, Jamie Bryant, Alix Hall and Elise Mansfield, University of Newcastle.

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# Key Messages

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- Older adults have complex and unique needs that can influence how and when cancer is diagnosed, the types of treatment that are offered, how well treatment is tolerated and treatment outcomes.
- This Evidence Check review identified 41 studies that specifically addressed barriers and enablers to cancer screening, diagnosis and treatment among adults aged 65 years and older.
- **Question 1:** The main barriers for older people at risk of and/or living with cancer to access and participate in timely cancer screening relate to lack of knowledge, fear of cancer, negative beliefs about the consequences of cancer, and hygiene concerns in completing testing. The main enablers to participation in timely cancer screening include positive/helpful beliefs about screening, social influences that encourage participation and knowledge.
- **Question 2:** The main barriers for older people at risk of and/or living with cancer to access and/or seek timely cancer diagnosis relate to lack of knowledge of the signs and symptoms of cancer that are distinct from existing conditions and ageing, healthcare accessibility difficulties, perceived inadequate clinical response from healthcare providers, and harmful patient beliefs about risk factors and signs of cancer. The main enablers to accessing and/or seeking a timely cancer diagnosis include knowledge of the signs and symptoms of cancer, and support from family and friends that encourage help-seeking for symptoms.
- **Question 3:** The main barriers for older people at risk of and/or living with cancer in accessing and completing cancer treatment include discrimination against patients in the form of ageism, lack of knowledge, patient concern about the adverse effects of treatment, predominantly on their independence, healthcare accessibility difficulties including travel and financial burden, and patients' caring responsibilities. The main enablers to accessing and completing cancer treatment are social support from peers in a similar situation, family and friends, the influence of healthcare providers, and involving patients in treatment decision making.
- **Implications.** The development of strategies to address the inequity of cancer outcomes in people aged 65 years and older in NSW should consider:
  - Increasing community members' and patients' knowledge and awareness by providing written information and decision support tools from a trusted source
  - Reducing travel and financial burden by widely disseminating information about existing support schemes and expanding remote patient monitoring and telehealth

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- Improving social support by promoting peer support, and building the support capacity of family carers
  - Addressing ageism by supporting patients in decision making, and disseminating education initiatives about geriatric oncology to healthcare providers
  - Providing interdisciplinary geriatric oncology care by including a geriatrician as part of multidisciplinary teams and/or expanding geriatric oncology clinics.

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# Executive summary

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## Background

The risk of receiving a diagnosis of cancer varies significantly throughout a person's life span. Cancer can be considered an age-related disease because the incidence of most cancers increases with age. In Australia in 2021, the mean age of receiving a diagnosis of cancer was 66.7 years.<sup>1</sup> It is estimated that about two in five people (or 43%) will be diagnosed with cancer by the age of 85.<sup>1</sup> Globally, by 2035 adults aged 65 years and older are expected to represent about 60% of all newly diagnosed cancer cases.<sup>2</sup>

Older adults have complex and unique needs. They are more likely to have chronic health conditions, impaired physical and cognitive function, and to experience physiologic age-related changes that can affect how and when cancer is diagnosed, the types of treatment that are offered, and how well treatment is tolerated. As a result of these complex needs, a widening of the survival gap between younger and older cancer patients has been identified as a matter of significant concern in many developed countries for more than a decade.<sup>3-5</sup>

The expected increasing cancer burden among older adults is likely to result in major challenges in ensuring the appropriate provision of clinical and health services to this population. The Cancer Institute is at the initial stages of a process to design strategies to address the inequity of cancer outcomes in people aged 65 years and older in NSW. As part of this process, the Institute commissioned an Evidence Check to:

1. Inform the development of a discussion paper on equity of cancer outcomes in older people at risk of and/or living with cancer
2. Inform a consultation process that will be undertaken with a wide range of stakeholders to identify the issues for older people who need to engage with cancer control services.

## Evidence Check questions

This Evidence Check aimed to address the following questions:

**Question 1:** What are the main barriers and enablers for older people at risk of and/or living with cancer to access and participate in timely cancer screening?

**Question 2:** What are the main barriers and enablers for older people at risk of and/or living with cancer to access and/or seek timely cancer diagnosis?



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**Question 3:** What are the main barriers and enablers for older people at risk of and/or living with cancer to access and complete cancer treatment (including cancer trials)?

## Summary of methods

The review team conducted an Evidence Check of the peer-reviewed and grey literature, limited by strict inclusion and exclusion criteria. Rapid reviews limit the comprehensiveness of the search while identifying key primary papers and published reviews to address the research questions.

To identify primary studies for inclusion, we searched the MEDLINE, PsycInfo and Cochrane databases using a combination of medical subject headings and keywords to identify relevant reviews, from which we identified primary peer-reviewed studies. Grey literature searches incorporated Google Scholar and Google searches, as well as manual review of relevant organisational websites of cancer control, ageing, healthcare professionals and national health agencies. Primary studies were included if they reported on barriers or enablers to accessing cancer screening, seeking a timely cancer diagnosis, and accessing and completing cancer treatment (including cancer trials) among older adults ( $\geq 65$  years), and were published in Australia, New Zealand, Canada or the UK from 2011 onwards.

We extracted data for included studies using a standardised data extraction form. The Mixed-Methods Appraisal Tool (MMAT) was used to assess study quality.<sup>6</sup> Data pertaining to barriers and enablers were synthesised separately for each research question according to categories of the Theoretical Domains Framework (TDF) version 2.<sup>7</sup>

## Key findings

A total of 41 studies ( $n = 38$  peer-reviewed studies and  $n = 3$  reports) met all inclusion and exclusion criteria and were included in the Evidence Check. Most of the studies were published in the UK (78%), with only a few studies identified from Australia (12%) and Canada (10%). Most studies used a qualitative approach (66%) and reported on barriers or enablers from the perspective of the healthcare user (86%; e.g. patient, family, support persons).

### Question 1

Seventeen studies reported on barriers and enablers related to cancer screening for older adults. Most of these papers were peer-reviewed scientific papers (94%) and related to cancer screening in the UK (85%). All reported on barriers and enablers from the perspective of healthcare users. The majority of papers related to colorectal screening (44%) followed by mixed cancer types (22%) and prostate screening (17%).

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The most prevalent barriers to cancer screening among older adults related to lack of knowledge (n = 10 studies), fear of cancer (n = 10 studies), negative beliefs about the consequences of cancer (n = 9 studies), and hygiene concerns (n = 7 studies).

The most prevalent enablers to cancer screening included positive/helpful beliefs about screening (n = 7 studies), social influences (n = 5 studies) and knowledge (n = 5 studies).

**Barriers:**

- Knowledge barriers included lack of understanding or awareness about the use of home colorectal screening tests, lack of awareness of the availability of screening programs, and lack of awareness about cancer, the signs and symptoms of cancer and cancer risk factors.
- Fear of cancer related to being diagnosed with cancer, cancer treatment and death.
- Negative beliefs about the consequences of cancer included cancer screening not being perceived as useful in the absence of cancer symptoms, low perceived individual susceptibility to cancer risk, fatalistic beliefs about the benefits of screening, and negative beliefs about the effect of age on cancer treatment outcomes.
- Hygiene concerns mostly related to colorectal screening and included patient concerns about collecting, storing and posting faeces samples.

**Enablers:**

- Helpful beliefs that facilitated participation in cancer screening included perceived personal benefits of an early diagnosis, and positive beliefs about the likely success of treatment options available if diagnosed.
- Encouragement to participate in screening by healthcare provider(s) and family and friends also enabled cancer screening.
- Previous engagement in cancer screening, previous individual experience of cancer, knowledge of the benefits of early detection, and awareness and recognition of the signs and symptoms of cancer also encouraged participation in screening.

**Question 2**

Fifteen studies reported on barriers and enablers to cancer diagnosis. Most of these papers were peer-reviewed scientific papers (87%) and related to cancer diagnosis in the UK (93%). Most papers reported on barriers and enablers from the perspective of healthcare users (87%) and related to diagnosis of lung cancer (27%), followed by breast cancer (20%) and mixed cancer types (20%).

The most frequently reported barriers to cancer diagnosis among older adults related to lack of knowledge (n = 9 studies), healthcare accessibility difficulties (n = 5 studies), perceived inadequate healthcare provider response (n = 4 studies), and harmful beliefs about risk factors, signs and symptoms (n = 4 studies).

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The most frequently reported enablers of cancer diagnosis were knowledge (n = 5 studies), and support from family and friends (n = 5).

**Barriers:**

- Knowledge barriers included a lack of understanding of the signs and symptoms of cancer, particularly those that were distinct and distinguishable from pre-existing conditions and ageing; and a lack of awareness about cancer, cancer risk factors and cancer recurrence.
- Healthcare accessibility difficulties mostly related to long waiting times to get appointments with general practitioners and specialists, and the burden of financial costs associated with further investigations.
- Inadequate clinical response from healthcare providers as perceived by patients mostly related to delayed investigation of symptoms and lack of follow-up review.
- Harmful patient beliefs about risk factors, signs and symptoms of cancer included low perceived individual susceptibility to cancer risk, low perceived seriousness of cancer signs and symptoms, fatalistic beliefs about the possibility of symptoms being cancer and beliefs that symptoms could be self-managed.

**Enablers:**

- Knowledge of the signs and symptoms of cancer, and awareness of 'unusual' or changes in symptoms facilitated cancer diagnosis.
- Encouragement from family and friends to seek help for symptoms also facilitated cancer diagnosis.

**Question 3**

Eighteen studies, including clinical trials, reported on barriers and enablers to cancer treatment. Most of these papers were peer-reviewed scientific papers (89%) and related to cancer diagnosis in the UK (67%). Most papers reported on barriers and enablers from the perspective of healthcare users (77%) and related to treatment of breast cancer (39%) and prostate cancer (28%).

The most frequently reported barriers to cancer treatment among older adults related to discrimination (n = 7 studies), lack of knowledge (n = 7 studies), concern about the adverse effects of treatment (n = 6 studies), healthcare accessibility difficulties (n = 6 studies) and competing demands and responsibilities (n = 5 studies).

The most frequently reported enablers of cancer treatment were knowing someone with cancer (n = 8 studies), influence of healthcare provider(s) (n = 8 studies), involvement in decision making (n = 7 studies) and support from family and friends (n = 5 studies).

**Barriers:**

- Discrimination barriers mostly related to perceived and actual ageism and involved patients not being offered the same type and number of treatments as younger patients.

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- Knowledge barriers related to lack of awareness across a range of issues including treatment options, treatment benefits, side effects of treatment, discharge from hospital, follow-up care, signs of cancer recurrence, psychosocial support services, self-management and referral procedures.
  - Concern about the adverse effects of treatment predominantly related to impact on independence and, to a lesser extent, quality of life, physical function, mental health, pre-existing medical conditions, recovery time and finances.
  - Healthcare accessibility difficulties mostly related to travel burden to receive treatment and financial cost associated with treatment-related parking, accommodation and non-medical support.
  - Caring responsibilities (usually a spouse) and other domestic duties influenced decisions about the type and timing of treatment.

**Enablers:**

- Peer support from a person in a similar situation enabled patients to be better prepared for and cope with treatment.
- As both trusted sources of support and technical experts, healthcare providers had significant influence on patients' treatment decisions.
- Practical and emotional support from family and friends influenced treatment decisions and assisted patients in coping with the demands of treatment.
- Involvement in treatment decision making including providing treatment choices, allowing time to reach treatment decisions, providing decision support and engaging in shared or patient-directed decision making facilitated treatment.

## Gaps in the evidence

- A limited number of studies focused explicitly on people aged 65-plus. Geriatric oncology has been heralded as the next frontier for oncology. High quality evidence specific to those aged 65-plus is needed to inform policy and practice for this vulnerable group.
- A limited number of studies were from Australia. Consequently, few studies reported barriers and enablers from a rural perspective.
- A limited number of studies included diverse older adults. The barriers and enablers experienced by priority populations including culturally and linguistically diverse people, Aboriginal and Torres Strait Islander people, individuals with a mental illness, LGBTQI+ people and the socioeconomically disadvantaged are not captured and need to be considered separately.

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# Methods

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## Aims and scope of the Evidence Check

We conducted a rapid review Evidence Check of the peer-reviewed and grey literature to answer the following research questions:

1. **Question 1:** What are the main barriers and enablers for older people at risk of and/or living with cancer to access and participate in timely cancer screening?
2. **Question 2:** What are the main barriers and enablers for older people at risk of and/or living with cancer to access and/or seek timely cancer diagnosis?
3. **Question 3:** What are the main barriers and enablers for older people at risk of and/or living with cancer to access and complete cancer treatment (including cancer trials)?

## Identification of peer-reviewed studies

This Evidence Check was conducted within a limited time frame (10 weeks). Because of the expected large volume of studies, we based our methods on those recommended by Cochrane for undertaking rapid reviews but with some slight modifications.<sup>8</sup> All methods were discussed and agreed with the consulting agency.

To identify primary studies for inclusion, we conducted searches of a combination of electronic databases, grey literature and key organisations. Searches of the electronic databases were restricted to reviews only because of the extensive results obtained, and relevant primary studies were subsequently sourced from the reference list of relevant reviews. We searched the MEDLINE, PsycInfo and Cochrane databases using a comprehensive search strategy developed in consultation with a research librarian. The search strategy included a combination of Medical Subject Headings (MeSH) and keywords and is provided in Appendix 1. The search was limited to reviews published from 2011 onwards in the English language. Identified reviews were de-duplicated in Endnote software and then imported into Covidence.<sup>9</sup> Reviews were excluded from consideration if they were published before 2011, focused exclusively on those aged <65 years, focused on a specific jurisdiction not including our regions of interest (Australia, Canada, UK and New Zealand), focused on the palliative care setting, focused on primary prevention activities, did not report on barriers or enablers, were not available in English, or a full-text copy was not publicly available. One reviewer screened titles and abstracts using Covidence software. A second reviewer then assessed full-text versions of remaining reviews and studies that met all criteria were retained for inclusion. Any discrepancies were resolved by consensus discussion.

The primary papers cited in each included review were then extracted into a REDCap<sup>10, 11</sup> database to form the sampling frame to identify eligible primary studies to include in the Evidence Check. We used this modified approach to standard review methods, sourcing relevant reviews from electronic

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database searches and using them as the sampling frame for eligible primary studies, to ensure we could complete a thorough and systematic check of the most relevant literature in the time frame available.

## Grey literature search strategy

We conducted a grey literature search to identify relevant peer-reviewed papers not found by the electronic database search, as well as evaluations and reports published by relevant cancer control, ageing, health professional and population health agencies. Our approach was as follows:

- **A Google scholar search** using the terms ‘aged or elderly or geriatric or cancer or cancer screening or cancer diagnosis or cancer treatment or barrier or impediment or challenge or hindrance or obstacle or facilitate or enable’. The search was limited to publications from 2011 onwards and 4140 hits were returned. The first 200 results were screened for relevance by one reviewer.
- **A Google scholar search** using the advanced search function. The following terms were entered as key words ‘aged or elderly or geriatric or screening or diagnosis or treatment or barrier or impediment or challenge or hindrance or obstacle or facilitate or enable’ and a specification was made that the term ‘cancer’ also had to appear in retrieved articles. The search was limited to publications from 2011 onwards and 5120 hits were returned. The first 100 results were screened for relevance by one reviewer.
- **A Google search** using the terms ‘aged or elderly or geriatric or cancer barrier or challenge or facilitate or enable’. No limits were applied to the search and 2,250,000 results were returned. The first 200 results were screened for relevance by one reviewer.
- **A review of relevant organisational websites** of cancer control, ageing, health professional and national health agencies (see Appendix 2) was undertaken by two reviewers who searched for relevant evaluations, reports or papers.

## Inclusion and exclusion criteria

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool was used to define key elements of the Evidence Check question and define study inclusion and exclusion criteria. SPIDER offers an alternative to the more frequently applied PICO (Population, Intervention, Comparison, Outcome) tool as it adapts the PICO components to better define research questions that are likely to be answered with the inclusion of qualitative and/or mixed methods research.

The inclusion and exclusion criteria are provided in Table 1. Primary studies were included if they reported on barriers and enablers to accessing cancer screening, seeking a timely cancer diagnosis, and accessing and completing cancer treatment (including cancer trials) among older adults ( $\geq 65$  years). Studies were included only if the sample exclusively included people aged 65 years and over; the mean or median age of the sample was 65 years or over; or the sample included multiple age groups, but results were reported separately for those aged 65 years and over. Published and grey literature (including third-sector and government reports, evaluations and briefings) published from 2011 onwards in Australia, New Zealand, Canada or the UK were included.

**Table 1**—Inclusion and exclusion criteria using the SPIDER tool

	<b>Include</b>	<b>Exclude</b>
<b>Sample</b>	<ul style="list-style-type: none"> <li>• Exclusive focus on older people aged 65 and over</li> <li>• Mean or median age of the sample is 65 years or over</li> <li>• Include multiple age groups, but results are reported separately for those aged 65 years and over</li> </ul>	<ul style="list-style-type: none"> <li>• Specific focus on samples aged &lt;65 (e.g. young adults with cancer)</li> <li>• Includes general population of those affected by cancer with a mean age unknown or &lt;65 years</li> </ul>
<b>Phenomenon of interest</b>	<ul style="list-style-type: none"> <li>• Barriers and/or enablers across the cancer trajectory including accessing cancer screening, seeking a timely cancer diagnosis, and accessing and completing cancer treatment (including cancer trials)</li> </ul>	<ul style="list-style-type: none"> <li>• Studies that report on outcomes of cancer for older people</li> <li>• Studies that report on cancer control activities provided in a palliative care setting</li> <li>• Studies that report on primary prevention activities to reduce the risk of developing cancer</li> </ul>
<b>Design</b>	<ul style="list-style-type: none"> <li>• Any design</li> </ul>	
<b>Evaluation</b>	<ul style="list-style-type: none"> <li>• Barriers and/or enablers relevant to acute care services (private and public), community settings, primary care, screening services and aged care</li> <li>• Patient, carer, community member and healthcare provider perspectives</li> <li>• Barriers and enablers identified in the results sections of paper or drawn from author insights in the discussion</li> </ul>	
<b>Research type</b>	<ul style="list-style-type: none"> <li>• Published or grey literature (including third-sector and government reports, evaluations, and briefings) published from 2011 onwards</li> <li>• Conducted in Australia, New Zealand, Canada, or the UK</li> </ul>	<ul style="list-style-type: none"> <li>• Educational theses</li> <li>• Editorials</li> <li>• Conference abstracts and proceedings</li> <li>• Papers where full text is not available</li> <li>• Case studies</li> </ul>

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## Data screening and extraction

Two reviewers assessed the full text of each identified paper or report against inclusion and exclusion criteria. Any discrepancies were resolved through consensus discussion.

Data for included studies were extracted using a standardised data extraction form in REDCap<sup>10, 11</sup> by one member of the research team and checked by a second. Extracted data included: author and year of publication; country where the study was conducted; publication type (peer-reviewed or grey literature); design; methods (qualitative, quantitative or mixed-methods); cancer type; setting; the perspective from which the barriers and enablers were reported (healthcare provider or healthcare user, inclusive of patient, carer or support person); study aim; and phase of the cancer trajectory that barriers and enablers related to (cancer screening, cancer diagnosis and/or cancer treatment, inclusive of clinical trials).

## Quality appraisal

Given the range of study types that were included, we used the Mixed-Methods Appraisal Tool (MMAT)<sup>6</sup> to assess study quality. The MMAT contains specific assessment criteria relevant to different study designs, including the following that were relevant to the designs included in this Evidence Check: qualitative, observational descriptive and mixed methods. We assessed all studies against two screening questions in addition to five questions specific to each study design. All questions relevant to qualitative, quantitative and mixed methods designs are answered for mixed methods study (see Appendix 3 for a copy of the MMAT). All assessment items were answered using the following response options 'yes', 'no' and 'can't tell'. All studies were rated independently by one reviewer and then checked by a second reviewer. Studies were classified as at risk of low quality if they scored 'no' or 'can't tell' to one of the screening questions or were rated as meeting <80% of the design-specific items. The overall classification of mixed methods studies was determined based on the lowest scoring component, as recommended.

## Data synthesis

Data pertaining to barriers and enablers were synthesised separately according to the three main primary outcomes: (1) screening, (2) diagnosis and (3) treatment. Two reviewers deductively coded barriers and enablers according to categories of the Theoretical Domains Framework (TDF) version 2.<sup>7</sup> The TDF provides a theoretical lens through which to view the cognitive, affective, social and environmental influences on behaviour. The TDF includes 14 domains: knowledge, skills, social/professional role and identity, beliefs about capabilities, optimism, beliefs about consequences, reinforcement, intentions, goals, memory, attention and design processes, environmental context and resources, social influences, emotion, and behavioural regulation. An overview of the TDF, including definitions and constructs, is provided in Appendix 4. The frequency for each category of barrier and enabler was tabulated and reported in structured summary tables.

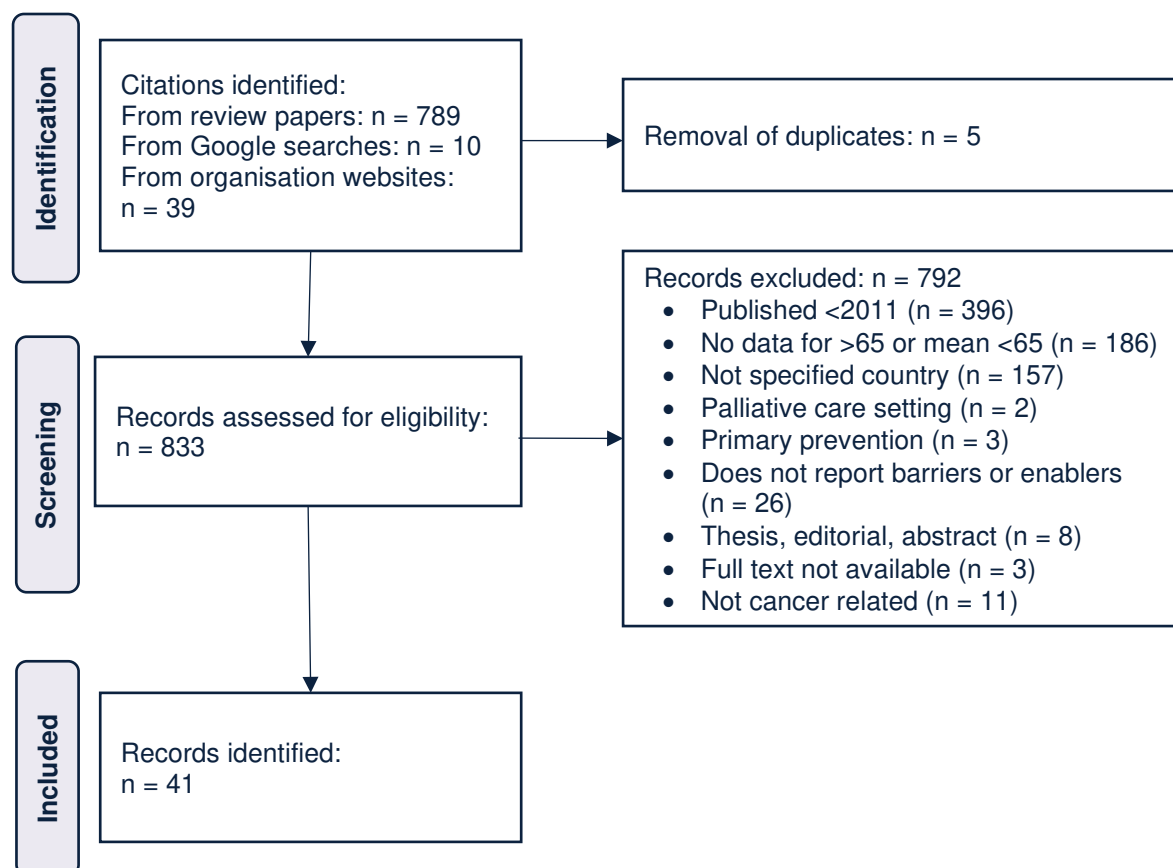


# Results

## Search results

The initial search of electronic databases to identify relevant review papers returned 713 results. Following removal of duplicates, we screened 693 records for inclusion, from which we identified 33 relevant reviews (see Appendix 5 for PRISMA flow chart). Identified reviews contained 789 citations (see Figure 1). Google and Google scholar searches identified an additional 10 papers, and 39 reports were identified from organisation websites. In total, we screened the titles and abstracts of 833 individual citations and found 792 were ineligible. A total of 41 individual studies met inclusion criteria and are included in the Evidence Check.

**Figure 1**—PRISMA flow chart: Identification of relevant studies and reports from identified reviews and grey literature searches



## Studies included in the Evidence Check

A summary of each study's characteristics is presented in Table 2 for the three cancer phases that are the focus of this Evidence Check (screening, diagnosis and treatment) and overall. Detailed study characteristics for individual studies are provided in Appendix 6. The number of studies focusing on the three cancer phases of interest were similar, with a slightly higher number focusing on treatment (n = 18), followed by screening (n = 17) and then diagnosis (n = 15). The majority of studies were scientific papers (93%), employed qualitative methods (66%) and used a cross-sectional design (90%). Most studies were conducted in the UK (78%) and no studies were conducted in New Zealand. Most studies were from the perspective of the healthcare user (e.g. patient, family, support persons) (84%) as opposed to that of the healthcare provider (16%).

**Table 2**—Summary of characteristics of included studies, n = 41

	Screening* n = 17 (%)	Diagnosis* n = 15 (%)	Treatment* n = 18 (%)	Total n = 41 (%)
<b>Publication type</b>				
Scientific paper	16 (94%)	13 (87%)	16 (89%)	38 (93%)
Report	1 (6%)	2 (13%)	2 (11%)	3 (7%)
<b>Study location</b>				
Australia	3 (17%)	1 (7%)	2 (11%)	5 (12%)
New Zealand	0	0	0	0
UK	14 (83%)	14 (93%)	12 (67%)	32 (78%)
Canada	0	0	4 (22%)	4 (10%)
<b>Methods</b>				
Quantitative	4 (28%)	2 (13%)	5 (28%)	11 (27%)
Qualitative	12 (67%)	11 (73%)	11 (61%)	27 (66%)
Mixed methods	1 (6%)	2 (13%)	2 (11%)	3 (7%)
<b>Design</b>				
Randomised controlled trial	0	0	1 (6%)	1 (2%)
Cohort study	0	0	1 (6%)	1 (2%)
Cross-sectional	17 (100%)	14 (93%)	15 (83%)	37 (90%)
Other	0	1 (7%)	1 (6%)	2 (5%)
<b>Cancer type</b>				
Breast	0	3 (20%)	7 (39%)	7 (17%)
Colorectal	8 (44%)	0	0	8 (20%)
Prostate	3 (17%)	2 (13%)	5 (28%)	8 (20%)
Lung	1 (6%)	4 (27%)	1 (6%)	6 (15%)
Mix	3 (22%)	3 (20%)	2 (17%)	6 (15%)
Other	2 (11%)	3 (20%)	3 (17%)	6 (15%)

	Screening* n = 17 (%)	Diagnosis* n = 15 (%)	Treatment* n = 18 (%)	Total n = 41 (%)
<b>Setting<sup>a</sup></b>				
Acute care	1 (6%)	5 (33%)	11 (52%)	15 (33%)
Community	11 (65%)	5 (33%)	7 (33%)	17 (38%)
Primary care	3 (18%)	3 (20%)	1 (5%)	7 (16%)
Screening services	1 (6%)	0	0	1 (2%)
Other	2 (12%)	2 (13%)	2 (10%)	5 (11%)
<b>Perspective<sup>a</sup></b>				
Healthcare user	17 (100%)	13 (81%)	17 (77%)	38 (84%)
Healthcare provider	0	3 (19%)	5 (23%)	7 (16%)

\*Cell totals will not equal total sample size as individual studies could report across the three cancer phases.

<sup>a</sup>Cell totals may not equal the total sample size of the sub-group because multiple answers may have been selected.

## Quality of evidence assessment

The quality appraisal ratings for the studies separated by the three research questions are provided in Appendices 7, 8 and 9.

All of the 17 studies that reported barriers and enablers to cancer screening met the two screening criteria. However, two quantitative descriptive studies were considered at risk of low quality with an overall rating on the MMAT of 60%. The poorest rated quality items were “the sample is representative of the target population” and “risk of non-response bias is low”.

Of the 15 studies that reported barriers and enablers to cancer diagnosis, one did not meet the two screening criteria. This study, by Forbat<sup>12</sup>, was a mixed-methods study rated as “can’t tell” for all but four items. For all the items that were not met there was insufficient information reported to allow for an adequate decision to be determined. One quantitative descriptive study was classified as being at risk of low quality, with an overall rating of 60% and rated as not meeting the criteria “sample is representative of the target population” and “risk of non-response bias is low”.

Of the 18 studies that reported on the barriers and enablers to cancer treatment and services, one of the two mixed-method studies and three of the five quantitative descriptive studies were classified as being at risk of low quality. The mixed-method study by Allen<sup>13</sup> provided insufficient information to determine whether it adequately met the quality criteria across four of the items. For the quantitative studies, the items “sample is representative of the target population”, “measures are appropriate” and “risk of non-response bias is low” were the most poorly met criteria.

## Question 1: Barriers and enablers to cancer screening

A total of 17 papers reported on barriers and enablers to cancer screening in older adults. Almost all (94%) of these papers were peer-reviewed scientific papers and 83% related to cancer screening in

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the UK. More than half were qualitative (67%) and reported on barriers and enablers in the community setting (65%), and all (100%) reported barriers and enablers from the perspective of healthcare users. Forty-four per cent of papers reported on barriers and enablers to colorectal screening, 22% reported on mixed cancer types, and 17% reported on prostate screening. No papers exclusively examined barriers or enablers to screening for breast cancer, although breast cancer was included in publications reporting mixed cancer types.

A synthesis of barriers and enablers to cancer screening according to the Theoretical Domains Framework (TDF) is provided in Table 3. Detailed barriers and enablers are provided in Appendix 10. The most commonly reported barriers to cancer screening for older adults were in the knowledge, emotion, belief about consequences and environmental context and resources domains of the TDF. Ten studies reported knowledge barriers that related to lack of knowledge about how to use colorectal screening tests including lack of understanding or misunderstanding of instructions provided<sup>14–17</sup> and low levels of literacy for interpreting instructions<sup>17, 18</sup>; lack of awareness about the availability of screening programs<sup>14, 15, 19</sup>; and lack of awareness about cancer generally<sup>14, 20</sup>, the signs and symptoms of cancer<sup>20, 21</sup> and cancer risk factors.<sup>20, 21</sup> Ten studies reported emotional barriers related to a fear of a cancer diagnosis and its outcomes, including of both cancer treatment and death.<sup>14–19, 22–24</sup> Other barriers in the emotion domain related to stigma of cancer<sup>15</sup> and stigma and embarrassment in discussing and undertaking testing.<sup>14–16, 22, 24</sup> Nine studies reported barriers in the beliefs about consequences domain related to harmful patient beliefs about risk factors, signs and symptoms of cancer. This included cancer screening not being perceived as useful in the absence of cancer symptoms<sup>14, 16–19, 23–26</sup>, low perceived individual susceptibility to cancer risk<sup>14, 17, 26</sup>, and fatalistic beliefs about the benefits of screening<sup>14, 17</sup>, being diagnosed with cancer<sup>23</sup> and the impact of age on cancer treatment outcomes.<sup>14</sup> Seven studies in the environmental context and resources domain related to hygiene concerns.<sup>14, 16–18, 23, 24, 26</sup> This included concerns about collecting, storing and posting faeces samples, reported in six studies related to colorectal screening<sup>14, 16–18, 24, 26</sup>, and one study that reported concerns about providing sputum samples for lung cancer screening.<sup>23</sup>

The most commonly reported enablers to cancer screening for older adults were in the beliefs about consequences, social influences and knowledge domains of the TDF. Seven studies reported that helpful beliefs about screening facilitated participation. This included the perceived personal benefit of an early diagnosis<sup>14, 15, 18–20, 23, 27</sup>, positive beliefs about the success of treatment options available if diagnosed<sup>15, 18, 20</sup>, a desire to engage in testing for diseases that become more prevalent with age<sup>20</sup>, perceptions of higher individual risk of cancer<sup>23</sup> and that participation in early screening can avoid the embarrassment of having to present to a GP later with symptoms.<sup>14</sup> Five studies reported that encouragement to participate in screening by healthcare providers<sup>16, 17, 20, 24</sup> and family and friends<sup>16–18</sup> encouraged participation. In the knowledge domain, previous engagement in screening<sup>15, 26</sup>, previous individual experience of cancer<sup>15, 26</sup>, knowledge of the benefits of early detection<sup>18, 24</sup>, and awareness and recognition of the signs and symptoms of cancer<sup>20</sup> all encouraged participation in screening.

**Table 3**—Synthesis of barriers and enablers to cancer screening according to the Theoretical Domains Framework (TDF), n = 17

TDF domain	Barriers	N	Enablers	n
<b>Knowledge</b>	Low community awareness or knowledge	n = 10 <sup>14–21, 24, 28</sup>	Community awareness or knowledge	n = 5 <sup>15, 18, 20, 24, 26</sup>
	Negative perceptions about the usefulness of screening	n = 1 <sup>27</sup>		
<b>Skills</b>	Practical barriers or limitations	n = 2 <sup>14, 18</sup>	Resources to support testing	n = 1 <sup>24</sup>
	Difficulty using tests	n = 2 <sup>14, 24</sup>		
<b>Social/professional role and identity</b>	Social construct of old age	n = 2 <sup>24, 26</sup>	Personal beliefs	n = 3 <sup>15, 18, 27</sup>
	Healthcare provider influences	n = 1 <sup>17</sup>		
	Gender constructs	n = 1 <sup>29</sup>		
<b>Beliefs about capabilities</b>	Lack of confidence	n = 1 <sup>14</sup>	N/A	n = 0
<b>Optimism</b>	N/A	n = 0	Positive attitudes/beliefs	n = 1 <sup>27</sup>
<b>Beliefs about consequences</b>	Scepticism about the benefits of screening tests	n = 1 <sup>14</sup>	Helpful beliefs about screening	n = 7 <sup>14, 15, 18–20, 23, 27</sup>
	Harmful patient beliefs about risk factors, signs, and symptoms	n = 9 <sup>14, 16–19, 23–26</sup>		
	Negative patient beliefs about cancer treatment	n = 2 <sup>18, 24</sup>		
<b>Reinforcement</b>	N/A	n = 0	N/A	n = 0

<b>Intentions</b>	Delay in using provided test	n = 2 <sup>16, 24</sup>	N/A	n = 0
<b>Goals</b>	N/A	n = 0	N/A	n = 0
<b>Memory, attention and decision processes</b>	Delay in deciding about participation in screening	n = 1 <sup>14</sup>	Information from healthcare providers	n = 1 <sup>24</sup>
			Time	n = 1 <sup>14</sup>
<b>Environmental context and resources</b>	Healthcare accessibility difficulties	n = 3 <sup>17, 23, 30</sup>	Healthcare accessibility	n = 1 <sup>17</sup>
	Practical concerns	n = 2 <sup>14, 16</sup>	Practical aspects of undertaking screening	n = 3 <sup>15, 16, 24</sup>
	Hygiene concerns	n = 7 <sup>14, 16-18, 23, 24, 26</sup>		
	Lack of information resources	n = 3 <sup>17, 18, 25</sup>		
<b>Social influences</b>	Competing priorities and responsibilities of patients	n = 3 <sup>15, 17, 25</sup>	Advocacy for others	n = 1 <sup>20</sup>
	Previous bad experiences	n = 4 <sup>14, 17, 18, 23</sup>	Encouragement to participate in screening	n = 5 <sup>16-18, 20, 24</sup>
	Lack of awareness about others who had participated	n = 1 <sup>14</sup>	Social support from spouse	n = 1 <sup>26</sup>
	Resistance to paternalism resulting in lack of engagement with health system	n = 1 <sup>26</sup>	Influence of others	n = 3 <sup>14, 20, 23</sup>
			Promotion of screening	n = 2 <sup>17, 24</sup>
			Altruism	n = 2 <sup>15, 23</sup>
			Relationships	n = 1 <sup>17</sup>

<b>Emotion</b>	Fear	n = 10 <sup>14–20, 22–24</sup>	Peace of mind	n = 3 <sup>18, 20, 23</sup>
	Stigma	n = 3 <sup>15, 16, 29</sup>		
	Embarrassment	n = 4 <sup>14, 17, 22, 24</sup>		
<b>Behavioural regulation</b>	N/A	n = 0	N/A	n = 0

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## Question 2: Barriers and enablers to cancer diagnosis

A total of 15 papers reported on barriers and enablers to cancer diagnosis in older adults. Almost all (87%) of these papers were peer-reviewed scientific papers and related to cancer diagnosis in the UK (93%). The majority of papers reported on studies that used qualitative methods (73%) and were cross-sectional (93%) in design. Papers mostly reported on barriers and enablers to diagnosis in the acute care (33%) and community (33%) settings, and from the perspective of healthcare users (87%). Most papers reported on barriers and enablers to diagnosis of lung cancer (27%) and breast cancer (20%). No papers exclusively examined barriers or enablers to diagnosis of colorectal cancer, although colorectal cancer was included in all three publications reporting mixed cancer types.

A synthesis of barriers and enablers to cancer diagnosis according to the Theoretical Domains Framework (TDF) is provided in Table 4. Detailed barriers and enablers are provided in Appendix 11. The most commonly reported barriers to cancer diagnosis for older adults were in the knowledge domain of the TDF, followed by the environmental context and resources domain, skills domain and beliefs about consequences domain. Nine studies reported knowledge barriers related to a lack of knowledge of the signs and symptoms of cancer, particularly those that were distinct and distinguishable from pre-existing conditions<sup>12, 30–34</sup> and ageing<sup>12, 32–34</sup>; lack of awareness about cancer generally<sup>12, 22</sup>, cancer risk factors<sup>28</sup> and cancer recurrence.<sup>35</sup> Five studies reported barriers in the environmental context and resources domain related to healthcare accessibility difficulties. This included long waiting times to get appointments with general practitioners and specialists<sup>30, 32, 33, 36, 37</sup>, insufficient consultation time<sup>32</sup>, financial costs<sup>30, 37</sup>, transport problems<sup>37</sup> and life events.<sup>30</sup> Four studies reported barriers in the skills domain related to inadequate clinical response from healthcare providers as perceived by patients. This included incomplete clinical history taking and physical examination<sup>32</sup>, lack of advice to patients on symptom monitoring<sup>33</sup>, delayed investigation of symptoms<sup>32–34, 36</sup>, and lack of follow-up review.<sup>32, 33</sup> Four studies reported barriers in the beliefs about consequences domain related to harmful patient beliefs about risk factors and signs and symptoms of cancer. This included low perceived individual susceptibility to cancer risk<sup>12</sup>, low perceived seriousness of cancer signs and symptoms<sup>38</sup>, fatalistic beliefs about the possibility of symptoms being cancer<sup>39</sup> and beliefs that symptoms could be self-managed.<sup>33</sup>

The most commonly reported enablers of cancer diagnosis for older adults were in the knowledge domain and social influences domain of the TDF. In the knowledge domain, five studies reported that awareness or knowledge facilitated cancer diagnosis. This included knowledge of the signs and symptoms of cancer<sup>30, 33, 40</sup>, particularly pain<sup>32</sup> and persistent cough<sup>34</sup>; awareness of ‘unusual’ or changing symptoms that are distinct from existing chronic symptoms<sup>33</sup>; and awareness of existing symptoms becoming poorly controlled or affecting activities.<sup>33</sup> In the social influences domain, five studies reported that support from family and friends facilitated cancer diagnosis. This involved family or friends recognising symptoms<sup>33</sup> and encouraging help-seeking for symptoms.<sup>12, 22, 30, 32, 33</sup>



**Table 4**—Synthesis of barriers and enablers to cancer diagnosis according to the Theoretical Domains Framework (TDF), n = 15

TDF domain	Barriers	n	Enablers	n
<b>Knowledge</b>	Low community awareness or knowledge	n = 9 <sup>12, 22, 28, 30–35</sup>	Community awareness or knowledge	n = 5 <sup>30, 32–34, 40</sup>
	Community perception of low susceptibility to or risk of cancer	n = 2 <sup>28, 32</sup>		
	Lack of healthcare provider knowledge	n = 2 <sup>31, 32</sup>		
<b>Skills</b>	Poor communication between healthcare provider and patient	n = 1 <sup>33</sup>	Healthcare provider response	n = 3 <sup>32, 33, 40</sup>
	Poor communication between primary and secondary care	n = 1 <sup>40</sup>		
	Inadequate healthcare provider response	n = 4 <sup>32–34, 36</sup>		
	Atypical or complex presentations	n = 2 <sup>36, 40</sup>		
<b>Social/professional role and identity</b>	N/A	n = 0	N/A	n = 0
<b>Beliefs about capabilities</b>	N/A	n = 0	N/A	n = 0
<b>Optimism</b>	N/A	n = 0	Patient positive attitude	n = 1 <sup>28</sup>
<b>Beliefs about consequences</b>	Harmful patient beliefs about risk factors, signs and symptoms	n = 4 <sup>12, 33, 38, 39</sup>	Helpful patient beliefs about symptoms	n = 2 <sup>12, 32</sup>
	Harmful patient beliefs about cancer causes	n = 1 <sup>32</sup>		

<b>Reinforcement</b>	N/A	n = 0	N/A	n = 0
<b>Intentions</b>	N/A	n = 0	N/A	n = 0
<b>Goals</b>	N/A	n = 0	N/A	n = 0
<b>Memory, attention and decision processes</b>	N/A	n = 0	N/A	n = 0
<b>Environmental context and resources</b>	Lack of information resources	n = 1 <sup>41</sup>	Healthcare accessibility	n = 3 <sup>30-32</sup>
	Workforce challenges	n = 1 (36)		
	Healthcare accessibility difficulties	n = 5 <sup>30, 32, 33, 36, 37</sup>		
	Patient non-compliance issues	n = 2 <sup>36, 40</sup>		
<b>Social influences</b>	Competing priorities and responsibilities of patients	n = 2 <sup>33, 39</sup>	Advocacy by family	n = 1 <sup>32</sup>
	Ageism/discrimination against patients	n = 1 <sup>35</sup>	Support from family/friends	n = 5 <sup>12, 22, 30, 32, 33</sup>
			Influence of knowing someone with cancer	n = 1 <sup>12</sup>
<b>Emotion</b>	Fear	n = 3 <sup>28, 32, 36</sup>	Fear	n = 1 <sup>39</sup>
<b>Behavioural regulation</b>	N/A	n = 0	Patient persistence	n = 1 <sup>30</sup>

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## Question 3: Barriers and enablers to cancer treatment

A total of 18 papers, including clinical trials, reported on barriers and enablers to cancer treatment among older adults. Almost all (89%) of these papers were peer-reviewed scientific papers, and two-thirds related to cancer treatment in the UK (67%). Most papers reported on studies that used either qualitative (61%) or quantitative (28%) methods and were cross-sectional (83%) in design. Papers mostly reported on barriers and enablers to treatment in the acute care (52%) and community (33%) settings, and from the perspective of healthcare users (77%). Most papers reported on barriers and enablers to the treatment of breast cancer (39%) and prostate cancer (28%). No papers exclusively examined barriers or enablers to treatment of colorectal cancer, although colorectal cancer was included in publications reporting mixed cancer types.

A synthesis of barriers and enablers to cancer diagnosis according to the Theoretical Domains Framework (TDF) is provided in Table 5. Detailed barriers and enablers are provided in Appendix 12. The most commonly reported barriers to accessing and completing cancer treatment were in the social influences domain and the environmental context and resources domain, followed by the beliefs about consequences domain, skills domain and knowledge domain. Seven studies reported barriers in the social influences domain that related to discrimination against patients. This involved discrimination against patients in the form of ageism<sup>28, 39, 41–44</sup>, whereby older patients were not offered the same treatments as younger patients (real and perceived), and racism.<sup>45</sup> Ageism was not specific to cancer type. Also in this domain, five studies reported that patients' caring and support responsibilities<sup>13, 22, 39, 46</sup> and not wanting to be a burden to other people<sup>28</sup> impeded their cancer treatment. Six studies reported barriers in the environmental context and resources domain related to healthcare accessibility, including travel burden<sup>13, 39, 46</sup>, financial cost<sup>13, 46</sup>, poor performance status and comorbidities<sup>47</sup>, and life events.<sup>35</sup> Also in this domain, four studies reported barriers to treatment related to workforce gaps. This included a lack of radiologists<sup>36</sup>, oncology nurses<sup>13</sup> and psychological support<sup>45</sup>; and insufficient time for consultations<sup>35</sup> and multidisciplinary team discussions of complex cases.<sup>13</sup> Barriers to clinical trials were also reported in this domain and included restrictive inclusion criteria<sup>13, 42</sup>, travel burden<sup>13, 42</sup> and randomisation.<sup>48</sup> Six studies reported barriers in the beliefs about consequences domain that related to patient concern about the adverse effects of treatment. This included impact on their independence<sup>28, 39, 49, 50</sup>, physical function<sup>39, 43</sup>, mental health<sup>39</sup>, pre-existing medical conditions<sup>41</sup>, quality of life<sup>49, 50</sup>, general health<sup>49</sup>, recovery time<sup>43</sup> and finances.<sup>43</sup> Also in this domain, four papers reported that harmful beliefs held by patients were a barrier to treatment. These included the belief that they were too old for treatments<sup>39, 49, 50</sup>, that treatment would stimulate other illnesses<sup>39</sup>, that treatment was ineffective<sup>39</sup>, that there was low survival benefit from treatment<sup>49</sup>, and that standard treatment was superior compared with clinical trial treatment.<sup>42</sup> Three studies reported barriers in the skills domain related to low health literacy of patients. Some patients lacked the computer skills to seek online information about treatment options<sup>39, 46</sup>, mistrusted the overwhelming volume of health information sites<sup>39, 46</sup>, or were illiterate.<sup>42</sup> Also in this domain, three studies reported that a barrier to treatment was poor communication between healthcare providers and patients<sup>35</sup>, characterised by healthcare providers not considering patients' feelings<sup>46</sup> and being brusque and insensitive.<sup>22</sup> Seven studies reported knowledge barriers related to lack of awareness about treatment options<sup>46</sup>, treatment benefits<sup>46</sup>, reconstruction<sup>41</sup>, the side effects of treatment<sup>13, 22, 35, 46</sup>, discharge from hospital<sup>45</sup>, follow-up care<sup>45</sup>, signs of cancer recurrence<sup>41, 45</sup>, available psychosocial support<sup>35, 37, 41, 46</sup>, self-management<sup>22</sup> and referral procedures.<sup>22</sup>

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The most commonly reported enablers to cancer treatment for older adults were in the social influences domain of the TDF, followed by the environmental context and resources domain and the memory, attention and decision processes domain. Eight studies reported enablers of treatment in the social influences domain related to knowing someone with cancer.<sup>22, 35, 39, 41, 43, 45, 46, 50</sup> This predominantly included peer support from a person in a similar situation.<sup>22, 35, 41, 45, 46</sup> Also in this domain, eight studies reported that healthcare providers had significant influence on patients' treatment decisions.<sup>28, 35, 37, 39, 41, 43, 49, 50</sup> As trusted sources of support and technical experts<sup>28, 35, 41</sup>, doctors' recommendations influenced patients' decisions to accept particular treatments.<sup>43, 49</sup> Five studies also reported that support from family and friends<sup>41</sup> influenced treatment decisions and coping with treatment. Four studies reported enablers in the environmental context and resources domain that related to information resources. Information tailored to the individual patient<sup>39, 46</sup>, short written information booklets<sup>41, 46, 49</sup>, decision support tools<sup>39, 46</sup> and cancer survivors' stories<sup>46</sup> were reported to facilitate treatment. Four studies also reported enablers related to healthcare accessibility. Volunteer drivers<sup>46</sup>, treatment orientation sessions<sup>46</sup>, a short time frame to referral<sup>35, 37</sup>, proximity to the cancer centre<sup>37</sup>, availability of equipment<sup>37</sup>, and the convenience of telephone rather than hospital-based follow-up<sup>51</sup> were reported to facilitate treatment. Seven studies reported treatment facilitators in the memory, attention and decision processes domain that related to involving patients in treatment decision making. Offering patients treatment choices<sup>39</sup>, allowing them adequate time to reach treatment decisions<sup>41, 50</sup>, providing them with decision support<sup>46</sup>, and engaging in shared or patient-directed decision making<sup>22, 35, 49</sup> were reported to facilitate treatment.

**Table 5**—Synthesis of barriers and enablers to cancer treatment according to the Theoretical Domains Framework (TDF), n = 18

TDF domain	Barriers	N	Enablers	n
<b>Knowledge</b>	Low patient awareness or knowledge	n = 7 <sup>13, 22, 35, 37, 41, 45, 46</sup>	Patient awareness or knowledge	n = 2 <sup>39, 46</sup>
	Lack of healthcare provider knowledge	n = 1 <sup>13</sup>		
<b>Skills</b>	Poor communication between healthcare provider and patient	n = 3 <sup>22, 35, 46</sup>	N/A	n = 0
	Poor communication between primary and secondary care	n = 1 <sup>13</sup>		
	Patient-perceived lack of GP skills	n = 1 <sup>45</sup>		
	Low health literacy of patients	n = 3 <sup>39, 42, 46</sup>		
<b>Social/professional role and identity</b>	Religious beliefs	n = 1 <sup>52</sup>	N/A	n = 0
<b>Beliefs about capabilities</b>	N/A	n = 0	Patient advocate	n = 1 <sup>6</sup>
			Patient coping	n = 1 <sup>28</sup>
<b>Optimism</b>	Patient's outwardly 'positive' attitude	n = 1 <sup>52</sup>	Patient positive attitude	n = 1 <sup>46</sup>
<b>Beliefs about consequences</b>	Harmful patient beliefs about treatment	n = 4 <sup>39, 42, 49, 50</sup>	Positive patient perceptions of treatment	n = 2 <sup>49, 51</sup>
	Patient concern about adverse effects of treatment	n = 6 <sup>28, 39, 41, 43, 49, 50</sup>		
	Patient concern	n = 3 <sup>43, 28, 48</sup>		

	Harmful healthcare provider beliefs about treatment	n = 1 <sup>13</sup>		
	Healthcare provider concerns	n = 1 <sup>13</sup>		
<b>Reinforcement</b>	N/A	n = 0	N/A	n = 0
<b>Intentions</b>	N/A	n = 0	N/A	n = 0
<b>Goals</b>	N/A	n = 0	Personal goal	n = 1 <sup>35</sup>
<b>Memory, attention and decision processes</b>	Patient involvement in decision making	n = 2 <sup>13, 35</sup>	Patient involvement in decision making	n = 7 <sup>22, 35, 39, 41, 46, 49, 50</sup>
	Negative healthcare provider attitudes towards clinical decision support tools	n = 1 <sup>13</sup>	Positive healthcare provider attitudes towards clinical decision support tools	n = 2 <sup>13, 51</sup>
<b>Environmental context and resources</b>	Information resources	n = 3 <sup>46, 49, 50</sup>		
	Workforce gaps	n = 4 <sup>13, 35, 36, 45</sup>	Information/educational resources	n = 4 <sup>39, 46</sup>
	Healthcare accessibility difficulties	n = 6 <sup>13, 35, 37, 39, 46, 47</sup>	Workforce	n = 2 <sup>13, 35</sup>
	Negative experience of healthcare facilities	n = 1 <sup>46</sup>	Healthcare accessibility	n = 4 <sup>35, 37, 46, 51</sup>
	Clinical trials involvement issues	n = 3 <sup>13, 42, 48</sup>		
<b>Social influences</b>	Competing priorities and responsibilities of patients	n = 5 <sup>13, 22, 28, 39, 46</sup>	Support from family/friends	n = 5 <sup>22, 35, 41, 43, 49</sup>
	Discrimination against patients	n = 7 <sup>28, 39, 41-45</sup>	Influence of knowing someone with cancer	n = 8 <sup>22, 35, 39, 41, 43, 45, 46, 50</sup>
	Sociocultural norms	n = 1 <sup>52</sup>	Influence of healthcare provider	n = 8 <sup>28, 35, 37, 39, 41, 43, 49, 50</sup>

	Influence of someone with cancer	n = 1 <sup>46</sup>		
	Lack of social support	n = 2 <sup>13, 22</sup>		
	Lack of continuity of care in primary care	n = 1 <sup>45</sup>		
<b>Emotion</b>	Fear	n = 4 <sup>37, 39, 46, 52</sup>	Fear	n = 1 <sup>49</sup>
<b>Behavioural regulation</b>	N/A		N/A	

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## Gaps in evidence

This Evidence Check review revealed several gaps in the evidence that should be taken into account when considering the application of the findings to inform policy development and could be the focus of future research.

**Few studies focused explicitly on those aged 65-plus.** Geriatric oncology is a relatively young field of medicine concerned with the diagnosis and treatment of cancer in the elderly. It has received increasing attention in recent years as the need to provide cancer-related care that addresses the special needs of the growing population of older people has been recognised. The relatively recent emergence of this field is reflected in the limited number of studies included in this Evidence Check that explicitly focused on people aged 65-plus. Given that cancer is an age-related disease, our search strategy was carefully designed to identify studies with a focus on older adults. However, it is likely that some studies relevant to the review, such as those that did not include the age-focused search terms in the title, abstract or keywords, may have been missed. Additionally, for studies that included people across a broad range of ages, unless the title or abstract mentioned older adults, it was not included in this Evidence Check. Geriatric oncology has been heralded as the next frontier in oncology. High quality evidence specific to those aged 65-plus is needed to inform policy and practice for this vulnerable group. This evidence could be generated by population-based longitudinal research tracking elderly people to better understand the onset, duration and frequency of the barriers and enablers of cancer screening, diagnosis and treatment over time.

**Few Australian studies.** The majority of studies in this Evidence Check were from the UK. Given the differences between the countries' healthcare systems, some findings such as those related to primary care may have more limited application to the Australian setting. Additionally, there are important differences between the two countries in demographic composition that have bearing on cancer policy. Approximately one-third of the Australian population live in a rural or remote area compared with only 15% of the UK population. Consequently, few studies included in this Evidence Check reported barriers and enablers from a rural perspective. This is an important gap in evidence because Australians living in rural or remote areas have poorer health outcomes, and poorer access to and use of healthcare services than people living in major cities.

**Few studies of diverse older adults.** Most studies in this Evidence Check were from the perspective of culturally homogeneous English-speaking healthcare users. Although culturally and linguistically diverse people make up nearly 45% of the Australian population, and 3.2% of Australians identify as Aboriginal and Torres Strait Islander, the barriers and enablers experienced by these populations are not captured in this Evidence Check. We also found no studies specifically focused on individuals with mental illness, LGBTIQ+ populations, or those of low socioeconomic status. These focus populations need to be considered separately using targeted literature reviews. A similar approach to the methodology used in this Evidence Check could be adopted, with cancer screening, diagnosis and treatment search terms combined with search terms specifically focused on each population. As these targeted searches would be expected to produce a smaller number of search results, the older adult search terms may not be necessary as data about the specific needs of older adults within these groups could be manually identified and extracted.



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**Few studies provided information about barriers and enablers from a healthcare provider perspective.** Most studies included in the Evidence Check provided information about barriers and enablers from the perspective of healthcare users, primarily patients and family members/carers. While this provides good evidence about barriers and enablers from a patient-centred viewpoint, this is an important gap as barriers and enablers are likely to be present at patient, provider and systems levels. Healthcare providers can offer alternative insights, and may identify healthcare provider and wider system-related barriers and enablers that may be largely hidden from patients.

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# Conclusions

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## Implications of findings for cancer care in NSW

This Evidence Check review suggests:

- **Increasing community members' and patients' knowledge and awareness.** Knowledge and access to information were key barriers and enablers to cancer-related care across all phases of the cancer trajectory. Despite the ubiquity of the internet as a source of information, low e-health literacy was identified as a barrier for this population. Simple written information tailored to the individual and decision-support tools, including larger text and visuals to support accessibility and understanding, would assist older adults to access information. It is preferred that information is provided by a trusted source (e.g. a healthcare provider), and it is critical that mass screening is supported by and encouraged by trusted health professionals. In addition to increasing knowledge and awareness, information is also an effective approach to prevent and address the negative attitudes, false beliefs and concerns identified as barriers to screening, diagnosis and treatment.
- **Reducing travel and financial burden.** Healthcare accessibility issues were identified as barriers to cancer-related care across all phases of the cancer trajectory. These burdens related to reduced physical mobility that constrain transportation options, proximity to cancer centres, and the costs associated with travelling for tests and treatment. Costs also factored in decisions about treatment options given this population typically consists of low-income earners (either retired or working part-time). Several government and non-government schemes providing practical support and financial support are available to assist with travel and costs. Information about these schemes should be widely disseminated, and the schemes reviewed to ensure they remain fit-for-purpose.

New models of care could be developed or expanded to increase access to care and reduce costs by reducing the need for older adults to travel for cancer-related care. Remote patient monitoring and telehealth oncology are promising approaches to provide care management in the patient's home and should be further explored.

- **Improving social support.** Social support from family and friends strongly influences participation in cancer screening, diagnosis and treatment. With the majority of cancer-related services and care provided in the community and outpatient settings, family (typically a spouse) assume a significant burden in providing emotional, practical and informational support. Family members often feel unprepared for this important role and would benefit from capacity building efforts to strengthen their confidence, skills and knowledge to provide this support. Support from someone in a similar situation enabled patients to be better prepared for and cope with treatment. Many credible non-government organisations offer peer support for patients and family carers, predominantly in the community setting, and information about these services should be widely

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disseminated. The peer worker model from mental health may have application in the cancer context.

- **Addressing ageism.** Perceived and actual discrimination in the form of ageism was a key barrier to treatment. Finding the balance between under and over-treating elderly patients is one of the challenges facing patients and their healthcare providers. Consideration of independence and quality of life are paramount for many patients. Patient involvement in treatment decision making, which includes being offered treatment choices and time to reach decisions, would facilitate treatment participation and completion among older adults. The use of decision support tools to aid in treatment decision making is supported by patients and healthcare providers.
- There has been increasing recognition that healthcare providers require additional competencies and skills to care for older adults. Education is an effective strategy to change attitudes, beliefs and behaviours. Education initiatives to increase the skills and knowledge of healthcare professionals caring for older adults could include integrating geriatric oncology into the curricula for medical, nursing and other allied health professionals; professional education; and broad dissemination of educational materials that are freely available.
- **Providing interdisciplinary geriatric oncology care.** The support and influence of key healthcare providers bolstered participation in screening, timely diagnosis and completion of cancer treatment. A key enabler of care was having a trusted healthcare provider such as a general practitioner or nurse who encouraged participation in appropriate screening tests at the right intervals, listened and took symptoms seriously, arranged appropriate and timely testing, followed up test results, could offer a trusted opinion about treatment options and provided whole-person care that considered other co-morbidities.

Models of care that encourage integrated approaches between oncologists, geriatricians and primary care can have beneficial effects such as minimising fragmentation of care, optimising patients' general health, ameliorating functional decline and assisting the patient and their oncologist with decisions about their cancer treatment. Including a geriatrician as part of a multidisciplinary team or expanding geriatric oncology clinics may facilitate the management of older people with cancer.

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# Appendices

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## Appendix 1—Search strategy

The search terms used for each database are summarised in the following tables. All searches were conducted on Monday 23 May 2022.

### Medline.

Database(s): Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily 1946 to May 23 2022

	Search terms	Number of results
1	exp Aged/	3,398,993
2	Aging/	244,975
3	(ag?ing or elder* or geriatri* or oct?genarian* or old age* or older adult* or older patient* or older population* or older subject* or senior* or retire*).ti,ab.	717,180
4	1 or 2 or 3	3,819,334
5	Neoplasms/	473,980
6	“Early Detection of Cancer”/	33,782
7	exp early diagnosis/ AND cancer.mp	36,837
8	missed diagnosis/ AND cancer.mp	37
9	(missed diagnosis AND cancer).mp	236
10	(cancer adj3 (screen* or diagnos* or treatment)).mp.	294,168
11	(early adj3 (detect* or prevent* or screen* or diagnos*)).mp. AND cancer.mp	84,185
12	((surgery or surgical or chemotherap* or adjuvant or neoadjuvant or radiation or radiotherapy or hormonal therap* or hormone therap* or endocrine therap* or psycho*support or follow-up or treatment or survivor*) and cancer).mp	1,067,151

13	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12	1,510,991
14	(barrier* or impede* or impediment* or facilitat* or challenge* or hindrance* or hinder* or obstacle* or hurdle* or adher* or bias* or enabl*).mp.	2,771,735
15	4 and 13 and 14	28,442
16	limit 15 to (English language and yr="2011 -Current")	19,294
17	review.ti.	604,744
18	16 and 17	551

## PsycInfo

APA PsycInfo <1806 to May Week 3 2022>

	Search terms	Number of results
1	exp older adulthood	10,102
2	exp aged/	2784
3	Aging/	84,553
4	(ag?ing or elder* or geriatri* or oct?genarian* or old age* or older adult* or older patient* or older population* or older subject* or senior* or retire*).ti,ab.	210,963
5	1 or 2 or 3 or 4	233,540
6	exp Neoplasms/ or exp/oncology	58,957
7	exp cancer screening/	5197
8	exp diagnosis/ AND cancer.mp	5137
9	Exp treatment/ AND cancer.mp	33,479
10	(misdiagnosis AND cancer).mp	31
11	(cancer adj3 (screen* or diagnos* or treatment)).mp.	21,429
12	(early adj3 (detect* or prevent* or screen* or diagnos*)).mp. AND cancer.mp	3263

13	((surgery or surgical or chemotherap* or adjuvant or neoadjuvant or radiation or radiotherapy or hormonal therap* or hormone therap* or endocrine therap* or psycho*support or follow-up or treatment or survivor*) and cancer).mp	36,294
14	Exp psychosocial outcomes/ and cancer.mp	25
15	Exp psychosocial factors/ and cancer.mp	5986
16	6 or 7 or 8 or 9 or 10 or 11 or 12 or 14 or 15	72,817
17	(barrier* or impede* or impediment* or facilitat* or challenge* or hindrance* or hinder* or obstacle* or hurdle* or adher* or bias* or enabl*).mp. or Exp Treatment barrier/	721,162
18	5 and 16 and 17	728
19	limit 19 to (English language and yr="2011 -Current")	436
20	review.ti.	166,987
21	19 and 20	26

## Cochrane

Date Run: 23/05/2022 02:18:58

	Search terms	Number of results
1	MeSH descriptor: [Aged] explode all trees	220,301
2	(ag*ng or elder or geriatri or oct?genarian or "old age" or "older adult" or "older patient" or "older population" or "older subject" or senior or retire):ti,ab,kw (Word variations have been searched)	2778
3	1 OR 2	311,746
4	MeSH descriptor: [Neoplasms] explode all trees	87,970
5	MeSH descriptor: [Early Detection of Cancer] this term only	1447
6	((cancer near/3 (screen or diagnos* or treatment))):ti,ab,kw (Word variations have been searched)	30,608
7	((surgery or surgical or chemotherap* or adjuvant or neoadjuvant or radiation or radiotherapy or hormonal therap* or hormone therap* or endocrine therap* or psycho*support or follow-up or treatment or survivor*) and cancer).mp):ti,ab,kw (Word variations have been searched)	2976

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8	4 OR 5 OR 6 or 7	110,012
9	((barrier* or impede* or impediment* or facilitat* or challenge* or hindrance* or hinder* or obstacle* or hurdle* or adher* or bias* or enabl*)):ti,ab,kw (Word variations have been searched)	148,909
10	3 and 8 and 9, with Cochrane Library publication date Between Jan 2011 and May 2022	1944
11	Cochrane reviews	136

## Appendix 2—Websites searched as part of grey literature search, by country

	Cancer control agencies	Ageing organisations	National health agencies	Professional bodies
UK	Cancer Research UK Prostate Cancer UK	Age UK Centre for Policy on Ageing Centre for Ageing Better Alzheimer's Society	UK Department of Health and Social Care UK Health Security Agency National Health Service	Royal College of General Practitioners Royal College of Radiologists Association of Cancer Physicians Royal College of Physicians UKONS – Oncology Nursing Society
AU	Cancer Australia Cancer Council Australia Cancer Council NSW Cancer Council Victoria Cancer Council Queensland Cancer Council Northern Territory Cancer Council Western Australia Cancer Council South Australia Cancer Council Tasmania Cancer Council ACT Victorian Cancer Agency Cancer Institute of NSW WA Cancer and Palliative Care Network Prostate Cancer Foundation of Australia Bowel Cancer Australia National Breast Cancer Foundation	Australian Association of Gerontology Council on the Ageing Aged and Community Services Australia Dementia Australia	Australian Department of Health Australian Institute of Health and Welfare	Royal Australian College of General Practitioners Cancer Nurses Society of Australia Royal Australian and New Zealand College of Radiologists Medical Oncology Group of Australia Royal Australian College of Physicians



	Leukaemia Foundation Lung Foundation Australia			
NZ	Te Aho O Te Kahu Cancer Control Agency Cancer Society of New Zealand Breast Cancer Foundation NZ Prostate Cancer Foundation NZ	Age Concern New Zealand Te Tari Kaumatua Office for Seniors	Ministry of Health NZ	Royal New Zealand College of General Practitioners General Practice NZ New Zealand Society for Oncology Cancer Nurses College
CA	Canadian Partnership Against Cancer Canadian Cancer Society BC Cancer Cancer Care Manitoba Cancer Care Alberta Saskatchewan Cancer Agency Cancer Care Ontario Ministère de la Santé et des Services Sociaux New Brunswick Cancer Network Nova Scotia Health Authority Cancer Care Program Canadian Breast Cancer Research Alliance	International Federation on Ageing National Institute on Ageing Age-Well Alzheimer Society of Canada	Health Canada Public Health Agency of Canada	College of Family Physicians of Canada Canadian Association of Radiation Oncology Canadian Association of Medical Oncologists Canadian Association of Nurses in Oncology

## Appendix 3—Mixed Methods Assessment Tool

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
<i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>					
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5. Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

## Appendix 4—Theoretical Domains Framework, version 2

Domain (definition)	Constructs
<b>1. Knowledge</b> (An awareness of the existence of something)	Knowledge (including of condition/rationale) Procedural knowledge Knowledge of task environment
<b>2. Skills</b> (An ability or proficiency acquired through practice)	Skills Skills development Competence Ability Interpersonal skills Practice Skill assessment
<b>3. Social/professional role and identity</b> (A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting)	Professional identity Professional role Social identity Identity Professional boundaries Professional confidence Group identity Leadership Organisational commitment
<b>4. Beliefs about capabilities</b> (Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use)	Self-confidence Perceived competence Self-efficacy Perceived behavioural control Beliefs Self-esteem Empowerment Professional confidence
<b>5. Optimism</b> (The confidence that things will happen for the best or that desired goals will be attained)	Optimism Pessimism Unrealistic optimism Identity
<b>6. Beliefs about consequences</b> (Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation)	Beliefs Outcome expectancies Characteristics of outcome expectancies Anticipated regret Consequents
<b>7. Reinforcement</b> (Increasing the probability of a response by	Rewards (proximal/distal, valued/not valued, probable/improbable)

arranging a dependent relationship, or contingency, between the response and a given stimulus)	Incentives Punishment Consequents Reinforcement Contingencies Sanctions
<b>8. Intentions</b> (A conscious decision to perform a behaviour or a resolve to act in a certain way)	Stability of intentions Stages of change model Transtheoretical model and stages of change
<b>9. Goals</b> (Mental representations of outcomes or end states that an individual wants to achieve)	Goals (distal/proximal) Goal priority Goal/target setting Goals (autonomous/controlled) Action planning Implementation intention
<b>10. Memory, attention and decision processes</b> (The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives)	Memory Attention Attention control Decision making Cognitive overload/tiredness
<b>11. Environmental context and resources</b> (Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour)	Environmental stressors Resources/material resources Organisational culture/climate Salient events/critical incidents Person × environment interaction Barriers and facilitators
<b>12. Social influences</b> (Those interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours)	Social pressure Social norms Group conformity Social comparisons Group norms Social support Power Intergroup conflict Alienation Group identity Modelling
<b>13. Emotion</b> (A complex reaction pattern, involving experiential, behavioural and physiological elements, by which the individual attempts to deal with a personally significant matter or event)	Fear Anxiety Affect Stress Depression Positive/negative affect Burn-out

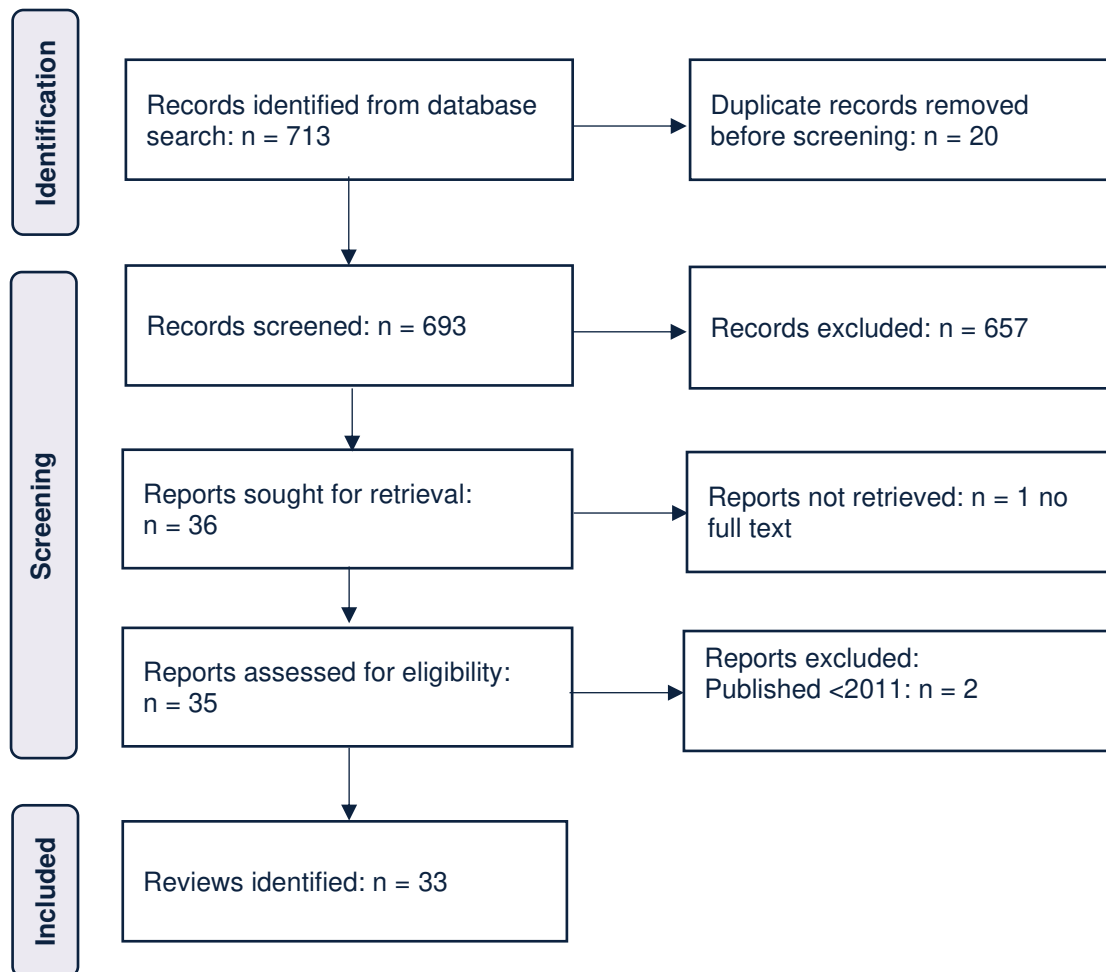
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**14. Behavioural regulation**  
(Anything aimed at managing or changing  
objectively observed or measured actions)

Self-monitoring  
Breaking habit  
Action planning

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## Appendix 5—PRISMA diagram for identification of review papers from electronic database search



## Appendix 6—Characteristics of included studies

Studies are presented alphabetically by stage of the cancer trajectory. Some papers are included multiple times in the table as they present barriers and/or enablers across both the screening and diagnosis phases (¥), diagnosis and treatment phases (\*), or across all three phases (^). Only barrier and enabler data related to the specific cancer stage are presented in each section.

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
<b>Screening</b>							
Anderson, 2013 <sup>20</sup> Scientific paper	UK	Cross-sectional Qualitative	Prostate	Acute care Healthcare user	<ul style="list-style-type: none"> <li>- Low community awareness or knowledge of cancer, the signs and symptoms of cancer and cancer risk factors</li> <li>- Fear of physically undergoing screening tests and loss of sexual function</li> </ul>	Participation in screening prompted by: <ul style="list-style-type: none"> <li>- Recognition of signs and symptoms of cancer</li> <li>- Helpful beliefs about screening including perceived personal benefit from early diagnosis, positive beliefs about the success of treatment options available if diagnosed, and beliefs about the need to engage in testing for diseases that become more prevalent with age</li> <li>- Desire to increase awareness of cancer by individuals who had been diagnosed</li> <li>- Encouragement to participate in screening by healthcare providers</li> <li>- Personal experience of a family member or friend with cancer</li> <li>- Screening considered a 'necessary evil'</li> </ul>	100%
Azar, 2022 <sup>17</sup> Scientific paper	Australia	Cross-sectional Qualitative	Breast, colorectal cervical	Community Healthcare user	<ul style="list-style-type: none"> <li>- Low community awareness or knowledge of the prevalence of cancer, how to use colorectal screening tests, and low levels of literacy</li> </ul>	<ul style="list-style-type: none"> <li>- Availability and convenience of testing appointments</li> <li>- Encouragement to participate in screening from healthcare providers</li> </ul>	80%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
					<ul style="list-style-type: none"> <li>- Reluctance to have screening completed by a male doctor</li> <li>- Harmful patient beliefs about risk factors, signs and symptoms including fatalistic beliefs about the benefits of screening because of perceived lack of treatment options, low perceived susceptibility to cancer risk, a perception that negative family history protected against cancer risk, and concerns about radiation (for breast screening)</li> <li>- Difficulty scheduling a screening appointment, waiting times and the need to travel</li> <li>- Screening not being promoted by general practitioners</li> <li>- Competing priorities and responsibilities of patients due to physical and mental health problems and caring for an elderly parent</li> <li>- Negative experiences of friends/family</li> <li>- Fear of painful/unpleasant past screening tests</li> <li>- Embarrassment at undertaking cervical screening</li> </ul>	<ul style="list-style-type: none"> <li>- Promotion of screening through invitations and reminder letters and mass and targeted local media</li> <li>- Long trusting relationships with healthcare providers</li> </ul>	
Bikker, 2019 <sup>18</sup>  Scientific paper	UK	Cross-sectional  Qualitative	Colorectal	Screening services  Healthcare user	<ul style="list-style-type: none"> <li>- Low levels of literacy</li> <li>- Physical mobility limitations and poor eyesight, which made completing the test difficult</li> <li>- Perception that negative family history protected against cancer risk</li> <li>- Negative patient beliefs about cancer treatment—cancer treatment perceived as harrowing</li> </ul>	<ul style="list-style-type: none"> <li>- Awareness of the benefits of early detection</li> <li>- Moral/civic duty to participate in screening</li> <li>- Helpful beliefs about screening including a perceived personal benefit from early diagnosis and positive beliefs about the success of treatment options available if diagnosed</li> </ul>	100%



Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
					<ul style="list-style-type: none"> <li>- Concerns about hygiene of collecting, storing and posting faeces samples</li> <li>- Lack of information resources via mass media about screening for some cancer types (bowel) compared with others (breast)</li> <li>- Previous bad experiences caring for family/friends with cancer</li> </ul>	<ul style="list-style-type: none"> <li>- Encouragement to participate in screening by family and friends</li> <li>- Screening perceived to provide peace of mind</li> </ul>	
Bradley, 2015 <sup>24</sup>  Scientific paper	UK	Cross-sectional  Qualitative	Colorectal	Community  Healthcare user	<ul style="list-style-type: none"> <li>- Inability to recognise screening invitation from junk mail</li> <li>- Low awareness of what the screening test was, and who had sent it</li> <li>- Difficulties using home-based tests</li> <li>- Participation in cancer screening associated with being perceived as old</li> <li>- Cancer treatment perceived as futile</li> <li>- Intended to participate in screening, but test put aside and ultimately did not (test kept indefinitely or put in bin)</li> <li>- Concerns about hygiene of collecting, storing and posting faeces samples</li> <li>- Fear of cancer diagnosis and its outcomes (both treatment and death)</li> <li>- Embarrassment</li> <li>- Embarrassment of undertaking bowel screening</li> </ul>	<ul style="list-style-type: none"> <li>- Knowledge about the benefits of early detection</li> <li>- Production of a video that explained how to do test, reducing the need to interact with faeces, using a test that required only one sample and having the GP undertake the test (rather than home test), and celebrity endorsement by someone who had been affected by bowel cancer all perceived as likely to increase participation</li> <li>- Talking to healthcare providers, discussing concerns and encouragement to participate by healthcare providers all bolstered participation</li> </ul>	100%
Dharni, 2017 <sup>15</sup>  Scientific paper	UK	Cross-sectional  Qualitative	Colorectal	Primary care  Healthcare user	<ul style="list-style-type: none"> <li>- Low awareness about the availability of screening programs</li> <li>- Lack of knowledge about how to use colorectal screening tests including lack of understanding or misunderstanding of instructions provided</li> <li>- Other physical and mental health problems and caring for elderly relatives were competing priorities</li> </ul>	<ul style="list-style-type: none"> <li>- Participation in screening promoted by:</li> <li>- Previous engagement in screening and individual experience of cancer</li> <li>- Religious beliefs and a moral/civic duty to participate</li> <li>- Helpful beliefs about screening including a perceived personal benefit from early diagnosis and positive beliefs about the success of</li> </ul>	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
					<ul style="list-style-type: none"> <li>- Stigma of cancer (generally), and of discussing cancer with others</li> </ul>	<ul style="list-style-type: none"> <li>- treatment options available if diagnosed</li> <li>- Ability to plan testing within daily schedule</li> <li>- Altruism about contributing to a cure for cancer and to avoid distress for family from dying from undetected cancer</li> </ul>	
Ekberg, 2014 <sup>26</sup>  Scientific paper	UK	Cross-sectional  Qualitative	Colorectal	Community  Healthcare user	<ul style="list-style-type: none"> <li>- Participation in cancer screening associated with being perceived as old</li> <li>- Screening not perceived as useful in the absence of cancer symptoms</li> <li>- Low perceived individual susceptibility to cancer risk</li> <li>- Concerns about hygiene of collecting, storing, and posting faeces samples</li> <li>- Resistance to paternalism resulting in lack of engagement with health system</li> </ul>	<ul style="list-style-type: none"> <li>- Previous engagement in screening and individual experience of cancer influenced participation in screening</li> <li>- Social support from spouse to undertake test at home facilitated participation</li> </ul>	100%
Hall, 2015 <sup>14</sup>  Scientific paper	UK	Cross-sectional  Qualitative	Colorectal	Primary care  Healthcare user	<ul style="list-style-type: none"> <li>- Low community awareness or knowledge of cancer, when screening is appropriate, and the availability of screening</li> <li>- Lack of understanding or misunderstanding of instructions provided for screening test</li> <li>- Mobility limitations</li> <li>- Lack of skills needed to take own samples and lack of confidence in undertaking sampling procedures</li> <li>- Preference for GP to undertake test</li> <li>- Colorectal screening tests perceived as unable to provide definitive answer regarding a diagnosis</li> <li>- Harmful patient beliefs including screening not perceived as useful in</li> </ul>	<ul style="list-style-type: none"> <li>- Participation in screening promoted by:</li> <li>- Perceived personal benefit from early diagnosis</li> <li>- Perception that screening avoids embarrassment of having to present to GP later with symptoms</li> <li>- Time to consider practicalities and implications of testing</li> <li>- Personal experience of family member or friend with cancer</li> <li>- Awareness of others who had engaged in screening</li> </ul>	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
					<p>the absence of cancer symptoms, fatalistic beliefs about the benefits of screening because of lack of treatment, decreased ability to fight off illness with age and low perceived susceptibility to cancer risk</p> <ul style="list-style-type: none"> <li>- Participation in screening perceived as low priority compared with other health priorities and other life events</li> <li>- Forgetting to use testing kit</li> <li>- Lack of access to suitable equipment to undertake faeces sampling</li> <li>- Practicalities of obtaining sample (regularity of bowel movement and where it occurs)</li> <li>- Concerns about hygiene of collecting, storing and posting faeces samples</li> <li>- Previous bad experiences with the healthcare system</li> <li>- Lack of awareness about others who had participated in screening</li> <li>- Fear of cancer diagnosis and its outcomes (both cancer treatment and death)</li> <li>- Embarrassment about discussing screening tests</li> </ul>		
Kerrison, 2021 <sup>21</sup>  Scientific paper	UK	Cross-sectional  Quantitative	Colorectal	Community and community pharmacies  Healthcare user	- Low community awareness or knowledge of the signs and symptoms of cancer and risk factors	N/A	60%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
^Macmillan, 2015 <sup>28</sup> Report	UK	Cross-sectional Mixed methods	All	Community Healthcare user	- Low community awareness or knowledge of who is eligible to participate in screening	N/A	80%
^Nanton, 2011 <sup>22</sup> Scientific paper	UK	Cross-sectional Qualitative	Prostate	Community Healthcare user	- Fear of physically undergoing screening tests, cancer diagnosis and its outcomes, and loss of sexual function - Embarrassment about undertaking digital rectal exam	N/A	100%
Palmer, 2014 <sup>16</sup> Scientific paper	UK	Cross-sectional Qualitative	Colorectal	Community Healthcare user	- Low community awareness or knowledge of how to use colorectal screening tests including lack of understanding or misunderstanding of instructions provided - Screening not perceived as useful in the absence of cancer symptoms - Delay in using provided test, despite intention to participate - Practicalities of obtaining sample (regularity of bowel movement and where it occurs) - Concerns about hygiene of collecting, storing and posting faeces samples - Collecting faeces considered a cultural taboo	- Preference for GP to undertake test (rather than a home-based CRC test) - Encouragement to participate in screening by healthcare providers and family and friends	100%
¥Parsonage, 2017 <sup>30</sup> Scientific paper	UK	Cross-sectional Qualitative	Breast colorectal lung ovarian	Cancer registry Healthcare user	- Difficulty scheduling a screening appointment	N/A	100%
Patel, 2012 <sup>23</sup>	UK	Cross-sectional	Lung	Primary care	- Healthcare accessibility difficulties including the need to travel for	Participation in screening promoted by:	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
Scientific paper		Qualitative		Healthcare user	<ul style="list-style-type: none"> <li>screening tests and the inconvenience of cancelled appointments</li> <li>- Concern about providing sputum samples</li> <li>- Previous bad experiences with doctors and hospitals</li> <li>- Previous negative experiences of screening among friends and family</li> <li>- Fear of cancer diagnosis and its outcomes (both cancer treatment and death)</li> </ul>	<ul style="list-style-type: none"> <li>- Helpful beliefs about screening including perceived personal benefit from early diagnosis and a perception of higher individual risk of cancer</li> <li>- Personal experience of family member or friend with cancer</li> <li>- Altruism related to improving research</li> <li>- Screening for reassurance</li> </ul>	
Seymour-Smith, 2016 <sup>29</sup> Scientific paper	UK	Cross-sectional Qualitative	Prostate	Community Healthcare user	<ul style="list-style-type: none"> <li>- Undertaking screening not seen as 'manly'</li> <li>- Cultural taboo of having certain body parts on display</li> </ul>	N/A	100%
Todorov, 2018 <sup>25</sup> Scientific paper	Australia	Cross-sectional Quantitative	Colorectal	Community Healthcare user	<ul style="list-style-type: none"> <li>- Screening not perceived as useful in the absence of cancer symptoms</li> <li>- Screening programs not being promoted/ recommended by general practitioners</li> <li>- Competing priorities and responsibilities of patients—not enough time/too busy</li> </ul>	N/A	80%
Varlow, 2014 <sup>19</sup> Scientific paper	Australia	Cross-sectional Quantitative	Colorectal	Community Healthcare user	<ul style="list-style-type: none"> <li>- Low community awareness or knowledge of the availability of screening programs</li> <li>- Screening not perceived as useful in the absence of cancer symptoms</li> <li>- Fear of cancer diagnosis and its outcomes (treatment and death)</li> </ul>	<ul style="list-style-type: none"> <li>- Perceived personal benefit from early diagnosis</li> </ul>	100%
Waller, 2015 <sup>27</sup>	UK	Cross-sectional	Breast colorectal	Community	<ul style="list-style-type: none"> <li>- Early detection not believed to result in mortality benefits</li> </ul>	<ul style="list-style-type: none"> <li>- Moral/civic duty to participate</li> </ul>	60%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
Scientific paper		Quantitative		Healthcare user		<ul style="list-style-type: none"> <li>- Positive attitudes/beliefs about the benefits of routine screening</li> <li>- Perceived personal benefit from early diagnosis</li> </ul>	
<b>Diagnosis</b>							
Birt, 2014 <sup>33</sup> Scientific paper	UK	Cross-sectional Qualitative	Lung	Acute care Healthcare user	<ul style="list-style-type: none"> <li>- Low community awareness or knowledge of the signs and symptoms of cancer distinct from pre-existing conditions and ageing</li> <li>- Healthcare providers being dismissive of patients' symptoms and concerns</li> <li>- Lack of advice from healthcare providers to patients about symptom monitoring, lack of follow-up review, delayed investigation of symptoms</li> <li>- Belief that symptoms could be self-managed</li> <li>- Difficulty getting timely appointments</li> <li>- Competing priorities and responsibilities of patients including caring responsibilities</li> </ul>	<ul style="list-style-type: none"> <li>- Community awareness or knowledge of the signs and symptoms of cancer, 'unusual' or changing symptoms that are distinct from existing chronic symptoms</li> <li>- Knowledge about existing symptoms that are increasingly poorly controlled and/or affecting activities</li> <li>- Healthcare provider follow-up of symptoms/vigilance even when symptoms seem straightforward</li> <li>- Support from family/friends encouraging symptom recognition and help-seeking/ attendance at primary care with symptoms</li> </ul>	100%
*Blows, 2011 <sup>35</sup> Scientific paper	UK	Cross-sectional Qualitative	Breast	Community Healthcare user	<ul style="list-style-type: none"> <li>- Low community awareness or knowledge of cancer recurrence</li> <li>- Ageism/discrimination against patients—concerns dismissed by GP as being 'old' and 'making a fuss'</li> </ul>	N/A	100%
*Burton, 2015 <sup>39</sup> Scientific paper	UK	Cross-sectional Qualitative	Breast	Acute care Healthcare user	<ul style="list-style-type: none"> <li>- Fatalistic beliefs about possibility of symptoms being cancer deter/delay symptomatic presentation</li> <li>- Competing carer responsibilities</li> </ul>	<ul style="list-style-type: none"> <li>- Feeling shocked, frightened and worried when cancer symptom found, which promoted seeking medical advice</li> </ul>	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
Caswell, 2017 <sup>34</sup> Scientific paper	UK	Cross-sectional Qualitative	Lung	Acute care Healthcare user	- Low community awareness or knowledge of the signs and symptoms of cancer distinct from pre-existing conditions and ageing - Delayed investigation of symptoms and/or referral	- Community awareness or knowledge of the signs and symptoms of cancer, particularly persistent cough	100%
Fenlon, 2012 <sup>41</sup> Scientific paper	UK	Cross-sectional Qualitative	Breast	Community Healthcare user	- Lack of information resources via mass media about older people being at risk of cancer	N/A	100%
Forbat, 2011 <sup>12</sup> Report	UK	Cross-sectional Mixed methods	Prostate	Community Healthcare user	- Low community awareness or knowledge of cancer, the signs and symptoms of cancer distinct from pre-existing conditions and ageing - Low perceived susceptibility to cancer risk	N/A	0%
George, 2022 <sup>37</sup> Scientific paper	Australia	Cross-sectional Qualitative	Breast prostate lung bowel other	Acute care Healthcare user Healthcare provider	- Healthcare accessibility difficulties including difficulty getting timely primary and secondary care appointments/ long waiting times, cost and transport	N/A	100%
Howell, 2013 <sup>31</sup> Scientific paper	UK	Cross-sectional Quantitative	Haemato-logical	Acute care Healthcare user	- Low community awareness or knowledge of the signs and symptoms of cancer, as distinct from pre-existing conditions - Lack of healthcare provider knowledge of the signs and symptoms of cancer as distinct from comorbidities	- Healthcare accessibility including repeat presentation to primary care or emergency departments during acute illness, which decreased time to diagnosis, and routine health checks or tests monitoring pre-existing comorbidities	100%
Howell, 2018 <sup>32</sup>	UK	Cross-sectional	Myeloma	Research network	- Low community awareness or knowledge of the signs and symptoms of cancer as distinct from pre-existing	- Community awareness or knowledge of the signs and symptoms of cancer, particularly pain	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
Scientific paper		Qualitative		Healthcare user	<ul style="list-style-type: none"> <li>conditions, ageing and non-serious changes in body or health</li> <li>- Community perception of low susceptibility to or risk of cancer</li> <li>- Lack of healthcare provider knowledge of cancer, the signs and symptoms of cancer, relevant investigations and test results</li> <li>- Inadequate healthcare provider response including incomplete clinical history taking and physical examination, lack of follow-up review by healthcare provider, delayed investigation of symptoms and/or referral</li> <li>- Harmful patient beliefs about cancer causes including self-blame for late diagnosis due to accepting initial non-cancer diagnosis</li> <li>- Healthcare accessibility difficulties including insufficient consultation time, referral delays and difficulty getting timely secondary care appointments</li> <li>- Fear, which delayed presentation for healthcare</li> </ul>	<ul style="list-style-type: none"> <li>- Healthcare willingness to reappraise symptoms and consider all diagnostic possibilities</li> <li>- Healthcare provider's prompt investigation and/or referral</li> <li>- Belief that second opinion will provide an alternative perspective</li> <li>- Healthcare accessibility including continuity of care from regular GP promotes early recognition of significant health changes, and private healthcare referral</li> <li>- Advocacy by family on behalf of patients in consultations or independent contact with GPs</li> <li>- Support from family/friends who encouraged help-seeking/attendance at primary care for symptoms</li> </ul>	
^Macmillan, 2015 <sup>28</sup> Report	UK	Cross-sectional  Mixed methods	All	Community  Healthcare user	<ul style="list-style-type: none"> <li>- Low community awareness or knowledge of cancer risk factors</li> <li>- Community perception of low susceptibility to or risk of cancer</li> <li>- Fear of cancer treatment deterred seeking help for symptoms</li> </ul>	<ul style="list-style-type: none"> <li>- Positive patient attitude that cancer isn't a death sentence</li> </ul>	80%
Mitchell, 2013 <sup>40</sup>	UK	Medical record audit	Lung	Primary care	<ul style="list-style-type: none"> <li>- Poor communication between primary and secondary care including non-</li> </ul>	<ul style="list-style-type: none"> <li>- Community awareness or knowledge of the signs and symptoms of cancer</li> </ul>	100%



Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
Scientific paper		Qualitative		Healthcare provider	<ul style="list-style-type: none"> <li>reporting of X-rays, test results, or discharge or follow-up arrangements</li> <li>- Atypical or complex presentations related to atypical symptoms, co-morbidity or plausible alternative diagnosis</li> <li>- Patient non-compliance issues including delay in re-presentation to GP with ongoing symptoms, decline referral from GP, decline to see GP when recommended by other healthcare provider, failure to attend appointments for investigations and decline hospital admission</li> </ul>	<ul style="list-style-type: none"> <li>- Healthcare provider not inappropriately reassuring patients</li> <li>- Healthcare provider follow-up of symptoms/ vigilance even when symptoms seem straightforward</li> <li>- Healthcare provider having a back-up plan or 'safety net' for dealing with an alternative outcome to the initial working diagnosis</li> </ul>	
^Nanton, 2011 <sup>22</sup> Scientific paper	UK	Cross-sectional Qualitative	Prostate	Community Health care user	<ul style="list-style-type: none"> <li>- Low community awareness or knowledge of cancer and the signs and symptoms of cancer</li> </ul>	<ul style="list-style-type: none"> <li>- Support from family/friends encouraged help-seeking/attendance at primary care for symptoms</li> </ul>	100%
Neal, 2015 <sup>36</sup> Scientific paper	UK	Cross-sectional Qualitative	Lung	Primary care Healthcare provider	<ul style="list-style-type: none"> <li>- Lack of radiologists</li> <li>- Healthcare accessibility difficulties including difficulty getting timely primary and secondary care appointments/long waiting times</li> <li>- Patient non-compliance issues, decline referral from GP, decline to see GP when recommended by other healthcare provider, and failure to attend appointments for investigations</li> <li>- Fear of unwanted outcome</li> </ul>	N/A	100%
¥Parsonage, 2017 <sup>30</sup> Scientific paper	UK	Cross-sectional Qualitative	Breast colorectal lung ovarian	Cancer registry Healthcare user	<ul style="list-style-type: none"> <li>- Low knowledge of the signs and symptoms of cancer as distinct from pre-existing conditions</li> <li>- Healthcare accessibility difficulties including difficulty getting timely primary</li> </ul>	<ul style="list-style-type: none"> <li>- Community awareness or knowledge of the signs and symptoms of cancer</li> <li>- Healthcare accessibility including routine health checks or tests monitoring pre-existing comorbidities</li> </ul>	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
					and secondary care appointments/ long waiting time, costs, and the impact of other life events	<ul style="list-style-type: none"> <li>or a previous malignancy that promoted diagnosis</li> <li>- Private healthcare referral</li> <li>- Support from family/friends that encouraged help-seeking/attendance at primary care for symptoms</li> <li>- Patient persistence to get GP to investigate more quickly</li> </ul>	
Whitaker, 2014 <sup>38</sup>  Scientific paper	UK	Cross-sectional  Quantitative	N/A (community sample)	Primary care  Healthcare user	- Low perceived seriousness of cancer signs and symptoms	N/A	60%
<b>Treatment</b>							
Allen, 2018 <sup>13</sup>  Report	UK	Cross-sectional  Mixed methods	All	Acute care, community, primary care  Healthcare user  Healthcare provider	<ul style="list-style-type: none"> <li>- Low patient awareness or knowledge of side effects</li> <li>- Lack of healthcare provider knowledge of older cancer patients' needs</li> <li>- Non-sharing of relevant patient information between primary and secondary care</li> <li>- Harmful healthcare provider beliefs about treatment including low survival benefits for older patients</li> <li>- Healthcare provider concerns about patient's fitness for treatment and the evidence of treatment effectiveness in older patients</li> <li>- Mismatch of patients' preferred level of involvement in treatment decision making</li> <li>- Lack of buy-in as to the value of geriatric assessment to inform treatment decision making and care plans</li> </ul>	<ul style="list-style-type: none"> <li>- Use of assessment to inform treatment decision making and care plans</li> <li>- Access to skilled staff including specialist cancer nurses, geriatricians and other specialists</li> </ul>	20%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
					<ul style="list-style-type: none"> <li>- Lack of community-based oncology nurses and lack of time for multidisciplinary team discussion of complex cases</li> <li>- Healthcare accessibility issues including cost/financial burden and travel burden</li> <li>- Clinical trials involvement issues including restricted inclusion criteria and travel burden</li> <li>- Competing priorities and responsibilities of patients including caring or support responsibilities</li> <li>- Difficulty accessing social care and practical support</li> </ul>		
Blows, 2011 <sup>35</sup> Scientific paper	UK	Cross-sectional Qualitative	Breast	Community Healthcare user	<ul style="list-style-type: none"> <li>- Low patient awareness or knowledge of side effects and available support</li> <li>- Poor communication between healthcare provider and patient</li> <li>- Mismatch in preferred level of involvement in treatment decision making</li> <li>- Insufficient consultation time</li> <li>- Healthcare accessibility issues including life events</li> </ul>	<ul style="list-style-type: none"> <li>- Personal goal to 'get on' with life</li> <li>- Shared or patient-directed decision making</li> <li>- Access to skilled staff including specialist cancer nurses, geriatricians, specialists</li> <li>- Shorter time since diagnosis</li> <li>- Peer support from person in a similar situation</li> <li>- Influence of healthcare provider as a trusted source of information and support</li> </ul>	100%
Burton, 2015 <sup>39</sup> Scientific paper	UK	Cross-sectional Qualitative	Breast	Acute care Healthcare user	<ul style="list-style-type: none"> <li>- Lack of computer skills to seek online information about treatment options</li> <li>- Overwhelming volume and mistrust of online health information sites</li> <li>- Harmful patient beliefs about treatment including being too old for treatments, cancer treatment would be ineffective,</li> </ul>	N/A	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
					<ul style="list-style-type: none"> <li>and concern treatment would stimulate other illnesses</li> <li>- Patient concern about adverse effects of treatment on physical function, mental health and independence</li> <li>- Burden of travel</li> <li>- Competing caring or support responsibilities</li> <li>- Discrimination against patients</li> <li>- Fear of procedures including anaesthesia, surgery and making the 'wrong' treatment decision</li> </ul>		
Davison, 2012 <sup>43</sup> Scientific paper	Canada	Cross-sectional Quantitative	Prostate	Acute care Healthcare user	<ul style="list-style-type: none"> <li>- Patient concern about adverse impacts of treatment on urinary and sexual function, recovery time and finances</li> <li>- Patient concern about regular active surveillance tests</li> <li>- Discrimination against patients based on age</li> </ul>	<ul style="list-style-type: none"> <li>- Support from family/friends</li> <li>- Influence of knowing someone with cancer</li> <li>- Influence of health care provider about specific treatment</li> </ul>	60%
Davison, 2011 <sup>44</sup> Scientific paper	Canada	Cross-sectional Quantitative	Prostate	Acute care Healthcare user	<ul style="list-style-type: none"> <li>- Discrimination against patients based on age</li> </ul>	N/A	40%
Fenlon, 2013 <sup>41</sup> Scientific paper	UK	Cross-sectional Qualitative	Breast	Community Healthcare user	<ul style="list-style-type: none"> <li>- Low patient awareness or knowledge of breast reconstruction, cancer recurrence and support</li> <li>- Patient concern about adverse effects of treatment on pre-existing medical conditions</li> <li>- Discrimination based on age</li> </ul>	<ul style="list-style-type: none"> <li>- Adequate time to make treatment decision</li> <li>- Provision of short written information booklets</li> <li>- Peer support from family and friends and others in a similar situation</li> <li>- Healthcare provider being a trusted source of information and support</li> </ul>	100%
George, 2022 <sup>37</sup>	Australia	Cross-sectional	Breast Prostate	Acute care	<ul style="list-style-type: none"> <li>- Lack of knowledge of support services such as financial support for travel</li> </ul>	<ul style="list-style-type: none"> <li>- Available equipment and proximity of cancer centre</li> </ul>	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
Scientific paper		Qualitative	Lung Bowel Other	Healthcare user and healthcare provider	<ul style="list-style-type: none"> <li>- Difficulty of travel and financial impact of travel and accommodation</li> <li>- Fearful of future outcomes</li> </ul>	<ul style="list-style-type: none"> <li>- Speedy referral process after diagnosis</li> <li>- Positive experiences and good rapport with healthcare providers</li> </ul>	
Harder, 2013 <sup>49</sup>  Scientific paper	UK	Cross-sectional  Qualitative	Breast	Acute care  Healthcare user	<ul style="list-style-type: none"> <li>- Harmful patient beliefs about treatment including belief that they are too old for treatment and will experience low survival benefit from treatment</li> <li>- Patient concern about adverse effects of treatment on independence, quality of life and general health</li> <li>- Overload of information</li> </ul>	<ul style="list-style-type: none"> <li>- Positive patient perceptions of treatment including prevention of recurrence and survival benefits</li> <li>- Shared or patient-directed decision making</li> <li>- Short written information booklets</li> <li>- Support from family/friends</li> <li>- Recommendation from doctor for specific treatment</li> <li>- Seeking a second opinion</li> <li>- Fear of recurrence</li> </ul>	100%
Lackman, 2020 <sup>42</sup>  Scientific paper	Canada	Cross-sectional  Quantitative	Breast Lung Melanoma Other	Acute care  Healthcare provider	<ul style="list-style-type: none"> <li>- Low health literacy, language barrier /illiterate</li> <li>- Harmful patient beliefs about treatment including that standard treatment is superior</li> <li>- Clinical trials involvement issues including restricted inclusion criteria and travel burden</li> <li>- Ageism</li> </ul>	N/A	80%
Leonard, 2011 <sup>48</sup>  Scientific paper	UK	Randomised controlled trial  Quantitative	Breast	Acute care  Healthcare user	<ul style="list-style-type: none"> <li>- Clinical trials involvement issues including restricted inclusion criteria, reluctance to accept randomisation, concern about undergoing chemotherapy</li> </ul>	N/A	60%
<sup>^</sup> Macmillan, 2015 <sup>28</sup>  Report	UK	Cross-sectional	All	Community  Healthcare user	<ul style="list-style-type: none"> <li>- Patient concern about adverse effects of treatment on independence</li> <li>- Patient concern about treatment side effects being worse than the cancer itself</li> </ul>	<ul style="list-style-type: none"> <li>- Perception of being better able to cope with cancer than younger people because of life experience,</li> </ul>	80%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
		Mixed methods			<ul style="list-style-type: none"> <li>- Not wanting to be a burden to other people</li> <li>- Ageism</li> </ul>	<ul style="list-style-type: none"> <li>and fewer worries about the practical impact of cancer treatment</li> <li>- Healthcare provider a trusted source of information and support</li> </ul>	
Margariti, 2021 <sup>45</sup> Scientific paper	UK	Cross-sectional Qualitative	Prostate	Community Healthcare user	<ul style="list-style-type: none"> <li>- Low patient awareness or knowledge of discharge, follow-up care and cancer recurrence</li> <li>- Patient-perceived lack of GP skills to manage side effects after treatment</li> <li>- Lack of psychological support</li> <li>- Racism</li> <li>- Continuity of care in primary care made it difficult to raise sensitive topics</li> </ul>	<ul style="list-style-type: none"> <li>- Peer support from person in a similar situation</li> </ul>	100%
Morgan, 2015 <sup>50</sup> Scientific paper	UK	Cross-sectional Qualitative	Breast	Acute care, community Healthcare user Healthcare provider	<ul style="list-style-type: none"> <li>- Harmful patient beliefs about treatment including being too old for treatment</li> <li>- Patient concern about adverse effects of treatment on independence and quality of life</li> <li>- Quality of life</li> <li>- Overload of information</li> <li>- Perceived withholding of information from patients by healthcare providers</li> </ul>	<ul style="list-style-type: none"> <li>- Adequate time to reach treatment decision</li> <li>- Influence of knowing someone with cancer</li> <li>- Influence of healthcare provider</li> </ul>	100%
^Nanton, 2011 <sup>22</sup> Scientific paper	UK	Cross-sectional Qualitative	Prostate	Community Healthcare user	<ul style="list-style-type: none"> <li>- Low patient awareness or knowledge of side effects, self-management and referral procedures</li> <li>- Poor communication between healthcare provider and patient perception that healthcare providers are brusque and insensitive</li> <li>- Competing caring or support responsibilities of patients</li> </ul>	<ul style="list-style-type: none"> <li>- Patient advocate—individuals who had been diagnosed took on role of alerting others to the illness and availability of treatment</li> <li>- Patient involvement in treatment decision making</li> <li>- Shared or patient-directed decision making</li> <li>- Support from family/friends</li> <li>- Peer support from person in a similar situation</li> </ul>	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
Tang, 2021 <sup>47</sup> Scientific report	Australia	Cohort Quantitative	Lung	Cancer registry Healthcare user	<ul style="list-style-type: none"> <li>- Individuals had poor performance status, comorbidities, dementia</li> <li>- Poor performance status, comorbidities and prior cancer affected clinical trial uptake rates</li> </ul>	N/A	100%
Wagland, 2020 <sup>52</sup> Scientific paper	UK	Cross-sectional Qualitative	Prostate	Cancer registry Healthcare user	<ul style="list-style-type: none"> <li>- Neglect to seek medical help as 'God will cure'</li> <li>- Patients' positive attitudes mask genuine concerns about physical and social functioning</li> <li>- Sociocultural norms that preclude discussion of medical issues, stigma and shame</li> <li>- Fear of hospitals</li> </ul>	N/A	100%
Williamson, 2018 <sup>51</sup> Scientific paper	UK	Cross-sectional Qualitative	Endometrial	Acute care Healthcare user Healthcare provider	N/A	<ul style="list-style-type: none"> <li>- Positive patient perceptions of ability to self-manage</li> <li>- Use of assessment to inform treatment decision making and care plans</li> <li>- Convenience of telephone rather than hospital follow-up</li> </ul>	100%
Wong, 2011 <sup>46</sup> Scientific paper	Canada	Cross-sectional Qualitative	Breast	Acute care Healthcare user	<ul style="list-style-type: none"> <li>- Low patient awareness or knowledge of treatment options, treatment benefits, side effects and psychosocial therapy</li> <li>- Poor communication between healthcare provider and patient results in overlooking patient's feelings</li> <li>- Lack of computer skills to seek online information about treatment options</li> <li>- Overwhelming volume and mistrust of online health information sites</li> <li>- Overload of information</li> <li>- Healthcare accessibility issues including cost and impact of life events</li> </ul>	<ul style="list-style-type: none"> <li>- Patient awareness or knowledge of clinical trials</li> <li>- Patient positive attitude</li> <li>- Patient provided with decision support</li> <li>- Provision of: information tailored to the individual patient; short written information booklets; decision support tools; and cancer survivor stories</li> <li>- Availability of volunteer drivers and treatment centre orientation sessions</li> </ul>	100%

Author/s, date publication type	Country	Design and methods	Cancer type/s	Setting and perspective	Barriers	Enablers	MMAT score
					<ul style="list-style-type: none"> <li>- Negative experience of healthcare facilities including cold treatment room and treatment machine malfunction</li> <li>- Logistical challenges of peer informants attending treatment sessions</li> <li>- Fear of side effects including tiredness/loss of energy</li> </ul>	<ul style="list-style-type: none"> <li>- Peer support from person in a similar situation</li> </ul>	



## Appendix 7—MMAT scoring: Screening

Study author (year)	Screening question: Clear research question?	Screening question: Data answers research question?	Qualitative approach appropriate?	Qualitative data collection methods adequate?	Findings adequately derived?	Interpretation sufficiently substantiated?	Coherence?	Sampling strategy relevant?	Sample representative of target population?	Measures appropriate?	Risk of non-response bias low?	Statistical analysis appropriate?	Adequate for mixed methods?	Components effectively integrated?	Components adequately interpreted?	Divergences & inconsistencies adequately addressed?	Components adhere to quality criteria of methods?	% main criteria met
<b>Mixed methods</b>																		
Macmillan Cancer Support, 2015 <sup>28</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Can't tell	80%
<b>Qualitative</b>																		
Anderson, 2013 <sup>20</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Azar, 2022 <sup>17</sup>	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes											80%
Bikker, 2019 <sup>18</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Bradley, 2015 <sup>24</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Dharni, 2017 <sup>15</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Ekberg, 2014 <sup>26</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Hall, 2015 <sup>14</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Nanton, 2011 <sup>22</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%

<b>Palmer, 2014<sup>16</sup></b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes								<b>100%</b>
<b>Parsonage, 2017<sup>30</sup></b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes								<b>100%</b>
<b>Patel, 2012<sup>23</sup></b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes								<b>100%</b>
<b>Seymour-Smith, 2016<sup>29</sup></b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes								<b>100%</b>
<b>Quantitative</b>															
<b>Kerrison, 2021<sup>21</sup></b>	Yes	Yes						Yes	Can't tell	Yes	No	Yes			<b>60%</b>
<b>Todorov, 2018<sup>25</sup></b>	Yes	Yes						Yes	Yes	Yes	Can't tell	Yes			<b>80%</b>
<b>Varlow, 2014<sup>19</sup></b>	Yes	Yes						Yes	Yes	Yes	Yes	Yes			<b>100%</b>
<b>Waller, 2015<sup>27</sup></b>	Yes	Yes						Yes	Can't tell	Yes	Can't tell	Yes			<b>60%</b>

## Appendix 8—MMAT scoring: Diagnosis

Study author (year)	Screening question: Clear research question?	Screening question: Data answers research question?	Qualitative approach appropriate?	Qualitative data collection methods adequate?	Findings adequately derived?	Interpretation sufficiently substantiated?	Coherence?	Sampling strategy relevant?	Sample representative of target population?	Measures appropriate?	Risk of non-response bias low?	Statistical analysis appropriate?	Adequate for mixed methods?	Components effectively integrated?	Components adequately interpreted?	Divergences & inconsistencies adequately addressed?	Components adhere to quality criteria of the methods?	% main criteria met
<b>Mixed Methods</b>																		
Forbat, 2011 <sup>12</sup>	Yes	Can't tell	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Yes	Can't tell	Can't tell	Can't tell	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	0%
Macmillan Cancer Support, 2015 <sup>28</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Can't tell	80%
<b>Qualitative</b>																		
Birt, 2014 <sup>33</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Blows, 2011 <sup>35</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Burton, 2015 <sup>39</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Caswell, 2017 <sup>34</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Fenlon, 2013 <sup>41</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
George, 2022 <sup>37</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Howell, 2018 <sup>32</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Mitchell, 2013 <sup>40</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Nanton, 2011 <sup>22</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%

<b>Neal, 2015<sup>36</sup></b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
<b>Parsonage, 2017<sup>30</sup></b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
<b>Quantitative</b>																		
<b>Howell, 2013<sup>31</sup></b>	Yes	Yes						Yes	Yes	Yes	Yes	Yes						100%
<b>Whitaker, 2014<sup>38</sup></b>	Yes	Yes						Yes	No	Yes	No	Yes						60%

## Appendix 9—MMAT scoring: Treatment

Study author (year)	Screening question: Clear research question?	Screening question: Data answers research question?	Qualitative approach appropriate?	Qualitative data collection methods adequate?	Findings adequately derived?	Interpretation sufficiently substantiated?	Coherence?	Sampling strategy relevant?	Sample representative of target population?	Measures appropriate?	Risk of non-response bias low?	Statistical analysis appropriate?	Adequate for mixed methods?	Components effectively integrated?	Components adequately interpreted?	Divergences & inconsistencies adequately addressed?	Components adhere to quality criteria of the methods?	% main criteria met
<b>Mixed methods</b>																		
Allen, 2018 <sup>13</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	No	Can't tell	Yes	Yes	Yes	Yes	Can't tell	20%
Macmillan Cancer Support, 2015 <sup>28</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Can't tell	80%
<b>Qualitative</b>																		
Blows, 2011 <sup>35</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Burton, 2015 <sup>39</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Fenlon, 2013 <sup>41</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
George, 2022 <sup>37</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Harder, 2013 <sup>49</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Margariti, 2021 <sup>45</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Morgan, 2015 <sup>50</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Nanton, 2011 <sup>22</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%
Wagland, 2020 <sup>52</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes											100%

<b>Williamson, 2018<sup>51</sup></b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes													<b>100%</b>	
<b>Wong, 2011<sup>46</sup></b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes														<b>100%</b>
<b>Quantitative</b>																					
<b>Davison, 2012<sup>43</sup></b>	Yes	Yes						Yes	Yes	Can't tell	No	Yes									<b>60%</b>
<b>Davison, 2011<sup>44</sup></b>	Yes	Yes						Yes	No	No	Can't tell	Yes									<b>40%</b>
<b>Lackman, 2020<sup>42</sup></b>	Yes	Yes						Yes	Yes	No	Yes	Yes									<b>80%</b>
<b>Leonard, 2011<sup>48</sup></b>	Yes	Yes						Yes	No	Yes	No	Yes									<b>60%</b>
<b>Tang, 2021<sup>47</sup></b>	Yes	Yes						Yes	Yes	Yes	Yes	Yes									<b>100%</b>

## Appendix 10—Identified barriers and enablers of cancer screening by domain

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<b>1. Knowledge</b> (An awareness of the existence of something)	<b>1.1 Low community awareness or knowledge of:</b> <ul style="list-style-type: none"> <li>- Cancer<sup>14, 20</sup></li> <li>- The prevalence of cancer<sup>17</sup></li> <li>- Signs and symptoms of cancer<sup>20, 21</sup></li> <li>- Risk factors<sup>20, 21</sup></li> <li>- When screening is appropriate to undertake<sup>14</sup></li> <li>- Availability of screening programs<sup>14, 15, 19</sup></li> <li>- Who is eligible to participate in screening<sup>28</sup></li> <li>- Recognition of the invitation separate from junk mail<sup>24</sup></li> <li>- How to use colorectal screening tests including lack of understanding or misunderstanding of instructions provided<sup>14–17</sup>, and low levels of literacy<sup>17, 18</sup></li> <li>- What the screening test was, and who had sent it<sup>24</sup></li> </ul> <b>1.2. Negative perceptions about the usefulness of cancer screening</b> <ul style="list-style-type: none"> <li>- Early detection not believed to result in mortality benefits<sup>27</sup></li> </ul>	<b>1.1 Community awareness or knowledge of:</b> <ul style="list-style-type: none"> <li>- Recognition of signs and symptoms of cancer<sup>20</sup></li> <li>- Previous engagement in screening<sup>15, 26</sup></li> <li>- Previous individual experience of cancer influenced participation in screening<sup>15, 26</sup></li> <li>- The benefits of early detection<sup>18, 24</sup></li> </ul>
<b>2. Skills</b> (An ability or proficiency acquired through practice)	<b>2.1 Practical barriers or limitations</b> <ul style="list-style-type: none"> <li>- Mobility limitations<sup>14, 18</sup></li> <li>- Poor eyesight made completing the test difficult<sup>18</sup></li> </ul> <b>2.2 Difficulty using tests</b> <ul style="list-style-type: none"> <li>- Difficulties using home-based tests<sup>24</sup></li> <li>- Skills needed to take own samples<sup>14</sup></li> </ul>	<b>2.1 Resources to support testing</b> <ul style="list-style-type: none"> <li>- Production of a video that explained how to do test<sup>24</sup></li> </ul>
<b>3. Social/professional role and identity</b>	<b>3.1 Social construct of old age</b> <ul style="list-style-type: none"> <li>- Participation in cancer screening associated with being perceived as old<sup>24, 26</sup></li> </ul>	<b>3.1 Personal beliefs</b> <ul style="list-style-type: none"> <li>- Religion<sup>15</sup></li> <li>- Moral/civic duty to participate<sup>15, 18, 27</sup></li> </ul>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
(A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting)	<p><b>3.2 Healthcare provider influences</b></p> <ul style="list-style-type: none"> <li>- Reluctance to have screening completed by male doctor<sup>17</sup></li> </ul> <p><b>3.3 Gender constructs</b></p> <ul style="list-style-type: none"> <li>- Undertaking screening not seen as ‘manly’<sup>29</sup></li> </ul>	
<b>4. Beliefs about capabilities</b> (Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use)	<p><b>4.1 Lack of skills/confidence</b></p> <ul style="list-style-type: none"> <li>- In undertaking sampling procedures<sup>14</sup></li> <li>- Perceived complexity of sampling procedures<sup>14</sup></li> <li>- Preference for GP to undertake test<sup>14</sup></li> </ul>	Nil identified
<b>5. Optimism</b> (The confidence that things will happen for the best or that desired goals will be attained)	Nil identified	<p><b>5.1 Positive attitudes/beliefs</b></p> <ul style="list-style-type: none"> <li>- About the benefits of routine screening<sup>27</sup></li> </ul>
<b>6. Beliefs about Consequences</b> (Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation)	<p><b>6.1 Scepticism about the benefits of screening tests</b></p> <ul style="list-style-type: none"> <li>- Colorectal screening tests perceived as unable to provide definitive answer regarding a diagnosis<sup>14</sup></li> </ul> <p><b>6.2 Harmful patient beliefs about risk factors, signs and symptoms</b></p> <ul style="list-style-type: none"> <li>- Screening not perceived as useful in the absence of cancer symptoms<sup>14, 16–19, 23–26</sup></li> <li>- Fatalistic beliefs about the benefits of screening because of lack of treatment (nothing can be done if screening test is positive)<sup>14, 17</sup></li> <li>- Fatalistic beliefs about the chances of getting cancer, and screening will not change that<sup>23</sup></li> </ul>	<p><b>6.1 Helpful beliefs about screening</b></p> <ul style="list-style-type: none"> <li>- Perceived personal benefit from early diagnosis<sup>14, 15, 18–20, 23, 27</sup></li> <li>- Positive beliefs about the success of treatment options available if diagnosed<sup>15, 18, 20</sup></li> <li>- Perception that screening avoids embarrassment of having to present to GP later with symptoms<sup>14</sup></li> <li>- Perception of higher individual risk of cancer<sup>23</sup></li> <li>- Beliefs about the need to engage in testing for diseases that become more prevalent with age<sup>20</sup></li> </ul>



Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
	<ul style="list-style-type: none"> <li>- Fatalistic beliefs related to age (decreased ability to fight off illness with age)<sup>14</sup></li> <li>- Low perceived susceptibility to cancer risk<sup>14, 17, 26</sup></li> <li>- Perception that older individuals were too old to benefit from cancer screening<sup>23</sup></li> <li>- Perception that negative family history protected against cancer risk<sup>17, 18, 23</sup></li> <li>- Concerns about radiation (for breast screening)<sup>17</sup></li> </ul> <p><b>6.3. Negative patient beliefs about cancer treatment</b></p> <ul style="list-style-type: none"> <li>- Cancer treatment perceived as harrowing<sup>18</sup>, difficult and futile<sup>24</sup></li> </ul>	
<p><b>7. Reinforcement</b> (Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus)</p>	Nil identified	Nil identified
<p><b>8. Intentions</b> (A conscious decision to perform a behaviour or a resolve to act in a certain way)</p>	<p><b>8.1 Delay in using provided test</b></p> <ul style="list-style-type: none"> <li>- Intended to participate in screening, but test put aside and ultimately did not (test kept indefinitely or put in bin)<sup>16, 24</sup></li> </ul>	Nil identified
<p><b>9. Goals</b> (Mental representations of outcomes or end states that an individual wants to achieve)</p>	Nil identified	Nil identified

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<p><b>10. Memory, attention, and decision processes</b> (The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives)</p>	<p><b>10.1 Delay in deciding about participation in screening</b></p> <ul style="list-style-type: none"> <li>- Participation in screening perceived as low priority compared with other health priorities<sup>14</sup></li> <li>- Participation in screening perceived as low priority compared with other conflicting priorities (e.g. stressful life events, caring for others)<sup>14</sup></li> <li>- Forgetfulness<sup>14</sup></li> </ul>	<p><b>10.1 Information from healthcare providers</b></p> <ul style="list-style-type: none"> <li>- Talking to healthcare providers and discussing concerns encouraged participation<sup>24</sup></li> </ul> <p><b>10.2 Time</b></p> <ul style="list-style-type: none"> <li>- Time to consider practicalities and implications of testing encouraged participation<sup>14</sup></li> </ul>
<p><b>11. Environmental context and resources</b> (Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour)</p>	<p><b>11.1 Healthcare accessibility difficulties</b></p> <ul style="list-style-type: none"> <li>- Difficulty scheduling a screening appointment<sup>17, 30</sup></li> <li>- Waiting times to have tests<sup>17</sup></li> <li>- The need to travel for screening tests<sup>17, 23</sup></li> <li>- Inconvenience of cancelled appointments<sup>23</sup></li> </ul> <p><b>11.2 Practical concerns</b></p> <ul style="list-style-type: none"> <li>- Access to suitable equipment to undertake faeces sampling<sup>14</sup></li> <li>- Practicalities of obtaining sample (regularity of bowel movement and where it occurs)<sup>14, 16</sup></li> </ul> <p><b>11.3 Hygiene concerns</b></p> <ul style="list-style-type: none"> <li>- Concerns about hygiene of collecting, storing and posting faeces samples<sup>14, 16–18, 24, 26</sup></li> <li>- Concern about providing sputum samples<sup>23</sup></li> </ul> <p><b>11.4 Lack of information resources</b></p> <ul style="list-style-type: none"> <li>- Via mass media about screening for some cancer types (bowel) compared with others (breast)<sup>18</sup></li> <li>- Screening programs not being promoted/recommended by general practitioners<sup>17, 25</sup></li> </ul>	<p><b>11.1 Healthcare accessibility</b></p> <ul style="list-style-type: none"> <li>- Availability and convenience of testing appointments<sup>17</sup></li> </ul> <p><b>11.2 Practical aspects of undertaking screening</b></p> <ul style="list-style-type: none"> <li>- Planning of testing within daily schedule facilitated completion<sup>15</sup></li> <li>- Limiting need for interacting with faeces<sup>24</sup></li> <li>- Using a test that required only one sample<sup>24</sup></li> <li>- GP to undertake test (rather than a home-based CRC test)<sup>16, 24</sup></li> </ul>
<p><b>12. Social influences</b> (Those interpersonal processes that can</p>	<p><b>12.1 Competing priorities and responsibilities of patients</b></p> <ul style="list-style-type: none"> <li>- Not enough time/too busy<sup>25</sup></li> </ul>	<p><b>12.1 Advocacy for others</b></p> <ul style="list-style-type: none"> <li>- Those who had been diagnosed emphasised importance of advocating and increasing awareness for others<sup>20</sup></li> </ul>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<p>cause individuals to change their thoughts, feelings, or behaviours)</p>	<ul style="list-style-type: none"> <li>- Other physical and mental health problems<sup>15, 17</sup></li> <li>- Caring for an elderly parent<sup>15, 17</sup></li> </ul> <p><b>12.2 Previous bad experiences</b></p> <ul style="list-style-type: none"> <li>- With doctors and hospitals<sup>23</sup> and the healthcare system<sup>14</sup></li> <li>- With caring for family/friends with cancer<sup>18</sup></li> <li>- Negative experiences of friends/family discouraged participation<sup>17, 23</sup></li> </ul> <p><b>12.3 Lack of awareness about others who had participated in screening<sup>14</sup></b></p> <p><b>12.4 Resistance to paternalism resulting in lack of engagement with health system<sup>26</sup></b></p>	<p><b>12.2 Encouragement to participate in screening</b></p> <ul style="list-style-type: none"> <li>- From healthcare provider(s)<sup>16, 17, 20, 24</sup></li> <li>- From family and friends<sup>16–18</sup></li> </ul> <p><b>12.3 Social support from spouse</b></p> <ul style="list-style-type: none"> <li>- To undertake test at home<sup>26</sup></li> </ul> <p><b>12.4 Influence of others</b></p> <ul style="list-style-type: none"> <li>- Personal experience of family member or friend with cancer prompted engagement with screening<sup>14, 20, 23</sup></li> <li>- Awareness of others who had engaged in screening prompted participation<sup>14</sup></li> </ul> <p><b>12.5 Promotion of screening</b></p> <ul style="list-style-type: none"> <li>- Celebrity endorsement by someone who had been affected by bowel cancer<sup>24</sup></li> <li>- Invitations and reminder letters<sup>17</sup></li> <li>- Mass media and targeted local media<sup>17</sup></li> </ul> <p><b>12.6 Altruism</b></p> <ul style="list-style-type: none"> <li>- About contributing to a cure for cancer through participation in screening<sup>15</sup></li> <li>- Related to improving research<sup>23</sup></li> <li>- To avoid distress for family<sup>15</sup></li> </ul> <p><b>12.7 Relationships</b></p> <ul style="list-style-type: none"> <li>- Long trusting relationships with healthcare providers encouraged participation<sup>17</sup></li> </ul>
<p><b>13. Emotion</b> (A complex reaction pattern, involving experiential, behavioural and physiological)</p>	<p><b>13.1 Fear</b></p> <ul style="list-style-type: none"> <li>- Of physically undergoing screening tests<sup>20, 22</sup></li> <li>- Of cancer diagnosis and its outcomes (both cancer treatment and death)<sup>14–19, 22–24</sup></li> <li>- Loss of sexual function<sup>20, 22</sup></li> <li>- Painful/unpleasant past screening tests<sup>17</sup></li> </ul>	<p><b>13.1 Peace of mind</b></p> <ul style="list-style-type: none"> <li>- Screening described as necessary evil<sup>20</sup></li> <li>- Screening provided peace of mind<sup>18</sup> and reassurance<sup>23</sup></li> </ul>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<p>elements, by which the individual attempts to deal with a personally significant matter or event)</p>	<p><b>13.2 Stigma</b></p> <ul style="list-style-type: none"> <li>- Of cancer<sup>15</sup></li> <li>- Of discussing cancer with others<sup>15</sup></li> <li>- Cultural taboo of collecting faeces<sup>16</sup> and having certain parts of body on display<sup>29</sup></li> </ul> <p><b>13.2 Embarrassment</b></p> <ul style="list-style-type: none"> <li>- Of undertaking cervical screening<sup>17</sup></li> <li>- Of undertaking digital rectal exam<sup>14, 22</sup></li> <li>- Of undertaking bowel screening<sup>24</sup></li> <li>- Of discussing screening tests<sup>14</sup></li> </ul>	
<p><b>14. Behavioural regulation</b> (Anything aimed at managing or changing objectively observed or measured actions)</p>	<p>Nil identified</p>	<p>Nil identified</p>

## Appendix 11—Identified barriers and enablers of cancer diagnosis by domain

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<b>1. Knowledge</b> (An awareness of the existence of something)	<b>1.1 Low community awareness or knowledge of:</b> <ul style="list-style-type: none"> <li>- Cancer<sup>12, 22</sup></li> <li>- Cancer risk factors<sup>28</sup></li> <li>- Signs and symptoms of cancer<sup>22</sup></li> <li>- Signs and symptoms of cancer as distinct from pre-existing conditions<sup>12, 30–34</sup> ageing<sup>12, 32–34</sup>, non-serious changes in body or health<sup>32</sup></li> <li>- Cancer recurrence<sup>35</sup></li> </ul> <b>1.2. Community perception of low susceptibility to or risk of cancer</b> <sup>28, 32</sup>  <b>1.3 Lack of healthcare provider knowledge of:</b> <ul style="list-style-type: none"> <li>- Cancer<sup>32</sup></li> <li>- Signs and symptoms of cancer<sup>31, 32</sup></li> <li>- Signs and symptoms of cancer as distinct from comorbidities<sup>31</sup></li> <li>- Relevant investigations<sup>32</sup></li> <li>- Test results<sup>32</sup></li> </ul>	<b>1.1 Community awareness or knowledge of:</b> <ul style="list-style-type: none"> <li>- Signs and symptoms of cancer<sup>30, 33, 40</sup>, particularly pain<sup>32</sup>, persistent cough<sup>34</sup></li> <li>- 'Unusual' or changing symptoms that are distinct from existing chronic symptoms<sup>33</sup></li> <li>- Existing symptoms increasingly poorly controlled and/or affecting activities<sup>33</sup></li> </ul>
<b>2. Skills</b> (An ability or proficiency acquired through practice)	<b>2.1 Poor communication between healthcare provider and patient</b> <ul style="list-style-type: none"> <li>- Healthcare provider dismissive of patients' symptoms and concerns<sup>33</sup></li> </ul> <b>2.2 Poor communication between primary and secondary care</b> <ul style="list-style-type: none"> <li>- Non-reporting of X-rays, test results, or discharge or follow-up arrangements<sup>40</sup></li> </ul> <b>2.2 Inadequate healthcare provider response</b>	<b>2.1 Healthcare provider response</b> <ul style="list-style-type: none"> <li>- Willingness to reappraise symptoms and consider all diagnostic possibilities<sup>32</sup></li> <li>- Not inappropriately reassuring patients<sup>40</sup></li> <li>- Follow-up of symptoms/vigilance even when symptoms seem straightforward<sup>40, 33</sup></li> <li>- Back-up plan or 'safety net' for dealing with an alternative outcome to the initial working diagnosis<sup>40</sup></li> <li>- Prompt investigation and/or referral<sup>32</sup></li> </ul>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
	<ul style="list-style-type: none"> <li>- Incomplete clinical history taking and physical examination<sup>32</sup></li> <li>- Lack of advice to patient about symptom monitoring<sup>33</sup></li> <li>- Lack of follow-up review by healthcare provider<sup>32, 33</sup></li> <li>- Delayed investigation of symptoms and/or referral<sup>32-34, 36</sup></li> </ul> <p><b>2.3 Atypical or complex presentations</b></p> <ul style="list-style-type: none"> <li>- Related to atypical symptoms, co-morbidity or plausible alternative diagnosis<sup>36, 40</sup></li> </ul>	
<p><b>3. Social/ professional role and identity</b> (A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting)</p>	Nil identified	Nil identified
<p><b>4. Beliefs about capabilities</b> (Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use)</p>	Nil identified	Nil identified
<p><b>5. Optimism</b> (The confidence that things will happen for the best or that desired goals will be attained)</p>	Nil identified	<p><b>5.1 Patient positive attitude</b></p> <ul style="list-style-type: none"> <li>- Cancer isn't a death sentence<sup>28</sup></li> </ul>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<p><b>6. Beliefs about Consequences</b> (Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation)</p>	<p><b>6.1 Harmful patient beliefs about risk factors, signs and symptoms</b></p> <ul style="list-style-type: none"> <li>- Low perceived susceptibility to cancer risk<sup>12</sup></li> <li>- Low perceived seriousness of cancer signs and symptoms<sup>38</sup></li> <li>- Fatalistic beliefs about possibility of symptoms being cancer deter/delay symptomatic presentation<sup>39</sup></li> <li>- Belief symptoms could be self-managed<sup>33</sup></li> </ul> <p><b>6.2. Harmful patient beliefs about cancer causes</b></p> <ul style="list-style-type: none"> <li>- Self-blame for late diagnosis due to accepting initial non-cancer diagnosis<sup>32</sup></li> </ul>	<p><b>6.1 Helpful patient beliefs about symptoms</b></p> <ul style="list-style-type: none"> <li>- Second opinion will provide an alternative perspective<sup>32</sup></li> <li>- Perceiving symptoms as serious or worrying hastens help seeking<sup>12</sup></li> </ul>
<p><b>7. Reinforcement</b> (Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus)</p>	<p>Nil identified</p>	<p>Nil identified</p>
<p><b>8. Intentions</b> (A conscious decision to perform a behaviour or a resolve to act in a certain way)</p>	<p>Nil identified</p>	<p>Nil identified</p>
<p><b>9. Goals</b> (Mental representations of outcomes or end states that an individual wants to achieve)</p>	<p>Nil identified</p>	<p>Nil identified</p>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<p><b>10. Memory, attention and decision processes</b> (The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives)</p>	<p>Nil identified</p>	<p>Nil identified</p>
<p><b>11. Environmental context and resources</b> (Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour)</p>	<p><b>11.1 Lack of information resources</b> - Via mass media about older people being at risk of cancer<sup>41</sup></p> <p><b>11.2 Workforce challenges</b> - Lack of radiologists<sup>36</sup></p> <p><b>11.3 Healthcare accessibility difficulties</b> - Difficulty getting timely primary and secondary care appointments/long waiting times<sup>30, 32, 33, 36, 37</sup> - Insufficient consultation time<sup>32</sup> - Cost/financial<sup>30, 37</sup> - Life events<sup>30</sup> - Transport<sup>37</sup></p> <p><b>11.4 Patient non-compliance issues</b> - Delay in re-presentation to GP with ongoing symptoms<sup>40</sup> - Decline referral from GP<sup>36, 40</sup> - Decline to see GP when recommended by other healthcare provider<sup>36, 40</sup> - Failure to attend appointments for investigations<sup>36, 40</sup> - Decline hospital admission<sup>40</sup></p>	<p><b>11.1 Healthcare accessibility</b> - Repeat presentation to primary care or emergency departments during acute illness decreased time to diagnosis<sup>31</sup> - Routine health checks or tests monitoring pre-existing comorbidities<sup>30, 31</sup> or a previous malignancy<sup>30</sup> promoted diagnosis - Continuity of care from regular GP promotes early recognition of significant health changes<sup>32</sup> - Private healthcare referral<sup>30, 32</sup></p>
<p><b>12. Social influences</b> (Those interpersonal processes that can</p>	<p><b>12.1 Competing priorities and responsibilities of patients</b> - Caring responsibilities<sup>33, 39</sup></p>	<p><b>12.1 Advocacy by family</b> - On behalf of patients in consultations or contacted GPs independently<sup>32</sup></p>



Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
cause individuals to change their thoughts, feelings or behaviours)	<b>12.2 Ageism/discrimination against patients</b> <sup>35</sup>	<b>12.2 Support from family/friends</b> - Symptom recognition <sup>33</sup> - Encourage help-seeking/attendance at primary care with symptoms <sup>12, 22, 30, 32, 33</sup>  <b>12.3 Influence of knowing someone with cancer</b> - Friend or family member with a history of cancer <sup>12</sup>
<b>13. Emotion</b> (A complex reaction pattern, involving experiential, behavioural and physiological elements, by which the individual attempts to deal with a personally significant matter or event)	<b>13.1 Fear</b> <sup>32</sup> - Of unwanted outcome <sup>36</sup> - Of cancer treatment—deterred seeking help for symptoms <sup>28</sup>	<b>13.1 Fear</b> - Shocked, frightened and worried when found cancer symptom <sup>39</sup>
<b>14. Behavioural regulation</b> (Anything aimed at managing or changing objectively observed or measured actions)	Nil identified	<b>14.1 Patient self-advocacy</b> - GP to investigate more quickly <sup>30</sup>

## Appendix 12—Identified barriers and enablers of cancer treatment by domain

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<b>1. Knowledge</b> (An awareness of the existence of something)	<b>1.1 Low patient awareness or knowledge of:</b> <ul style="list-style-type: none"> <li>- Treatment options<sup>46</sup></li> <li>- Treatment benefits<sup>46</sup></li> <li>- Breast reconstruction<sup>41</sup></li> <li>- Side effects<sup>13, 22, 35, 46</sup></li> <li>- Discharge<sup>45</sup></li> <li>- Follow-up care<sup>45</sup></li> <li>- Cancer recurrence<sup>41, 45</sup></li> <li>- Psychosocial therapy<sup>46</sup></li> <li>- Support<sup>35, 37, 41</sup></li> <li>- Self-management<sup>22</sup></li> <li>- Referral procedures<sup>22</sup></li> </ul>	<b>1.1 Patient awareness or knowledge of:</b> <ul style="list-style-type: none"> <li>- Different treatment options<sup>39</sup></li> <li>- Practicalities of treatment options<sup>39</sup></li> <li>- Impact of treatment options on independence, risk of recurrence and spread<sup>39</sup></li> <li>- Clinical trials<sup>46</sup></li> </ul>
	<b>1.2 Lack of healthcare provider knowledge of:</b> <ul style="list-style-type: none"> <li>- Older cancer patients' needs<sup>13</sup></li> </ul>	
<b>2. Skills</b> (An ability or proficiency acquired through practice)	<b>2.1 Poor communication between healthcare provider and patient:</b> <sup>35</sup> <ul style="list-style-type: none"> <li>- Overlooked patient's feelings<sup>46</sup></li> <li>- Brusque and insensitive<sup>22</sup></li> </ul>	Nil identified
	<b>2.2 Poor communication between primary and secondary care</b> <ul style="list-style-type: none"> <li>- Non-sharing of relevant patient information<sup>13</sup></li> </ul>	
	<b>2.3 Patient-perceived lack of GP skills to:</b> <ul style="list-style-type: none"> <li>- Manage side effects after treatment<sup>45</sup></li> </ul>	
	<b>2.4 Low health literacy of patients</b>	

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
	<ul style="list-style-type: none"> <li>- Lack of computer skills to seek online information about treatment options<sup>39, 46</sup></li> <li>- Overwhelming volume and mistrust of online health information sites<sup>39, 46</sup></li> <li>- Language barrier/illiterate<sup>42</sup></li> </ul>	
<b>3. Social/professional role and identity</b> (A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting)	<b>3.1 Religious beliefs</b> <ul style="list-style-type: none"> <li>- Neglect to seek medical help as 'God will cure'<sup>52</sup></li> </ul>	Nil identified
<b>4. Beliefs about capabilities</b> (Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use)	Nil identified	<b>4.1 Patient advocate<sup>22</sup></b>  <b>4.2 Patient coping</b> <ul style="list-style-type: none"> <li>- Better able to cope with cancer than younger people because of life experience, and fewer worries about the practical impact of cancer treatment<sup>28</sup></li> </ul>
<b>5. Optimism</b> (The confidence that things will happen for the best or that desired goals will be attained)	<b>5.1 Patient's outwardly positive attitude</b> <ul style="list-style-type: none"> <li>- Masks genuine concerns about physical and social functioning<sup>52</sup></li> </ul>	<b>5.1 Patient's positive attitude<sup>46</sup></b>
<b>6. Beliefs about consequences</b> (Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation)	<b>6.1 Harmful patient beliefs about treatment including:</b> <ul style="list-style-type: none"> <li>- Too old for treatments<sup>39, 49, 50</sup></li> <li>- Treatment would stimulate other illnesses<sup>39</sup></li> <li>- Treatment was ineffective<sup>39</sup></li> <li>- Low survival benefit from treatment<sup>49</sup></li> <li>- Standard treatment superior<sup>42</sup></li> </ul> <b>6.2 Patient's concern about adverse effects of treatment on:</b> <ul style="list-style-type: none"> <li>- Physical function<sup>39</sup> including urinary<sup>43</sup> sexual<sup>43</sup></li> </ul>	<b>6.1 Positive patient perceptions of treatment including:</b> <ul style="list-style-type: none"> <li>- Prevention of recurrence<sup>49</sup></li> <li>- Survival benefits<sup>49</sup></li> <li>- Ability to self-manage<sup>51</sup></li> </ul>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
	<ul style="list-style-type: none"> <li>- Mental health<sup>39</sup></li> <li>- Independence<sup>28, 39, 49, 50</sup></li> <li>- Pre-existing medical conditions<sup>41</sup></li> <li>- Quality of life<sup>49, 50</sup></li> <li>- General health<sup>49</sup></li> <li>- Recovery time<sup>43</sup></li> <li>- Finances<sup>43</sup></li> </ul> <p><b>6.3 Patient concern about:</b></p> <ul style="list-style-type: none"> <li>- Regular active surveillance tests<sup>43</sup></li> <li>- Treatment side effects being worse than the cancer itself<sup>28</sup></li> <li>- Undergoing chemotherapy<sup>48</sup></li> </ul> <p><b>6.4 Harmful healthcare provider beliefs about treatment including:</b></p> <ul style="list-style-type: none"> <li>- Low survival benefits for older patients<sup>13</sup></li> </ul> <p><b>6.5. Healthcare provider concerns about:</b></p> <ul style="list-style-type: none"> <li>- Patient's fitness for treatment<sup>13</sup></li> <li>- Evidence of treatment effectiveness in older patients<sup>13</sup></li> </ul>	
<p><b>7. Reinforcement</b> (Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus)</p>	Nil identified	Nil identified
<p><b>8. Intentions</b> (A conscious decision to perform a behaviour or a resolve to act in a certain way)</p>	Nil identified	Nil identified
<p><b>9. Goals</b> (Mental representations of outcomes or end states that an individual wants to achieve)</p>	Nil identified	<p><b>9.1 Personal goals</b></p> <ul style="list-style-type: none"> <li>- To 'get on' with life<sup>35</sup></li> </ul>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<p><b>10. Memory, attention and decision processes</b> (The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives)</p>	<p><b>10.1 Patient involvement in decision making</b> - Mismatched preferred level of involvement<sup>13, 35</sup></p> <p><b>10.2 Negative healthcare provider attitudes towards clinical decision support tools</b> - Lack of buy-in as to the value of geriatric assessment to inform treatment decision making and care plans<sup>13</sup></p>	<p><b>10.1 Patient involvement in treatment decision making</b> - Offered treatment choices<sup>39</sup> - Adequate time to reach treatment decision<sup>41, 50</sup> - Shared or patient-directed decision making<sup>22, 35, 49</sup> - Provided with decision support<sup>46</sup></p> <p><b>10.2 Positive healthcare provider attitudes towards clinical decision support tools</b> - Support use of assessment to inform treatment decision making and care plans<sup>13, 51</sup></p>
<p><b>11. Environmental context and resources</b> (Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour)</p>	<p><b>11.1 Information resources issues</b> - Overload of information<sup>46, 49, 50</sup> - Perceived withholding of information from patients by healthcare providers<sup>50</sup></p> <p><b>11.2 Workforce gaps</b> - Lack of radiologists<sup>36</sup> - Lack of community-based oncology nurses<sup>13</sup> - Lack of time for multidisciplinary team discussion of complex cases<sup>13</sup> - Lack of psychological support<sup>45</sup> - Insufficient consultation time<sup>35</sup></p> <p><b>11.3 Healthcare accessibility issues</b> - Cost/financial burden<sup>13, 37, 46</sup> - Life events<sup>35</sup>, travel burden<sup>13, 37, 39, 46</sup> - Poor performance status, comorbidities, dementia<sup>47</sup></p> <p><b>11.4 Negative experience of healthcare facilities</b></p>	<p><b>11.1. Information/educational resources</b> - Information tailored to the individual patient<sup>39, 46</sup> - Short written information booklets<sup>41, 46, 49</sup> - Decision support tools<sup>39, 46</sup> - Cancer survivors' stories<sup>46</sup></p> <p><b>11.2 Workforce</b> - Access to skilled staff including specialist cancer nurses, geriatricians, specialists<sup>13, 35</sup></p> <p><b>11.3 Healthcare accessibility</b> - Volunteer drivers<sup>46</sup> - Treatment centre orientation sessions<sup>46</sup> - Shorter time since diagnosis<sup>35</sup>/ timely referral<sup>37</sup> - Proximity to cancer centres<sup>37</sup> - Available equipment<sup>37</sup> - Convenience of telephone follow-up<sup>51</sup></p>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
	<ul style="list-style-type: none"> <li>- Cold treatment room<sup>46</sup></li> <li>- Treatment machine malfunction<sup>46</sup></li> </ul> <p><b>11.5 Clinical trials involvement issues</b></p> <ul style="list-style-type: none"> <li>- Restricted inclusion criteria<sup>13, 42, 48</sup></li> <li>- Travel burden<sup>13, 42</sup></li> <li>- Randomisation<sup>48</sup></li> </ul>	
<p><b>12. Social influences</b> (Those interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours)</p>	<p><b>12.1 Competing priorities and responsibilities of patients</b></p> <ul style="list-style-type: none"> <li>- Caring or support responsibilities<sup>13, 22, 39, 46</sup></li> <li>- Don't want to be a burden to other people<sup>28</sup></li> </ul> <p><b>12.2 Discrimination against patients</b></p> <ul style="list-style-type: none"> <li>- Ageism<sup>28, 39, 41–44</sup></li> <li>- Racism<sup>45</sup></li> </ul> <p><b>12.3 Sociocultural norms</b></p> <ul style="list-style-type: none"> <li>- Medical issues not discussed<sup>52</sup></li> <li>- Stigma and shame<sup>52</sup></li> </ul> <p><b>12.4 Influence of someone with cancer</b></p> <ul style="list-style-type: none"> <li>- Logistical challenges of peer informants attending treatment sessions<sup>46</sup></li> </ul> <p><b>12.5 Lack of social support</b></p> <ul style="list-style-type: none"> <li>- Difficulty accessing social care and practical support<sup>13, 22</sup></li> </ul> <p><b>12.6 Lack of continuity of care in primary care</b></p> <ul style="list-style-type: none"> <li>- Difficulty raising sensitive topics<sup>45</sup></li> </ul>	<p><b>12.1 Support from family/friends</b><sup>41, 22, 35, 49, 43</sup></p> <p><b>12.2 Influence of knowing someone with cancer</b><sup>50, 43</sup></p> <ul style="list-style-type: none"> <li>- Death of a friend or family member with a history of cancer<sup>39</sup></li> <li>- Peer support from person in a similar situation<sup>22, 35, 41, 45, 46</sup></li> </ul> <p><b>12.3 Influence of healthcare provider</b><sup>50</sup></p> <ul style="list-style-type: none"> <li>- Doctor's approval of patient's treatment decision<sup>39</sup></li> <li>- Trusted source of information and support<sup>28, 35, 41</sup></li> <li>- Recommendation from doctor for specific treatment<sup>43, 49</sup></li> <li>- A second opinion<sup>49</sup></li> <li>- Good rapport with patient<sup>37</sup></li> </ul>

Domain (definition)	Barriers (articles where cited)	Enablers (articles where cited)
<p><b>13. Emotion</b> (A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event)</p>	<p><b>13.1 Fear</b></p> <ul style="list-style-type: none"> <li>- Of hospitals<sup>52</sup></li> <li>- Of procedures including anaesthesia and surgery<sup>39</sup></li> <li>- Of making the ‘wrong’ treatment decision<sup>39</sup></li> <li>- Of side effects including tiredness/loss of energy<sup>46</sup></li> <li>- Of future outcomes<sup>37</sup></li> </ul>	<p><b>13.1 Fear</b></p> <ul style="list-style-type: none"> <li>- Of recurrence<sup>49</sup></li> </ul>
<p><b>14. Behavioural regulation</b> (Anything aimed at managing or changing objectively observed or measured actions)</p>	<p>Nil identified</p>	<p>Nil identified</p>

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