

Determining Research Priorities for Cancer Survivorship: consultation and evidence review

TECHNICAL APPENDIX: No. 1

Scoping of research evidence regarding the health and well-being of cancer survivors: Psychological and social problems faced by cancer survivors, and their physical and practical well-being

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December 2009

Final version following revisions agreed by NCSI research work stream March 2010

INTRODUCTION

This report presents the evidence from a rapid scoping and synthesis of published literature review papers on the health and well-being of cancer survivors. The scoping of research evidence has taken into account the National Cancer Survivorship Initiative's (NCSI) work streams' mapping exercises for breast, colorectal, prostate, lung and less common cancers and also primary research papers published since the publication of the included reviews.

AIMS

- To establish what is known about the problems faced by cancer survivors in relation to their health and well-being following primary cancer treatment
- To identify gaps in the evidence base and make recommendations for further research

METHODS

Overview:

The review was undertaken by two teams, one focusing on psychological and social problems experienced by cancer survivors (led by Foster) and the other on their physical and practical well-being (led by Amir). Both teams used a systematic process to scope the literature.

Principles of systematic review that were retained included identifying search engines, formulating search terms, generating inclusion and exclusion criteria, and assessing abstracts independently. However, this differed from traditional systematic approaches in that only published review articles were examined. A data extraction sheet was used to document findings from literature reviews meeting eligibility criteria. Quality of reviews was assessed on the following seven criteria: a well-defined question; a substantial comprehensive effort to search for all relevant literature; appropriate criteria for selecting and rejecting studies; included studies of high methodological standard; process unbiased, transparent and reproducible; results clearly displayed for all included studies; and conclusions accurately reflect the evidence reviewed. This checklist was informed by Critical Appraisal Skills Programme (CASP: Public Health Resource Unit, 2006) and Centre for Reviews and Dissemination Guidance (CRD, 2008), and resulted in a score out of 7.

Primary data papers published since the review searches in each area were then identified to make an assessment as to whether research had begun to address under-researched areas identified in the included review papers.

The NCSI work streams' mapping exercises for breast, colorectal, prostate, lung and less common cancers were taken into account to compare research priorities identified in these mapping exercises with the research evidence captured by the scoping exercise.

Scoping of reviews

Electronic Databases

The following electronic databases were searched to include research evidence from a wide range of academic disciplines

- Medline
- CINAHL (cumulative index to nursing and allied health literature)
- Embase
- PsychINFO
- Web of science
- BNI
- Cochrane database of systematic reviews

Inclusion criteria:

- English language
- Articles published between 2000 and 2009 (review articles published since 2000 include primary data studies published before this date)
- Research focussed on health and well-being in the acute, sub acute, long term and disease free phases
- All cancers
- Patients diagnosed ≥ 18 years
- Literature review articles (This included systematic, narrative or other types of reviews of research evidence. Reviews of quantitative and qualitative research were equally eligible.)

Exclusion criteria:

- Childhood and adolescent cancer

- Biomedical data (e.g., drug trials, clinical trials)
- Diagnosis; Active treatment phase; or End of life was the explicit focus of the paper
- Review articles other than research literature reviews e.g., retrospective data review; review of treatment outcome; review of an individual patient case
- Quality score less than or equal to 2 (on a 7 point scale) (scoring informed by CASP: Public Health Resource Unit, 2006)

Procedure

Once duplicates were removed, abstracts and titles of review articles considered potentially relevant were selected for further examination. The bibliographic details, keywords, abstracts, website address (where available) of all identified studies were imported into one database. Relevant studies were selected for synthesis by examining the full published paper and using the inclusion/exclusion criteria. Data were extracted and summarised from the full published paper using a data extraction sheet. As a quality assurance measure 20% were independently extracted by a second researcher.

To gauge the quality of the reviews different approaches were taken across the health and well being review and the solutions review. As mentioned above each review identified for possible inclusion in the problems in health and well being element of the scoping review was awarded a quality score (out of 7) as a broad indication of quality. A review was included if it achieved a score of 2 or greater. Our judgement of study quality of the research studies included in the reviews was drawn from commentary available in the systematic reviews and is thus only a broad assessment of this feature of the research and relies on what we could infer from comments made by the original review authors. For us to define the quality of each study included in the reviews would have required a detailed analysis of each individual study and was beyond the scope of a scoping review.

Consequently, we only provide a very broad and general indication of whether the quality of research evidence encompasses low, medium, or high quality research

In terms of quantity of research contained in the reviews we found we could not always do this precisely and therefore do not offer a precise number in relation to the reviews. For example, sometimes review authors did not state explicitly the number of studies they reviewed on a topic area but may have referenced studies throughout the text in relation to that topic area and these were counted. Because there was scope for error in counting these we chose to use approximations (this was particularly the case for the health and well being review). Therefore we provide bands as an indication of quantity of research to

indicate low, moderate or high amounts of research. In Tables 2 and 4 that follow amount refers to the amount of studies in relation to each review described with the terms Low, Moderate, and High applied to indicate ≤ 5 studies, 6-10 studies, ≥ 11 respectively. In Table 6 amount refers to amount of studies overall across the reviews located in relation to a topic area whereby 0-15 studies = Low, 16-55 studies = Moderate and 56+ = High. We were not convinced that simply giving the number of studies without reviewing them all for size and quality would be that useful.

Findings from the reviews were summarised under eleven headings agreed in advance by the full Rapid Review research team, led by Professor Alison Richardson and Professor Julia Addington-Hall, (depression, anxiety, general distress, fear of recurrence, fatigue, pain, sexual problems, physical disability, cognitive impairment, finance/employment/work, social needs). These headings were agreed in collaboration with the funders of the Review as being both likely to be important issues affecting cancer survivors and being feasible to explore within the time scale of the rapid review. Additional headings were agreed by the Scoping research team in response to issues emerging from the literature review. Findings from each review paper were summarised under one or more heading as appropriate.

Psychological and social problems

The search terms used for this section of the review included: cancer* OR tumor* OR malignan* OR oncolog* OR carcin; psycholog* or psychosoci*; survivor (see Appendix I for full list). Further search terms were then added for: depression, anxiety, distress and fear of recurrence.

Using these terms, 4,051 papers were initially identified. After removing duplicates, the abstracts of 3,651 papers were screened, of which 42 full papers were examined, and 38 summarised using the data extraction sheet. Sixteen review papers met the inclusion criteria (Figure 1).

Physical and practical problems

The search terms used included: cancer* OR Tumor* OR malignan* OR oncolog* OR neoplasm* OR carcin*; physical fitness/exertion; well being; income; poverty; social change/class; finances; employment; work; income; pension; salaries; all adults. Further search terms were then added for: sexual dysfunction; lympho*; bladder; neuropathy; neurotoxicity and cognitive dysfunction. 5,121 papers were identified initially. 5,081 abstracts were screened and 88 full papers examined. Forty-two papers were summarised

using the extraction sheets, of which nine were found to meet the inclusion criteria. (Figure 2)

Primary data articles

The systematic scoping of literature focused on assimilating information from published literature review articles that met the inclusion criteria. More recent primary data articles would therefore not be included. In order to scope recent developments in the field, a search for primary research papers in areas identified as under-researched in the included reviews was conducted. Key words and search terms were developed to cover the gaps in research identified by the reviews. The psychological and social problems search was restricted to PsychInfo and Cinahl as these databases gave the highest number of relevant hits during the systematic scoping of the literature: timing was restricted to publication dates since the relevant review. The physical and practical problems search was restricted to the Web of Science database for similar reasons: timing was restricted to publications between 2006 and 2009. Given the limited time frame an impact factor of 3.1 or above was chosen as the quality marker for primary data papers.

NCSI Mapping project

The NCSI Mapping project aimed to map the survivorship journey of people with cancer and identify where research is needed. Key issues and research questions have been identified by stakeholders (patients, health professionals, charities and carers). It has focused on the four major cancers: bowel, breast, lung and prostate cancer. Cancer 52 representing the views of those with less common cancers met in June 2009 to undertake similar work and generated many research questions. Both scoping review teams were tasked with comparing their findings with those which emerged from the NCSI Mapping project and from the Cancer 52 project. Due to time constraints the source of this information is the summary of reports for the more common cancers (Flynn and Groot, 2009), rather than the whole reports submitted by the individual charities.

Figure 1: Psychological and social problems: process of literature search

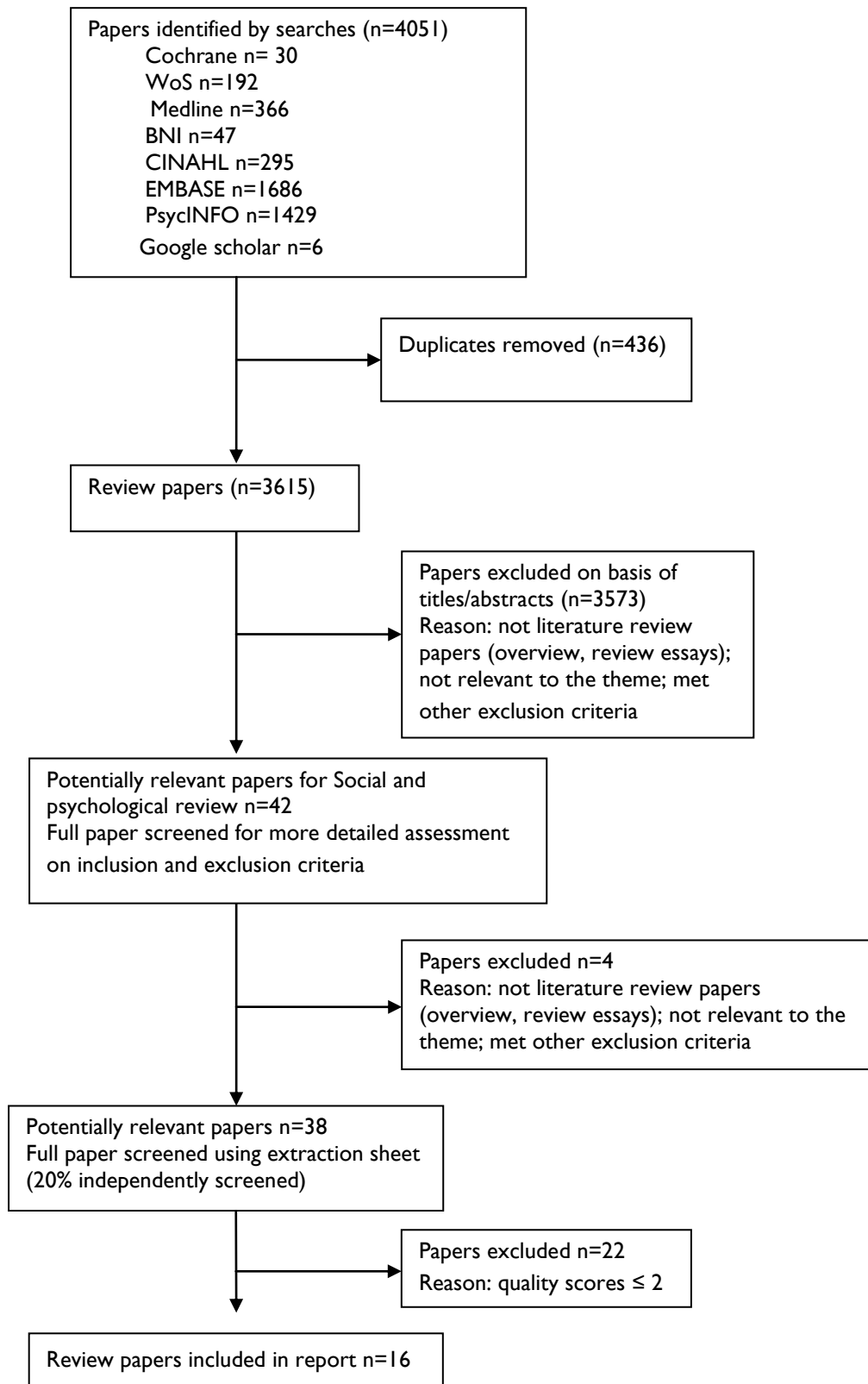
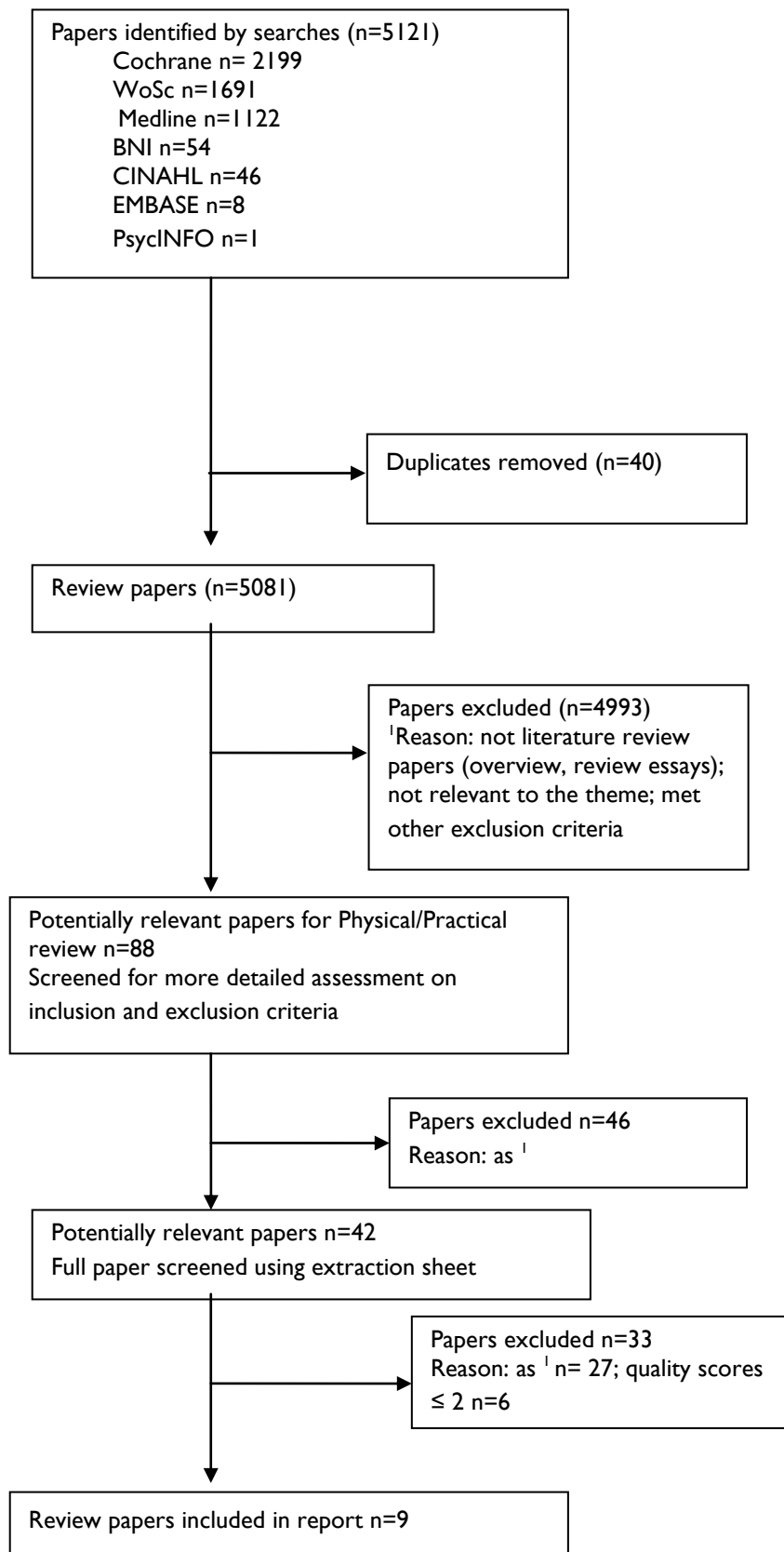


Figure 2. Physical and practical problems: process of literature search



FINDINGS

A bibliography at the rear of this report contains a full list of the reviews and primary papers included in this scoping review.

Scoping of reviews

1) Psychological and social problems

Table 1 summarises the sixteen review papers included in this section of the scoping review, the number of primary data papers captured by the review and quality score. This review of reviews is based on a substantial number of primary studies (1,557 in total, although this may include some duplication).

Most of the reviews included in this scoping report did not focus on a specific cancer site but included survivors of various cancer sites. This makes it difficult to draw conclusions about whether and how psychological and social problems differ in survivorship between diagnostic groups. The only individual diagnostic group to have featured significantly in this research to date is breast cancer, with reviews having focused specifically on women with breast cancer as well as the majority of participants in 'mixed' gender and cancer type reviews being women with breast cancer.

The reviews also allow few conclusions to be drawn about the impact of the stage of cancer, treatment type or time since diagnosis as most reviews have included research with mixed characteristics in these respects, or lacked details about these issues. Importantly, in terms of the aims of this review, most of the research has not given enough detail to classify participants in terms of the NCSI Survivorship Framework phases. The most common description, when it occurs, seems to be 'time since diagnosis' but this does not indicate the status of the survivor e.g. if they are disease free or receiving treatment. This is an important omission in survivorship research and indicates the embryonic nature of the research field.

Ten out of the sixteen included reviews focussed on quality of life (QoL) and general psycho-social implications of surviving cancer (five reviews each). Other reviews focussed on specific groups such as older people, rural women or African-American women. Findings from each review were summarised under eleven headings agreed in advance of the review, together with others developed as the review progressed (Table 2).

Table 1: Psychological and social problems: summary of the 16 review papers

Paper reference	Time scale covered in review	Quality score (I7)	General focus of paper	Cancer site	Gender	Number of studies included in review
Arden-Close et al (2008)	1994-2007	7	Ovarian cancer and psychological distress	Ovary	Women	18
Bettencourt et al (2007)	1806-2006	6	Experience of rural women with breast cancer	Breast	Women	41
Bloom et al (2007)	1998-2006	6	Quality of life adult cancer survivors	Mixed	Mixed	53
Falagas et al (2007)	1979-2006	5	Psychosocial effect of breast cancer	Breast	Women	31
Fleer et al (2004)	1980-2003	7	Quality of life of testicular cancer survivors	Testes	Men	23
Foster et al (2009)	1960-2006	7	Psychosocial implications cancer (>5 yrs)	Mixed	Mixed	43
Lockwood-Rayermann et al (2006)	1983-2005	3	Survival issues in Ovarian cancer	Ovary	Women	32
Mols et al (2005)	1997-2004	6	Quality of life in breast cancer	Breast	Women	10
Morris et al (2007)	1995-2002	3	Patient reported family distress	Mixed	Mixed	5
Park & Gaffey (2007)	Up to Jan 2007	6	Psychosocial factors and health behaviour change	Mixed	Mixed	30
Petticrew et al (2002)	1966-2002	6	Psychological coping in cancer	Mixed	Mixed	37
Rao & Denmark-Wahnefried (2006)	Not stated	3	Older cancer survivors, quality of life	Mixed	Mixed	Not specified
Russell et al (2008)	1998-2007	6	Quality of life of African American women with breast cancer	Breast	Women	26
Vivar & McQueen (2005)	1985-2004	3	Informational and emotional needs survivors of breast cancer	Breast	Women	Not specified
Vivar et al (2009)	1980-2007	6	Psychosocial impact of recurrence on cancer survivors and family	Mixed	Mixed	52
Weber et al (2005)	1970-2004	5	Psychosocial consequences of prostate cancer	Prostate	Men	1156

Table 2: Psychological and social problems: summary of findings from reviews meeting inclusion criteria, mapped against survivorship issues

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research ¹	Quality of research ²	Scope	Conclusion
<p><u>Depression</u></p> <ul style="list-style-type: none"> • Arden-close et al (08) (as part of review into psychological distress) • Foster et al (09) (as part of review into psychosocial implications) • Falagas et al (07) (as part of review of psychosocial issues and survival outcome) • Lockwood-Rayermann (06) (as part of review into survivorship issues) 	<p>High</p> <p>Moderate</p> <p>High</p> <p>Moderate</p>	<p>Moderate - high</p> <p>Moderate</p> <p>Low-high</p> <p>Unclear</p>	<p>Ovarian cancer, female only, stage mixed</p> <p>Mixed gender, mainly women with breast cancer, mainly USA, 5 years post diagnosis</p> <p>Breast cancer only, women, USA, mixed stages</p> <p>Ovarian cancer, women only, mixed/unclear</p>	<p>Good evidence for a relationship between younger age, being diagnosed with more advanced disease, more physical symptoms and shorter time since diagnosis with increased levels of anxiety and/or depression</p> <p>Overall psychological distress similar to normal population or healthy controls but around 20-30% of survivors report long term psychological problems such as depression (1 study) and clinically significant depression (1 study)</p> <p>Depression was one of the factors associated with decreased breast cancer survival, but the role of these was not verified in all studies, in 9 studies no impact</p> <p>Significant levels of depression and anxiety found (6 studies)</p>

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
<ul style="list-style-type: none"> Weber et al (05) (as part of review of psychosocial consequences of prostate cancer) 	High	Unclear	Men with prostate cancer	Men undergoing androgen ablation therapy vulnerable to depression – research into screening initiatives needs
<p><u>Anxiety</u></p> <ul style="list-style-type: none"> Lockwood-Rayermann (06) (as part of review into survivorship issues) Arden-close et al (08)(as part of review into psychological distress) Foster et al (09) (as part of review into psychosocial implications) Falagas et al (07) (as part of review of psychosocial issues and survival outcome) 	Moderate	Moderate	Ovarian cancer, women only, mixed/unclear	Significant levels of depression and anxiety found (6 studies)
	High	Moderate	Ovarian cancer, female only, stage mixed	Good evidence for a relationship between younger age, being diagnosed with more advanced disease, more physical symptoms and shorter time since diagnosis with increased levels of anxiety and/or depression
	Low	Moderate	Mixed gender, mainly women with breast cancer, mainly USA, 5 years post diagnosis	‘Overall psychological distress similar to normal population or healthy controls but around 20-30% of survivors report long term psychological problems such.. as anxiety’ (2 studies)
	High	Low-high	Breast cancer only, mainly USA, mixed stages	One study linked higher anxiety with higher recurrence rates, 1 with reduced survival rates , but 9 studies showed no impact

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
<p><u>General distress</u></p> <ul style="list-style-type: none"> • Arden-close et al (08) (as part of review into psychological distress) • Foster et al (09) (as part of review into psychosocial implications) • Park & Gaffrey (07) (distress as impact on behaviour change) 	<p>High</p> <p>Moderate</p> <p>High</p>	<p>Moderate</p> <p>Moderate</p> <p>Unclear</p>	<p>Ovarian cancer, female only, stage mixed</p> <p>Mixed gender, mainly women with breast cancer, mainly USA, 5 years post diagnosis</p> <p>Mixed cancer site, mixed stages.</p>	<p>‘Demographic, disease and quality of life factors correlated with distress and a few studies assessed possible psychological and immunological correlates’ which they say could be future area for research</p> <p>Overall psychological distress similar to normal population (2 studies) or healthy controls (2 studies); psychological distress has been associated with poorer QoL (4 studies) and low economic status (3 studies) Head and neck cancer may be more susceptible.</p> <p>Distress - symptoms of anxiety and depression as well as negative effect more generally, is related to poorer health behaviours, but mixed results.</p>
<p><u>Fear of recurrence</u></p> <ul style="list-style-type: none"> • Foster et al (09) (as part of review into psychosocial implications) • Lockwood –Rayermann (06) (as part of review into survivorship issues) 	<p>Low</p> <p>Moderate</p>	<p>Moderate</p> <p>Moderate</p>	<p>Mixed gender, mainly women with breast cancer, mainly USA, 5 years post diagnosis</p> <p>Ovarian Cancer, female only, stage unclear/mixed</p>	<p>Fear of follow up tests and recurrence reported by substantial proportion of survivors (2 studies); survivors of lung, head and neck cancers most vulnerable (2 studies); 31% clinically depressed.</p> <p>Fear of recurrence, remembrance mentioned in 8 studies. Rarely studied ‘Check up anxiety’ and ‘CA-125 obsession’ (1 study).</p>

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
<ul style="list-style-type: none"> Vivar et al (09) (review into impact of recurrence on survivors and family) Bloom et al (07) psychological QoL as part of multi-dimensional QoL review) 	High	Low - moderate	Mixed cancer, but mainly spouses of breast and ovarian cancer survivors	Recurrence is distressing for survivor and families. Care should not be addressed just to survivors, but should also include the families' general well-being long term.
<p><u>Social needs</u></p> <p><u>Impact on family</u></p> <ul style="list-style-type: none"> Foster et al (09) (as part of review into psychosocial implications) Vivar et al (09) (as part of a review into impact of recurrence) Morris et al (07) (review into family distress) 	Low	Low-moderate	Mixed gender, mainly women with breast cancer, mainly USA, 5 years post diagnosis	Survivors expressed satisfaction with social and marital relationships (2 studies); or cancer as the reason for divorce (1 study); differences in friendships and relationships reported (1 study). Breast cancer survivors reported family relationships closer but friends often avoided them (1 study)
	High	Unclear	Mixed cancer, but almost half studies were breast cancer	Families suffer when patient has cancer and recurrence, not just the patient. Some spouses report more suffering. Narrative review.
	Low	Low	Mixed gender, mainly women with breast cancer, mainly USA, 5 years post diagnosis	Significant levels of patient reported family distress reported in all 5 studies.

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
<u>Social function</u> <ul style="list-style-type: none"> Foster et al (09) (as part of review into psychosocial implications) 	Low	Unclear	Mixed gender, mainly women with breast cancer, mainly USA, 5 years post diagnosis	Levels of social functioning similar in cancer survivors to control groups (3 studies)
<u>Social support (general)</u> <ul style="list-style-type: none"> Bloom et al (07) (as part of QoL) 	Low	Unclear	2 breast cancer studies	Perceived social support positively associated with mental well-being
<ul style="list-style-type: none"> Bloom et al (07) (as part of QoL) 	Low	Unclear	2 cervical cancer studies	A significant association between higher levels of social support and less cancer specific distress.
<ul style="list-style-type: none"> Bloom et al (07) (as part of QoL) 	Low	Unclear	1 colorectal cancer study	Social network scores (no. of friends, relatives community organisations) positively associated with mental health outcomes among survivors.
<ul style="list-style-type: none"> Arden-Close et al (08) (as a correlate of distress) 	Low	Moderate	Ovarian cancer, female only, stage mixed	‘Some evidence’ – more perceived social support is linked to less distress
<ul style="list-style-type: none"> Mols et al (05) (social support as a predictor of QoL) 	Low	Moderate	Breast cancer, female only stage mixed, 5 years post diagnosis	Social support was one of the strong predictors of positive QoL (4 studies)
<ul style="list-style-type: none"> Falagas et al (07) (social support as linked with survival outcome) 	High	Low	Breast cancer, women, range of stages	‘Some evidence’ – ‘More perceived social support is associated with less distress’ 4 studies show Social support and 2 studies perceived social support, is one of the factors associated with increased survival from breast cancer. 8 studies – no impact.

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
<ul style="list-style-type: none"> Bettencourt et al (07) (as part of a review of rural/urban differences) Park and Gaffey (07) (social support as part of behaviour change) Russell et al (08) (as part of QoL review of African American women with breast cancer) Weber et al (05) (as part of review of psychosocial consequences of prostate cancer) 	<p>High</p> <p>Moderate</p> <p>Moderate</p> <p>High</p>	<p>Unclear</p> <p>Unclear</p> <p>Unclear</p> <p>Unclear</p>	<p>Breast cancer, women, rural and urban</p> <p>Mixed cancer site, mixed stages</p> <p>African American women with breast cancer</p> <p>Men with prostate cancer</p>	<p>Most rural women perceived enough social support (2 studies), most would not trade supportive rural community for convenience of urban living (1 study). Rural women less access to social/mental health workers (2 studies) or other breast cancer survivors (2 studies).</p> <p>Social support/perceived social support appears helpful in making adaptive changes, particularly in exercise.</p> <p>Social support an important factor in coping with breast cancer for QoL for AA women with breast cancer (5 studies);inadequate social support linked to poorer mood and family wellbeing (2 studies)</p> <p>Social support ill defined concept. Most looked at support groups although underused by men with prostate cancer – more research needed</p>
<p><i>Psychosocial problems captured by the reviews but not included in initial eleven survivorship issues</i></p>				
<p><u>Body image (sexuality, intimacy)</u></p> <ul style="list-style-type: none"> Foster et al (09) (as part of review into psychosocial implications) 	<p>Moderate</p>	<p>Moderate</p>	<p>Mixed gender, mainly breast cancer, gynaecological, testicular, leukaemia</p>	<p>Sexual problems were reported by survivors of breast (3 studies); gynaecological (2 studies); testicular (2 studies); leukaemia (1 study); lymphoma (1 study)</p>

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
<ul style="list-style-type: none"> • Mols et al (05) (as part of QoL review) • Lockwood Rayermann (06) (as part of review of survivorship issues) • Fler et al (06) (as part of QoL review) 	Moderate	Low-moderate	Female only, breast cancer only 5 yrs post diagnosis	Sexual functioning was a problem (6 studies); one study reported 69% of women with partners were sexually active but lack of desire (56%) lack of arousal(46%) lack of enjoyment (35%), no orgasm (38%)
<p><u>Psychological coping</u></p> <ul style="list-style-type: none"> • Petticrew et al (02) (survival and recurrence linked to coping styles) <p><u>Quality of Life</u></p> <ul style="list-style-type: none"> • Arden-Close et al (08) (as linked to distress) 	High	Low	Mixed cancer, USA/Canada and Europe, mainly breast cancer.	Little consistent evidence that psychological coping styles play an important part in survival from or recurrence of cancer
	Low	Moderate - high	Ovarian cancer, female only, stage mixed	‘Strong level of evidence that poorer quality of life is linked to more distress.’

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
<ul style="list-style-type: none"> Foster et al (09) (as part of review into psychosocial implications) 	High	Low-moderate	Mixed gender, mainly women with breast cancer, mainly USA, 5 years post diagnosis	Some survivors reported troublesome physical problems in the long term, which were associated with poorer QoL (3 studies); variability in QoL scores due to treatment (3 studies); advance disease and other problems (3 studies), age (1 study). Positive association of QoL with self esteem (1 study) and being in control (1 study)
<ul style="list-style-type: none"> Mols et al (05)(a review into QoL) 	Moderate	Moderate	Female only, breast cancer only, 5 yrs post diagnosis	Most studies reported that long term survivors of breast cancer experienced good overall QoL, especially those that did not need chemotherapy, had support, relatively high income, no other disease. More research needed into interventions
<ul style="list-style-type: none"> Lockwood-Rayermann (06) as part of a review into survivorship issues 	High	Low-moderate	Ovarian cancer, female only, mixed/unclear stage	Only 11 out of 22 studies looked specifically at QoL in ovarian cancer, QoL changes over time and subjective, mixed findings on positive/negative QoL. More research needed into QoL for ovarian cancer survivors.
<ul style="list-style-type: none"> Fleer et al (04) (a QoL review) 	High	Moderate-high	Men only, testicular cancer, mixed stages/time span	The majority of testicular cancer survivors in both stronger (n=7) and poorer quality studies reported good QoL. After treatment QoL increased and negative consequences of cancer on life decrease. Methodological problems mean more research is needed.

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
<ul style="list-style-type: none"> Russell et al (08) (QoL review) 	High	Low-moderate	USA, African American women with breast cancer	African American women with breast cancer experienced a variety of QoL deficits that affected physical and psychological functioning. Psychosocial well being varied for AA women
<ul style="list-style-type: none"> Rao et al (06) (small part of review into older people with cancer) 	Low	Unclear	Older people 65+, stage not stated, cancer mixed	Varies, mainly physical components considered, not much research looking at older people QoL. Concludes needs more research into QOL for older people with cancer.

¹ Amount of research defined as approximate number of studies included in each review: Low ≤ 5 studies, Moderate 6-10 studies, High ≥ 11..

² Quality of research: This refers to the original systematic reviewers' comments on the overall quality of studies included in their review and the terms Low, Moderate and High used to infer quality of evidence.

ii) Physical and practical problems

Table 3 summarises the nine review papers included in this section of the review. Two hundred and eighty two primary studies are reported in these reviews (not excluding possible duplication), including research from 1950 onwards.

As in the assessment of reviews on psychological and social problems reported above, these review papers contained too little information on disease stage or treatment to enable the phase of survivorship to be identified. Again, most papers (six out of nine) included patients with a variety of cancer diagnoses, although the focus on breast cancer was somewhat less evident in these review papers with reviews on single sites focusing on ovarian, prostate and testicular cancer. Three papers reviewed evidence on general symptoms associated with cancer survivorship, one on sexual functioning, two on fatigue, one on unmet needs, and the remaining two on impact on employment.

Findings from the reviews are summarised under relevant headings from the eleven survivorship issues agreed in advance of the review (Table 4).

Table 3: Physical and practical problems: summary of the nine review papers

Paper Reference	Time scale covered in review	Quality scores (/7)	General focus of paper	Cancer site	Gender	Number of studies included in the review
Lockwood-Rayermann (2006)	1983-2008	3/7	General symptoms	Ovarian cancer	Female	32
Eton & Lepore (2002)	1992-2002	3/7	Health Related QoL and general symptoms	Prostate cancer	Male	32
Jonker-Pool et al. (2001)	1975-2000	4/7	Sexual functioning	Testicular cancer	Male	36
Servaes et al., (2002)	1980-2001	7/7	Fatigue	Mixed cancers	Mixed	16
Visovsky & Schneider (2003)	1998-2003	3/7	Fatigue and menopausal symptoms	Mixed cancers	Mixed	94
Spelten et al. (2002)	1985-1999	5/7	Return to work	Mixed cancers	Mixed	14
De Boer et al. (2009)	1996-2008	7/7	Unemployment	Mixed cancers	Mixed	36
Harrison et al. (2009)	1950-2006	6/7	Unmet needs	Mixed cancers	Mixed	14
Avis & Demling (2008)	2002-2007	3/7	General symptoms of the older cancer survivors	Mixed cancers	Mixed	8

Table 4: Physical and practical problems: summary of findings from the literature reviews which met inclusion criteria, classified by survivorship issues.

ISSUES	PROBLEMS			
	Amount of research ¹	Quality of research ²	Scope	Conclusion and opportunity
Physical problems:				
<u>Peripheral Neuropathy</u> Lockwood-Rayerman (2006)	Low	Unclear	Ovarian cancer, women only	Significant level of peripheral neuropathy was found in patients treated with cisplatin and taxanes.
<u>Fatigue</u> Lockwood-Rayerman (2006)	Low	Unclear	Ovarian cancer, women only	Evidence on the prevalence of fatigue even after the completion of treatment, and its effect on daily functioning.
Servaes et al (2002)	High	Moderate-high	Mixed cancers – 12 Breast – 6 Prostate – 2 Melanoma – 1 Lung – 1	Good evidence indicating that fatigue is a significant problem for approximately one-third of cancer survivors.
Visovsky & Schneider (2003)	High	Unclear	Mixed cancers & genders	Evidence suggests that cancer-related fatigue continues after the cancer treatment is completed. Higher level of fatigue affects quality of life, functional status and symptom management. Fatigue was found to be associated with pain, sleeping disturbances and menopausal symptoms.

ISSUES	PROBLEMS			
	Amount of research	Quality of research	Scope	Conclusion and opportunity
Avis & Deimling (2008)	Low	Unclear	Mixed cancers & genders, old people	Fatigue was one of the biggest problems cited by old survivors surrounding disease recurrence.
Pain Lockwood-Rayerman (2006)	Low	Unclear	Ovarian cancer, women only	Most ovarian cancer pain is caused by the tumour, and is fairly common.
Servaes et al (2002)	Low	Moderate – high	Mixed cancers, mainly women with breast cancer.	Good evidence for the association of fatigue severity with pain. However, it has not been specified whether fatigue was caused by the pain itself or by pain medication.
Visovsky & Schneider (2003)	Moderate	Unclear	Mixed cancers & genders	Patients (unknown stage) frequently reported a link between fatigue and pain
Avis & Deimling (2008)	Low	Unclear	Mixed cancers & genders, old people	Pain was the most commonly reported symptom, however, co morbidities and non cancer symptoms were stronger correlates of pain.

ISSUES	PROBLEMS			
	Amount of research	Quality of research	Scope	Conclusion and opportunity
<p><u>Lymphodema</u> Lockwood-Rayerman (2006)</p>	Low	Unclear	Ovarian cancer, women only	Lymphodema has been considered as a problem, but little conclusive research was found
<p><u>Bladder dysfunction</u> Lockwood-Rayerman (2006)</p>	Low	Unclear	Ovarian cancer, women only	Bladder dysfunction, although a commonly reported side effect for the cytotoxic drugs rarely is accounted for in studies of ovarian cancer.
Eton & Lepore (2002)	Moderate	Moderate	Prostate cancer, men only	Bladder dysfunction problems and damage to the kidneys may cause electrolyte imbalance. More studies are needed to clarify the trajectory of urinary function in men treated for prostate cancer
<p><u>GI problems</u> Lockwood-Rayerman (2006)</p>	Moderate	Unclear	Ovarian cancer, women only	Bowel problems are common side effect which can appear during and after treatment.
Eton & Lepore (2002)	Moderate	Moderate	Prostate cancer, men only	Bowel problems are linked to the treatment and are more likely to occur after treatment, especially after radiotherapy.

ISSUES	PROBLEMS			
	Amount of research	Quality of research	Scope	Conclusion and opportunity
<p><u>Eating problems</u> Lockwood-Rayerman (2006)</p>	Low	Unclear	Ovarian cancer, women only	Appetite changes and alterations in taste were evident in ovarian cancer survivors. Weight gain was also evident.
<p><u>Sexual problems</u> Lockwood-Rayerman (2006)</p>	Moderate	Unclear	Ovarian cancer, women only	Sexual problems caused by the surgery and by several medications. Symptoms identified are vaginal dryness and lack of libido.
Jonker-Pool et al (2001)	High	Moderate	Testicular cancer, men only	Good evidence describing symptoms associated with testicular cancer treatments. Symptoms that have been identified include loss of desire, erectile disorder, orgasmic dysfunction, ejaculation disorder, decrease in sexual activity and general sexual dysfunction
Eton & Lepore (2002)	High	Moderate	Prostate cancer, men only	Moderate evidence on the treatment impact on patients' sexual function. Men with localised PRCa report more sexual problems than men without PRCa. Some problems seem to be associated with the disease irrespective of type of treatment.

ISSUES	PROBLEMS			
	Amount of research	Quality of research	Scope	Conclusion and opportunity
Harrison et al (2009)	High	Moderate – high	Mixed cancers: Breast – 2 Gyn. – 2 Prostate – 4 Melanoma – 1 Unknown – 1	Sexuality was included within the list of un-met needs. Evidence suggests that unmet needs are more likely to be present in larger number of individuals who have completed their treatment long ago.
Menopausal problems Visovsky & Schneider (2003)	Low	Unclear	Breast cancer, Women only	Menopausal symptoms are linked to the severity of fatigue.
Sleep Lockwood-Rayerman (2006)	Moderate	Unclear	Ovarian cancer, women only	Causes of sleep problems have not been extensively investigated, and they are mentioned in the context of strategies of coping with fatigue.
Visovsky & Schneider (2003)	Low	Unclear	Mixed cancer, mixed genders (no details)	Fatigued patients often reported sleep disturbances. There is some evidence to assume that sleep disturbances increase the levels of fatigue. However, other studies concluded that pain, and not fatigue, was the main cause of sleep disturbances.

ISSUES	PROBLEMS			
	Amount of research	Quality of research	Scope	Conclusion and opportunity
Servaes et al (2002)	Moderate	Moderate – high	Mixed cancers – 3 Breast cancer – 2 Lung cancer – 1	Good evidence for the association between fatigue and sleep problems. A change in sleep patterns was among the most frequently mentioned symptoms to which patients attributed their fatigue.
<u>Cognitive dysfunction</u> Lockwood-Rayerman (2006)	Low	Unclear	Ovarian cancers, women only	Cognitive dysfunction is a new phenomenon reported by ovarian cancer survivors, which requires further investigation.
<u>Physical functioning</u> Lockwood-Rayerman (2006)	Moderate	Unclear	Ovarian cancers, women only	Side effect of cytotoxic drugs is bone marrow depression which can affect patients' physical performance.
Eton & Lepore (2002)	Low	Moderate	Prostate cancer, men only	Men treated with RP reported some physical dysfunction, but these problems diminish over time.
Avis & Deimling (2008)	Low	Unclear	Mixed cancers	Cancer affects physical functioning more than the psychological functioning in older cancer survivors. Older cancer survivors have more co-morbidities and poorer functioning than non-cancer individuals.

ISSUES	PROBLEMS			
	Amount of research	Quality of research	Scope	Conclusion and opportunity
Practical problems: <u>Employment</u> De Boer et al (2009)	High	Moderate – high	Breast – 10 Blood – 7 Testicular 3 Prostate – 2 Female reproductive – 2 Others – 8 Mixed – 4	Cancer survivors are 1.37 times more likely to be unemployed. Survivors of breast cancer, GI cancers and female reproductive cancers are especially likely to be unemployed.
Spelten et al (2002)	High	Moderate	Mixed cancers – 5 Breast – 3 Hodgkin's – 2 Testicular – 2 Leukaemia – 2	The non-supportive work environment, manual labour, fatigue and having head and neck cancer were found to be negatively associated with the return to work.
<u>Finances</u> Harrison et al (2009)	High	Moderate	Mixed cancers- 4 Breast – 2 Gyn. – 2 Prostate – 4 Melanoma – 1 Unknown – 1	5-13% of cancer survivors noted unmet needs in the financial domain of their life.

¹ Amount of research defined as approximate number of studies included in each review: Low ≤ 5 studies, Moderate 6-10 studies, High ≥ 11..

² Quality of research: This refers to the original systematic reviewers' comments on the overall quality of studies included in their review and the terms Low, Moderate and High used to infer quality of evidence.

Primary data articles

Psychological and social problems

The search of PsychInfo resulted in 38 primary data papers and of Cinahl, 31. Once duplicates had been removed and inclusion criteria checked, thirty-one primary data papers were selected.

A general conclusion from the reviews was that research into cancer survivorship needs to be larger in scale, over longer periods of time, more focussed and of better methodological quality. It appears that to some extent this is occurring. Four longitudinal studies were identified (although these are considering only the short-term (up to two years, rather than the more long term up to five years or longer). Two studies do consider the longer term issue of being disease free. Research into transitions experienced by cancer survivors was identified as a need by the cancer charity stakeholders (see below) and one study has considered this.

Areas identified in the literature reviews as requiring more research and where good quality research has been undertaken are: spiritual aspects (three studies); post traumatic stress (three studies); different cultures/ethnic groups (three studies); positive aspects of having cancer such as psychological growth (three studies); sexuality/body image issues (three studies); partners/ families experiences (three studies) and fear of recurrence (three studies). Research has also been carried out with survivors of cancer highlighted as previously neglected populations such as older people (six studies) and men (eight studies).

In terms of the type of cancer, breast cancer continues to be in the majority with twelve pieces of good quality primary research carried out. A small amount of good quality research mainly identifying needs/QoL issues has been carried out in gynaecological (one study), colorectal (one study), and testicular (one study) cancer. Lung cancer was identified as under researched and one study has been published, but there are none specifically in haematological, head and neck, prostate, lymphoma or less common cancers. It was recommended in many of the reviews that research needed to focus upon specific cancer types: this appears to be happening to some extent, but it is of note that seven studies were mixed cancer types.

It is of note that no research published in quality journals with impact factors >3.1 seems to have considered ethnic minority groups in the UK or cancer survival in any other minority/hard to reach or rarely researched groups.

A criticism from some reviews was that different measures were being used and consequently comparisons across research studies were difficult. Five studies have been published developing and validating measures for identifying survivors' needs. It is not clear yet whether this will enable the development and use of robust agreed measures by researchers or just add to the greater variety available.

Physical and practical problems

Thirty papers from the Web of Science met the quality and inclusion criteria, including publication in journals with an impact factor of ≥ 3.1 . A brief summary of the primary research papers reviewed is included in Table 5. There is some evidence of improved research design with, for example, more longitudinal and prospective designs, large representative samples drawn from national population databases and more comparisons with age-matched populations without cancer.

Table 5. Physical and practical problems: summary of primary research papers meeting inclusion criteria

Paper References	Focus of the review	Number of papers	Cancer site	Methods
Grossman et al. (2008) Roscoe et al. (2007)	Fatigue	2	Mixed/Breast	Retrospective/ healthy controls
Ahmed et al. (2008) Hayes et al. (2008) Beesley et al. (2007)	Lymphoedema	3	Breast (2)/ Gynaecological	Population based cohort/ Population based cross sectional retrospective survey
Allareddy et al. (2006) Dahl et al. (2007) Mols et al. (2009) Park et al. (2007)	Sexual problems	4	Bladder/Testicular/ Prostate/Cervical	Population based sample/ Healthy controls
Leining et al. (2006)	Menopausal symptoms	1	Breast	Population based sample
Somani et al. (2007) Mols et al. (2009)	Bladder problems	2	Urinary track/ Prostate	Prospective cohort study/ Population based sample/ Healthy controls
Somani et al. (2007) Krouse et al. (2009)	Bowel dysfunction	2	Urinary track/ Rectal	Prospective cohort study/ Matched cross-sectional
Saquib et al. (2007) Schneider et al. (2007) Weathers et al. (2006) Bae et al. (2006)	Eating & weight	4	Breast (2) Colorectal Stomach	Population based prospective Population based retrospective Qualitative
Arndt et al. (2006) Bowen et al. (2007) Matei et al. (2009)	Physical function	3	Colorectal/ Breast/ Ovarian Germ Cell	Population based cohort/ Population based prospective / Healthy controls
Peuckmann et al. (2009)	Pain	1	Breast	Population based retrospective
Roscoe et al. (2007)	Sleep	1	Mixed	Retrospective
Absolom et al. (2008)	Ovarian failure	1	Women with history of gonad toxic therapy	Medical case note audit
De Bruin et al. (2009)	Malignant mesothelioma	1	Hodgkin lymphoma	Population based retrospective
Haugnes et al. (2009)	Decreased pulmonary function	1	Testicular	Population based retrospective

Paper References	Focus of the review	Number of papers	Cancer site	Methods
Neuhouser et al. (2008)	Vitamin D insufficiency	1	Breast	Multi ethnic cohort
Bradley et al. (2006) Carlsen et al. (2008) De Boer et al. (2008) Lee et al. (2008) Short et al. (2008) Taskila et al. (2007).	Employment	6	Breast & prostate/ Mixed/ Stomach/ Lymphoma/ Testicular / Prostate	Population based retrospective/ population based cohort/ Prospective cohort/ Healthy controls
Arndt et al. (2006)	Financial	1	Colorectal	Population based cohort

NCSI Mapping Project

Psychological and social problems

A number of areas emerge from both the NCSI work stream reviews on bowel, breast, lung and prostate cancers and from the scoping review into psychological and social problems as needing further research. These are: interventions (including comparing treatments, coping with symptoms and so on); quality of life: changes over time; psycho-sexual issues; long term consequences of cancer survivorship; follow-up: anxiety related to follow-up and surveillance; needs of and support for partners, carers and family; needs of and support for black and ethnic minority groups; experiences at specific times such as recurrence; urban and rural differences; and guilt.

The work streams identified a number of areas for further research which did not emerge from the scoping review: support needs; information needs; stigma of diagnosis for survivor and family; socio-economic issues; anger; complementary therapy; and improving communication.

Although a common cancer, the poor survival rate associated with lung cancer has meant that research into any aspect of survivorship in lung cancer remains limited and there is, therefore, a substantial need for research to identify needs. Breast cancer, bowel cancer and prostate cancer are not rare cancers and their survival rates are better, but those affected by these cancers still argue for more research identifying their needs and experience. The reviews included in this scoping report also indicate that research investigating survivors'

needs and experiences is required, but emphasises also that this needs to be well designed and lead to interventions or means of assessing and identifying survivors at risk of problems and possible areas for intervention.

As regards less common cancers, there is some agreement between the issues identified by Cancer 52 and those issues identified in these literature reviews. Agreement is focused around the need for more research into: long term effects of cancer and treatment including after formal treatment; longitudinal research into how people's needs change over time; body image and appearance; ways of enhancing quality of life; impact and support during key events such as recurrence; anxiety associated with follow-up.

Cancer 52 identified a number of areas for future research which did not emerge from the scoping review. These included the need for more information and support; different and best treatment options; co-ordination and continuity of care; infrastructure for providing care; communicating information to health professionals such as GPs about less common cancers; genetic aspects – second cancer, risk to children; child-adult transitions; being 'clear' of cancer; adapting to 'new normal'; dealing with 'anticipatory grief'; complementary therapy; health behaviours and life style to enhance prognosis, quality of life; prioritising needs; and identifying those at risk of recurrence.

Physical and practical problems

As is apparent from the above analysis, a common issue raised by all of the Mapping reports is the need for more and better research to explore survivors' needs and experiences. This is in line with the findings from the physical and practical problems scoping review, as well as from the psychological and social review. A number of specific areas of agreement in this area between the reviews and the Mapping reports are evident. For example, in relation to bowel cancer, there is agreement on the need for more research into the long-term effects of radiotherapy and chemotherapy, and into psychosocial issues of patients with permanent stoma. Both identify the long-term effects of treatments on quality of life, and information for work and finance as priority research areas in breast cancer. In prostate cancer three areas are seen as needing more research: the impact of loss of sexual function and desire, the long-term impact of treatments, and work, finance and social care needs. In relation to lung cancer there is agreement that the impact of stigma on patients and families and the impact of social deprivation and inequalities need more research. The review papers and the mapping exercises agreed that research should lead to appropriate interventions to provide survivors with appropriate solutions.

There is some agreement between the issues identified by Cancer 52 in relation to less common cancers and those issues identified in the literature reviews. More research is needed into: the physical effects of the disease and treatment, specifically the loss of fertility associated with the gynaecological cancers; effective second-line treatments for less common cancers; effectiveness of complementary therapies; difficulties in the workplace as a result of lack of awareness among employers and colleagues of the needs of people with less common cancers.

DISCUSSION

The aims of this scoping review were to establish what is known about the problems experienced by cancer survivors in relation to their health and well-being following primary cancer treatment, to identify gaps in the evidence base and make recommendations for further research. These issues have been explored in relation to two aspects of health and well-being: psychological and social problems, and physical and practical issues. Systematic review methods have been used to scope published literature reviews, and this has been supplemented by a search for recent primary data papers. Findings from analysis of the literature reviews have been compared to conclusions on gaps in and priorities for research from the NCSI Mapping project and the work of Cancer 52 on less common cancers.

Overview of findings

An overview of the main findings from the scoping reviews now follows. These are drawn together in summary form in Table 6.

Depression

This is an important problem and there is good evidence for a significantly increased rate of depression in cancer survivors during and soon after active treatment. However, there is less evidence concerning long term survivors; persistent and recurrent depression is likely to be a problem for an important minority. Those most at risk are people who are younger, female and who have more advanced disease. Much of the evidence is limited to women with breast cancer.

Anxiety

There is modest evidence for increased levels of anxiety after treatment and this is connected with anxiety over check-ups and medical follow up appointments. There is little evidence concerning long term survivors but anxiety is likely to be a problem for a small

proportion. Those most at risk are younger, have more physical symptoms are closer to point of diagnosis and have more advanced disease. Most of the evidence is limited to women, particularly those with breast and ovarian cancer. Fear of recurrence is an increasingly well documented problem that persists in the long-term in patients and family members and contributes to the anxiety experienced by a substantial proportion of survivors.

Emotional distress

There is moderately strong evidence that cancer survivors suffer from increased distress during and soon after active treatment but less evidence for the presence of substantially increased distress in long term survivors. However, within the group of long term survivors there are individuals (for example those with actual and fear of recurrence) who have high levels of distress meriting help. Those most at risk include women, those with lower socio economic status (SES) and those with disabling and disfiguring cancers such as head and neck cancers. Most of the evidence is limited to women with breast cancer.

Social needs

The social impact of cancer and the influence of social support on outcomes such as emotional well being and quality of life have been studied in mixed (but mainly breast cancer) populations. There is a small amount of evidence to suggest social functioning does not differ in cancer survivors from the general population. There is modest evidence that level of perceived social support is positively associated with factors such as mental well-being and quality of life. Studies of the nature of needs of family members and informal caregivers and best ways to meet these were a priority identified through consultation. The psychosocial implications of cancer survivorship for family members have not been well studied. The evidence we have suggests distress in family members persists in the five years following diagnosis. Much of the evidence is limited to women with breast cancer.

Fatigue and physical functioning

Impairment in physical function has been commonly researched in relation to fatigue or other symptoms whereupon physical function is studied as a secondary outcome. There is strong evidence that cancer survivors experience fatigue soon after treatment but only modest evidence in the longer term and unclear how or if this differs from the general population. There is modest evidence to demonstrate fatigue is associated with other symptoms such as pain and sleep disturbance and that it has impact on quality of life. Most

evidence relates to disease free women with breast and ovarian cancer and survivors of Hodgkin's Lymphoma.

Pain

There is a very large literature on pain. The systematic reviews and more recent publications indicate that pain is a problem for many cancer survivors and specifically that chronic pain is more prevalent in breast cancer survivors compared to the general population. Radiotherapy and younger age are predictors. Some cancer treatments may cause pain.

Sexual function

There is strong evidence that cancer and its different forms of treatment can have consequences for a person's sexual function. This issue has been most studied in ovarian, testicular prostate cancer, bladder and cervical cancer. There is modest evidence to suggest symptoms that accompany treatment induced menopause are distressing. We need better understanding of those most at risk, how best to assess patients and the impact of experiencing a disruption in sexual function.

Cognitive functioning

There is some evidence that cognitive dysfunction occurs as a consequence of cancer treatment ('chemobrain') and affects quality of life, but much of the evidence is limited to women with breast cancer. We need more understanding of the incidence, course and effect of alterations in cognitive function in cancer survivors.

Employment, finance and return to work

This important problem emerged strongly from the consultation exercise but has received little attention from researchers. We have a reasonable understanding of the issues and problems people confront as they try to return to work and there is good evidence that those who have survived cancer are more likely to be unemployed than the general population. There is also good evidence that those who have head and neck cancer, do a job that involves manual labour and perceive their work environment to be unsupportive are less likely to return to work. More understanding is needed of the effect of different types of cancer treatment, different types of cancer and other factors on return to work.

Table 6: Overview of review findings

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research ¹	Quality of research ²	Scope	Conclusion
<u>Psychological</u> Depression	Moderate	Low-high	Mostly women - mostly breast and ovarian cancer, men - prostate cancer	<i>Moderate amount of evidence that cancer survivors experience depression - particularly those who are younger, have more advanced disease, more physical symptoms - but evidence is mainly focused on women with breast cancer.</i>
Anxiety	Moderate	Low-high	Mostly women - mostly breast and ovarian cancer	<i>Overall similar levels of anxiety to general population- moderate evidence that some cancer survivors (up to 30%) experience high levels of anxiety. Moderate evidence for a relationship between younger age, being diagnosed with more advanced disease, more physical symptoms and shorter time since diagnosis with increased levels of anxiety. Inconclusive results on the role of anxiety in recurrence and survival outcome. Evidence is mainly focused on women with breast cancer.</i>
General distress	Moderate	Low-high	Mostly women - mostly breast and ovarian cancer	<i>Moderate amount of evidence that cancer survivors have similar levels of general distress to healthy controls. Distress is associated with poorer QoL, lower SES, and head and neck cancer survivors may be more vulnerable to distress. Evidence mostly based on women with breast cancer.</i>
Fear of recurrence	High	Low-high	Mostly women - mostly breast and ovarian cancer	<i>High evidence that fear of recurrence is a concern for cancer survivors and their families. Evidence mostly based on women with breast cancer.</i>

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
<u>Social needs</u>				
Social function	Low	Unclear	Mixed, mainly breast cancer	<i>Low evidence that levels of social functioning similar in cancer survivors to control groups. Evidence mainly based on women with breast cancer.</i>
Social support	Moderate	Unclear	Mixed, mainly breast cancer	<i>Moderate evidence that perceived social support is positively associated with mental well-being, less distress and, higher levels of QOL. Inconclusive evidence that social support is linked to survival from breast cancer. Evidence mainly based on women with breast cancer.</i>
<u>Physical</u>				
Fatigue	High	Moderate	Ovarian, Hodgkin's disease, breast and mixed cancers	<i>There is strong evidence that cancer survivors experience fatigue soon after treatment, but there is a need to explore its prevalence among the long term survivors and its association with other physical symptom (i.e. pain and sleep)</i>
Physical functioning	Low	Unclear	Mixed cancers, mainly in relation to older cancer survivors	<i>Low evidence of the side effect of treatments on patients' physical performance. Older cancer survivors have poorer physical functioning than non-cancer. More information is needed from younger survivors.</i>
Pain	Moderate	High	Mixed cancers, mainly in relation to fatigue	<i>Moderate amount of evidence that cancer survivors experience pain, mainly as a result of the treatment – but evidence is mainly related to fatigue.</i>
Sexual function	High	Moderate	Ovarian, testicular and mixed cancers	<i>Strong evidence of the consequences of cancer treatment for survivors' sexual function. However more evidence is needed on how survivors cope with these difficulties.</i>

PROBLEMS	SUMMARY OF REVIEW FINDINGS			
	Amount of research	Quality of research	Scope	Conclusion
Cognitive function	Low	Unclear	Ovarian cancer only	<i>There is evidence that some treatment for ovarian cancer might affect cognitive function, more information is needed about this problem amongst other cancer survivors and more understanding of the incidence and course of this problem.</i>
<u>Practical</u> Work/employment	Moderate	High	Mixed cancers	<i>There is modest evidence of substantial survivors need, but little evidence of assessment of risk, and little separation of personal (e.g. early retirement) versus medical (disability, body image) factors in predicting unemployment. There is an (unquantified) need for support for employers.</i>
Finance	Low	Moderate	Mixed cancers	<i>Very little evidence of the financial consequences of cancer. There is a need for more understanding how cancer and its treatment affect the financial situation of the survivor and his family.</i>

¹ Amount of research defined as approximate number of studies included in the reviews on a particular topic : Low = ≤ 15 studies, Moderate = 16-55 studies, High = ≥ 56 studies. A study might have been counted more than once if it appeared in more than one review.

² Quality of research: This refers to the original systematic reviewers' comments on the overall quality of studies included in their review. Terms Low- Moderate - High and Unclear have been applied to give a broad indication of quality of research inferred in the reviews.

Limitations of the scoping review

This research was commissioned by the NCSI/Macmillan Cancer Support to inform the research agenda of the NCSI. It was commissioned as a rapid scoping review rather than a full systematic review to enable it to be completed in time to inform the work of the NCSI. The focus of the research has therefore been on addressing the research aims to the best possible standard within the time available. It was therefore appropriate to search the literature primarily for published literature review articles, rather than for primary research, in two areas: psychological and social well-being and physical and practical needs of cancer survivors. Relevant and important findings will have been excluded from this scoping review if they were not included in any of the review papers. In order to understand the likely impact of recent papers being excluded from reviews included in the scoping review, primary papers published since the publication of the review papers were analysed. This analysis suggested that some of the deficits identified in research in terms of design and focus are being rectified.

Focusing exclusively on published review papers can generate a bias towards certain types of research. This is because most systematic literature reviews use a hierarchy of evidence that rates findings from Randomised Control Trials more highly than other studies, with qualitative studies coming at the bottom of the hierarchy. Whilst this is likely to be appropriate when assessing the efficacy and cost-effectiveness of interventions, it is less relevant to reviews of papers of, for example, patients' experiences. Similarly, the criteria for appraising the quality of quantitative studies are well developed whilst those for qualitative studies are less so (Pearson, 2004). Consequently, qualitative studies are often poorly represented in literature reviews, although interest in qualitative literature synthesis is growing. It is likely that this research is under-represented in the review, as is research from disciplines which publish in journals with low average citation impacts (such as nursing and palliative care).

The scoping reviews can also only be as good as the quality of the reviews they are based on. In the psychological and social review, the quality was on the whole good, with ten out of the 16 papers scoring six or above on the seven point quality scale. In contrast, only three out of nine reviews in the physical and practical review scored as highly, with four out of nine scoring only three – the lowest score possible given that reviews scoring two or below were excluded (compared with four out of 16).

Because of these issues, it is recommended that full systematic review techniques are used to examine the evidence in areas where this scoping review has suggested there is sufficient evidence to make this exercise worthwhile i.e. areas where there is at least a moderate amount of evidence. Only 5 systematic reviews were identified in the psychological and social searches that met the eligibility criteria so there is scope for systematic reviews in several areas of survivorship including: depression, anxiety, general distress (systematic review for ovarian cancer has been conducted) and fear of recurrence.

Concluding comments

Future research should address the limitations identified within this report. Since most of the reviewed evidence lacked a theoretical framework of survivorship future research should seek to address this. Well designed research comparing treatment groups, considering changes in psychological variables over time and different events such as recurrence, reporting the role of culture, race or ethnicity or less common cancers is very limited. More longitudinal and prospective studies, using standardised measures and appropriate samples are needed. For example research focusing on less heterogeneous samples in terms of variables such as length of time since diagnosis, type of cancer, age and treatment. It is difficult to draw firm conclusions when researchers vary so much in their use and measurement of key concepts such as definitions and measurement of long term, QoL, survivor, distress, urban/rural and so on. The current health status of survivors is rarely reported - such as disease free, undergoing current treatment, which type of treatment received in the past so this should be addressed in future research so that interventions can be developed and tested accordingly. In addition, studies have rarely controlled for important covariates including co morbidities/symptoms and their interaction/impact. In order to clearly assess the impact of cancer and its treatment there is a need for matched comparisons with non-cancer populations. Finally, more research on less common cancers is necessary.

Appendix I: Table and description of scope process

Psychological consequences for survivors following treatment

Database	Limitations	Hits Psychology	Hits Social
CINAHL	2000-2009 English Age: Adult Publication type: Review	70	225
BNI	2000-2009 Type (child\$cancer or adolescent\$cancer). and combine this with the other terms using NOT	13	34
EMBASE	2000-2009 English Age: 18-65, 65+years Human Review publication, Article Male Female	1682	4
Medline	2000-2009 English Age – 19+ years, 45-64, 65 and over Human Publication type: Review Male/Female	346	20
Psychinfo	2000-2009 English Age: 18yrs older, 18-29, 30-39, 40-64, 65yrs and older, 85 years and older. Human Male/Female Literature Review, Systematic review	1009	420
Web of Science	2000-2009 English Review Science citation index Expand (SCI Expanded-1970-present). Social Science Citation Index (SSCI – 1970- present). Conference Proceedings Citation index Science (CPCI-S- 1990-Present)	186	6
Cochrane	All of the Cochrane Library, all records 2000- 2009 Choose ' Title abstract, or keywords' before typing search terms Childhood cancer removed manually from the result: Not (child* cancer or adolescent* cancer) Tick all boxes Cochrane Database of Systematic Reviews (Cochrane Reviews)	3	27

	<input type="checkbox"/> Database of Abstracts of Reviews of Effects (Other Reviews) <input type="checkbox"/> Cochrane Central Register of Controlled Trials (Clinical Trials) <input type="checkbox"/> Cochrane Methodology Register (Methods Studies) <input type="checkbox"/> Health Technology Assessment Database (Technology Assessments) <input type="checkbox"/> NHS Economic Evaluation Database (Economic Evaluations) <input type="checkbox"/> About The Cochrane Collaboration (Cochrane Groups)		
Total		3,309	736

Search Terms Psychology

CINHAL

- 1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin = 106483 hits
- 2) psychological or psychosocial = 177876 hits
- 3) psycholog\$ or psychosoci\$ = 1 hit
- 4) cancer* OR tumor* OR malignan* OR oncolog* OR carcin = 14461 hits
and psycholog\$ or psychosoci\$
- 5) Survivor = 1216 hits
- 6) 5 and 3 and 1 = 176 hits
- 7) 5 and 3 and 1 with limitations = 0 hits
- 8) 5 and 3 and 1 with limitations (search mode) smart text = 0 hits
- 9) 5 and 3 and 1 with limitation (search mode) Boolean/Phrase = **70 hits**

N.B Informed by the Librarian to start with the CINHAL search engine as this has its own thesaurus. Different combinations were tried initially which were guided by a report on systematic appraisal of the research evidence (Okamoto, Wright, Foster, (2007).

EMBASE

- 1) cancer\$OR tumor\$ or malignan\$ or oncolog\$OR carcin = 171040 hits
- 2) psycholog\$ or psychosoci\$ = 126311 hits
- 3) Survivor\$ = 24171 hits
- 4) 3 and 2 and 1 = 316698 hits
- 5) 3 and 2 and 1 with limitation = **1682 hits**

MEDLINE

- 1) cancer*\$OR tumor\$ or malignan\$ or oncolog\$ or carcin\$. = 424271 hits
- 2) psycholog\$ or psychosoci\$ = 216708 hits
- 3) Survivor\$ = 29200 hits
- 4) 3 and 2 and 1 = 347 hits
- 5) 3 and 2 and 1 with limitations = **346 hits**

PsychINFO

- 1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin = 34990 hits
- 2) psycholog* or psychosoci* = 1438418 hits
- 3) Survivor = 13100 hits
- 4) 3 and 2 and 1 = 1009 hits
- 5) 3 and 2 and 1 with limitations = 7 hits

WEB of Science

- 1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin = 1000,000 hits
- 2) psychological* or psychosocial* = 86,185 hits
- 3) Survivor* = 5,278 hits
- 4) 3 and 2 and 1 = 186 hits
- 5) 3 and 2 and 1 with limitations = **16 hits**

BNI

- 1) cancer* or tumor* or malignan* or oncolog* or carcin = 9715
- 2) psycholog\$ or psychosoci\$ = 6900
- 3) Survivor* = 715
- 4) 3and 2 and 1 = 13
- 5) 3 and 2 and 1 with limitations = **13**

Cochrane

- 1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin = 5821 hits
- 2) psychological* or psychosocial = 5821 hits
- 3) Survivor* = 5821 hits
- 4) 3 and 2 and 1 = 3 hits
- 5) 3 and 2 and 1 with limitations = **3 hits**

Search Terms Social

CINAHL

1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin	= 108223 hits
2) Survivor*	= 11509 hits
3) Social*	= 94789 hits
4) 3 and 2 and 1	= 445 hits
5) 3 and 2 and 1 with limitations	= 225 hits

BNI

1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin	= 9781 hits
2) Survivor*	= 714 hits
3) Social*	= 5539 hits
4) 3 and 2 and 1	= 34 hits
5) 3 and 2 and 1 with limitations	= 34 hits

EMBASE

1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin	= 1018087 hits
2) Survivor*	= 24425 hits
3) Social*	= 169095 hits
4) 3 and 2 and 1	= 854 hits
5) 3 and 2 and 1 with limitations	= 4 hits

Medline

1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin	= 897613 hits
2) Survivor*	= 29423 hits
3) Social*	= 196088 hits
4) 3 and 2 and 1	= 844 hits
5) 3 and 2 and 1 with limitations	= 20 hits

PsychINFO

1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin	= 35395 hits
2) Survivor*	= 13217 hits
3) Social*	= 675269 hits
4) 3 and 2 and 1	= 557 hits
5) 3 and 2 and 1 with limitations	= 420 hits

Web of Science

1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin	= 100,00 hits
2) Survivor*	= 5140 hits
3) Social*	= 100,00 hits
4) 3 and 2 and 1	= 120 hits
5) 3 and 2 and 1 with limitations	= 6 hits

Cochrane

- 1) cancer* OR tumor* OR malignan* OR oncolog* OR carcin = 5821 hits
- 2) Survivor* = 5821 hits
- 3) Social = 1638 hits
- 4) 3 and 2 and 1 = 132 hits
- 5) 3 and 2 and 1 with limitations = 27 hits

Search Terms Physical and Practical Well-Being

Cochrane

- 1) cancer or neoplasm* or tumor* or oncolog* or carcin* or malignan* = 71524
- 2) physical fitness or physical or physical exertion = 29489
- 3) well being = 68011
- 4) income or occupation or work or poverty or benefit or finances or salary or employ* or pension = 75241
- 5) 1 and 2 = 2024
- 6) 1 and 3 = 8868
- 7) 1 and 4 = 11260
- 8) 5 or 6 or 7 with limitations = 2199

WEB of Science

- 1) cancer or neoplas* or tumor* or oncolog* or carcin* or malignan* >100000
- 2) cancer or neoplas* or tumor* or oncolog* or carcin* or malignan* with limitations = 8823
- 3) physical fitness or physical or physical exertion >100000
- 4) physical fitness or physical or physical exertion with limitations = 5300
- 5) well being >100000
- 6) well being with limitations = 6043
- 7) income or occupation or work or poverty or benefit or financ* or salary or pension or employ* >100000
- 8) income or occupation or work or poverty or benefit or financ* or salary or pension or employ* with limitations = 4245
- 9) 4 and 2 = 229
- 10) 6 and 2 = 1037

11) 8 and 2	= 619
12) 9 or 10 or 11	= 1691

PsychINFO

1) Neoplasm including related terms	=14907
2) Cancer including related terms	= 11592
3) Oncology including related terms	= 2074
4) Physical fitness or physical exertion or physical including related terms	= 4116
5) Well being including related terms	= 14588
6) Income or occupation or poverty including related terms	= 10611
7) Finances or employment including related terms	= 18144
8) Work or pension or salary or benefit including related terms	= 4828
9) 1 or 2 or 3	= 28535
10) 6 or 7 or 8	= 32676
11) 9 and 4	= 36
12) 9 and 5	= 192
13) 9 and 10	= 328
14) 11 or 12 or 13	= 549
15) With limitations	= 1

EMBASE

1) Cancer including related terms	= 14365
2) Neoplasm including related terms	= 164060
3) Oncolog* including related terms	= 3
4) Physical fitness or physical exertion or physical including related terms	= 8904
5) Well being including related terms	= 23163
6) Income or occupation or poverty including related terms	= 13125
7) Finances including related terms	= 10016
8) Employment including related terms	= 7653

9) Work or pension or salary or benefit including related terms	= 9404
10) 1 or 2 or 3	= 177733
11) 6 or 7 or 8 or 9	= 39093
12) 10 and 4	= 39
13) 10 and 5	= 332
14) 10 and 11	= 382
15) 13 or 12 or 14	= 747
16) 15 with limitations	= 8

BNI

1) Neoplasm including related terms	= 248
2) Cancer	= 9519
3) Oncolog*	= 680
4) Physical fitness or physical exertion or physical	= 3486
5) Well being	= 742
6) Income or occupation or poverty	= 713
7) Finance\$	= 562
8) Employ\$	= 1969
9) Work or pension or salary or benefit	= 6704
10) Review	= 9360
11) 1 or 2 or 3	= 9621
12) 8 or 6 or 7 or 9	= 9411
13) 11 and 4	= 357
14) 11 and 5	= 90
15) 11 and 12	= 293
16) 13 or 15 or 14	= 694
17) 16 and 10	= 58
18) 17 with limitations	= 54

CINAHL

1) Cancer\$	= 90662
2) Exp neoplasms	= 0
3) Tumo?r\$ or malignan\$ or neoplasm\$ or oncolog* or carcin\$	= 26590
4) Physical fitness or physical exertion or physical	= 108868
5) Well being	= 12894
6) Income or finance\$ or employ\$ or work or pensions or (salaries and fringe benefits) or occupation or poverty	= 130544
7) 1 or 2 or 3	= 102829
8) 4 and 7	= 4751
9) 5 and 7	= 1134
10) 6 and 7	= 4091
11) 8 or 9 or 10	= 9105
12) 11 with limitations	= 46

MEDLINE

1. exp Neoplasms/
2. cancer\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
3. tumo?r\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
4. malignan\$.mp.
5. neoplas\$.mp.
6. oncolog*.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
7. carcin\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
8. 6 or 4 or 1 or 3 or 7 or 2 or 5
9. Physical Fitness/ or Physical Exertion/
10. physical.mp. [mp=title, original title, abstract, name of substance word, subject heading word]
11. 9 or 10

12. well being.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

13. income/ or occupations/ or poverty/ or social change/ or social class/ or social conditions/

14. financ\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

15. employ\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

16. Work/

17. work.mp. [mp=title, original title, abstract, name of substance word, subject heading word]

18. income/ or pensions/ or "salaries and fringe benefits"/

19. 13 or 14 or 15 or 16 or 17 or 18

20. 8 and 11 21. 8 and 12 22. 8 and 19 23.

20 or 21 or 22 24. limit 23 to (english language and "review articles" and humans and yr="2000 -Current" and "all adult (19 plus years)")

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