



# The photoinitiated reaction pathway of full-length cyanobacteriochrome Tlr0924 monitored over 12 orders of magnitude

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Supporting people with active and advanced disease: a rapid review of the evidence

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# SUPPORTING PEOPLE

WITH ACTIVE  
AND ADVANCED  
DISEASE

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

A rapid review of the evidence

January 2014



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# Executive summary

## Introduction

### Background

An increasing number of cancer patients are living with the effects of their disease for significant lengths of time prior to reaching the end-of-life phase. The Active and Advanced Disease (AAD) working group was set up within the National Cancer Survivorship Initiative (NCSI) to consider issues of service design and delivery for people in this situation. They commissioned this rapid review of evidence to meet the following aim:

To review the literature on selected cancers in order to identify implications for the development of services to support patients experiencing difficulties associated with active and advanced disease.

### Defining 'active and advanced disease'

'Active and advanced disease' is not a term widely used in the literature, nor is it as yet clearly defined within NCSI documents. We therefore needed to create a working definition to guide this review. To achieve this we drew on three sources of information:

- The small amount of literature which does use the AAD term with reference to cancer patients

- The wider literature on definitions of survivorship
- An email consultation with 16 health professionals and researchers with knowledge of cancer survivorship issues.

On the basis of this, we propose the following working definition of 'active and advanced disease' in cancer:

'Active and advanced disease' (AAD) relates to physical, psychological and/or social problems experienced by people with cancer that is exhibiting local or wider (including metastatic) spread for solid tumours, or is significantly worsening for non-solid tumours. We exclude from the definition problems specifically associated with diagnosis and the immediate effects of first line treatment. We also exclude those issues that relate particularly to terminal care.

### Search strategy

Given the potentially unmanageable scope of this review, we chose to focus on three types of cancer which have different trajectories, impacts on patients' lives and support needs: bowel, prostate and multiple myeloma. Our main search term was

[cancer type] + SUPPORT; we then used a further 18 terms and applied nine exclusion criteria developed through an initial scoping search on bowel cancer. (See full report for details of search terms and exclusion criteria.) We used the following search engines: Medline, CINAHL, Web of Science and Cochrane. We also searched for grey literature with SIGLE, King's Fund, Social Care online and NCAT. To ensure contemporary relevance and keep the literature search manageable we restricted it to items published since 2003, in English.

The search procedure involved the following steps:

1. Abstracts of all initial searches were reviewed by two members of the team.

Those clearly not meeting the aims of the review were rejected.

2. Full papers were retrieved for those abstracts not rejected at stage one, and reviewed against exclusion criteria. Those to which one or more exclusion criteria applied were rejected.
3. In the course of reviewing the final selection, additional targeted searches were carried out where we identified areas of literature that had been overlooked.

## Findings

For reasons of length we will not attempt to summarise the cancer-specific findings – please see the full report for the detail of these. Instead we will highlight the key issues that emerged in relation to each cancer type. The over-arching issues that we identified across the three cancers are presented in our Discussion section.

### Bowel cancer

Our initial search identified 312 abstracts; following further examination as outlined above we retained 58 items for review. Key issues emerging were:

- Co-morbidity and age
- Chemotherapy in advanced disease Follow-up
- Information needs
- Partners' and carers' involvement in decision-making and support
- Assessment of patient needs and concerns
- Transport, financial hardship and access to care.

### Prostate cancer

We identified 417 abstracts in our initial search, retaining 81 in the final review. Key issues were:

- Patient quality of life





- Patient experience:
  - Sexual problems, urinary incontinence and other physical symptoms
  - Psychological symptoms
  - Spirituality
- Information needs of patients and partners
- Impact on partners and wider family
- Psychosocial support and educational interventions
- Online and written informational and educational resources.

### **Multiple Myeloma**

A total of 350 abstracts was identified in the initial search. Following the further steps of our procedure we retained 111 items in the review.

Key issues were:

- Fatigue and pain
- Information for patients: what to convey and how
- Supporting significant others
- Multidisciplinary working and the involvement of palliative care services
- Treatment strategies to minimise inconvenience to patients and families

- Availability of ‘best practice’ treatment
- Fear of recurrence.

### **Discussion**

Examining both the similarities and the differences in the literatures relating to our three selected cancers, we identified six main themes that need to be considered in the development of services for patients affected by AAD. These are summarised below, followed by suggested priorities for future research and development.

#### **Recognising patient concerns**

Professionals do not always recognise their patients’ priorities in care and support. This may be because they tend to look at patient experience through the lens of their own professional perspective and specialist interest. Also, there is good evidence that patients may play down some symptoms and concerns because they are resigned to them as ‘inevitable’ consequences of their illness, its treatment, and/or simply their age.

#### **Patient and significant other information needs**

The importance of clear, timely and properly targeted information for patients with cancer at all stages (and their significant others)





has long been acknowledged. Nevertheless, this was highlighted as a continuing area of concern for patients and families affected by AAD. We found evidence for the potential effectiveness of interventions to enhance the provision and utilisation of information in a range of settings and formats. Online information can be very useful, but given the age profile of many cancers (including those we looked at), other media remain important.

These include the use of telephone contacts, either for routine follow-up or as part of a targeted educational and support intervention, and printed material.

### **Involving and supporting significant others**

Significant others (family members and/or friends) are a crucial source of support for patients with AAD; it is therefore important that they themselves are supported. We identified more research – including more evaluations of interventions – targeted at the significant others of prostate cancer patients than bowel and multiple myeloma patients. Although the evidence regarding the effectiveness of such interventions is patchy, there was enough to suggest that involving significant others alongside patients – as in some prostate cancer support groups – can be helpful for both parties.

### **Issues of collaborative working**

Effective communication and collaboration between different professionals is often essential to ensure the best possible care and support for patients with AAD (though often literature on this topic was aspirational rather than reporting on good practice). Not only the type of cancer but also the type of treatment patients were receiving could make a major difference to the range of services with which they were in contact. Hospital-based medical specialists are not necessarily the best clinicians to understand and meet the support needs of AAD patients; the potential of nurses (especially clinical nurse specialists and advanced nurse practitioners) to address their needs was frequently highlighted. However, there was a lack of reference in this literature to the actual or potential role of community nurses – or even GPs – in supporting AAD patients.

### **Costs of advanced disease and support interventions**

Within our chosen cancers we found minimal evidence concerning the costs of AAD, either directly to patients and families or to the wider economy. What little we found tended to be focused on personal costs – for instance, how transport issues impacted on uptake of services. The wider literature on the costs of cancer tends not to specify stage of disease and either looks





at cancer as a whole, or includes a selection of specific cancers by convenience with little or no site-specific analysis. It is reasonable to extrapolate from some of this general literature that some of the costs may be higher for patients living with active, advanced disease than those with earlier stage disease or in long-term remission. For example, AAD patients may be receiving ongoing treatment, may be unable to work or have to take significant time off from work, and may have multiple service involvement.

### **Neglect of minority perspectives**

In all our cancers, authors expressed concerns about the lack of research and/or interventions aimed at the support needs of minority groups – especially ethnic minorities but also gay men in relation to prostate cancer. (Sexuality is not considered in the bowel and myeloma literatures relating to AAD at all as far as we could see).

### **Future research and development priorities**

On the basis of this review we would suggest the following priority issues for further research and related service development:

1. There is a need to develop and evaluate methods for improving staff awareness of how patients and significant others are affected by AAD. Multidisciplinary initiatives may be of value, as a way to counter the tendency for clinical staff (and researchers) to look at patient concerns through their 'specialist lens'.
2. Further development is needed of measures and assessment tools sensitive to quality of life issues for patients with active and advanced disease.
3. We need to develop a better understanding of how different segments of the population of patients affected by AAD and their significant others understand and make use of information relevant to their circumstances.

This would include looking at such factors as age, gender, ethnicity and education level in relation to different communication media and contexts, and the impact of this on access to services.





The timeliness of information to address the concerns of AAD patients at different points of the disease trajectory should also be an important focus.

4. Support interventions including significant others need to be developed and evaluated across all cancer types for those affected by AAD. Services generally should consider how they can better engage with patients' key social support networks. Some of the interventions we have identified for prostate cancer patients and their partners may provide a useful model, though the circumstances relating to specific cancer types need to be borne in mind. Also, interventions and service developments need to consider wider family and friendship networks, and the specific needs of people from ethnic and sexual minorities.
5. Collaborative working between professions, services and sectors is crucial to the support of people affected by AAD. New staff roles – or changes to existing roles – could play a part in facilitating this. Developments such as the Macmillan One-to-One projects, nurse-led telephone follow-up, and the roll-out of the Midhurst approach to community palliative care may serve as exemplars, though it will be important to ensure that specific issues relating to AAD are addressed.
6. Research into the costs of cancer (personal, NHS and for the wider economy) needs to include more focused attention on the experiences of those affected by AAD and its treatment.



# 1. Introduction

## 1.1 Background: the NCSI AAD group

The National Cancer Survivorship Initiative (NCSI, 2010) was set up in response to the NHS Cancer Reform Strategy (Department of Health, 2007) as a collaboration between Macmillan Cancer Support, the Department of Health and NHS Improvement, with the goal to achieve a better understanding of the experiences of cancer survivors and to advocate for the provision of services to support them. Within this broad remit, it was recognised that there was a particular group of patients whose needs were commonly neglected; people who were experiencing the ongoing effects of cancer beyond first-line treatment but who were not at end of life. The Active and Advanced Disease (AAD) working group was created to consider issues of relevance to such people.

## 1.2 Aims of this review

This project set out to meet the following aim:

To review the literature on selected cancers in order to identify implications for the development of services to support patients experiencing difficulties associated with active and advanced disease.

## 2. Defining 'active and advanced disease'

'Active and advanced disease' is not a term that has been widely and routinely used in the literature up to now. In order to carry out an evidence search we therefore needed to formulate a working definition. To assist us in doing this we undertook two exercises. First, we carried out a search of the literature for material discussing issues of definition in relation to 'active and advanced disease' and terms that might overlap with it. Second, we informally consulted professionals and researchers with an interest in this area as to their understanding of the term and thoughts about its utility.

### 2.1 Definitions of active and advanced disease in the literature

We performed a Google Scholar<sup>1</sup> search to identify any papers using the exact phrase 'active and advanced disease' or 'active advanced disease' and also including the term 'cancer'. Our search produced 36 items. By way of comparison, the exact term 'cancer survivorship' produced 10,500 items, with 642 in the current year (2013) up to April. Looking further at the AAD items, 12 referred to non-cancer conditions (including liver diseases, lupus, HIV and endometriosis) leaving a total of 24 items using the term

AAD in relation to cancer. Amongst these items, most related to a single cancer or group of cancers; only five were about cancer in general. In the remaining 19, what was immediately striking was the high number relating to cancers of the blood or lymphatic system – 12 articles were in this category (Hodgkins lymphoma = 4, Non-Hodgkins lymphoma = 1, leukemias = 5, multiple myeloma = 2), compared to 7 for all others.

We obtained full text copies of all the articles retrieved in the above search and looked at exactly how and in what context the term 'active (and) advanced disease' was used. It was immediately evident that not one of the publications we found gave a full, conceptual definition of this term. Although not presenting a formal definition, the report commissioned by the NCSI on 'Determining Research Priorities for Cancer Survivorship' (Richardson et al, 2011; including technical appendices 2: Ziegler et al and 3: Armes et al) goes further than any other source to locate an 'active and advanced disease' stage in the cancer survivorship journey. It depicts AAD as beyond the post-treatment phase, remission and initial recurrence, but not incorporating end-of-life. The flow-chart used to depict stages of survivorship recognises that progression between them is not

purely linear – some patients may enter an ‘active and advanced’ phase straight from diagnosis, rather than after remission and recurrence.

Amongst the rest of the articles retrieved, two gave highly technical operational definitions where they had carried out comparisons between an active and advanced group and an early stage group in stem cell treatment for acute myeloid leukemia and associated conditions (Bertz et al, 2012; Krauter et al, 2011). In other articles the term was most commonly used to refer to patients with refractory illness (eg Merl, Hoimes, Pham, & Saif, 2009), or as a contrast to patients whose illness was ‘disease free’/‘inactive’ (eg Whiteside, 2006; Henderson et al, 1974) or early stage (Gladue, Brown, & Zwillich, 2010). One article located AAD (at least by implication) at the latter end of the survivorship spectrum (Cella, 1987); another made reference to the NCSI AAD workstream in locating AAD in a ‘long-term phase’, distinguishing it from a long-term ‘disease free’ state (Jefford et al, 2013). In one article addressing, ‘the aftermath of lung cancer’, the term AAD is used to refer to patients who *do not* go on to survive long-term (Maliski, Sarna, Evangelista, & Padilla, 2003).

## 2.2 Consultation with professionals and researchers

To supplement our search of the literature for usage of the term ‘active and advanced disease’ we carried out an informal consultation of personal contacts with expertise and experience in the areas of survivorship and palliative care. We asked them to describe what the term ‘active and advanced disease’ meant to them, and how (if at all) they used it. In a few cases we asked some further more specific questions to clarify their positions. Overall we had responses from 16 people (everyone we contacted); these included three nurses, seven doctors, four pharmacists and two others (one palliative care researcher without a health professional background and one health service manager). Exactly half of the respondents (eight) were working only as practitioners; the other half had academic posts with varying levels of current or recent clinical involvement. Five of the respondents were members of the MacPaCC group (Macmillan Palliative Care research collaborative). After we had received the email responses NK discussed some of the general issues arising at a meeting of MacPaCC in March 2013.



It was immediately apparent that 'active and advanced disease' was not a term commonly used by our respondents. Some explicitly stated that they did not use it ('It's not a phrase we use and isn't at all easy to answer': Specialist Palliative Care Pharmacist). Ten of the sixteen defined 'active' and 'advanced' as quite separate things: some constructed a definition of the combined term by working out where the two overlapped, while others did not provide any such definition.

'My "gut feeling" would be that "active and advanced disease" (it seems to be a single term) that the cancer, previously diagnosed, was (a) still present, and therefore not "cured", and (b) had spread from the original site, either by metastases (ie distant spread) or by local spread.'

**(Academic GP)**

'Active disease and advanced disease are two different things to me. Active disease means that the cancer (in this case) is growing or worsening (for non-solid tumors), cells are differentiating and dividing abnormally. Advanced disease may or may not be active but it is a late stage of the disease where there has been spread not only referring to distant metastasis but also to local/regional spread that is causing problems in other systems of the body.'

**(Nurse, Clinical Researcher)**

For those respondents who did attempt to define the term there was strong agreement that AAD includes patients whose disease had spread either locally or through metastases (or both). There were differing views, though, on whether it should exclude those where cure remained a possibility and similarly as to whether the term should encompass those who are 'actively dying'. Three respondents excluded patients in remission from the definition of AAD.







'I think it means disease that is not currently in remission, and is in the advanced stages – ie probably only suitable for a palliative approach to care, unlikely to be curable.'

**(Nurse, clinical researcher recently in practice)**

“Active and advanced disease” in a cancer patient to me means they could still be receiving potentially curative treatments with a view to achieving remission.'

**(Macmillan Specialist Palliative Care Pharmacist)**

One respondent – a consultant oncologist – began her response by emphasising that concepts such as AAD were likely to vary in meaning for different cancer sites, because of differing trajectories. Three referred to AAD in relation to long-term conditions (LTCs) other than cancer; one (a community pharmacist) mentioned 'some cancers' alongside a range of chronic and deteriorating LTCs for which she might apply the term AAD. In contrast, our community matron respondent suggested a

rather different interpretation of AAD with regard to LTCs and cancers. While she took 'active' to mean 'causing symptoms' for both types of condition, she saw 'advanced' cancer as referring to '...entering the last stages of the disease you know the end won't be long'. In contrast she saw 'advanced' LTCs as 'could be weeks/months or 2–3 years.'

In the discussion at the MacPaCC meeting, NK summarised the main points emerging from the email responses. (Note that five of those we consulted by email were also present at the meeting). Colleagues reinforced the view that defining AAD is problematic. Nevertheless, they recognised that there are patients who are living with and significantly affected by cancer but not at end of life, for whom appropriate support may not exist or may be difficult to access. A strong concern arising from the discussion was that any definition of AAD should not be used to determine eligibility for services. Access should be based on individual patient need rather than whether a person fits a category such as AAD.





## 2.3 Survivorship and AAD

Difficulties in defining AAD reflect wider challenges in terminology relating to the illness trajectories experienced by cancer patients. Even well-established terms such as 'palliative', 'supportive' and 'end-of-life' are recognised as potentially problematic (Hui et al, 2013). However, debates about the notion of 'survivorship' are of most direct relevance to the focus of this review. The concept of cancer survivorship originates in America, and is usually attributed to the work of Mullan (1985). Having had personal as well as professional medical experience of cancer he was concerned that the needs of those living past a cancer diagnosis were neglected. Mullan (1985) used the term 'cancer survivor' to apply to all cancer patients from diagnosis to end-of-life, and many within the survivorship movement continue to do so. For example, the National Coalition for Cancer Survivors in the US says a cancer survivor is 'anyone living with a history of cancer – from the moment of diagnosis through the remainder of life' (Astrow, 2012). The NCSI also uses a broad definition, from primary treatment through to active and advanced disease (NCSI, 2010). In contrast, many of those involved in policy and practice development

define survivorship as a distinct stage in the cancer 'journey'. In the US, the Committee on Cancer Survivorship of the National Cancer Board (Hewitt, Greenfield & Stovall, 2005) defined survivorship as the phase of care following primary treatment. Empirical research commonly operationalises survivorship in terms of either the end of 'active treatment' or a number of years post-treatment, though both these approaches are fraught with difficulty (see Khan, Rose & Evans, 2012a, for a useful discussion of these issues).

Despite the widespread use of the concept of survivorship and of the term 'cancer survivor' there remain strongly differing opinions about it amongst clinicians, academics and patients. Those who support the notion of cancer survivorship see it as empowering for patients (Deimling, Bowman, & Wagner, 2007) and believe that it helps focus attention on the provision of services beyond the historical emphasis on diagnosis and treatment on one hand and end-of-life on the other (Hoffman & Stovall, 2006; Richards, Corner & Maher, 2011). Those critical point out that as a very broad term it may conceal important differences amongst those to whom the label is attached (Bell & Ristovski-Skijepcevic, 2013). Many patients do not feel





comfortable with the term (Khan, Harrison, Rose, Ward, & Evans, 2012b) perhaps more so in the UK than the US – and its use may serve to reinforce a ‘cancer patient’ identity rather than help people move on from successful treatment (Astrow, 2012; Khan, et al, 2012b). Khan et al (2012a) argue that for some people the term ‘survivor’ may actually increase fears by giving the impression that cancer mortality rates are higher than they are.

The debates about the concept of cancer survivorship are highly relevant to the question of how we define ‘active and advanced disease’. The term is used by the NCSI to refer to a particular subset of ‘survivorship’ and with much the same aims as those who have promoted the wider term; to draw attention to needs, ensure this category of people affected by cancer is considered in policy and practice developments, and enhance the availability of support. However, the use of the term AAD to apply to a particular group of people has some of the same potential pitfalls as we have noted regarding ‘survivorship’; it may be so broad as to obscure crucial differences in the needs and concerns amongst the people to whom it is applied, and it may not be understood or seen as helpful by

cancer patients themselves. As one of our email respondents said:

I will say that the terms are jargon and whatever clinicians and researchers call it we should check that patients and families know/understand what we mean by them.

**(Nurse, Clinical Researcher)**

In the discussion of the concept of AAD at MacPaCC, many members were concerned that it could end up being used in a ‘tick-box’ fashion, to allow – or deny – patients access to particular services. There was a strong feeling that services should be responsive to individual needs and not ‘rationed’ to those who meet criteria that are inevitably to some extent arbitrary.





## 2.4 A working definition of Active and Advanced Disease

While recognising that defining what constitutes active and advanced disease is problematic, we needed at least a working definition to guide our literature search. We hoped that our examination of the findings from this search would itself throw light upon the issue of definition. With a view to the issues discussed above, we did not feel it would be realistic to try to define a distinct stage of survivorship that could be called 'active and advanced disease' for any and all cancers. Rather, we took the view that the term highlights a range of problems which people may experience when their cancer has certain features. We therefore used the following working definition to guide our search:

'Active and advanced disease' (AAD) relates to physical, psychological and/or social problems experienced by people with cancer that is exhibiting local or wider (including metastatic) spread for solid tumours, or is significantly worsening for non-solid tumours. We exclude from the definition problems specifically

associated with diagnosis and the immediate effects of first line treatment. We also exclude those issues that relate particularly to terminal care.

This definition overlaps with that recently suggested for 'chronic cancer' (Harley, Pini, Bartlett & Velikova, 2012) but is not identical. Here, 'active and advanced disease' is a broader concept as, unlike chronic cancer it includes those for whom active anti-cancer treatments that can slow progression are not available.



# 3. Search strategy

In this section we will explain how we went about searching the literature in order to meet the aims of the review. We will cover our choices of: particular cancers upon which to focus; search terms and exclusion criteria; search engines. We will conclude by describing how we managed the search procedure and went about identifying key papers within our overall search results.

## 3.1 Selecting cancers for the search

It was clear from an initial overview of the literature and from the work described above on defining AAD that there are important differences between types of cancer as to what counts as AAD and the support needs associated with it. In addition, given that AAD refers to a broad, heterogenous group of patients that cannot easily be distinguished from other categories, it was well beyond the scope and resources of this rapid review to attempt to examine literature relating to any and all cancers. In consultation with the project commissioners at Macmillan, we therefore decided to focus on three cancers with different trajectories, impacts on patients' lives and likely support needs. Our chosen cancers are: bowel cancer, prostate

cancer and multiple myeloma. In our searches we included research relating to any one or more of our chosen cancers either on their own or alongside other cancers.

## 3.2 Search terms and exclusion criteria

Throughout our search of the literature, our main search term was SUPPORT paired with the names of each of the three chosen cancers in turn. We then added a series of other search terms that would help to ensure we focused on issues relevant to the support of people living with AAD. We also identified exclusion criteria to help us reject abstracts that were retrieved through our searches but did not help us to meet our aims. (Note that we included literature relevant to the support needs of carers/significant others.) In order to keep the search manageable and to ensure evidence was of contemporary relevance we restricted our search to material published no earlier than 2003.

We trialed our search terms and exclusion criteria through an initial search on bowel cancer, and made some adjustments to them as a result. The final list is shown in table 1, on the next page:



**Table 1: Search terms and exclusion criteria**

Search term	Exclusion criteria
[cancer type] + support +	Does not relate (at least in part) to people with active and advanced disease
<ul style="list-style-type: none"> <li>• Intervention</li> <li>• Symptoms</li> <li>• Co-morbidity</li> <li>• Treatment effects Family</li> <li>• Carers</li> <li>• Costs/benefits</li> <li>• Survivorship</li> </ul>	<ul style="list-style-type: none"> <li>• Basic biomedical research</li> <li>• Animal-based research</li> <li>• Where the only or main focus is on screening</li> <li>• Where the only or main focus is on diagnosis (including clinical and/or psycho-social issues of diagnosis)</li> </ul>
<ul style="list-style-type: none"> <li>• Secondary</li> <li>• Psycho-social</li> <li>• Recurrence</li> <li>• Progression</li> <li>• Services</li> <li>• Palliative</li> <li>• Side effects</li> <li>• Peer support</li> <li>• Social networking</li> <li>• Patient information sharing</li> </ul>	<ul style="list-style-type: none"> <li>• Focus on first-line treatment and its immediate effects</li> <li>• Focus on terminal phase (treatment and/or management of final days/hours of life)</li> <li>• Prevention/public health</li> <li>• Non-UK settings where the issues discussed are not relevant to UK health service or societal contexts</li> <li>• Narrowly focused on methodological developments</li> </ul>





### 3.3 Search engines

We used the following search engines for our searches in relation to each cancer:

Medline, CINAHL, Web of Science and Cochrane (systematic reviews, trials and register).

### 3.4 Search procedure

For each of the chosen cancers we searched using [NAME OF CANCER] + SUPPORT plus each of the other search terms. Where initial results suggested a more focused search might be helpful we further refined. Abstracts of all initial search results were then retrieved and reviewed by two members of the team, applying the exclusion criteria and categorised as *definite inclusion for review*, *possible inclusion for review*, and *rejection*. Full papers were then retrieved for the definite and possible inclusion categories, and checked again against the exclusion criteria. A final selection was then made and these papers reviewed. As we began to identify key issues from the articles we were reading, from time to time additional material was uncovered that could contribute to our understanding – for instance through following up citations.

We also periodically checked for relevant material published while we were carrying out the search. One outcome of this process was the identification for each cancer of a relatively small number of key papers that were especially relevant to the aims of this rapid review. These included empirical studies, reviews and theoretical articles. They may be seen as constituting a 'recommended reading' list for those interested in active and advanced disease in relation to the chosen cancers; summary details of these are provided in the appendix.

#### Searching grey literature

The AAD group directed us to relevant grey literature, particularly publications from the National Cancer Survivor Initiative (NCSI). We also searched relevant cancer charities for each individual cancer plus the following sources;

- SIGLE
- Kings Fund
- Social Care online
- NCAT



# 4. Findings

In this section we will present the findings from our review for each of the three cancer types in turn. We will provide an overview of the outcomes of the search process related to each cancer, before moving on to highlight key issues emerging from the publications we reviewed. In identifying key issues we focused on the aims of this review as a whole and therefore looked particularly at areas where the literature had clear implications for policy and practice related to the support of people living with AAD. In a few cases, we have drawn attention to areas where there are substantial and significant gaps in the literature that warrant future research to ensure people with AAD can be properly supported.

## 4A. Bowel cancer

Bowel or Colorectal Cancer (CRC) is the fourth most commonly diagnosed cancer in the UK and the second most common cause of cancer death. In 2010 there were 40,695 new cases, 22,834 (56%) in men and 17,861 (44%) in women. Almost two thirds of cancers occur in the colon and just over a third in the rectum including the anus (Cancer Research UK [CRUK], 2013). Patients presenting with advanced disease at diagnosis are more likely to have colon cancer. In the recent National Bowel Cancer Audit (National Bowel Cancer Audit [NBCA], 2012) nearly a third of those with colon cancer were found to have stage T4 disease when undergoing major surgery and a higher proportion of people with a primary tumour in the colon underwent initial surgery as an emergency. As a consequence postoperative mortality rates were high in those with colon cancer, overall around 5.1% of cases (NBCA, 2012). The audit recognised much effort had been directed at improving outcomes by changing clinical practice yet a number of challenges remained, not least the complexities of care management particularly in a cancer that disproportionately affects older people.





We undertook an initial search based on the terms and exclusion criteria described above, which yielded 312 abstracts. Review of the abstracts resulted in 58 articles being retained. Most abstracts and articles retrieved in related to CRC populations treated with 'curative intent', or recruited people with different cancers including colorectal. Much of the research, particularly that related to psychosocial needs of people with bowel cancer beyond initial treatment, excluded those with active and advanced disease. As a proportion of individuals will go on to develop metastatic disease<sup>2</sup> some articles were included where the focus of the research was not limited to those likely to survive disease free beyond five years, and/or included participants where the stage of disease was unclear. The terms 'active' or 'advanced' disease across the bowel literature were infrequently and inconsistently applied; this is similar to the ambiguity surrounding the terms 'palliative' and 'survivor' (NBCA 2012, van Mechelen et al, 2012) and sometimes used interchangeably. No study used the combined term 'active and advanced' although some used advanced disease alone. Those studies where the term advanced disease was used consistently tended to refer to

a sub-population of CRC survivors including: those living with (active) cancer from diagnosis, or recurrence of disease following treatment with curative intent (Phillips & Currow, 2010), or with local (unresectable) disease or with metastatic disease (Simmonds, 2000) that may not be curable (Leighl et al, 2011).

The first scoping of active and advanced disease in bowel cancer identified a number of issues. These were used as the basis for a series of targeted searches related to specific topics and a further 76 articles were identified, relating to: to co-morbidity and age, chemotherapy in advanced disease, follow-up, information needs, partners'/carers' involvement in decision-making and support, patient adjustment and concerns beyond initial treatment, and transport, financial hardship and access to care. Table 2 (in appendices) contains 'key articles' retained from the initial scoping review that remained salient after further consideration and significant articles identified from the subsequent targeted reviews.





#### 4A.1 Co-morbidity and age

Bowel cancer affects the older population disproportionately (Dunn et al, 2006; CRUK, 2013) and approximately three quarters of new cases occur in those aged 65 or over (NICE 2011). In the period 2008–2010 (NBCA 2012) the majority of new cases of CRC were diagnosed in people over 65 years of age (73%), and over 40% in those over 75 years. In general older people are more likely to experience bowel cancer alongside existing health problems (Bellury et al, 2011; Movsas & Extermann, 2012). Age and co-morbidity combined can bring added complexity and burden to treatment, reducing quality of life (Bellury et al, 2011; Dunn et al, 2006; Fu, Zhao, Gao, Barber & Liu, 2011; Hornbrook et al, 2011; Steginga, Lynch, Hawkes, Dunn, & Aitken, 2009), increased levels of postoperative mortality and lower overall five year survival – the latter not necessarily attributable to cancer (Pedrazzani et al, 2009). Older cancer survivors ( $\geq 70$  years or over) are more likely to report poorer self-rated health and make more frequent visits to the doctor compared with people without cancer of a similar age (Grosv, Fossa & Dahl, 2011). This may be a reflection of feeling vulnerable as a consequence of

having cancer (Shaha & Cox, 2003), and having heightened awareness of bodily cues. They may also be less reticent to present symptoms to a health provider than non-cancer populations of a similar age. The complexity of how comorbidity affects patients with CRC and the way they use services is under-researched (Bellury et al, 2011).

Current NICE Guidance states 'treatment and care should take into account patients' needs and preferences' (2011: 5). Yet Beaver et al (2007) found patient willingness to engage in decision-making was perceived as age related by some clinicians. Whilst some older patients may well adopt a passive role in consultations there was evidence that the way in which choices were presented by clinicians often confused rather than enabled (Keating et al, 2010; Sarfati et al, 2009; Simpson & Whyte, 2006). Confusion could be compounded by levels of health literacy or socialised behaviours, all contributing to a perception of unwillingness to be involved (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman & Rudd, 2004) and 'doctor knows best'. In Beaver et al's (2007) qualitative interview study, with a purposive sample of clinicians (n=35) drawn from a range of disciplines





representing the multidisciplinary cancer team, choice 'was frequently qualified to describe a process of leading, negotiating, suggesting and explaining' (p.729). They also found those patients who actively enquired were more likely to be presented with choices.

In general co-morbidities are associated with poorer outcomes but not all non-cancer conditions and their treatments appear to have similar effects. Some conditions such as previous malignancy, chronic obstructive pulmonary disease (COPD) or cardiovascular disease (CVD) in colon cancer, and COPD, hypertension, and diabetes accompanied by hypertension in rectal cancer may influence treatment and survival due to the underlying pathology, treatment interactions or debilitating effects of the co-existing illness (Lemmens et al, 2005). Existence of co-morbidities may also guide treatment choice and/or influence clinicians to use non-standard treatments to reduce toxicity effects on patients already burdened with other conditions (Samarasinghe & Wiles, 2012; Hornbrook et al, 2011). The complexities of case management when overlaid with non-cancer illness, or complications associated with late presentation with extensive disease requiring emergency intervention, are

more likely to impact on cancer outcomes (NBCA, 2012). There is also some evidence that co-morbidity and socioeconomic deprivation may have some impact on survival and non-cancer death (Shankaran, Jolly, Blough & Ramsey, 2012; Wrigley et al, 2003).

Patients may experience some anxieties about interactions between cancer treatment and treatments for pre-existing conditions. They may also be concerned about cancer treatment exacerbating pre-existing conditions (Simpson & Whyte, 2006). Since much care of long term illness is now managed in primary care this interplay between existing conditions and CRC may result in complex presentation in primary care. Little evidence was found that identified the role of GPs (Hanks, Veitch & Harris, 2008) or other primary care clinicians such as community matrons involved in complex chronic case management (McHugh, Horne, Chalmers & Luker, 2009). Ipsos MORi (2012), identified that 38% of cancer patients had contacted their GP with cancer related concerns in the previous six months; what is unknown is the number of primary care contacts for non-cancer related concerns and the inter-relationships between the two.





People experience bodily cues or sensations that may or may not indicate illness as part of daily life (Miaskowski, Dodd, & Lee, 2004; Miaskowski, Auizerat, Dodd & Cooper, 2007). Interpretation and day-to-day management of symptoms often falls to the patient, family and carers. Symptoms, irrespective of cause, when unrelieved can have a negative impact on quality of life, functioning and mood particularly in advanced disease (Dodd, Cho, Cooper, & Miaskowski, 2010; Smith et al, 2006; Miaskowski et al, 2004, 2007; Walsh & Rybicki, 2006). Recognising symptoms that occur together, in clusters and over time, may improve assessment, speedier management and bring therapeutic benefit to patients (Fan, Filipczak & Chow, 2007; Walsh and Rybicki, 2006; Taylor, Richardson & Cowley, 2011) particular those experienced by people with AAD.

Certain clinical signs such as bowel obstruction, perforation and change in bowel habits are hypothesised to indicate poorer prognosis at initial presentation; likewise bowel obstruction and change in bowel habits is seen more frequently in those with 'early' recurrence in bowel cancer (Kanwar, Poolla & Majumdar, 2012). Much of the symptom cluster research is at an early stage and has been undertaken with heterogeneous groups of cancer patients (including

some bowel cancer), breast (Dodd et al, 2010), lung cancer, or people receiving adjuvant chemotherapy (Skerman, Yates & Battistutta, 2012). Symptom cluster research offers a range of potential benefits for understanding and intervening to support CRC patients with AAD (Brant et al, 2011; Fan et al, 2007; Miakowski et al, 2004, 2007; Skerman, 2010; Skerman et al, 2012; Walsh and Rybicki, 2006).

#### **4A.2 Chemotherapy in advanced disease**

Chemotherapy treatment for advanced colorectal cancer<sup>3</sup> is aimed at prolonging survival, controlling symptoms and maintaining or improving quality of life. Over a decade ago a review concluded that significant improvements in survival (25%) were gained from chemotherapy for advanced CRC (Best et al, 2000). The same review concluded that chemotherapy was effective across age bands with some caveats. People aged 75 years and older were poorly represented in clinical trials, so there was limited data to confirm, or refute, effectiveness of chemotherapy in this group, alongside poor reporting of dose reduction used to minimise treatment toxicity (Simmonds, 2000; Grov, et al, 2011). Age may also be an influencing factor in terms of





access to chemotherapy for AAD in patients with CRC (Lemmens et al, 2005; Keating et al, 2008), and may influence how clinicians present treatment choices particularly in relation to adjuvant or palliative chemotherapy, and invitations to participate in trials (Beaver et al, 2007; Leighl et al, 2011).

A number of different delivery and support models were identified for individuals undergoing chemotherapy for advanced cancer. One Italian study involved a psychological assessment undertaken by a clinical psychologist with ongoing monitoring over the course of treatment with positive results (Pugliese et al, 2006). Most of the UK studies tested different nurse-led models of supportive care associated with the administration of oral capecitabine, driven by the advantages this therapy offers in terms of convenience and cost effectiveness (Oakley et al, 2010). There is, nevertheless, recognition that toxicity can be a problem despite survival benefits (Craven, Hughes, Burton, Saunders & Molassiotis, 2013) and concerns have been raised about safe practice, monitoring and availability of nurse-led support for oral chemotherapy in general (Oakley et al, 2010). An audit of a nurse- and pharmacist-led home-based chemotherapy service for patients receiving first line treatment with oral capecitabine (MacLeod et al, 2007),

found high patient satisfaction and level of support reassuring. Similarly a trial comparing home care support versus normal care found symptom management was better and use of unplanned services lower in those receiving home care (Molassiotis et al, 2009). A follow on audit by the same team comparing outcomes from standard care, nurse-led home care and nurse-led telephone support for patients receiving oral capecitabine found telephone follow up was as effective as standard care for management of some toxicities (chest pain, vomiting, nausea, insomnia) and similar impact to home care with other symptoms such as diarrhoea and insomnia, (Craven et al, 2013). The audit authors recommended a full RCT with economic assessment to assess cost-effectiveness of different support models.

The interplay between co-morbidities, co-incidence of symptoms and time over a course of chemotherapy is largely unmapped (Brant et al, 2011; Ekholm, Grönberg, Börjeson, & Berterö, 2013; Skerman 2010; Skerman et al, 2012). Brant et al (2011) modelled incidence of common symptoms such as depression, distress, fatigue, pain and sleep disturbance over the timeline of chemotherapy, with a heterogeneous sample of cancer patients. They found co-morbidities were a significant predictor of fatigue





at baseline and sleep disturbance over the course of treatment (Brant et al, 2011). Greater levels of pain were associated with those receiving both chemotherapy and radiotherapy. Early work examining symptom clustering and chemotherapy has begun to identify clusters that appear stable over time independent of treatment and primary tumour site (Skerman et al, 2012).

### 4A.3 Follow-up

Approximately 50% of people with colorectal cancer survive beyond five years disease free and some will experience distressing physical, functional and, or psychological consequences of the disease and its treatment (Appleton, Goodlad, Irvine, Poole & Wall, 2013; Baravelli et al, 2009; Samarasinghe & Wiles, 2012; Taylor & Morgan, 2011). A challenge for health providers is providing adequate follow up<sup>4</sup> that meets the support needs of disease-free survivors with complex needs, whilst ensuring optimum surveillance for those at greater risk of recurrence or developing secondary disease, or requiring management of AAD. Numerous approaches for integrating surveillance, detection and support to optimise quality of life have been investigated (Samarasinghe & Wiles, 2012; Baravelli et al, 2009; Cusack & Taylor, 2010). Whilst surveillance

may represent security and symbolise hopefulness for some, for others it engenders feelings of vulnerability, uncertainty, abandonment (Simpson & Whyte, 2006) and anticipatory anxiety particularly when awaiting outcome of investigations (Simpson & Whyte, 2006; Sjövall, Gunnars, Olsson, & Thomé 2011). Conventionally, patients attend outpatient face-to-face consultations with a medical clinician (surgeon or oncologist) but evidence suggests information needs are not always met, and appointments can initiate anticipatory anxiety, and general dissatisfaction (Beaver et al, 2010; Sjöval et al, 2011; Taylor, 2008). Also variability across providers and individual clinicians in terms of frequency, content and duration has been noted (Barravelli et al, 2009, Samarasinghe and Wiles, 2012; NHS East Midlands Cancer Network, 2011). Regularity of hospital visits may provide security whereas being told no curative treatment is available, and reducing frequency of surveillance and/or referral to other services or specialists can for some engender feelings of being 'cast off' by the cancer services (Jefford et al, 2011).

Much of the literature reviewed relating to follow-up is based on patients originally treated with 'curative intent' but these delivery models may offer a template for service design for those experiencing





advanced disease. Living with the fear of recurrence appears as a major concern for patients and their families, understandably given that a proportion will experience further disease. Nurse-led face-to-face appointments for symptom monitoring, eliciting concerns, and information provision have been introduced and well received in various settings (Beaver et al, 2010; Cusack & Taylor, 2010). Nurse specialists were consistently rated highly in terms of information giving and personalising the experience of care (Beaver et al, 2011; Cusack & Taylor, 2010; Ipsos MORI, 2012). A review examining the nurse specialist delivered telephone follow up (TFU) in CRC (Cusack & Taylor 2010) established TFU was acceptable to most patients and resource effective. Although advanced disease populations were not included in these studies their findings regarding acceptability to patients are of potential relevance. An area that requires attention is the development of the skills needed for telephone-based monitoring and patient education needs.

Various risk stratified care pathways have been piloted in test communities (Ipsos MORI, 2012). Findings suggest barriers to change may be linked to cultural and resource issues in, and across, organisations. These could act as barriers to experimentation or reconfiguring

support to enable patients to become more self-managing (Ipsos MORI, 2012). Patient-held care plans, survivorship care plans, and treatment records have received attention as a mechanism to enhance communication, avoid patients becoming 'lost in transit' (Baravelli et al, 2009) and enable self-management and may become particularly important in any shift to self-care models.

An Australian study examined the potential of a patient-led, cancer coordination system using a web-based platform (Sheeran, Milne, Holmes, Tidhar, & Aranda, 2012). This was developed and tested with patients with modest success as organisational barriers limited operability. During testing it became apparent that as a patient's health status declined their ability to use the technology became more limited (Milne, Sheeran, Holmes, Tidhar, & Aranda, 2012). Although such systems have much potential to improve communication between patients, carers and primary and secondary care they have major operability challenges.

#### **4A.4 Information needs**

Understanding complex information regularly appeared in the literature as challenging for patients and their relatives (Appleton et al, 2013;





Jefford et al, 2011; Leighl et al, 2011) and dissatisfaction was frequently reported. This is unsurprising, as the cancer journey for any individual person will vary according to type, stage, treatment and response (King et al, 2010). The evidence indicates that information is inconsistent, fragmented and the patient voice not well represented (van Mossel et al, 2011).

Information-giving should be individualised, time sensitive and presented in ways that meet the needs and preferences of the patients, and significant others (O'Connor, Coates & O'Neill, 2010; van Mossel et al, 2012). For example Morrison et al (2012) found patients expressed greater need for information 24 months after diagnosis than earlier, in relation to recurrence, and recognition and understanding of long term complications of treatment. Areas identified as particularly important to those with rectal cancer were the patients' and families' roles in, and preparation for investigations, treatment and ongoing care responsibilities, and psychosocial concerns such how to talk to friends and family about diagnosis and prognosis, relationships, body image and sexual functioning (O'Connor et al, 2010). A recent Australian mapping of CRC information resources (King et al, 2010) identified gaps related to specific transition

points – diagnosis, treatment decision-making, discharge, primary care support – but makes no mention of any needs beyond the nebulous 'post-treatment' phase. A recent comprehensive review of CRC information needs research (van Mossel et al, 2011) identified a number of notable omissions and/or areas with less evidence that need further scrutiny. These included dietary advice, radiation treatment, 'coping' and 'how to do' personal surveillance. Diagnosis and treatment are centre stage in the CRC information literature and what people wanted was time sensitive and individualised information that included 'how to do' guidance to support self-monitoring, self-care, decision-making and making the most of every contact with health services (King et al, 2010; O'Connor et al, 2010; van Mossel et al, 2012). Also van Mossel et al (2012) refer to a 'Post-Treatment Information Package for People with Colorectal Cancer' developed from their review which they were piloting (corresponding author contacted) which may have some useful content in the context of AAD in bowel cancer and transferability to a UK population.

A study involving a group of 'well enough' CRC participants explored their preferences for what information should populate content of a peer support programme; they







identified information about disease, treatments, side effects, how to be involved in decision-making, physical symptoms and palliative care as most important (Ieropoli, White, Jefford & Akkerman, 2011). Internet was the least preferred mode of delivery, but travel, carer responsibilities and having a stoma were reported as barriers to more participatory modes. Face-to-face group peer support was preferred as it afforded opportunities to share experiences.

Information related to 'choice' (Beaver et al, 2007), and specifically choice in advanced disease (Keating et al, 2010; Leighl et al, 2011), commonly involves discussion of chemotherapy and communication of clear, consistent relevant information (King et al, 2010). Clinician ambivalence about 'best' course of management may be discernible to patients, and how choices are presented appears to contribute to confusion and may influence level of participation (Simpson & Whyte 2006; O'Connor et al, 2010).

An approach likely to facilitate greater patient involvement in decision-making is the use of decision aids (DA) as these have the potential to improve knowledge, lower decisional conflict and increase levels of patient participation in decision-making (O'Connor et al, 2010; Stacey et al, 2011). Including patients as active participants in such interventions

can lead to improved knowledge, more accurate expectations, and choices that are well-aligned with their own values (Staley, 2009). One study relevant to this review by Leighl et al (2011) compared standard medical consultations with consultations involving use of a DA. They found that the DA (information booklet, audio/digital accompanying narration) increased patients' understanding of prognosis, options, benefits and overall understanding without increasing anxiety.

An area that seems to receive less coverage in patient information needs research is dietary advice (Dunn et al, 2006; van Mossel et al, 2012). This is a striking omission given that there is good evidence that diet impacts on symptom management for CRC patients (Knowles et al, 2013; Landers, McCarthy, & Savage, 2012; NBCA, 2012) and diet is associated with increased relative risk of recurrence and mortality in Stage III CRC patients (Meyerhardt et al, 2012). Van Mossel et al (2011) in a recently published comprehensive scoping review mapped the literature concerning information needs across the colorectal care continuum. Interestingly the cancer care continuum timeline they adopted categorised 'post-treatment (survivorship)' and 'end-of-life' but made no reference to AAD. They concluded that people





with CRC want information about managing bowel problems, diet and nutrition but that this interest is not mirrored in the research literature.

The benefits of exercise on wellbeing are well known, as are the positive effects it can have for those with active disease, and for survivors generally (Lowe, Watanabe, Baracos, & Courneya, 2009; Lynch et al 2008a). For example a Canadian study designed to examine the relationship between physical activity and quality of life recruited a sample of cancer patients (n=11 [22%] CRC) with a life expectancy of 3–12 months (Lowe et al, 2009). They found those undertaking physical activity (walking 30 minutes or more per day) had better self-reported quality of life. Also Meyerhardt et al (2006) found that people presenting with stages I-III CRC who increased their activity levels after diagnosis reduced their relative risk of recurrence and overall mortality. Exercise as a discrete information category appeared infrequently in studies, though it may be subsumed in general well-being advice and/or linked with fatigue management (Thraen-Borowski, Trentham-Dietz, Edwards, Koltyn & Colbert, 2013).

On a cautionary note van Mossel et al (2011) highlighted that the research literature may provide coverage of an information need but that does not necessarily mean that people with

CRC, or those significant in providing support (particularly partners and immediate caregivers) have expressed it as a need; it may merely represent the interest of researchers.

#### **4A.5 Partners'/carers' involvement in decision-making and support**

A number of studies identified that the needs and concerns of partners went unnoticed in contrast to those of the person with cancer (Williams & Bakitas 2012; Sjövall et al, 2011; Taylor, 2008). Psychological symptoms of distress, underscoring the shared nature of a cancer, such as high levels of stress, anxiety, depression were reported as was reduced quality of life (McLean et al, 2008; Pereira, Figueiredo & Fincham, 2012). A number of studies (Altschuler et al, 2009; Ekholm et al, 2013; Fitzell & Pakenham, 2010; Ohlsson-Nevo, Andershed, Nilsson & Anderzén-Carlsson, 2012; Pereira et al, 2012; Sjövall et al, 2011; Williams & Bakitas, 2012) identified unmet needs of carers, although relationships to the person with bowel cancer were not always clear and the term 'carer' or 'caregiver' often meant partner or spouse. Little literature emerged about the needs of sexual minorities in relation to CRC. Various reasons can be given for this invisibility such as the fact that sexual orientation data





is not routinely included in health records including cancer registrar data (Boehmer , Ozonoff & Miao, 2011), the needs of this population may not be different, or perceived as different, and/or have yet to come to the attention of researchers.

Studies suggest that the concerns and anxieties of partners/carers were similar to those of patients. Partners found a cancer diagnosis life changing, that it altered relationship dynamics, could be socially isolating, and that systems for managing care often excluded them from receiving treatment and prognosis information or from involvement in decision-making (Ekholm et al, 2013; Ohlsson-Nevo et al, 2012; Sjövall et al, 2011; Williams & Bakitas 2012). Yet much of the literature revealed expectations about roles carers could (and perhaps should) play: 'maintain a shroud of silence' about doubts and fears (Williams and Bakitas 2012:781), share the illness (Ohlsson-Nevo et al, 2012), become a caregiver (Sjöval et al, 2011), carry caregiving burden (Cotrim & Pereira, 2008), act as 'cheer leader' and strive to demonstrate sincere, unconditional regard (Altschuler et al, 2009). These 'roles' and the requirement to 'stay in character' understandably may become more demanding when living with the uncertainties of active and advanced disease. Reinforcing positive aspects

of the role, open communication, and acknowledging the 'social foundation' of a caregiver's life (Williams & Bakitas, 2012; Zulman et al, 2012) were identified as successful strategies for developing resilience.

Higher levels of social support are generally associated with better patient and carer adjustment (Fitzell & Pakenham, 2010) but much of the attention has focused on the distress or burden experienced (Ekholm et al, 2013) – possibly to the neglect of more positive or affirming aspects of caregiving (Fitzell & Pakenham, 2010; Williams & Bakitas 2012). There was limited literature examining how different gender, ethnicity or social inequality impacted on care burden or access to social support. Other studies (Altschuler et al, 2012; McLean et al, 2008; Ohlsson-Nevo et al, 2012; Pereira et al, 2012; Sjöval et al, 2011) examined (spousal) relationship functioning. Fitzell and Pakenham (2010) examined predictors of adjustment outcomes in CRC carers (84% partners/spouses) and found stress appraisal, subjective interpretation of threat, and higher levels of social support as strongest predictors of carers' adjustment. One Portuguese study found that when people with CRC were experiencing depression they were more likely to have partners who were also depressed and vice versa (Pereira et al, 2012).





A number of studies described interventions designed to support people with CRC and their partners. For example McLean et al (2008) demonstrated a significant positive effect on couple functioning, and improvement in symptoms of depression (greater in patients) from an intervention using eight, once weekly sessions of Emotionally Focused Couple Therapy (EFT) with patients with advanced cancer (only 2 GI) and their partners. Zulman et al (2012) developed a supportive-educative programme (FOCUS) adapted from an in-person to a tailored web-based format with end-users – people with CRC and carers. Operability and acceptability testing was largely positive even with older users and those with limited IT experience.

#### **4A.6 Patient adjustment and concerns beyond initial treatment**

Numerous descriptions of the period of CRC survivorship following initial treatment with curative intent discuss the omnipresence of cancer (Shaha & Cox, 2003) and living in a state of fearful watchfulness. Research identifies feelings of uncertainty (Sjöval et al, 2011) linked with fears of recurrence (Appleton et al, 2013; Dunn et al, 2006; Morrison et al, 2012), and fears about withdrawing from the close attention of the health

care system at end of treatment (Jefford et al 2011). People living with CRC may engage in a range of strategies to monitor their bodies (Taylor et al 2011, Morrison et al, 2012). McCaughan, Parahoo & Prue (2011) found that social comparison with other cancer patients could have very different meanings for different people. For some, it was experienced as helpful, while others found it so unhelpful that they actively avoided interactions with their fellow patients. These different responses have potential relevance to the types of support intervention that might be offered.

A number of studies examined or identified 'benefit finding' in which the person with CRC recognised benefits or gains from their illness experience (Altschuler et al, 2009; Dunn et al, 2006; Simpson & Whyte, 2006; Rinaldis, Pakenham & Lynch, 2012). Benefit finding does not seem to be associated with higher overall quality of life measurement but is with some subscales in some studies. However, a relationship was found between satisfaction with social support and benefit finding (Rinaldis et al, 2012). Benefits identified included heightened family risk awareness, participation in surveillance, recognition of what is important, and awareness of 'being loved'.





Some authors have suggested that CRC patients may become more socially isolated than other cancer patients, due to age, comorbidities, stigmatisation as a consequence of surgery (particularly ostomy) (Lynch et al, 2008b; Althschuler et al, 2009), side effects of treatment such as flatus, faecal frequency and incontinence (Hamilton, Jackson, Abbott, Zullig & Provenzale, 2011; Ieropoli et al, 2011). Another US study reported patients with cancer of the rectum receive less professional social support than colon cancer patients (Hamilton et al, 2011). In the UK as all patients should be referred to a nurse specialist (stoma care nurse/colorectal nurse specialist) irrespective of treatment this is less likely. However, the recent audit identified 10–15% of colorectal cases were recorded as not seen by a nurse specialist, the number could be higher as around 19% of all cases had the information missing (NBCA, 2012); this may be related to levels of emergency surgery.

The impact of ostomy on patients concerns, needs and quality of life outcomes varies across studies and does not appear to be directly associated with permanency of stoma (Hamilton et al, 2011; Hornbrook et al, 2011). The NBCA (2012) identified that a significant number of patients had a stoma at 12 months post initial surgery and this 'should alert all teams to the

on-going necessity for support in the community' (NBCA, 2012: 9). Ostomy related difficulties included irritated peristomal skin, odour, noise and need to empty pouch frequently (Lynch et al 2008b). Restitution of anal defaecation can result in troublesome bowel function leading to decreased quality of life (Appleton et al, 2013; Taylor and Morgan 2011).

#### **4A.7 Transport, financial hardship and access to care**

The establishment nearly two decades ago of specialisation, tumour site-specific multidisciplinary teams and treatment pathways has had a direct impact on survival for both colon and rectal cancer (Morris, Haward, Gilthorpe, Craigs & Forman, 2006), but for some may have inadvertently created new barriers to treatment and support access (Jones et al, 2008). These include issues related to transport; for example, in a Welsh study of cancer outpatients (including CRC patients) car parking was one of the highest rated unmet needs (Morrison et al, 2012). For some CRC survivors experiencing distressing treatment-related complications – particularly faecal incontinence and urgency (Appleton et al, 2013) – transport, parking and geography may be influential in decision-making regarding treatment and out-patient attendance.





#### 4A.8 Neglected areas

The dearth of literature relating to primary care was striking; only one paper identified the role of GPs (Nazareth et al, 2008) and none related to other primary care professionals involved in supporting and managing people with long term conditions such as community matrons, practice nurses and district nurses. This is in spite of the fact that CRC is predominantly a disease of older people and experience of cancer in later life is mediated by other health (co-morbidity) and life challenges (including disability). The evidence we have reviewed shows that co-morbidities are often of concern to bowel cancer patients with active, advanced disease and also that they may struggle with the costs and practicalities of travel to specialist centres. There is surely a need for more involvement of community-based services for these patients, and for research to inform the development of interventions and evaluate their effectiveness.

It is apparent from this review that the bowel cancer experience is different for different people and may change over time for individual patients and those close to them. While interventions must of course be informed by evidence they must also be flexible enough

to encompass variation in patient and carer needs and experiences. A 'one-size fits all' approach will not necessarily gain universal approval irrespective of the evidence. The ability of service developers to tailor new initiatives to varying needs is hampered by the relative lack of research relating to certain groups in this population – especially ethnic and sexual minorities.

Colorectal cancer is a shared experience involving the patient, their partner and/or families and sometimes their wider social network. Those individuals who feel socially isolated and without an established support network undoubtedly require particular attention as there was some evidence this may impact on outcomes. For those who are well-supported, we need a better understanding of how services should engage with them and where appropriate involve them in support interventions. Information-sharing is a crucial area to address. The patient rightly should be 'centre-stage' and the focus of professionals, but partners and/or other significant caregivers need to be considered as supporting actors, not mere extras. Extending the theatrical metaphor, it was evident in our review that sometimes they are denied access to the script and often cut out of important scenes altogether.





A number of articles, largely from the UK, described and tested novel approaches for follow-up and administration of chemotherapy, while others described different technologies that could be used as platforms for support, enhanced contact and surveillance. It must be recognised that interventions designed for research and the realities of care delivery may be different. Economic modeling of interventions is important, but successful real-world implementation requires a better knowledge of the enablers and barriers to adoption and assimilation (Greenhalgh, Robert, Macfarlane, Bate & Kyriakidou, 2004). Healthcare services are complex and dynamic and service re-design inevitably brings a clash of cultures and norms (Iles & Sutherland, 2001). Assuming what works in research can be transplanted and assimilated into other organisations would be naïve, yet few studies provided details of the change process needed to introduce different models of care. As identified in the NBCA (2012) audit there is a need 'to explore the intricacy of processes of care and outcome that has a bearing on both the lives of patients that need palliative solutions and those that survive the consequences of altered bowel activity and changed body image' (NBCA, 2012: 68). Our review would confirm this.

#### **4B. Prostate cancer**

Prostate cancer is the third most commonly-diagnosed cancer in the UK – and the most commonly-diagnosed amongst men. In 2010 there were 40,975 new diagnoses, and 10,721 deaths (CRUK 2013). Within the literature, the term 'advanced' prostate cancer is most consistently used to refer to patients who have developed metastatic disease. Such patients may be treated with hormone therapy until the disease becomes hormone refractory and only palliative treatment is offered, which may include chemotherapy. A further category of relevance to this review is 'locally advanced' prostate cancer; these patients may or may not be suffering from symptoms and may be managed under 'watchful waiting' schemes or be in receipt of a range of treatment options, including surgery, radiotherapy and hormone therapy. Prostate-specific androgen (PSA) levels are a key indicator used to assess disease progression.

The initial search based on the search terms and exclusion criteria described in the introduction produced 417 abstracts. These were reduced in the next stage of the search process to a total of 65 articles; a further 16 were identified in supplementary searches resulting in a total of 81 in the final review. Thirteen items were identified as 'key articles'; summary details of these are given in Table 3, in the appendix.





### 4B.1 Patient quality of life

We consider here evidence relating to Quality of Life (QoL) or Health-related Quality of Life (HRQOL) in general, especially as measured by standard instruments for these constructs. Evidence focusing on specific symptoms follows. The literature presents a complex picture of how prostate cancer impacts on men's QoL. Korfage et al (2005) found that HRQOL of prostate cancer patients five years after diagnosis was at least equal to that of the general population in US and Dutch studies. Nevertheless, there is considerable evidence for the deleterious effects of prostate cancer treatments on QoL, though these effects are highly specific to particular treatments (Penson, Litwin & Aaronson, 2003; Sanda et al, 2008). Where studies have compared QoL of men with advanced disease (usually defined as metastatic) with that of men with localised/early disease, they consistently show the former have lower QoL (eg Berglund et al, 2007). In a UK survey, Lintz et al (2003) found patients with advanced disease had lower scores on all quality of life areas (physical, role, emotional, cognitive and social functioning), compared to those with early/localised disease. Penson et al, (2003) argue that in men with advanced/metastatic disease, 'quality of life often becomes the primary desired outcome' (p.1653).

An important issue in research examining quality of life in men with advanced prostate cancer is 'response shift'. Response shift occurs in quality of life measures where respondents' perception of what counts as 'normal' shift from the baseline as illness progresses. Thus symptoms that they would have rated as having a significant impact on quality of life early in illness may be discounted in later ratings. Korfage, Hak, de Koning, & Essink-Bot (2006) argue that this occurs in men with advanced prostate cancer, where men accept urinary and bowel dysfunction as persistent side effects and do not consider these as part of their 'health'. Consequently, when completing generic QoL measures, the importance of these symptoms may not be revealed. Faithfull, Cockle-Hearne & Khoo (2010) point out that clinicians as well as patients may see urinary symptoms as an inevitable aspect of ageing and downplay their importance as a symptom of cancer and its treatment. In some respects this phenomenon might reflect helpful adjustment to the realities of advanced disease, but it poses a challenge for researchers trying to accurately assess the long-term effects of prostate cancer and its treatment. One strategy to address this is to develop QoL measures targeted at specific domains relevant to prostate cancer (eg Eton, Shevrin, Beaumont, Victorson & Cella, 2010; Ritvo, et al, 2005).







There is evidence that health professionals' perceptions of patients' concerns may not always concur with the views of the patients themselves. A recent US-based study (Sonn, Sadetsky, Presti, & Litwin, 2013) compared patient and physician perceptions of quality of life in relation to the specific areas of fatigue, pain, and sexual, urinary and bowel dysfunction. They found that these differed in all domains; in particular physicians ranked urinary and sexual dysfunction higher than the patients did, with the reverse true for fatigue and pain. Correspondence between patient and physician perceptions did not improve over time. While the reasons behind these discrepancies may be complex, including the reframing of what counts as 'health' as noted above, they do at least suggest there may be a need to improve training for doctors (and other HCPs) in eliciting concerns of prostate cancer patients.

#### **4B.2 Patient experience:**

##### **(i) Sexual problems, urinary incontinence and other physical symptoms**

Sexual problems are prominent in the literature as a major concern for men with advanced prostate cancer; specifically loss of libido, erectile dysfunction and impotence linked to treatment (Carter, Bryant-Lukosius,

DiCenso, Blythe & Neville, 2011; Galbraith, Hays & Tanner, 2012; Korfage et al, 2006; Lintz et al, 2003; Maliski, Rivera, Connor, Lopez, & Litwin, 2008; Rivers et al, 2011; van Andel et al, 2008). Issues of sexual function are often discussed in relation to their impact on couple relationships (Badr, Carmack & Cindy, 2009; Rivers et al, 2011) and to men's sense of masculinity (Eton, et al, 2010; Galbraith et al, 2012; Galbraith, Fink, & Wilkins, 2011; Maliski, et al, 2008; Sanders, Pedro, Bantum & Galbraith, 2006; Song et al, 2012), and maintaining effective relationships is a major challenge for men with prostate cancer (Song, et al, 2012). In terms of sexual function issues, married men are two to three times more likely than single men to have some psychological needs in this regard (Lintz, et al, 2003) and sexual concerns are high on men's agendas (Galbraith, Arechiga, Ramirez & Pedro, 2005). Notwithstanding low satisfaction in this area, Galbraith et al (2005) found that few men sought treatment. Men with advanced disease are more likely to report some need in relation to sexual dysfunction than those whose cancer was localised (Carter, et al, 2011; Lintz, et al, 2003). Even amongst older men sexual concerns are significant (van Andel, Visser, Hulshof, Horenblas & Kurth, 2003), though in the late stages of illness they





may decline in importance relative to other issues (Lindqvist, 2011).

Urinary incontinence is also a dominant issue of concern (Boonzaier et al, 2009; Carter, et al, 2011; Eton, et al, 2010; Faithfull et al, 2010; Korfage, et al, 2006; Lindqvist, 2011; van Andel et al, 2008; Zhang, Strauss, & Siminoff, 2006). Faithfull et al (2010) found that 97% of men treated for prostate cancer reported lower urinary tract symptoms, half of which were classed as moderate to severe. Mols et al (2009) examined the long-term problems of men in the southern Netherlands five to ten years post-diagnosis. They found 48% of participants reported urinary incontinence, compared to 74% reporting erection problems and 14% bowel leakage. As has been found in other studies, treatment modality made a significant difference to specific outcomes. (Note 18% of participants were identified as stage TIII or TIV at diagnosis; staging at data collection is not reported, nor is the relationship between staging and extent of problems.) Other physical symptoms – which are frequently consequences of treatment rather than of the illness itself – include bowel control problems, pain and hot flashes, (Eton, et al, 2010; Lindqvist, 2011; Lintz, et al, 2003; Steginga, Pinnock, Gardner, Gardiner, & Dunn, 2005). A further important effect of treatment is insomnia and

sleep disorder/disturbance (Dirksen, Epstein & Hoyt 2009; Savard et al, 2005). This may be linked to other symptoms – for instance, pain or hot flashes may disturb patients' sleep. Sleep difficulties can cause or add to problems of fatigue and result in cognitive dysfunction (Engstrom, 2005). The inter-connectedness of symptoms is very apparent here.

Evidence relating to the impact of the above symptoms specifically in the context of advanced disease is limited. Carter et al (2011) found that the physical symptoms of concern to men with advanced disease differed between those with hormone-sensitive and those with hormone-refractory prostate cancer, largely in relation to the effects of the different treatment regimes. While both groups suffered fatigue, the hormone-sensitive men were bothered by hot flashes, breast soreness and feelings of weakness, while the hormone-refractory men complained of nausea and loss of appetite.

It is worth noting that while the literature typically distinguishes between physical and psychological symptoms, in reality they are often closely intertwined. For example, anxiety may affect sexual function, and pain is widely recognised to always include a psychological component (Keefe, Rumble, Scipio,





Giordano & Perri, 2004). This underscores the importance of an holistic approach to patient support. Lindqvist et al (2011) argue that we need to consider 'the symptom experience as an integrated whole' (p.311); their study focuses on the meaning-making engaged in by men with hormone-refractory prostate cancer.

### **(ii) Psychological symptoms**

Psychological symptoms (in addition to those specifically related to sexual function) include depression, anxiety, and psychological distress (Couper et al, 2010; Dirksen, et al, 2009; Lintz, et al, 2003; Purnell et al, 2011; Voerman et al, 2007). These symptoms are likely to be inter-related: for instance, Dirksen et al (2009) found significant relationships between depression, distress, and insomnia, with half of the men suffering clinically significant insomnia also experiencing clinically significant depression. Sharpley, Bitsika and Christie (2010) found a relatively high incidence of anxiety-depression co-morbidity. Kahana et al (2011) argue that the complex impacts of long-term cancer survivorship in prostate, colorectal and breast cancer can be seen as post-traumatic transformations, which may have positive as well as negative aspects for survivors. A focus group study by Wallace and Storms (2007) found altered life perspectives

of those men living with hormone-treated advanced prostate cancer.

An Australian study by Couper et al (2010) found far greater psychological deterioration in the 12 months after diagnosis for men diagnosed with advanced disease (ie metastatic) compared to early stage disease. The notion that the psychological consequences of prostate cancer may differ between early stage and advanced disease is supported in a study by Segrin and Badger (2010), which found that social support was positively related to depression in early stage but negatively in advanced disease. They suggest that a high level of social support may have been unhelpful to men with newly diagnosed localised disease because it served as an unwelcome reminder of their condition. In contrast, men with advanced disease are likely to experience distressing symptoms and side-effects of treatment and therefore require support from others in coping with these.

### **(iii) Spirituality**

Within the palliative and supportive care literature spirituality has long been recognised as a key aspect of overall wellbeing (McClain, Rosenfeld & Breitbart, 2003); it is also relevant to survivorship (Vachon, 2008), including people with advanced disease. In a study of men with both





local/regional and metastatic prostate cancer, spirituality was positively and significantly associated with higher scores in all general and disease specific QoL measures (Krupski et al, 2006). In a sample of 367 men with prostate cancer, 203 of whom were classified as having advanced disease, Nelson et al (2009) found a small relationship between intrinsic religiosity and depression but a strong negative association between spirituality and depression. A main component in reducing depression when exploring religiosity and spirituality, is a sense of meaning and peace. Thus it could be important to develop men's sense of meaning through activities/interventions (not exclusively religion-based) in order to achieve this. However, it is important to note that the association between religiosity and/or spirituality and QoL in cancer patients is complex, and caution is required in developing spiritual interventions (Hamrick & Diefenbach, 2006).

#### **4B.3 Information needs of patients and partners**

Information needs emerge strongly as an issue of concern for prostate cancer patients, including those with advanced disease – see especially, Carter et al (2011). They relate to all aspects of the experience and stages of the illness

trajectory, from diagnosis though to end of life issues, though the side effects of illness and treatment are a particularly strong concern (see Boberg et al, 2003; Galbraith et al, 2012, Lintz et al, 2003).

The view that information needs persist and change beyond diagnosis and treatment of early-stage illness is stressed in several studies (Galbraith et al, 2012; Nanton, Docherty, Meystre, & Dale, 2009; Rozmovits & Zeibland, 2004; Vachon, 2008). For example, Nanton et al's (2009) UK-based focus group study found that effective communication of information by health professionals was important to patients at very different stages in the illness trajectory, and that information-seeking was part of an active coping strategy for some men. Grimsbo, Finset and Ruland (2011) highlighted a lack of information for patients after hospital treatment, describing them as feeling they were 'left in a void'.

#### **4B.4 Impact on partners and wider family**

There is a fairly substantial amount of literature on how prostate cancer impacts on men's partners, although this is overwhelmingly focused on heterosexual couples (Blank, 2005). The well-being of partners is recognised as important





both because of their crucial role in supporting men and because of the potential deleterious consequences for their own health. Rees et al (2005) found that partners actually had higher psychological morbidity than patients. Swore-Fletcher et al (2008) identified clinically meaningful levels of psychological symptoms in female caregivers, which had a negative impact on their functional status and quality of life. The literature on wider family and friendship networks is much smaller. We identified one paper that directly examined the way family members beyond spouses/significant others were affected by a man's prostate cancer (Segrin, Badger, & Figueredo, 2011). This suggested that wider family members were strongly affected by the patient's prostate cancer, and that adult children were actually more depressed than spouses/significant others. Note that this study (which also included families of breast cancer patients) does not state what proportion of prostate patients had advanced disease.

Several articles found in our search illustrate the interdependence in psychological wellbeing between men with prostate cancer and their partners (eg Galbraith et al, 2005; Harden et al, 2009; Ko et al, 2005). As with the Segrin et al (2011) article, cited above, these papers do not distinguish in their analyses between

advanced prostate cancer patients and those at earlier stages (though all include some advanced patients in their samples). In contrast, Song et al (2012) directly compared dyads with patients in three different phases of illness: localised, biochemical recurrence and advanced. They found that open communication was highest in couples with advanced disease at baseline, and that it decreased over time for all groups. Furthermore, increased uncertainty about the illness was associated with decreased open communication, suggesting that when uncertainty is high, patients and spouses may be unsure what to say and be anxious not to raise concerns that would distress each other and themselves. This study points to the need for interventions to be designed to meet the specific needs and challenges for communication relating to specific phases of illness.

In the same RCT that was used as a source of data by Song et al (2012), Northouse et al (2007a) examined dyads of patients and spouses in relation to their psychosocial status and quality of life. Dyads were in three disease phase groups: newly diagnosed, biochemical recurrence and advanced (defined as metastatic disease at diagnosis or progression shown on diagnostic scans). They found that the psychosocial experiences of dyads at the same phase were similar, but they differed





from those at other phases. Dyads in the advanced phase had the highest levels of distress; these patients had the lowest physical quality of life and their spouses had the lowest emotional quality of life of the entire sample. The authors argue that this evidence supports the need for phase-specific programmes of care for couples affected by prostate cancer.

#### **4B.5 Psychosocial support and educational interventions**

There are many accounts in the literature of psycho-social support interventions for men with prostate cancer, though not all report robust evaluations of their effectiveness. In common with other cancers, support groups have become a widely-used resource for prostate cancer patients, sometimes including their (female) partners as well. Other interventions include home or community-based educational and/or therapeutic programmes (eg Chambers, Foley, Galt, Ferguson & Clutton, 2012; Northouse et al, 2007; Snyder et al, 2009), and telephone (Badger et al, 2011; Scura, Budin & Garfing, 2004) and internet support services (Ruland et al, 2013). Interventions may combine several of these elements. While it is hard to come to general conclusions about such interventions – given the variety

in format, content and evaluation methods – it does appear that they can be useful, especially in relation to meeting informational needs (Arrington, Grant & Vanderford, 2005). There is some suggestion that female partners may find them more useful in terms of social support than the men themselves (Northouse et al, 2007a).

Detailed studies of specific psychosocial support groups have provided useful insights into their dynamics. Arrington et al (2005) found discursive practices and structural features of groups served to inhibit emotional support. Groups were predominantly focused on informational support. Bottorff et al (2008), looked at women's participation in Canadian prostate cancer support groups and found they adopted roles congruent with stereotypically feminine positions: social facilitator (the most common), background supporter or cancer co-survivor.

When we focus on men with advanced disease, the evidence is much more sparse. We found very few interventions aimed specifically at this group, and in a fairly recent systematic review, Chambers, Pinnock, Lepore, Hughes and O'Connell (2011) highlight the paucity of research targeting men with advanced disease. Where





studies note the inclusion of men with advanced disease in interventions they generally do not present any specific analyses for this group. We summarise below the main findings from the few studies that either relate to advanced disease-specific interventions or offer clear insights for these patients.

Chambers et al (2012) piloted an intensive mindfulness based cognitive therapy group intervention specifically for men with advanced prostate cancer based on a cancer specific manual with additional, advanced prostate cancer-specific components. They found that mindfulness-based cognitive therapy groups have utility for these patients with the potential to reduce anxiety, avoidance, and fearfulness of cancer recurrence. An unexpected finding was that the group experience and supportive exposure to other men with rapidly advancing disease enhanced acceptance of their condition. Thus there appeared to be a synergy between mindfulness and peer support in a group context.

Northouse et al (2007a) evaluated a psychosocial intervention for couples. The 'FOCUS Programme', originally devised for breast cancer patients and their families, consisted of three 90-minute home visits and two 30-minute telephone sessions delivered over a four month period. They looked at its impact on dyads

where the patient was at initial diagnosis, biochemical recurrence or advanced phases of illness. Intervention patients showed lower uncertainty and better communication with spouses at four months from the start of the intervention, while spouses showed a wider range of psychosocial benefits, with some enduring to eight and 12 month assessments.

Boonzaier et al (2009) provide a useful account of the development of an Australian psycho-educational group intervention for men receiving radiotherapy for prostate cancer, delivered at pre-treatment, midtreatment, treatment completion and posttreatment stages. Although not focused particularly on men with advanced disease, an important feature that could be usefully applied in the advanced disease context was the modular design, whereby the group could opt to receive specific modules to meet their emerging concerns. Note that Arrington et al (2005) report the development of separate topic-specific subgroups within the 'Man-to-Man' support group programme.

The 'Between Men' programme was a seven-weekly psychosocial rehabilitation programme in Sweden, delivered by health professionals. Three different conditions were evaluated over a one year period: physical training alone, information alone, or a combination of the





two. Forty-two (20%) of the 211 participants had metastases at recruitment. An initial evaluation (in which results for advanced disease patients were not reported separately) found very high participant satisfaction with the programme; given a choice of programmes for the future, most participants opted for the information alone or combined programmes (Berglund, Petersson, Eriksson, & Haggman, 2003). However, an evaluation of the effect of the programme on anxiety/depression and HRQOL found no significant improvements for any groups of patients. The authors suggest that the high drop-out rate (c.20%) and the complex design may have had an impact on the ability of the evaluation to detect an effect. Future studies with simpler designs enabling higher power are recommended.

#### **4B.6 Online and written informational and educational resources**

The growth in the use of online resources by cancer patients is widely recognised, so it is unsurprising that the great majority of literature we found about informational resources related to online material, with several studies specifically including prostate cancer patients. (As with the material on psycho-social interventions, discussion

rarely highlights any specific issues for advanced disease patients.) Examples of the kind of resources available include:

Macmillan Cancer Voices:  
**[opportunities.macmillan.org.uk/p\\_homepage.aspx](http://opportunities.macmillan.org.uk/p_homepage.aspx)**

Healthtalk online: **[healthtalkonline.org/cancer/Prostate\\_Cancer](http://healthtalkonline.org/cancer/Prostate_Cancer)**

Prostate Cancer UK:  
**[prostatecanceruk.org](http://prostatecanceruk.org)**

Prostate Cancer Foundation of Australia: **[prostate.org.au/articleLive/pages/Advanced-Prostate-Cancer.html](http://prostate.org.au/articleLive/pages/Advanced-Prostate-Cancer.html)**

Prostate Cancer Foundation (US):  
**[pcf.org/site/c.1eJRIROrEpH/b.5699537/k.BEF4/Home.htm](http://pcf.org/site/c.1eJRIROrEpH/b.5699537/k.BEF4/Home.htm)**

Research suggests an interest in, and willingness to use, online resources amongst prostate cancer patients. For example, Shapiro et al (2004) found there was substantial interest amongst US prostate cancer patients in online resources. Pinnock, Jones, and The Education Committee of the Australian Prostate Cancer Collaboration (2003) describe the development of an Australian site for prostate cancer patients, which after two years was receiving 150,000 hits a month. Rozmovits and Ziebland (2004) used interviews and focus groups with UK breast and prostate cancer patients to explore what they wanted from informational websites.







They found a clear preference for non-commercial sites, and for those associated with recognised centres of excellence. Participants showed awareness of the potential pitfalls of internet-based health information, and would often look at a range of sites to help them make sense of a particular issue. In a Norwegian RCT, Ruland et al (2013) found improvements in symptom distress amongst breast and prostate cancer patients who accessed an internet-based support system. Seale, Ziebland and Charteris-Black (2006) compared the ways the internet was used by men with prostate cancer and women with breast cancer. They found the men used it mainly for information-seeking about treatment and medical personnel while the women used it more for social and emotional support.

We only found one article reporting an intervention using printed informational material (Preyde, Hatton-Bauer, Cunningham & Panjwani, 2012). In this study, 50 men evaluated a pamphlet on distress and supportive care for prostate cancer patients. Participants were recruited through attendance at a regional cancer centre in the US (Newly attending patients were excluded because of concerns about potential overburdening with information.) Participants found the pamphlet useful and easy to read, though made some suggestions for

improvement and many felt they would have liked to have received the information earlier. Analysis does not separate out the views of patients with advanced disease. In their discussion, the authors note that less than half of their participants (mean age = 71) reported that they were interested in accessing the internet for information. Given the age profile of prostate cancer generally, we feel this is unlikely to be an attitude unique to this study and raises questions about the predominant focus on internet-based resources noted above.

#### **4B.7 Neglected areas**

We found minimal evidence relating to the experiences and/or needs of ethnic minority men within the UK in relation to advanced prostate cancer. This is in spite of the fact that prostate cancer mortality rates are two to three times higher for men born in the West Indies and West Africa than for those born in England and Wales (Wild, Fischbacher, Brock, Griffiths & Bhopal, 2006). (Note also that for some ethnic minority groups Standardised Mortality Rates are lower than for the country as a whole – especially those from the Indian sub-continent and Eastern Europe.) Similarly, even looking at the international literature Chambers et al (2011) noted in their systematic review the neglect of minority groups (including ethnic minorities)





in psycho-social interventions for prostate cancer. The few studies of prostate cancer in African-American men certainly suggest there are distinctive issues for this group (Rivers et al, 2011) and it seems plausible that the same could be true for ethnic minority groups in the UK.

The conceptualisation of prostate cancer as a 'couples' disease' has in many ways been beneficial in promoting interventions and research studies that address the condition in the context of relationships. However, it is perhaps responsible for the neglect of attention to the perspectives of single men. We only found one study that addressed the experiences of unpartnered men with prostate cancer. Kazer et al (2011) found that doctors played a particularly important role in decision-making for these men in the absence of a partner with whom to discuss options. On the whole, the men were able to find other sources of support and appeared to be self reliant in terms of emotional responses and managing day to day tasks of disease management. However, such men may need support in developing new relationships. There is clearly a need for more research to build on this single qualitative study.

A related issue is that the notion of a 'couples' disease' almost always implicitly (and in empirical studies sometimes explicitly) defines the

couple as heterosexual. Blank highlighted in 2005 the absence of research on gay, bisexual and transgender men, and our own search suggested there has been little change since then. We found very few studies referring to gay men and prostate cancer, and none of these looked particularly at advanced disease. Blank, 2005 argues that some of the issues of significant concern may be different for gay men than heterosexual men, given differences in characteristics of sexual activity. They may have different patterns of social support, and may also face real or perceived prejudice from health professionals. Kleinmann et al (2012) agrees that the sexual preference and behaviour of men who have sex with men (MSM) renders them at risk of a reduced QoL. They cite a study just outside our date range by Fergus, Gray and Fitch (2002) who found that erectile dysfunction was especially of concern because anal penetration can require higher erectile function than vaginal penetration. In addition MSM were less likely to be in a monogamous relationship and more likely to have a new partner than heterosexual men – erectile dysfunction may be a major concern in this context.

While the literature certainly recognises physical symptoms such as pain and fatigue in men with advanced prostate cancer, these do not seem to receive as much





attention as urinary symptoms and sexual problems (and the psychosocial impacts associated with them). Certainly the interventions we located that were of most relevance to AAD concerns tended to focus on these areas and/or general psychosocial support issues. The recent findings by Sonn et al (2013) that doctors under-reported patient concerns regarding pain and fatigue and over-reported concerns regarding urinary and sexual problems supports this argument.

#### 4C. Multiple myeloma

Multiple Myeloma (MM) is the 17th most common cancer overall in the UK. It has a higher incidence in men than women. In 2009 there were 4,784 newly diagnosed cases, and in 2010 a total of 2,633 deaths (CRUK, 2013). About three in ten patients are diagnosed with asymptomatic (or 'smouldering') myeloma. The progress of MM is usually classified according to the ISS, based on levels of serum albumin and serum  $\beta$ 2 microglobulin. Patients at the highest stage, III, are likely to have more severe symptoms and a worse prognosis than those at lower stages. However, as MM is incurable, and markedly varied in its progress, a clear definition of 'active and advanced disease' is difficult to provide. Treatment

aims to control the disease and commonly involves a combination of chemotherapy and steroids, with a range of other treatments to help manage symptoms. Younger and healthier patients may be offered stem cell transfusion (either from their own cells or a donor), though this group represent a minority of all MM patients – note that CRUK figures suggest 71% of newly diagnosed MM patients are aged 65 and over (CRUK, 2013).

The initial search based on the terms and exclusion criteria described earlier produced 350 abstracts. Close scrutiny of the abstracts and for those not immediately rejected the full papers, plus the addition of items subsequently identified, resulted in the inclusion of a total of 111 articles in the final review. Nine items were identified as 'key articles'; summary details of these are given in table 4 (see appendix).

##### 4C.1 Fatigue and pain

Numerous strategies are available for treatment of relapsed/refractory multiple myeloma dependent on age, prognostic factors, comorbidities, the quality and duration of response to prior therapy, and the number of relapses, and there currently exists no generally accepted standard treatment (van de Donk et al, 2011). Rapidly evolving treatment





options mean that there is a new and growing need to recognise and manage the cumulative side-effects of treatment in myeloma in, including those that may seem minor to doctors but which may have an important impact on patient quality of life (Mohty et al, 2010; Rome, Doss, Miller & Westphal, 2008; Smith, Bertolotti, Curran & Jenkins, 2008; Tariman, Love, McCullagh & Sandifer, 2008). Lessons learned from late effects of cancer and its treatments conventionally applied to curable malignancies may be of increasing importance in multiple myeloma (Snowden et al, 2011).

Fatigue and pain appear to be particularly troubling symptoms which do not always appear to be well recognised or well managed (eg Hall et al, 2013; Molassiotis et al 2011a; Molassiotis et al, 2011b; Snowden et al, 2011; Wagner et al, 2012). Recently published guidelines for best practice provision of supportive care in multiple myeloma (Snowden et al, 2011) note that these symptoms may be under-recognised, and that it is important that healthcare professionals probe patients with regard to symptoms of pain and fatigue. In Molassiotis et al's (2011b) study of everyday living with multiple myeloma, patients expressed resignation about symptoms and side effects including pain and fatigue issues, and so did not continue to express them as present symptoms in

medical consultations. Note that there is a discrepancy in several studies (eg Harris et al, 2009; Wagner et al, 2012) between what doctors consider important to manage – primarily physical symptoms – and what is important to patients and their families, who have a more psychological focus. Thus, patients (and their carers) may feel it inappropriate to seek information, help and support about such issues from health care professionals.

#### **4C.2 Information for patients: what to convey, and how**

This area is often difficult in cancer generally, but there are particular issues that arise in relation to multiple myeloma. A key factor here is the very substantial increase in treatment options in recent years (eg Bird et al, 2011; Messori, Maratea, Nozzoli, & Bosi, 2011; Harousseau, 2010) though the trajectory of the illness, the nature of its symptoms and the side-effects of treatment also present challenges for information sharing (Lobb et al, 2009; Snowden, et al, 2011). Most recent guidelines highlight the need for information and support to be tailored to individual needs as far as possible (Bird et al, 2011). Patients and their significant others may be overwhelmed by information which they do not want and/or understand (eg Potrata, Cavet, Blair,





Howe, & Molassiotis, 2011; Maher & de Vries, 2011). When they do want to explore key information, they sometimes feel they do not have sufficient opportunities to do so with health care professionals (eg Kelly & Dowling, 2011), or feel unable to ask questions or express their concerns due to fears they may be wasting health care professionals' time (eg Maher and De Vries, 2011). Molassiotis et al (2011b) found that patients and carers had a general lack of expectation with regards to what help could be accessed, as well not wanting to 'bother' doctors with 'emotional problems because that wasn't their job' or being fearful of overburdening 'busy' staff.

Education around the importance of medication adherence is highlighted as a concern, especially with regard to preventative drugs which do not have an obvious benefit to immediate patient well-being and which may have troubling side-effects. For example, bisphosphonate treatment is known to have a significant effect in preventing and reducing skeletal complications in multiple myeloma (Aapro, Saad, & Costa, 2010; Terpos et al, 2009). Adherence to bisphosphonate treatment has a direct impact on the treatment's efficacy in reducing or delaying skeletal complications. However, as a preventative treatment where positive effects may not be evident, and which can have

troublesome side effects, patients need effective information and education to maximise adherence and compliance (Maxwell, 2007; McGrath & Holewa, 2010; Morris & Cruickshank, 2010). In a study by McGrath, Patton and Leahy (2009) patients reported that it was the exception rather than the norm to be fully informed regarding side effects of steroids. Similarly, there is a lack of education around the use of complementary and alternative medicines (Molassiotis et al, 2005).

### 4C.3 Supporting significant others

There is evidence that significant others play an important role in helping people live with advanced multiple myeloma (Kelly & Dowling, 2011; Maher & de Vries, 2011; Molassiotis et al, 2011a; Molassiotis et al, 2011b; Potrata et al, 2011) and equally that the illness has an impact on close personal and wider social relationships (eg Cachia et al, in press). However, surprisingly few studies have assessed the experience of myeloma patients themselves (Potrata et al, 2011) and although significant others are repeatedly mentioned in this literature as playing an important role both in providing crucial support and in giving patients a reason to 'carry on' (eg Kelly & Dowling, 2011; Maher & de Vries, 2011), there is very little work indeed which incorporates their perspective.





In an interview study with 15 myeloma patients (Potrata et al, 2011), participants reported that family and friends were supportive in both practical and emotional ways – but were also responsible at times for causing patients' substantial distress. Several patients in this study reported moving back in with family as a result of their condition as they could no longer afford mortgages or rents, and the authors suggest that friends seem also to play a far greater role than is generally realised, taking on potentially substantial practical and financial burdens (this highlights the importance of using a wider definition of 'close' or 'significant' other, rather than focusing solely on 'carers' in research). However, patients also reported that others could cause distress through well-meaning but poorly received enquiries after the patient's health – the authors suggest this merits further attention as it could lead to social isolation or impaired social interactions at a time when patients need them most.

Two studies, both undertaken by Molassiotis and colleagues in UK settings (2011a, 2011b), focus on unmet supportive care needs reported by both myeloma patients and their informal caregivers. These papers provide the most comprehensive insight we identified in the literature into issues faced by significant others. In both studies, fewer close others than patients participated – Molassiotis et al

(2011a) reported that the primary reason given for non-participation of caregivers was 'didn't want to think about patient's illness' so findings may in fact under-represent the extent of problems faced by caregivers.

In the first study (Molassiotis et al, 2011a), 132 patients and 93 partners participated in a questionnaire study, completing a supportive care needs scale and a measure of anxiety and depression. The survey was conducted at a mean time of five years post diagnosis. A greater proportion of partners than patients (a third compared to a quarter) reported unmet supportive care needs. Similarly rates of anxiety were higher amongst partners (48.8%) than patients (27.4%). A number of additional unmet supportive care needs were reported by partners only. These included a need for help to manage ongoing side-effects and/or complications experienced by patients as a result of treatment; provision of up to date information and information provided in a way that was understandable; the timely availability of local health care service available; emotional support for themselves; help in dealing with the changes that myeloma has caused to the patient. The authors conclude that long-term supportive care services should be available to provide support for both patients and their partners in relation to their unmet needs.





The second paper by the same Manchester team (Molassiotis et al, 2011b) reports on an interview study with 20 myeloma patients and 16 informal caregivers (mostly spouses). Myeloma was found to have had a significant impact on emotional, role, social and work-related areas of life for both patients and their caregivers. No caregivers had been given any information directed specifically at them at any point, and there was low expectation amongst participants generally as to what information was available to caregivers.

Overall, the emotional and practical cost of myeloma seemed greater for caregivers than for patients themselves, with patients seeming less engaged with their illness than caregivers. Caregivers were often providing practical and emotional support by neglecting their own needs and some caregivers felt unable to seek outside help or support as they felt the patient 'would not allow it'.

Caregivers reported significant current and future concerns including difficulties in balancing their own lives and caring for the patient (social restrictions and negative impact on work and employment as a result of caring responsibilities were reported), a sense of helplessness when the patient was in pain and fears about how they would manage in the future when the patient became more unwell. Both patients and caregivers reported concealing

stressful situations from the other in an effort to protect, though this was found to result in feelings of isolation. Caregivers also reported seeking out information about myeloma but filtering before relaying to the patient. Overall, the authors conclude that caregivers seem particularly vulnerable to high caring demands in myeloma, and that concerted action by healthcare professional should be directed towards this potentially overlooked group.

#### **4C.4 Multidisciplinary working and the involvement of palliative care services**

There are frequent references in the literature to the importance of multidisciplinary working, though much of this appears to be aspirational, rather than evidencing actual practice (Lobb et al, 2009; Snowden et al, 2011). Lobb et al (2009) found that unmarried patients with haematological malignancies including multiple myeloma expressed a greater unmet need for better communication amongst healthcare professionals in coordination of their care, and suggest that spouses may be playing an important but unacknowledged care co-ordination role. Molassiotis et al (2011b) suggest that continuity of care between specialist hospital care and care post-completion of treatments may need addressing.





In an interview study including 15 British myeloma patients, Potrata et al (2011) found that 'mobility difficulties' were reported to cause patients considerable distress, but that these were financial rather than physical problems – long waits for disability allowances from social services meant that patients were having to finance necessary equipment such as ramps and lifts in their homes themselves. This may point to problems in appropriate linked-up working between different services and service provision which may warrant further attention.

The fact that patients' primary medical involvement is often with haematologists rather than oncologists may affect the other services they link in to, including contact with palliative care (Howell et al, 2010). Given that for the great majority of patients multiple myeloma is incurable, and that they may live with the condition for many years, involvement of palliative care services well before the end of life may be helpful (Manitta, Zordan, Cole-Sinclair, Nandurkar & Philip, 2011; Epstein, Goldberg & Meier, 2012). However, capacity issues for services and to some extent patient resistance may be a barrier to this (Snowden et al, 2011).

#### **4C.5 Treatment strategies to minimise inconvenience to patients and families**

Managing multiple myeloma (including the consequences of treatment) often requires medical interventions such as drug interventions (including oral or intravenous bisphosphonates) and repeated blood transfusions over extended periods of time. There is evidence that it might be feasible to deliver some of the required interventions in the home environment, and that this may have significant benefits for the quality of life of patients and families (eg Johnson et al, 2006; Kelly, Meenaghan & Dowling, 2010; Meenaghan et al, 2010). Meenaghan and colleagues (2010) successfully trialled a consultant-led nurse-coordinated service for home administration of bortezomib in Ireland. Johnson et al (2006) trialled a programme of Hospital in the Home Care following stem cell transplantation treatment in Australia. A nurse attended patients' homes daily, administering IV medications, collecting blood samples, and providing red cell transfusions if necessary. Results suggest that, with adequate infrastructure support and rigorous patient selection, this model of care is safe and feasible. It is encouraging to note service providers' concern to introduce new treatment paradigms in a







way which acknowledges the importance of patient preference and convenience (eg Morgan, Krishnan, Jenner & Davies, 2006), given the introduction of a number of novel and efficacious therapies for multiple myeloma over the last fifteen years.

#### **4C.6 Availability of 'best practice' treatment**

There has been considerable controversy over access to new treatments for multiple myeloma in recent years. For example, the use of the proteasome inhibitor bortezomib in multiple myeloma was rejected by NICE in 2006, a decision that was reversed the following year following strong opposition from various groups (see Mehta & Low, 2007; Low, 2007). Additionally, some treatments that may be very helpful are not yet widely available to all patients in the UK – for example, surgical procedures to manage vertebral compression fractures (Garland, Gishen, & Rahemtulla, 2011).

#### **4C.7 Fear of recurrence**

Multiple Myeloma is a condition characterised by periods of treatment and varying (shortening) periods of remission, which progresses at variable speed in different individuals (King & Morris, 2004). Understandably then, even the

suspicion of relapse can trigger 'incredible new fear' in patients (Durie, 2005). Literature on patient (and close others) experiences in multiple myeloma is generally limited compared to other cancer conditions and it is recognised that there is a need for more research into patient and family experience (Grundy & Ghazi, 2009). This is likely due to at least in some part to the fact it is only relatively recently that new treatment approaches have changed the traditional paradigm for management of the condition and that the survivorship agenda is thus a fairly recent concept in the context of myeloma.

Fears about future illness are, though, repeatedly emerge in what literature there is available as a primary concern for both patients and their close others. In an Australian questionnaire study of 66 patients with haematological malignancies including myeloma who had completed treatment, Lobb et al (2009) found that 'help managing the fear of recurrence' was one of the most frequently reported unmet needs. Younger patients were found to report greater needs for help in this respect. Cocks et al (2007) report on the development of a tool to assess quality of life in myeloma and identified 'future perspective' as a key concern. In their phenomenological study of eight myeloma patients, Maher and de





Vries (2011) identified a constant state of uncertainty (uncertain future, when will disease return, what will side effects of treatment be) as central – the need to control this pervaded all themes identified.

Fears about future illness course are also emerging as a clear concern for those close to patients as well as patients themselves. Molassiotis et al (2011a) looked at reported unmet supportive care needs amongst both myeloma patients and their partners. Managing concerns about myeloma returning was reported as an unmet supportive care need by both patients and close others. Additionally, anxious and depressed patients reported double the number of unmet needs, and unmet needs in partners correlated with patient unmet needs. In a further paper reporting on interviews with myeloma patients and their informal caregivers about the effects of myeloma on their lives, Molassiotis et al (2011b) found that carers reported a number of fears for future, including concerns about how to manage when patients unable to care for themselves in the future. Similarly, patients reported that fears of relapse and uncertainty about the future could provoke intense anxiety about otherwise minor symptoms.

#### 4C.8 Neglected areas

Rates of multiple myeloma are about twice as high in people from African and Afro-Caribbean communities, yet this group is under-represented in research. This is seldom commented upon in the myeloma literature. It is known that those from ethnic minority backgrounds are less likely to participate in research and in randomised control trials generally (Hussain-Gambles, Atkin, & Leese, 2004; Potrata, et al, 2011). Potrata et al (2011) are to be commended for their efforts to purposely recruit from ethnic minorities in an effort to redress this imbalance and recruited 26.7% of their participants from ethnic minority backgrounds.

Older patients are under-represented in myeloma trials and research, despite higher myeloma incidence in this population. Our experience of reviewing the literature supported other authors' conclusions that much of the research relates to the experiences of those myeloma patients who have undergone aggressive autotransplantation procedures (eg Potrata et al, 2011). As this tends to be an earlier stage treatment and is often not available to those of more advanced age, much of the literature does not relate meaningfully to those with 'active and advanced disease'.





Additionally, according to Molassiotis et al (2011a), this group of patients is not representative of MM patients overall as only a minority undergo blood stem cell transplants.

It was noticeable in the results of our search that some topics that are quite prominent in the literature for other cancers appeared very infrequently in relation to people with advanced multiple myeloma. These included in particular: financial pressures and concerns, spirituality and sexuality/sexual dysfunction. The limited literature that we did find suggests that such issues are relevant to multiple myeloma. Wagner et al (2012) found that doctors tended to focus solely on physiological disease manifestations when questioned in relation to factors impacting on quality of life in myeloma, whilst patients themselves additionally considered their mental health and sexual function as important in this context. Sherman, Simonton, Latif, Spohn & Tricot (2005) found that 'negative religious coping' (ambivalent or conflicted religious responses) was associated with significantly poorer functioning on measures of depression, distress, fatigue, mental health and pain in multiple myeloma patients preparing for stem cell transplantation treatment whilst neither general religiousness or positive religious coping were

associated with outcome. Work and financial problems for both patients and their families were mentioned by some authors (eg Bird et al, 2011; Potrata et al, 2011). Overall though, these issues are under-researched areas in comparison to other cancers.



# 5. Discussion

In this section we will reflect on the process of carrying out this rapid review of evidence, and highlight key issues across the selected cancers that are relevant to the concerns of the NCSI AAD group specifically:

- recognising patient concerns
- patient and significant other information needs, involving and supporting significant others, issues of collaborative working
- the costs of advanced disease and support interventions
- neglect of minority perspectives.

Finally we will suggest priorities for future research and development.

## 5.1 Reflection on the review process

The topic of support for people affected by active and advanced disease proved a complex and challenging one on which to conduct an evidence review. There were two main reasons for this. Firstly, the term 'active and advanced disease' is used very infrequently in the literature (as we saw in the introduction to this report); we therefore had to identify a range of other terms that might direct our search towards the kind of problems in which the NCSI group were interested. Secondly, in much of the literature that we found, the lessons relevant specifically to an

AAD group were hard to extract because often researchers did not clearly distinguish the problems and/or outcomes specific to patients of interest to this review. We found numerous studies which identified 'advanced disease' patients as part of their sample, but which did not analyse data in a way that revealed whether and in what ways they were different from earlier-stage cancer patients. These factors inevitably created more ambiguity than would be ideal in applying the inclusion and exclusion criteria – hence even restricting ourselves to three cancers and to publications in the last ten years our initial search identified over 1,000 items.

The difficulties in carrying out this search are not only of technical interest with regard to the process of conducting an evidence review. Rather, we would argue that they reflect ambiguity in how researchers and professionals understand the experience of AAD and uncertainty in how best to provide support to patients with such problems. For researchers and service developers, people affected by AAD may be 'off the radar', existing as they do in a liminal zone between recovery and supportive palliative care. On the research side, we would suggest that there are both pragmatic methodological and (perceived) ethical reasons for the relative lack of work clearly focused on those



affected by AAD. Patients with problems associated with AAD may be harder to recruit than those with earlier phase disease, or those who are in long-term remission, and their condition may make them more likely to drop out of a study after recruitment. Similarly, new interventions may be targeted at less 'risky' groups, resulting in AAD perspectives being absent or less prominent in related evaluation research – for example see the evaluation of telephone follow-up in CRC by Beaver and colleagues (Beaver et al, 2007, 2010, 2011). In terms of ethics, researchers may be reluctant to burden patients who are seriously ill with the demands of taking part in research, or may be prevented from so doing by health professional gatekeepers. Note though that there is evidence that even patients with very advanced disease welcome the offer to assist with research (Hardy, King & Firth, 2012) and that such participation may have a positive impact on well-being (Staley, 2009).

The essential messiness of this review process led us to taking a 'bottom-up' approach to organising our findings, focusing on issues relevant to AAD that emerged strongly in each cancer. We also noted what appeared to be significant gaps in each of the bodies of literature. The fact that some issues occur in relation to one (or two) of our selected cancers but not the

other(s) does not mean they were not addressed at all in the latter; rather, it shows differences in the weight of recent (i.e last 10 years) research attention across cancers. To some extent this might reflect different trajectories of advanced disease in the three cancers we examined. For example, fear of recurrence emerged strongly in our bowel cancer and multiple myeloma searches but was much less prominent in the AAD prostate cancer publications.

A final point to note about the review process overall is that many of the articles we have included report on research and service evaluations from outside of the UK – especially from Australia, the US, Canada and (to a lesser extent) North-West Europe/Scandinavia. This reflects the relatively small amount of UK-based work looking directly at AAD issues. Although we excluded articles where we felt the cultural context seriously limited relevance to the UK situation, caution is still required in the conclusions drawn from studies in non-UK settings.

## 5.2 Key common issues across cancers

### (i) Recognising patient concerns

There was evidence across the chosen cancers that professionals do not always recognise the concerns





that are priorities for patients with advanced disease. We would suggest there are two main reasons for this. Firstly, there is a tendency for professionals (and researchers) to look at patient experience through the lens of their own specialist interest. Thus Sonn et al (2013) showed that urologists relatively overstated prostate cancer patient concerns with urinary problems and sexual dysfunction and understated concerns with pain and fatigue. Harris et al (2009) and Wagner et al (2012) suggested that haematologists may underestimate the extent to which myeloma patients are troubled by psycho-social concerns. Secondly, patients with advanced disease may downplay some symptoms and treatment effects because they are resigned to them as 'inevitable' consequences of their condition and its management. We see this manifest in the phenomenon of 'response shift' in quality of life measures for patients with longer-term illness (Kahana et al, 2011).

### **(ii) Patient and significant other<sup>5</sup> information needs**

The importance of clear, timely and properly targeted information for patients with cancer at all stages (and their significant others) has long been recognised by service providers and especially by charities such as Macmillan, Marie Curie and those dedicated to specific forms of cancer.

Nevertheless, this was highlighted as a continuing area of concern for patients and families affected by AAD across the three cancers we looked at. We found evidence for the potential effectiveness of interventions to enhance the provision and utilisation of information in a range of settings and formats (eg the use of decision aids for patients with advanced colorectal cancer considering chemotherapy; Leighl et al, 2011). Online information can be very useful, but given the age profile of most cancers (including those we looked at), other media remain important. The use of telephone contacts, either for routine follow-up (eg Cusack & Taylor, 2010) or as part of a targeted educational and support intervention (eg Northouse et al, 2007a) can be a viable option, and well-designed printed materials remain valuable (Preyde et al, 2012).

### **(iii) Involving and supporting significant others**

The importance of the support given to patients with AAD by family members and/or friends is recognised in all three cancers. Linked to this is the need to ensure significant others themselves are supported. The research evidence for the impact of advanced cancer on significant others is strongest for prostate cancer and least strong for myeloma. Furthermore, we found the same pattern in terms of





evidence for interventions involving and/or targeted at significant others. Although the evidence regarding the effectiveness of such interventions is patchy, there is enough to suggest that involving significant others alongside patients – as in some prostate cancer support groups – can be helpful for both parties (eg Chambers et al, 2011; McLean et al, 2008).

#### **(iv) Issues of collaborative working**

In all our cancers there was some degree of recognition that effective communication and collaboration between different professionals was necessary to ensure the best possible care and support for patients with AAD (though often this was aspirational rather than reporting on good practice). Not only the type of cancer but also the type of treatment patients were receiving could make a major difference to the range of services with whom they were in contact. For example, in a Canadian study, advanced prostate cancer patients who were hormone refractory were likely to receive care in regional centres with access to a wide range of professionals while those with hormone sensitive disease had little or no contact with professionals other than their urologists (Carter et al, 2011). There was recognition that hospital-based medical specialists were not necessarily in the best position to

understand and meet the support needs of such patients (Grundy & Ghazi, 2009). The potential role of nurses, especially advanced nurse practitioners, in addressing the needs of AAD patients was highlighted quite frequently, including in studies that reported interventions and/or service developments utilising their skills (eg Lindqvist, 2011; Meenaghan et al, 2010). However, there was a lack of reference in this literature to the actual or potential role of community nurses – or even GPs – in supporting AAD patients.

#### **(v) Costs of advanced disease and support interventions**

Research on the costs of cancer includes that which focuses on the costs to patients and families of living with the consequences of disease and its treatment, and that which is concerned with wider economic costs. Within our selected cancer types, we found minimal information on either of these issues relating specifically to active and advanced disease. What little we found tended to be focused on personal costs – for instance, how transport issues impacted on uptake of services (eg Morrison et al, 2012). Much of this was in settings which differed in potentially important ways from the UK, such as the body of literature concerned with access to services in rural Australia (eg Corboy, McLaren & McDonald, 2011).





The wider literature on the costs of cancer tends not to be specific about stage of disease and often looks at cancer as a whole, or includes a selection of specific cancers by convenience with little or no cancer-specific analysis (eg Sharp, Carsin & Timmons, 2012; Timmons, Gooberman-Hill, & Sharp, 2013). In a fairly recent review (Brooks, Wilson & Amir, 2011) most articles included focus on the costs of early stages of cancer – around diagnosis and initial treatment. It is reasonable to extrapolate from some of this general literature that some of the costs (both for patients/families and for the health service and wider economy) may be higher for patients living with active, advanced disease than those with earlier stage disease or in long-term remission. For example, AAD patients may be receiving ongoing treatment, may be unable to work or have to take significant time off from work, and may have multiple service involvement. There is unquestionably a need for future research looking at costs specifically associated with active and advanced disease.

#### **(vi) Neglect of minority perspectives**

In all our cancers, authors expressed concerns about the lack of research and/or interventions aimed at the support needs of minority groups – especially ethnic minorities but

also gay men in relation to prostate cancer. (Sexuality is not considered in the bowel and myeloma literatures relating to AAD at all as far as we could see.)

### **5.3 Future research and development priorities for supporting patients with active and advanced disease**

We will concentrate here on those areas for potentially fruitful future research and development that are likely to be relevant across many (if not all) cancer types.

1. There is a need to develop and evaluate methods of improving staff awareness of how patients and significant others are affected by active and advanced disease. Initiatives that involve professionals from across the range of disciplines and specialisms involved with particular cancers may be of value, as a way to counter the tendency for staff to look at patient concerns through their 'specialist lens' as noted above.
2. Further development of measures and assessment tools sensitive to quality of life issues for patients with active and advanced disease is needed.







3. We need to develop a better understanding of how different segments of the population of patients affected by AAD and their significant others understand and make use of information relevant to their circumstances. This includes looking at such factors as age, gender, ethnicity and education level in relation to different communication media and contexts. The timeliness of information to address the concerns of AAD patients should also be an important focus.
4. Support interventions including significant others need to be developed and evaluated across all cancer types for those affected by AAD. Services generally should consider how they can better engage with patients' key support networks. Some of the interventions we have identified for prostate cancer patients and their partners may help inform intervention and service design, though the circumstances relating to specific cancer types need to be borne in mind. Importantly, interventions and service developments need to look more widely at significant others than the rather narrow focus on heterosexual partners/spouses that dominates the prostate cancer literature. Similarly, the specific needs of people from ethnic minorities affected by AAD – both patients and family caregivers – need more research to support targeted interventions.
5. Collaborative working between professions, services and sectors is crucial to the support of people affected by AAD. New staff roles – or changes to existing roles – could play a part in facilitating this. Developments such as the Macmillan One-to-One projects, nurse-led telephone follow-up, and the role-out of the Midhurst approach to community palliative care may serve as exemplars, though it will be important to ensure that specific issues relating to AAD are addressed.
6. Research into the costs of cancer (personal, NHS and for the wider economy) needs to include more focused attention on the experiences of those affected by AAD and its treatment.



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# Appendix

## Key papers for bowel cancer, prostate cancer and multiple myeloma

**Table 2. Key papers for bowel (colorectal) cancer**

	Full reference	Summary details
1	<p>Craven, O., Hughes, C. A., Burton, A., Saunders, M. P., &amp; Molassiotis, A. (2013). Is a nurse-led telephone intervention a viable alternative to nurse-led home care and standard care for patients receiving oral capecitabine? Results from a large prospective audit in patients with colorectal cancer. <i>European Journal of Cancer Care</i> 229(3), 413–419.</p>	<p><b>Prospective audit (UK)</b></p> <p>Comparison of three models (home nursing [n=83], nurse-led telephone [n=298] and standard care [n=81]) of care for patients receiving oral capecitabine (adjuvant and metastatic therapy) for colorectal cancer.</p> <p>Longitudinal prospective evaluation comparing outcomes of nurse-led telephone support with data from previous randomised controlled trial (Molassiotis et al 2009).</p> <p>Key findings:</p> <ul style="list-style-type: none"> <li>• Improved toxicity symptom management with nurse-led telephone support compared to standard care and similar level as home care for some symptoms (vomiting and oral mucositis) but not others (diarrhoea and insomnia).</li> <li>• Nurse-led telephone model also had low incidence of drug errors, less serious toxicities, low use of GP or unplanned hospitalisation.</li> </ul>
2	<p>Leighl, N. B., Shepherd, H. L., Butow, P. N., Clarke, S. J., McJannett, M., Beale, P. J., ...Tattersall, M. H. (2011). Supporting treatment decision making in advanced cancer: a randomized trial of a decision aid for patients with advanced colorectal cancer considering chemotherapy. <i>Journal of Clinical Oncology</i>, 29(15), 2077–2084.</p>	<p><b>Randomised trial (Australia)</b></p> <p>Study of 207 patients with advanced colorectal cancer considering first line chemotherapy. Random allocation to standard medical consultation or consultation with a decision aid (DA).</p> <p>Patients receiving the DA intervention had:</p> <ul style="list-style-type: none"> <li>• Greater increase in understanding of prognosis, options, risks and benefits, and higher overall understanding.</li> <li>• Levels of anxiety, decisional conflict, treatment decisions and achievement of involvement preferences were similar irrespective of allocation.</li> </ul> <p>Authors suggest DAs in advanced cancer could improve informed consent.</p>



Full reference	Summary details
3	<p><b>Prospective observational study (USA)</b></p> <p>Participants with stage III colorectal cancer (n=832) recruited into adjuvant chemotherapy trial. Instruments: Physical activity questions used to calculate metabolic equivalent task (MET) score. At six months a physical activity assessment undertaken.</p> <p>Key finding:</p> <ul style="list-style-type: none"> <li>Physical activity after diagnosis associated with reduction in rates of recurrence and overall mortality.</li> </ul>
4	<p><b>In-depth case study using qualitative interviews (UK)</b></p> <p>UK in-depth case study qualitative interview study with people with cancer (breast [n=12/3] and colorectal [n=9/4]) nominated close person and a primary and secondary health care professional (HCPs). Paper reports seven cases only.</p> <p>Key findings:</p> <ul style="list-style-type: none"> <li>Patients who proactively take control are more likely to influence continuity of care than those who depended on HCPs or disengaged.</li> <li>Patients who did not confide in their close person were less likely to get assistance with continuity or engage in care.</li> <li>Difference between clinicians' and patients' perspective of what constituted reasonable waiting times (appointments, investigations, results, etc).</li> <li>Communication was hampered by loss of letters, delay in transfer between secondary and primary care.</li> <li>Continuity enhanced by a long term relationship; clinical nurse specialists and GPs well regarded and perceived as facilitators of continuity of care.</li> </ul>





Full reference	Summary details
<p>5 O'Connor, G., Coates, V., &amp; O'Neill, S. (2010). Exploring the information needs of patients with cancer of the rectum. <i>European Journal of Oncology Nursing</i>, 14(4), 271–277.</p>	<p><b>Survey (UK)</b></p> <p>Participants with rectal cancer diagnosed in previous 18 months (only excluded if experiencing 'very advanced' disease). Adapted Toronto Information Needs Questionnaire (TINQ) administered to 42 people, 40 responded.</p> <p>Key findings:</p> <ul style="list-style-type: none"> <li>• High level of information needs and not adequately met.</li> <li>• Stoma care nurse specialists (SCNS) most valued source of information.</li> <li>• Interpersonal communication with a HCP rated as preferred mode of communication. Information related to investigative tests least well met and treatment most well met.</li> <li>• Lees satisfied with information related to long-term physical, physiological and social aspects of the disease.</li> <li>• Considerable variation suggesting need for individualised tailored information.</li> </ul>
<p>6 Pereira G. M., Figueiredo, A. P., &amp; Fincham, F. D. (2012). Anxiety, depression, traumatic stress and quality of life in colorectal cancer after different treatments: A study with Portuguese patients and their partners. <i>European Journal of Oncology Nursing</i>, 16(3), 227–232.</p>	<p><b>Field quasi-experiment (Portugal)</b></p> <p>141 patients (62% males, 38% females) and 67 partners (39% males and 61% females) receiving surgery only, surgery with chemotherapy or surgery with radiotherapy. 48% had diagnosis &gt; 1 year and 29% for recurrence. Instruments: Patients: Hospital Anxiety and Depression Scale (HADS) and Quality of Life –Cancer (QOL–CA2); Partners: Beck Depression Inventory (BDI) State Trait Anxiety Inventory (STAI), Impact of Events Scale (IES–R).</p> <p>Key findings:</p> <ul style="list-style-type: none"> <li>• Patients receiving surgery alone and their partners had lower levels of psychological distress. Patients receiving surgery and chemotherapy had higher levels of traumatic stress and psychological morbidity.</li> <li>• Patients who received surgery/chemotherapy and surgery/radiotherapy had more treatment effects.</li> <li>• Patients with a diagnosis &gt; 1 year showed more global traumatic stress symptoms. Depressed patients more likely to have depressed partners.</li> <li>• Patients reporting recurrence showed significantly higher levels of global traumatic stress but no evidence that this was treatment group related.</li> <li>• Multi-modality treatment may engender greater/less psychological morbidity and reinforce need to assess patients and partners.</li> <li>• Some evidence of post traumatic stress disorder (PTSD) reported particularly associated with recurrence.</li> </ul>





Full reference	Summary details
7	<p><b>Sjövall, K., Gunnars, B., Olsson, H., &amp; Thomé, B. (2011). Experiences of living with advanced colorectal cancer from two perspectives – inside and outside. <i>European Journal of Oncology Nursing</i> 15(5), 390–397.</b></p> <p><b>Qualitative interview study (Sweden)</b></p> <p>13 participants with advanced CR cancer (defined as receiving palliative chemotherapy but not end of life with no cognitive dysfunction/cerebral metastases) and nine partners (spouse or living with).</p> <p>Three categories emerged from patient participants: Being inside/outside of the health system, striving for normality, value of life and vulnerability. Two categories related to partners: Living in an altered relationship and living in the shadow of the disease.</p> <p>Key findings:</p> <ul style="list-style-type: none"> <li>• ‘Belonging’ to the health system and using medical monitoring information to plan/evaluate was important – possible implications for follow up.</li> <li>• Partners felt excluded from participation (by clinicians/sometimes patient) in care/treatment.</li> </ul>
8	<p><b>Thoresen, L., Frykholm, G., Lydersen, S., Ulveland, H., Baracos, V., Birdsell, L., &amp; Falkner, U. (2011) The association of nutritional assessment criteria with health-related quality of life in patients with advanced colorectal carcinoma. <i>European Journal of Cancer Care</i> 21, 505–516</b></p> <p><b>Analysis of data from terminated RCT (Norway)</b></p> <p>Study involving people with colorectal cancer (Stage IV) who volunteered to participate in an RCT to compare dietary counseling to standard practice. (Trial terminated due to crossover between the two arms; patients followed up for two years or until death.)</p> <p>Data collected at baseline and three months. Instruments: haemoglobin (Hb), albumin and C-reactive protein (CRP), EORTC QLQ-C30 Version 3, anthropometric measurements (BMI), dietary intake (Energy intake using Diet 32 software), sarcopenia (CT Scan), nutritional risk score (NRS-2002), subjective global assessment (SGA) and cachexia definition (EPCRC Cachexia).</p> <p>Key findings:</p> <ul style="list-style-type: none"> <li>• Weight loss at three months associated with reduced QoL, physical and social functioning and increased fatigue, pain and dyspnoea.</li> <li>• Variation in number of people defined as cachexic dependent on measure used (EPCRC alone compared with EPCRC-SGA).</li> <li>• QoL score constant in those whose weight was stable.</li> </ul>







Full reference	Summary details
9	<p>van Mossel, C., Alford, M., &amp; Watson, H. (2011). Challenges of patient-centred care: practice or rhetoric. <i>Nursing Inquiry</i>, 18(4), 278–289. doi:10.1111/j.1440-1800.2011.00523.x</p> <p><b>Scoping review</b></p> <p>Examined information needs (psychological, medical, social, practical, financial, nutritional and support) of people who have or have had colorectal cancer. 869 articles reviewed and 239 met the inclusion criteria. Categorised literature into 10 broad information themes (with 82 sub-categories) and five source categories and 19 subcategories.</p> <p>Key findings:</p> <ul style="list-style-type: none"> <li>• Only 64/239 (27%) contained views of people with colorectal cancer.</li> <li>• Little literature written by dieticians or nutritionists or on radiotherapy.</li> <li>• Treatment related information had greatest coverage followed by rehabilitation/post treatment Coping (10%) and minimal attention to surveillance health information and end-of-life concerns Post treatment 'survivorship' accounted for 42% but much was non-stage specific (62%).</li> </ul>
10	<p>Williams, A. L., &amp; Bakitas, M. (2012). Cancer family caregivers: a new direction for interventions. <i>Journal of Palliative Medicine</i>, 15(7), 775–783. doi: 10.1089/jpm.2012. 0046</p> <p><b>Qualitative interview study (USA)</b></p> <p>Interviews with 135 caregivers of patients with colorectal or lung cancer; analysed using phenomenological methods. All patients receiving chemotherapy but no other information given about grade/prognosis. Four themes emerged:</p> <ul style="list-style-type: none"> <li>• <i>Becoming a caregiver</i>: related to hearing the diagnosis.</li> <li>• <i>New and altered relations</i>: as a consequence of changed caregiving role/responsibilities relationship with self, patient, others and health care system changed. Feelings of social isolation as a consequence of new roles and lack of time with health professionals.</li> <li>• <i>Personal responses to caregiving</i>: Various coping strategies described immersion in information and distraction in trivial activities to 'stop thinking'; also remaining positive, optimistic and hopeful.</li> <li>• <i>Antecedent and social context</i>: Caregiver responses were influenced by previous experience and helpful/burdensome social network.</li> </ul> <p>Authors suggest overlap of findings with caregivers of those receiving palliative care particularly the cheerleader role where 's/he must maintain a shroud of silence around all negative emotions and doubts' (p781).</p>



# Appendix

## Key papers for bowel cancer, prostate cancer and multiple myeloma

**Table 3. Key articles on prostate cancer**

	Full reference	Summary details
1	Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A., J. (2011). The Supportive Care Needs of Men With Advanced Prostate Cancer. <i>Oncology Nursing Forum</i> , 38(2), 189–198. doi: 10.1188/11.ONF.189–198	<p><b>Qualitative study (Canada)</b></p> <p>Participants were 12 men with hormone-sensitive pc. 17 men with hormone-refractory prostate cancer.</p> <p>Setting: outpatient cancer and urology clinics in central western Ontario.</p> <p>Explored supportive care needs, priority needs, and suggestions for improvements to the delivery of care.</p> <p>Participants identified prostate cancer-specific information and support to maintain their ability ‘to do what they want to do’ as priority needs.</p>
2	Chambers, S. K., Pinnock, C., Lepore, S. J., Hughes, S., & O’Connell, D. L. (2011). A systematic review of psychosocial interventions for men with prostate cancer and their partners. <i>Patient Education &amp; Counseling</i> , 85(2), e75–88.	<p><b>Systematic review</b></p> <p>Examined 21 studies (RCTs) dated 1999 to 2009.</p> <p>Group cognitive- behavioural and psycho-education interventions appear to help promote psychological adjustment and QoL.</p> <p>Coping skills training for dyads improved QoL for spouses.</p> <p>Few interventions targeted at men with advanced cancer or at minority groups (by ethnicity or sexuality).</p> <p>Trial quality low overall.</p> <p>Noted limitations in research in terms of effective ways to improve men’s (and their partners’) adjustment to prostate cancer at any disease stage. There is an urgent need for interventions for men with advanced cancer and their families that focus on implications of advanced disease and the burden of caregiving for spouses.</p>



Full reference	Summary details
3	<p>Cockle-Hearne, J., &amp; Faithfull, S. (2010). Self-management for men surviving prostate cancer: a review of behavioural and psychosocial interventions to understand what strategies can work, for whom and in what circumstances. <i>Psycho-Oncology</i> 19, 909–922</p> <p>Evidence review on the best approaches for developing self-management programmes.</p> <p>Included RCTs from international literature, published over past 12 years.</p> <p>Key conclusions were:</p> <ul style="list-style-type: none"> <li>• Self management viable/appropriate to provide health care solutions.</li> <li>• Importance of targeting need and promoting motivation.</li> <li>• Integration into clinical practice requires training, resources and commitment.</li> <li>• Existing programmes tend to show lack of sustained effect over time.</li> <li>• May be ‘teachable moments’ close to diagnosis and treatment.</li> <li>• Needs differ across the disease trajectory and homogenous interventions may fail.</li> </ul>
4	<p>Eton, D. T., Shevrin, D. H., Beaumont, J., Victorson, D., &amp; Cella, D. (2010). Constructing a conceptual framework of patient-reported outcomes for metastatic hormone-refractory prostate cancer. <i>Value in health</i>, 13(5), 613–623. doi: 10.1111/j.1524-4733.2010.00702</p> <p><b>Interview and survey study (USA)</b></p> <p>Interviews with 15 patients with metastatic, hormone refractory prostate cancer (HRPC) – asked to identify most important symptoms, complications, concerns to consider when assessing the value of treatment.</p> <p>Survey – 10 practitioners asked to determine/judge which outcomes endorsed by patients were attributable to the disease (symptoms) versus treatment (side effects). Classifications of each concern into: (i) disease, symptom, (ii) treatment side effect, (iii) both symptom and side effect or iv psychological concern.</p> <p>Patients endorsed 11 concerns as relevant and important to HRPC.</p> <p>Conceptual frameworks derived from patient-reported outcomes can be useful in assessment strategies: both for developing new measures or for choosing between existing ones.</p>





	Full reference	Summary details
5	Galbraith, M. E., Hays, L., & Tanner, T. (2012). What men say about surviving prostate cancer: complexities represented in a decade of comments. <i>Clinical journal of oncology nursing, 16</i> (1), 65–72.	<p><b>Qualitative, descriptive, narrative analysis of open-ended survey questions (USA)</b></p> <p>135 participants provided answers to two open-ended questions.</p> <p>Participants expressed the complexity of the experience. Sexual and other physical symptoms impacted their entire life. Acknowledgment, information, and help from others aided recovery.</p> <p>Men needed more information and education about treatments and effects.</p> <p>Conclusions:</p> <ul style="list-style-type: none"> <li>• Unmet need for long term interventions with information being delivered during and beyond treatment.</li> <li>• Future research needs to assess reactions of partners for a fuller picture.</li> <li>• Clinical interventions should move towards a more integrated approach.</li> </ul>
6	Kahana, B., Kahana, E., Deimling, G., Sterns, S., & VanGunten, M. (2011). Determinants of altered life perspectives among older- adult long-term cancer survivors. <i>Cancer Nursing, 34</i> (3), 209–218. doi: 10.1097/NCC.0b013e3181fa56b0	<p><b>Cross-sectional survey</b></p> <p>288 survivors of breast, colorectal, and prostate cancer. 58% female, 33% African American, and 67% white (mean age, 72.5 years).</p> <p>Appraisals of the cancer experience as stressful/generating worry/stigmatizing significantly associated with diverse PTT outcomes.</p> <p>Posttraumatic transformations are related to the view that cancer is a continuing worrisome and stigmatising experience.</p> <p>Nurses have a unique opportunity to discuss with patients potentially life-changing nature of the cancer experience. This type of discussion can enhance cancer survivors' mental health.</p>





Full reference	Summary details
7	<p><b>Qualitative interview study (USA)</b></p> <p>Semi-structured interviews with 17 men with prostate cancer, 14 Caucasian and three Black, mean age 63.</p> <p>Examined how men without partners (MwP) make decisions about PC treatment/manage treatment side effects/ obtain information and support.</p> <p>Five themes emerged: going it alone; diagnosis and prostate cancer treatment decision-making; sources of information and support; aftermath of prostate cancer; coping strategies.</p> <p>Conclusions:</p> <ul style="list-style-type: none"> <li>• MwP may need to be identified in order to ensure they are coping/ can access support.</li> <li>• MwP may have enhanced coping compared to partnered men.</li> <li>• MwP may need support in new relationships and managing side effects.</li> <li>• Role of physicians in decision making process of MwP is unique.</li> </ul>
8	<p><b>Qualitative study (Netherlands)</b></p> <p>Interviews with 33 patients, six years after primary treatment.</p> <p>Primary prostate cancer treatment often results in suboptimal urinary, bowel and/or sexual function, yet patients often report high HRQoL scores. Discrepancy raises the question of the meaning of side effects to patients.</p> <p>Found participants did not take such dysfunctions into account when completing QoL measures because saw these as inevitable part of their lives with prostate cancer – producing a ‘response shift’ in QoL measures through a change in men’s ‘internal standards’.</p> <p>Can be seen as positive adaptation – normalisation of changed lives. BUT may distort QoL measures in research and assessment, and could affect screening and treatment decisions based on such measures.</p>
9	<p><b>Qualitative study (Sweden)</b></p> <p>Interviews with 20 men, aged 46 to 80 years.</p> <p>Bodily changes and skeletal metastases were extensive; physical burden profoundly affected men’s QoL.</p> <p>Results support paramount importance of symptom alleviation and also of dialogue between patients and health care providers.</p> <p>Oncology nurses well placed to help men and partners in obtaining necessary information to cope with challenges.</p>





	Full reference	Summary details
10	<p>Lintz, K., Moynihan, C., Steginga, S., Norman, A., Eeles, R., Huddart, R., ...Watson, M. (2003). Prostate cancer patients' support and psychological care needs: Survey from a non- surgical oncology clinic. <i>Psycho-Oncology</i>, 12(8), 769-783. doi: 10.1002/pon.702</p>	<p><b>Cross-sectional survey (UK)</b></p> <p>Participants: 210 men with localised (69%) or advanced (metastatic: 30%) disease. Mean age 69.7 years. Recruited from specialised tertiary referral cancer centres.</p> <p>Found significant unmet psychological and health systems/information needs. Most commonly reported were 'fears about cancer spreading' (44%), 'concerns about the worries of those close to you' (43%) and 'changes in sexual feelings' (41%).</p> <p>Overall needs were well met in the domain of patient care and support.</p> <p>Men with advanced disease (ie metastatic) scored lower on most QoL categories, and had greater levels of depression than those with localised disease.</p>
11	<p>Northouse, L. L., Mood, D. W., Montie, J. E., Sandler, H. M., Forman, J. D., Hussain, M., ... Kershaw, T. (2007a). Living with prostate cancer: patients' and spouses' psychosocial status and quality of life. <i>Journal of Clinical Oncology</i>, 25(27), 4171-4177.</p>	<p><b>Randomised clinical trial (USA)</b></p> <p>Spouse dyads, randomised to control group (n=123) or intervention group (n=112).</p> <p>Intervention consisted of a family-based educational and support programme, based on the FOCUS Program for breast cancer but modified for prostate. Participants received five sessions – three at home and two by telephone – delivered by specially trained nurses. Outcome data were collected at four month, eight month and 12 month intervals from baseline (start of programme).</p> <p>At four months, intervention patients were significantly less uncertain and reported better communication with spouses than controls. Intervention spouses showed significantly better scores than controls on communication with partner, quality of life, and self-efficacy, and significantly lower negative appraisal of caregiving, hopelessness, uncertainty and symptom distress.</p> <p>At eight months spouses in the intervention had better physical QoL than controls (but not mental QoL), lower uncertainty, better communication and fewer problems related to the patient's urinary incontinence. At 12 months, the significant positive differences in communication, physical QoL, and self-efficacy continued. Intervention spouses showed significantly greater use of active coping than controls at 12 months (though this had not been apparent at earlier measurement points).</p> <p>There were no significant benefits for intervention patients over controls at eight or 12 months. Study provides good evidence for the value of such interventions in terms of the health and well-being of spouses of men affected by prostate cancer.</p>





Full reference	Summary details
12	<p><b>Secondary analysis of longitudinal data from RCT (USA)</b></p> <p>Based on data from the same RCT as described above in Northouse et al (2007).</p> <p>Examined the patterns of change in communication between couples and which factors affected this over time, including phase of illness (localised, biochemical recurrence, advanced).</p> <p>Within dyads, men and their partners reported similar levels of open communication at time of diagnosis. Patients and spouses with localised cancer reported less open communication at diagnosis than those with recurrent or advanced. However, levels of communication decreased over time regardless of phase of illness at diagnosis.</p> <p>Levels of communication were higher where dyads reported higher social support, lower uncertainty and fewer hormonal symptoms.</p> <p>A lack of open communication may compromise men’s relationship with their partners and their psychological adjustment to prostate cancer. Such communication tends to decline over the illness trajectory, despite the fact that in advanced cancer there is an increasing need for couples to share thoughts, feelings and information about treatment decisions and caregiving needs.</p> <p>Interventions could facilitate couples’ interaction and mutual support during survivorship, with potential benefits to both parties.</p>
13	<p><b>Prospective study</b></p> <p>Analysis of two national cohorts of a total of 1366 men treated for localised PC. 15% had PSA scores of 10.1–20 and 5% scores over 20.</p> <p>The study compared and contrasted patient and physician perceptions of quality of life in relation to: fatigue, pain, sexual, urinary and bowel dysfunction over time.</p> <p>While urinary problems and sexual dysfunction were major concerns for patients, their relative importance was over-stated by physicians in comparison to the patients themselves; in contrast, physicians relatively understated patient concerns with pain and fatigue. Correspondence in perceptions did not improve over time.</p> <p>It is important for all levels of HCPs to be trained in acknowledging and addressing impairments in QoL from prostate cancer and its treatments.</p>





**Table 4. Key articles on multiple myeloma**

	Full reference	Summary details
1	<p>Bird, J. M., Owen, R. G., D'Sa, S., Snowden, J. A., Pratt, G., Ashcroft, J., ...UK Myeloma Forum. (2011). Guidelines for the diagnosis and management of multiple myeloma 2011. <i>British Journal of Haematology</i>, 154(1), 32–75. doi: 10.1111/j.1365-2141.2011.08573.x</p>	<p><b>Best practice guidelines (UK)</b></p> <p>Produced by the British Committee for Standards in Haematology in conjunction with the UK Myeloma Forum (UKMF). Intended to be used in conjunction with Snowden et al (2011) guidelines for supportive care.</p> <p>Recommendations for clinical practice are provided under the following headings. These include management of refractory and relapsed myeloma.</p>
2	<p>Cachia, E., Eiser, C., Ezaydi, Y., Greenfield, D. M., Ahmedzai, S. H., &amp; Snowden, J. A. (In Press). Living with advanced but stable multiple myeloma: A study of the symptom burden and cumulative effects of disease and intensive treatment on health-related quality of life. <i>Journal of Pain and Symptom Management</i>.</p>	<p><b>Survey (UK)</b></p> <p>(N = 32, median age 55 at Dx, 61 at assessment.)</p> <p>All had had haematopoietic stem cell transplantation and subsequent treatment for at least one episode of progressive disease.</p> <p>Measures of HRQoL, pain, peripheral neuropathy, concerns. Clinical history, treatment and current meds from case notes. Serum IL-6 and TNF- also measured.</p> <p>Despite disease stability, intensively-treated long-term myeloma survivors have significantly compromised HRQoL associated with symptom burden. Specific issues include:</p> <ul style="list-style-type: none"> <li>• Progressive work disability and early retirement. Restricted social and physical activities.</li> <li>• Fatigue and pain affecting physical functioning.</li> <li>• Concerns re loss of independence, shortened life expectancy (especially re life with partner).</li> <li>• Concerns re pain and sexuality positively correlated with concerns re rejection.</li> </ul>







	Full reference	Summary details
3	<p>Grundy, M., &amp; Ghazi, F, (2009). Research priorities in haemato-oncology nursing: results of a literature review and a Delphi study. <i>European Journal of Oncology Nursing</i>, 13(4), 235–249.</p>	<p><b>Literature review and Delphi study (UK)</b></p> <p>Lit. rev. 1996–2008, 90 articles included. Delphi questionnaire to 1444 UK nurses working in field.</p> <p>Final list of 33 research priorities identified. The following areas relevant to AAD are identified as under-researched/requiring more attention:</p> <ol style="list-style-type: none"> <li>1 Studies including older participants and those with a poor prognosis.</li> <li>2 Need for more longitudinal/prospective research examining patient experience and QoL.</li> <li>3 Patient experience research linked to testing of nursing interventions.</li> <li>4 Research relating to employment/return to work.</li> <li>5 Side effects. Patients usually experience multiple side effects which are often inter-related, so exploration of ‘symptom clusters’ may be more useful for future research.</li> <li>6 Impact on family/significant others, including financial hardship. Almost nothing on caregivers whose relative receiving a treatment other than SCT.</li> <li>7 Organisational issues (context of care, role development and nurse led care). Particularly important to develop home-based care and follow-up.</li> </ol>
4	<p>Howell, D. A., Roman, E., Cox, H., Smith, A. G., Patmore, R., Garry, A. C., &amp; Howard, M. R. (2010). Destined to die in hospital? Systematic review and meta-analysis of place of death in haematological malignancy. <i>BMC Palliative Care</i>, 9(9), 1–8.</p>	<p><b>Systematic review and meta-analysis</b></p> <p>Haematological (but not MM) specific.</p> <p>Patients with haematological cancers more than twice as likely to die in hospital as those with other cancers. Why? Potential contributory factors identified include:</p> <ul style="list-style-type: none"> <li>• The complex transition from an active or curative approach to a palliative approach to care – a transition which is not always clear in haematology.</li> <li>• The increasing number of salvage therapies, resulting in continued treatment even in the very late stages of disease – may give rise to sentiments of denial or the continued hope of a response, both in patients and practitioners.</li> <li>• Close relationships between patients and haematology teams may result in less knowledge of and access to community-based palliative care services.</li> </ul>





Full reference	Summary details
5	<p><b>Meenaghan, T., O'Dwyer, M., Hayden, P., Hayat, A., Murray, M., &amp; Dowling, M. (2010). Home administration of bortezomib: making a difference to myeloma patients' lives. <i>European Journal of Oncology Nursing</i>, 14(2), 134–136.</b></p> <p><b>Trial of home administration of bortezomib (Spain)</b></p> <p>Drug requires frequent IV admin (usually twice a week for two consecutive weeks with a 10 day rest period). Admin takes only 10 seconds but patients can spend up to six hours per visit in day unit (and often have to travel long distances to get there).</p> <p>Haematologist identified suitable patients (high functioning, compliant with other meds). Home admin co-ordinated by haematology specialist nurses. At home visits, routine bloods and physical assessment also undertaken and patients questioned about side effects.</p> <p>Once drug reconstituted, has to be delivered to patient within an eight hour window so requires good co-ordination between hospital pharmacy and home admin nurses.</p> <p>Good communication between nurse co-ordinating service and home admin nurse also vital to facilitate prompt reporting of any side effects.</p> <p>Successful pilot. Planned to enrol 10 – enrolled 23. Excellent patient feedback. No serious side effects. Vast majority maintaining treatment.</p>
6	<p><b>Molassiotis, A., Wilson, B., Blair, S., Howe, T., &amp; Cavet, J. (2011a). Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. <i>Psycho-Oncology</i>, 20(1), 88–97. doi: 10.1002/pon.1710</b></p> <p><b>Cross-sectional survey (UK)</b></p> <p>132 patients and 93 partners; all patients at least one year post treatment (Dx). Focus of study on longer term needs in MM survivors.</p> <p>Sought to identify nature and range of unmet supportive needs and QoL levels amongst MM patients and their partners.</p> <ul style="list-style-type: none"> <li>• a quarter of patients and a third of partners reported unmet supportive care needs.</li> <li>• presence of side effects of treatment was the single most important variable in predicting unmet supportive care patient needs. Unmet needs in partners correlated with patient unmet needs.</li> <li>• 27.4% of patients reported anxiety and 25.2% depression; amongst significant others.</li> <li>• 48.8% reported anxiety and 13.6% depression. Anxious/depressed patients had more than double unmet needs than non-anxious/depressed patients.</li> <li>• Note that fewer partners than patients recruited – primary reason for non- participation 'didn't want to think about partner's illness' – so this may in fact under-represent extent of problem.</li> <li>• Given that 35.9% of patients report pain 'currently', suggests that pain management is suboptimal.</li> <li>• Long term supportive care should provide support to both patients and their partners. Need to optimise symptom management to improve patient QoL.</li> </ul>





Full reference	Summary details
7	<p data-bbox="244 477 611 754">Molassiotis, A., Wilson, B., Blair, S., Howe, T. and Cavet, J. (2011b). Living with multiple myeloma: experiences of patients and their informal caregivers. <i>Supportive Care in Cancer</i>, 19, 101–111.</p> <p data-bbox="620 477 1072 512"><b>Qualitative interview study (UK)</b></p> <p data-bbox="620 531 1516 602">20 MM patients and 16 informal caregivers (usually spouse) exploring the experience of myeloma five years after treatment (Dx).</p> <ul data-bbox="620 620 1533 1888" style="list-style-type: none"> <li data-bbox="620 620 1533 691">• Significant impact of MM reported on emotional, role, social and work related areas of life for both patients and caregivers.</li> <li data-bbox="620 710 1533 816">• Caregivers were providing support to patients (practical and emotional) almost exclusively, and often at the expense of their own needs.</li> <li data-bbox="620 834 1533 905">• Both parties concealed stressful situations from the other in an attempt to protect, but this resulted in isolation.</li> <li data-bbox="620 924 1533 1512">• Findings from patient interviews: 1) <b>Current and future concerns</b> – frustration at current limitations imposed by illness on everyday activities; having to rely on others and related guilt; difficulty in accepting change in self-image; fears of relapse and uncertainty about future. 2) <b>Effects of myeloma on daily life</b> – fatigue and pain as most troubling symptoms; long term effects of treatment still impacting on life (though not currently undergoing treatment). 3) <b>Practical, functional and emotional coping</b>: practical – use of aids (sometimes refused because of embarrassment); information – some eager to gather, others preferred to avoid); covering (concealing) and protecting others reported as coping strategy. Not wanting to bother health care professionals with concerns. 4) <b>Unmet needs</b> – continuity of care especially when initial treatment finished; a sense of resignation about symptoms that could not be managed well – patients stopped mentioning at consultations. Not wanting to bother doctors with emotional problems. Support groups unpopular.</li> <li data-bbox="620 1531 1533 1888">• Findings from caregiver interviews: 1) <b>Current and future concerns</b> – difficulties balancing own lives and caring for patient; helplessness when patient in pain; fears for future, when pats unable to care for themselves in any way. 2) <b>Effects on daily life</b> – social restrictions; impact on own working life. 3) <b>Practical, functional and emotional coping</b> – sense of ‘duty’ attached to caring – not perceiving self as ‘carer’; filtering information to patients. 4) <b>Unmet needs</b> – lack of information specifically designed for carers; found it difficult to speak to doctors; sometimes did not understand info given by HCPs due to use of jargon.</li> </ul>





Full reference	Summary details
8	<p>Potrata, B., Cavet, J., Blair, S, Howe, T. and Molassiotis, A. (2011). Understanding distress and distressing experiences in patients living with multiple myeloma: an exploratory study. <i>Psycho-Oncology</i> 20(2), 127-134.</p> <p><b>Qualitative interview study (UK)</b></p> <p>15 patients living with MM.</p> <ul style="list-style-type: none"> <li>Five themes around distress emerged: 1) <b>Distress from experienced symptoms</b> (difficulties with mobility caused considerable distress, but financial rather than physical – long wait to receive DLA, often had to pay themselves for needed mobility equipment); 2) <b>Distress from body image changes</b>; 3) <b>Distress caused by family and friends</b> (Family and friends were overall praised for their support, but were also reported as causing distress. Noted that living with myeloma often represented a substantial financial burden, especially for younger patients – several had to move back in with parents or families as could not afford mortgage/rent. Friends found to play a far greater role than is generally recognised, practically and financially); 4) <b>Distress from myeloma related info</b>; 5) <b>Distress from SCT</b>.</li> </ul>
9	<p>Snowden, J. A., Ahmedzai, S. H., Ashcroft, J., D'Sa, S., Littlewood, T., Low, E., Lucraft, H., Maclean, R., Feyler, S., Pratt, G. and Bird, J (2011). Guidelines for supportive care in multiple myeloma 2011. <i>British Journal of Haematology</i> 154(1), 76–103.</p> <p><b>Best practice guidelines on supportive care in multiple myeloma</b></p> <p>Produced by the British Committee for Standards in Haematology in conjunction with the UK Myeloma Forum (UKMF). Intended to be used in conjunction with Bird et al (2011) guidelines for management.</p> <p>Recommendations for supportive care in myeloma cover following areas: pain management, peripheral neuropathy; skeletal complications; infection; anaemia; haemostasis and thrombosis; sedation; fatigue; nausea; vomiting; anorexia; constipation; diarrhoea; mucositis; bisphosphonate induced osteonecrosis of jaw; complementary therapies; holistic needs assessment; end of life care.</p>



# References

1. As we suspected the term AAD was not well-used in the literature. High retrieval rather than high specificity was our main concern; there is evidence that Google Scholar consistently achieves higher retrieval rates than other search engines (Cecchino, 2010).
2. 15–25% of newly diagnosed patients have mCRC at diagnosis and 25% of early stage CRC patients will develop metastases (Fu et al, 2011).
3. See NICE Guidance 131 (NICE, 2011) for current guidance for chemotherapy for advanced and metastatic CRC.
4. NICE Guidance (2011) states that all patients with primary CRC should be offered follow-up care and re- investigation should occur if there is any suspicion of recurrent disease. Follow-up investigations should cease if risks are greater than benefits and, or the patient can no longer tolerate treatment (NICE 2011). Other than medical tests (CT scans of chest, abdomen and pelvis, surveillance colonoscopy, and serum carcinoembryonic antigen tests [CEA]) NICE guidance recommends follow up should begin four to six weeks after initial treatment (NICE 2011).
5. We use the term 'significant other' here rather than carer, for two reasons. Firstly, not all those close to a patient with AAD may consider themselves – or be considered by services – to be a carer; secondly, we believe it is important to consider networks of support beyond a patient's spouse/partner.

For more information please contact [Recoverypackage@macmillan.org.uk](mailto:Recoverypackage@macmillan.org.uk)



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