Shared care in prostate cancer: the role of primary care
Introduction

The incidence of prostate cancer in the UK increased from 33 to 97 per 100 000 between 1975 and 2007 as a result of increased detection rates (associated with prostate-specific antigen [PSA] screening and incidental diagnosis after transurethral resection of the prostate) and improved survival.¹ The 10-year survival rate is 60%¹ and the number of men living with prostate cancer is rising, with prevalence currently estimated at 215 000 in the UK.²

Increasing numbers of men are requesting a PSA test, placing the GP at the forefront of screening and diagnosis of prostate cancer. Current advice is that any man aged over 50 who asks for a PSA test after careful consideration of the implications should be given one. All GPs have received a summary of the evidence about the advantages and disadvantages of screening and preprinted information leaflets for men from the Prostate Cancer Risk Management Programme (www.cancerscreening.nhs.uk/prostate).

There have been persistent problems delivering adequate treatment for prostate cancer. In 2004, a joint study by the National Audit Office and the Department of Health found that men with prostate cancer reported a worse experience of care than patients with other types of cancer.³ They described longer delays before appointments, shorter consultation times and a lack of information about the adverse effects of treatment, and they were less likely to have a named nurse in charge of their care.

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Roger Kirby and Mike Kirby have received funding from the pharmaceutical industry for research, conference attendance, lecturing and advice.
Prostate cancer should arguably be considered as a chronic disease rather than a potentially terminal cancer and there is a growing demand on resources for monitoring and treatment. The secondary sector alone lacks the capacity to cope with increasing numbers of patients but the primary sector lacks the expertise necessary to manage treatment without support. Shared care arrangements offer a means of making the best use of resources in both sectors.

There are no universally agreed definitions on what constitutes shared care and most management guidelines do not provide adequate detail about follow-up in primary care for men with prostate care. In the US, the concept of survivorship care has been created to describe the long-term surveillance and health maintenance of people living with cancer. Its essential components, defined by the US Institute of Medicine, encompass the key aspects of management after initial treatment (Box 1). In the UK, these roles fall under the remit of shared care – usually meaning an agreement between providers in the primary and secondary sectors for one or more aspects of care that may include specifications for monitoring, treatment and/or referral.

In 2002, NICE published guidance on services for urological cancers. Noting that urological cancer services had lagged behind those for other cancers, it recommended establishing local and specialist multidisciplinary teams with responsibility for liaising with GPs; improvements in information provision for patients; and palliative care support for the primary care team. In particular, it called for documented clinical policies for shared care for men with prostate cancer managed in the community, specifying criteria for referral back to the local urological cancer team, and access to a specialist nurse for primary care teams, patients and carers.

Guidance for multidisciplinary teams specifies the need for support from primary care at all levels of the management of prostate cancer and emphasises the importance of regular communication between the two (Box 2).

Primary care is now assuming a greater role in prostate cancer treatment. A 2008 audit of three UK practices caring for a total of 41 men with prostate cancer found that 16 were receiving hormonal treatments and 9 were undergoing watchful waiting; 23 had two or more GP consultations annually. Care was provided solely by the GP for 10 patients and the others received hospital-based or shared care.

But problems remain. In a recent UK qualitative study involving 35 men with prostate cancer, patients expressed support for a greater role for primary care in follow-up but, perhaps reflecting a lack of communication between the primary and secondary sectors and patients, there was a lack of clarity about what care GPs should offer and concern that recall systems were not effective.

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**BOX 1. Essential components of survivorship care in the US**

- Prevention of recurrent and new cancers, and of other late effects
- Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects
- Intervention for consequences of cancer and its treatment:
  - medical problems such as lymphoedema and sexual dysfunction
  - symptoms, including pain and fatigue
  - psychological distress experienced by cancer survivors and their caregivers
  - concerns related to employment, insurance and disability
- Coordination between specialists and primary care providers to ensure that all of the survivor’s health needs are met

**BOX 2. Points for communication between the multidisciplinary team and the primary care team**

- Timely provision of detailed discharge or outpatient summaries
- Explanation of why a treatment route has been decided upon
- The patient’s response to the chosen treatment
- Sharing of protocols
- Online educational resources
- Agreement on prescribing policies
- Provision of contact numbers for requests for information
The 2008 audit highlighted several important management issues (Box 3). Most were due to lack of consistency between the primary and secondary sectors in the processes of care and administration, emphasising the need for close collaboration between care providers. The issues that made prostate cancer particularly challenging for primary care included a lack of evidence on which to base decisions about treatment and follow-up policies; variation in clinical practice between trusts and between urologists; poor communication from secondary care; and an uncomplaining patient group.

WHEN IS SHARED CARE APPROPRIATE?

The NICE clinical guideline on the diagnosis and treatment of prostate cancer recommends that primary care should have responsibility for watchful waiting. Men with stable PSA and no significant treatment complications after two years should also be followed up outside hospital. Watchful waiting is an option, but not the preferred choice, for men with low-, intermediate- or high-risk disease.

Watchful waiting has no curative intent. It is suitable for men with local disease for whom radical treatment offers no clear benefit, such as older men with significant comorbidities who are more likely to die of causes other than their prostate cancer. The purpose of this approach is to monitor for symptoms such as urine outflow obstruction that indicate disease progression and to carry out a PSA measurement annually.

Watchful waiting for prostate cancer is carried out according to a protocol agreed between the multidisciplinary team and the primary care organisation. Patients will be seen exclusively in primary care and may not use a specialist service unless referred. It is therefore essential that the practice can provide the necessary supportive and psychosocial care and has an effective recall system.

Active surveillance is indicated for men with indolent disease who could benefit from radical treatment if their disease progresses. It is the preferred choice of treatment for those with localised low-risk prostate cancer (PSA ≤10ng/ml and Gleason score ≤6 and T1–T2a) and is an option for men with intermediate-risk disease (PSA 10–20ng/ml or Gleason score 7 or T2b–2c). NICE states that active surveillance is particularly suitable for a subgroup of men with low-risk localised prostate cancer who have clinical stage T1c, a Gleason score of 3+3, a PSA density of <0.15ng/ml/ml and who have cancer in less than 50% of their total number of biopsy cores with <10mm of any core involved.

Active surveillance entails periodic biopsy (requiring attendance at hospital) and PSA measurement at intervals in between. After radical treatment, NICE recommends that follow-up should be outside of hospital with at least an annual PSA for men who have received local treatments and have a stable PSA two years post-treatment, though they should have direct access to the multidisciplinary team.

Many shared care protocols to facilitate prescribing of prostate cancer treatment by the GP have been developed in the NHS (examples are available online). Typically, they describe the treatment to be provided under the protocol (usually a single drug) and set out the responsibilities of the specialist and the GP. Clinical responsibility for the treatment prescribed falls to the person who prescribed it. The aim of a shared care protocol is to clarify clinical roles and to define how responsibility is divided between primary and secondary care.

Shared care is not appropriate for patients with higher-risk prostate cancer or who need intensive surveillance of...
disease progression and the effects of treatment. Patients with unstable disease, who are having difficulties with treatment (such as adverse effects) or who are at increased risk of complications, such as ureteric obstruction or spinal cord compression, are unlikely to be considered for shared care. GPs have a right not to agree to shared care, in which case responsibility remains within secondary care. GPs should not accept responsibility for prescribing treatment under a shared care protocol if they do not have sufficient knowledge of the drug or the resources to provide the support patients need.

WHAT INFORMATION CAN PRIMARY CARE EXPECT?
The success of shared care depends on effective communication between GPs and their colleagues in secondary care, and with the patient, but there is often a lack of guidance on the information to be provided to GPs to help them offer appropriate care.

Shared care protocols for drug treatment, though generally clear about the roles of the primary and secondary sectors, do not always specify what information specialists should provide. For example, the protocols for prescribing luteinising hormone-releasing hormone (LHRH) analogues for prostate cancer developed by Sheffield Teaching Hospitals NHS Trust detail the information the consultant is required to give the GP (Box 4).\(^\text{12–14}\) In addition, the consultant agrees to inform the GP in writing how to give maintenance therapy and how to monitor and record treatment. By contrast, other protocols for hormonal therapy contain no provisos for information sharing.\(^\text{15,16}\)

THE GP’S ROLE IN SHARED CARE
GPs should consider what information they need to enable them to provide care effectively and safely. If there is a written share care agreement, they should ensure that it lists their requirements. In the case of watchful waiting and active surveillance, GPs should have clear lines of communication and referral with the multidisciplinary team and agree what and how frequently information will be exchanged.

The GP should ensure that men with prostate cancer, their families and carers understand the condition and the options for treatment so that they can make informed decisions.\(^\text{8}\) Information should be provided in a culturally appropriate way, taking into account any special needs\(^\text{10}\) – this is where the GPs’ relationships with their patients can improve on hospital care, where patients may see a different doctor at each visit. The information a GP provides should be consistent with that provided in secondary care – another example of the importance of good communication with the multidisciplinary team. The GP should also be prepared to assume the role of advocate if the patient wishes.\(^\text{8}\)

The family doctor should be prepared to enquire about the psychosocial and sexual impact of prostate cancer and its treatment. Men who are candidates for radical therapy should be given the opportunity to discuss their treatment with specialists. Anxiety, depression and erectile dysfunction are common among men with prostate cancer;\(^\text{17}\) in addition, androgen depletion therapy causes gynaecomastia and fatigue. These problems may not be volunteered by patients\(^\text{8}\) and individuals differ in the support they want.\(^\text{9}\) The NICE guideline includes detailed guidance on the management of treatment-related adverse effects (Table 1).\(^\text{10}\)

WHEN TO REFER BACK TO THE MULTIDISCIPLINARY TEAM
Watchful waiting and active surveillance involve regular monitoring. Evidence of progression indicates the need for referral to the multidisciplinary team to assess the value of further treatment including palliative radiotherapy or hormonal therapy. The most obvious symptoms of local spread of prostate cancer are a rapidly rising PSA level or urinary obstruction; recurrence or metastasis are likely to cause bone pain and systemic signs such as weight loss and malaise.\(^\text{10,11}\) The decision to proceed to radical therapy should be made ‘in the

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**BOX 4. Sheffield Teaching Hospitals NHS Trust. Information to be given to the GP by the consultant in shared care protocols for prescribing LHRH analogues**\(^\text{12–14}\)

- Diagnosis of patient’s clinical condition with relevant clinical details
- Details of patient’s treatment to date
- Details of treatment to be undertaken by GP – this should include reasons for choice of treatment, dose, frequency of treatment, number of doses to be given before review by consultant, any other treatment or drugs that the patient is to receive
- Details of how the patient is to be motivated and how this is to be recorded
- Details of possible side-effects of treatment
- Details of contact arrangements for emergency treatment of problems encountered
- Whenever the consultant sees the patient, he or she will send a written summary within 14 days to the patient’s GP
light of the individual man’s personal preferences, comorbidities and life expectancy and this is another opportunity for the GP to provide support.

In the case of shared care agreements for treatment, the GP should be able to recognise the adverse effects of the drug and, depending on the specifications of the shared care protocol, adjust the dose accordingly or refer the patient back to the multidisciplinary team.

**SUMMARY**
Prostate cancer is becoming, for many men, a chronic disease requiring long-term management in the community. GPs can share care with the secondary sector by providing watchful waiting, active surveillance and prescribing drug therapy.

The essential component of a successful partnership is good communications between primary and secondary care, and with patients. GPs should ensure that their colleagues in secondary care provide the support and information they need to provide appropriate care.

### Table 1. NICE guidance on the management of adverse effects of treatment

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<th>Bowel disorders</th>
<th>Erectile dysfunction</th>
<th>Urological disorders</th>
<th>Androgen deprivation therapy</th>
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| Men presenting with symptoms consistent with radiation-induced enteropathy should be fully investigated (including using flexible sigmoidoscopy) to exclude inflammatory bowel disease or malignancy of the large bowel and to ascertain the nature of the radiation injury. Particular caution should be taken with anterior wall rectal biopsy following brachytherapy because of the risk of fistulation | Prior to treatment, men and their partners should be warned that treatment for prostate cancer will result in an alteration of sexual experience, and may result in loss of sexual function | **Before treatment:**
  - Men experiencing troublesome urinary symptoms should be offered a urological assessment  
**During treatment:**
  - Warn of the likely effects on their urinary function | Synthetic progestogens (administered orally or parenterally) are recommended as first-line therapy for the management of troublesome hot flushes |
| Men treated with radical radiotherapy for prostate cancer should be offered flexible sigmoidoscopy every 5 years | Potential loss of ejaculation and fertility | **After treatment:**
  - Ensure that men with troublesome urinary symptoms have access to specialist continence services for assessment, diagnosis and conservative treatment | If oral therapy is used, it should be given for 2 weeks, and re-started, if effective, on recurrence of symptoms |
| Steroid enemas should not be used for treating men with radiation proctopathy | Sperm storage should be offered | **This may include coping strategies, along with pelvic floor muscle re-education, bladder retraining and pharmacotherapy** | Men starting long-term bicalutamide monotherapy (>6 months) should receive prophylactic radiotherapy to both breast buds within the first month of treatment |
| | Ensure that men and their partners have early and ongoing access to specialist erectile dysfunction services | **Refer men with intractable stress incontinence to a specialist surgeon for consideration of an artificial urinary sphincter** | A single fraction of 8 Gy using orthovoltage or electron beam radiotherapy is recommended |
| | Phosphodiesterase type 5 (PDE5) inhibitors are the drugs of first choice for erectile dysfunction | The injection of bulking agents into the distal urinary sphincter is not recommended to treat stress incontinence | If radiotherapy is unsuccessful in preventing gynaecomastia, weekly tamoxifen should be considered |
| | If PDE5 inhibitors fail to restore erectile function or are contraindicated, other options are vacuum devices, intraurethral inserts or penile injections, or penile prostheses | | Inform men starting androgen withdrawal therapy that regular resistance exercise reduces fatigue and improves quality of life |
REFERENCES


