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Personalising care along the cancer journey: and the use of cancer intelligence

Follow-up and survivorship

Professor Clare Wilkinson

Professor of General Practice / Chair NCRI PCCSG
North Wales Centre for Primary Care Research
Bangor University

Cancer Outcomes Conference 2013 – Brighton

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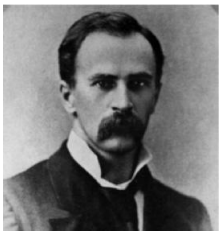

The practice of medicine is an art, not a trade; a calling, not a business; a calling in which your heart will be exercised equally with your head.

what is appropriate for the textbook case can turn out to be completely unsuitable in individual cases

Personalised care for cancer follow-up

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- Why is it important?
- What might it look like?
- How do we change things to get there?

…a story told through the exemplar of prostate cancer..

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Primary care Prostate Cancer F-U group (Oxford, Wales, Edinburgh)

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NCRI National Cancer Research Institute

- **SR of cancer f-u secondary vs primary care** *(Lewis BJGP 2008)*
- **Practice audit** *(Neal RD 2009)*
- **Systematic review of international guidelines** *(McIntosh BJC 2009)*
- **Qualitative study of survivors** *(OBrien 2012 BJU, OBrien 2011 Pat Ed Couns)*
- **Case note review in primary care** *(unpublished)*
- **Editorial - Personalised cancer follow-up** (*Watson BJC 2012)*
- **Randomised trials in progress – Prospectiv Mac Re-design the system project** *(Watson Oxford, Wilkinson Wales; 2012-14)*

CANCER RESEARCH UK

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Primary Care Clinical Studies Group NCRI

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– Screening
– Early Diagnosis
– Survivorship

.

NCRI National Cancer Research Institute

NCRN

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- ***Why is it important?***
- What might it look like?
- How do we change things to get there?

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Because it's common and chronic

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- 2 million people living with or beyond cancer in the UK 3.2%
  - Causes increased physical, social, psychological and employment problems
  - Not that different from diabetes, heart disease, epilepsy
  - QoF, information systems, clinical prediction tools are lacking
  - We need to develop primary care oncology in the UK

NCRI National Cancer Research Institute

NCRN

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Because it is increasing : The Lifetime Risk of Being Diagnosed with Prostate, Lung and Bowel Cancer*, UK, Male, 1975-2030

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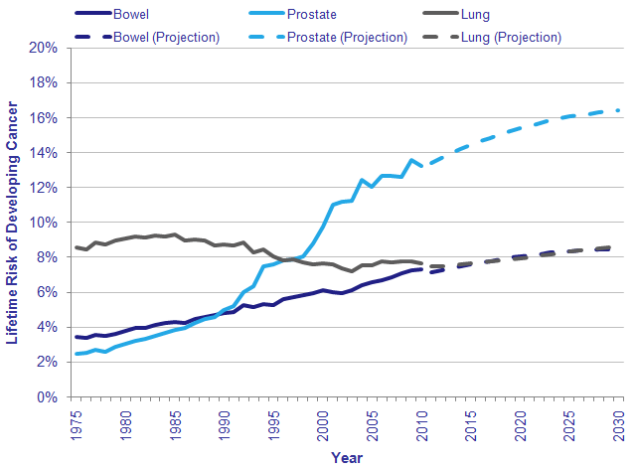

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Because late effects from cancer are problematic

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Table 1b Long-term and late effects following prostate cancer treatment (Shahinian *et al*, 2005; Ganz, 2009; Smith *et al*, 2009; Harrison *et al*, 2011)

Treatment effect	Incidence	Timing	Risk factors
Urinary incontinence	12.3% Following radical prostatectomy at 3 years 2.7% following radiotherapy at 3 years 7% following brachytherapy at 3 years 4.3% following hormone treatment at 3 years	Immediate – can be long term with problems resolving in some instances	Problems more common following radical prostatectomy
Bowel problems	3.5% Following radical prostatectomy at 3 years 14.5% following radiation therapy at 3 years 9.3% following brachytherapy at 3 years 6.4% following hormone treatment at 3 years	Sometimes immediate, sometimes delayed, can be long term with problems resolving over time in some instances	Problems more common following radiotherapy
Erectile dysfunction	77.4% following radical prostatectomy at 3 years 67.9% following radiotherapy at 3 years 72.1% following brachytherapy at 3 years 97.8% following hormone therapy at 3years	Immediate, often long term. Treatments can sometimes be effective and sometimes the problem will resolve over time	Radical prostatectomy, radiotherapy, hormone treatment
Risk of fracture	5 years post-diagnosis, 19.4% of men receiving hormone therapy with fractures compared with 12.6% of those who had not received hormone therapy.	Delayed effect	Hormonal treatment
Anxiety/depression Hot flushes	Up to 75% of patients	Can occur at any time	Trait anxiety Hormonal treatment

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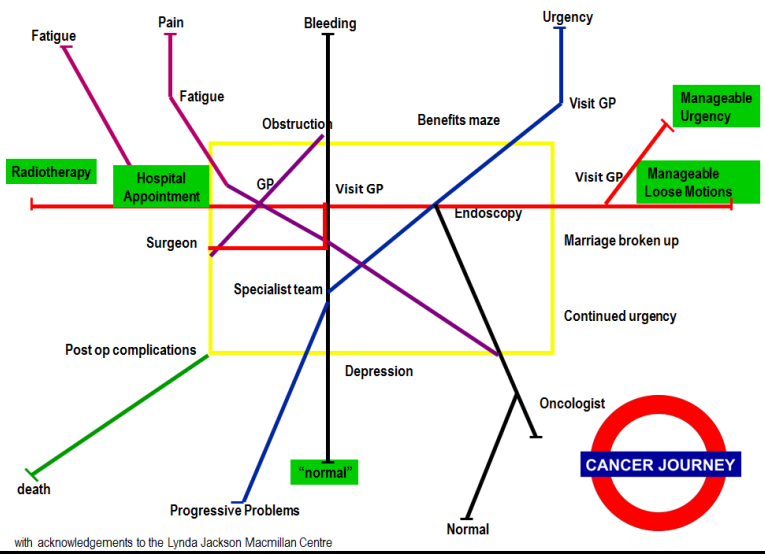

with acknowledgements to the Lynda Jackson Macmillan Centre

…because of our patient's stories…

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[redacted]

CONSULTANT UROLOGICAL SURGEON

[redacted]

DATE OF OPERATION: 02.03.13 DATE OF TYPING: 12.03.13

[redacted]

Operation: Flexible check cystoscopy

Surgeon: [redacted]

Anaesthesia: LA

Indications: Known CA prostate, history of radical radiotherapy for recurrent TCC bladder.

Findings: Urethra normal. Prostate slightly occlusive . The bladder itself shows some telangiectatic lesions particularly around the bladder base and the lower posterior bladder wall but no evidence of obvious tumour recurrence.

Plan: Flexible check cystoscopy in 6 months.

[redacted]

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Swyddfa'r Gweithredwyr / Executives' Office,
Ysbyty Gwynedd, Penrhosgarnedd
Bangor, Gwynedd LL57 2PW
Gwefan: www.pbc.cymru.nhs.uk / Web: www.bcu.wales.nhs.uk

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Primary care record excerpt 15/3/13

s. c/o shoulder pain / knee pain, poor symptom control OA, awaiting R TKR, active problems include hypertension, loose stools (colonoscopy N 2012)

o. poor ROM L shoulder, tender over capsule anterior/ posteriorly, knee isq.

a. Main prob today OA.

p. Avoid NSAIDs, simple analgesia, physio referral done, chase TKR appt.

Findings – casenote analysis

240 primary care records men with Ca prostate

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Co-morbidity	n	%
Significant heart disease	158	65.8
Chronic neurological condition	106	44.2
Severe mental health problem	53	22.1
Chronic kidney/liver disease	39	16.2
Other malignancy in past 10 years	37	15.4
Diabetes	34	14.2
Asthma / COPD	29	12.1

Numbers of co-morbidities	n	%
0	24	10.0
1	75	31.2
2	76	31.7
3	40	16.7
4	18	7.5
5	5	2.1
6	2	0.8
Total	**240**	**100.0**

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[redacted]

DEPARTMENT OF UROLOGY
CLINICAL NURSE PRACTIONER

[redacted]

DATE OF CLINIC: [redacted] DATE OF TYPING: 30.03.13

[redacted]

I reviewed Mr Williams in clinic today.. He is a gentleman of 93 years who was referred with a raised PSA of 12ng/ml.

He recently underwent cystoscopy which found re-growth of his prostate. However, in view of him not having any symptoms we have decided not to intervene any further,

Mr Williams tells me today that he remains well .and denies and bothersome urinary symptoms. In view of his age we would suggest that he does not require any further PSA monitoring and we will therefore discharge him back to the care of his GP.

Dictated but not signed

[redacted]

cc [redacted]

File copy

30 APR

two further psa

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Swyddfa'r Gweithredwyr / Executives' Office,
Ysbyty Gwynedd, Penrhosgarnedd
Bangor, Gwynedd LL57 2PW
Gwefan: www.pbc.cymru.nhs.uk / Web: www.bcu.wales.nhs.uk

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Primary care record
4 April 2013

s. Acute home visit for ?UTI – dysuria, poor stream, general debility, depression. nephew is carer (nearby),known ca prostate/gout/IHD

o. ??uraemic, illkempt, afebrile, sats n, p 72sr bp 142/78, Abdo – bladder distended, no other masses, non tender, low mood. For bloods, MSU, review at home with results, ref DN, OT, discuss care with nephew

Findings – casenote analysis

duplication of effort

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	n	%
Psychosocial factors		
Primary care	**74**	**30.8**
Secondary care	**16**	**6.7**
Incontinence		
Primary care	91	37.9
Secondary care	82	34.2
Bowel disorder		
Primary care	58	24.2
Secondary care	51	21.2
Sexual function		
Primary care	62	25.8
Secondary care	49	20.4
Gynaecomastia		
Primary care	6	2.5
Secondary care	7	2.9

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Patient Perception, Preference and Participation

"I wish I'd told them": A qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment

Rosaleen O'Brien [a,*], Peter Rose [a], Christine Campbell [b], David Weller [b], Richard D. Neal [c], Clare Wilkinson [c], Heather Mcintosh [b], Eila Watson [d]

on behalf of the Prostate Cancer Follow-up Group

[a] Department of Primary Health Care, University of Oxford, Headington, Oxford OX3 7LF, UK
[b] Community Health Sciences, General Practice, University of Edinburgh, UK
[c] Department of Primary Care & Public Health, School of Medicine, Cardiff University, UK
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Keywords:
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Cancer
Follow-up
Psychosexual
Qualitative
Partners

ABSTRACT

Objective: To gain insight into patients' experiences of follow-up care after treatment for prostate cancer and identify unmet psychosexual needs.
Methods: Semi-structured interviews were conducted with a purposive sample of 35 patients aged 59–82 from three UK regions. Partners were included in 18 interviews. Data were analyzed using constant comparison.
Results: (1) Psychosexual problems gained importance over time, (2) men felt they were rarely invited to discuss psychosexual side effects within follow-up appointments and lack of rapport with health care professionals made it difficult to raise problems themselves, (3) problems were sometimes concealed or accepted and professionals' attempts to explore potential difficulties were resisted by some, and (4) older patients were too embarrassed to raise psychosexual concerns as they felt they would be considered 'too old' to be worried about the loss of sexual function.
Conclusion: Men with prostate cancer, even the very elderly, have psychosexual issues for variable times after diagnosis. These are not currently always addressed at the appropriate time for the patient.
Practice implications: Assessments of psychosexual problems should take place throughout the follow-up period, and not only at the time of initial treatment. Further research examining greater willingness or reluctance to engage with psychosexual interventions may be particularly helpful in designing future interventions.

Experiences of follow-up after treatment in patients with Prostate Cancer: A qualitative study

Follow-up system failure

"I went to my doctor. I said nothing was done about my six-month check. I suppose I'm alright? I feel alright.." He was later re-referred)... "Nothing was said about having forgotten about me the last four years... I'm not picking on anybody... but I'm just saying that I was forgotten"

Follow-up system failure

"I missed out having a blood test... and that went up slightly (the next test)... I don't think anybody dropped me a note and said 'Now is the time to...' I felt I could handle it quite satisfactorily so I was quite happy. So if one was finding fault, that's where there had been a drop off one might say. When I go now, the nurse will say 'I'll see you again on a particular date'... and I make a note of it and do it"

Describing Incontinence

"I felt it was something that I got on with (alone)". He described how he "resorted to making home made nappies". Rather than being offered, or asking for, support.

Describing psycho sexual problems

"Immediately postoperatively the question of impotence doesn't really come in to your head... I think it's only later on you have to... face-up to how you handle that... There's not a lot of... counselling from either the primary care or the hospital in terms of the psychological aspect".

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Personalised care for cancer follow-up

- Why is it important?
- ***What might it look like?***
- How do we change things to get there?

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Complete care pathway for a patient with a diagnosis of cancer

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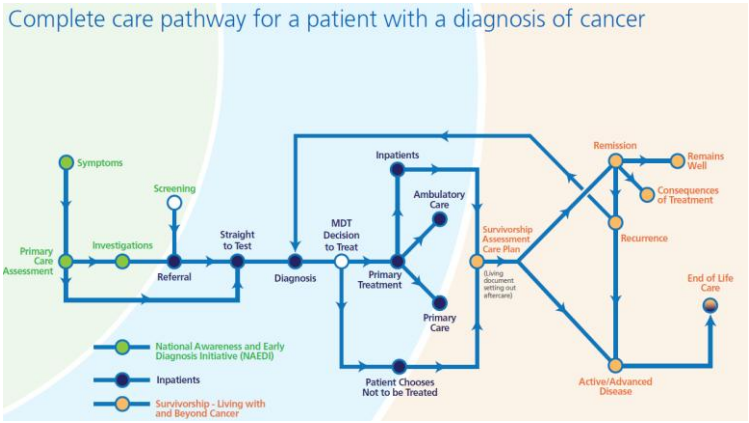

NHS

NHS Improvement

Cancer

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British Journal of Cancer (2009) 100, 1852 – 1860

www.bjcancer.com

Follow-up care for men with prostate cancer and the role of primary care: a systematic review of international guidelines

HM McIntosh[1,*], RD Neal[2], P Rose[3], E Watson[4], C Wilkinson[2], D Weller[1] and C Campbell[1] on behalf of the Prostate Cancer Follow-up Group

[1]Community Health Sciences – General Practice, University of Edinburgh, 20 West Richmond Street, Edinburgh EH9 9DX, UK; [2]Department of Primary Care and Public Health, North Wales Clinical School, Cardiff University, Gwenfro Unit 5, Wrexham Technology Park, Wrexham LL13 7YP, UK; [3]Deptartment Primary Care, University of Oxford, Old Road Campus, Headington, Oxford OX3 7LF, UK; [4]School of Health and Social Care, Oxford Brookes University, Jack Straws Lane, Marston, Oxford OX3 0FL, UK

The optimal role for primary care in providing follow-up for men with prostate cancer is uncertain. A systematic review of international guidelines was undertaken to help identify key elements of existing models of follow-up care to establish a theoretical basis for evaluating future complex interventions. Many guidelines provide insufficient information to judge the reliability of the recommendations. Although the PSA test remains the cornerstone of follow-up, the diversity of recommendations on the provision of follow-up care reflects the current lack of research evidence on which to base firm conclusions. The review highlights the importance of transparent guideline development procedures and the need for robust primary research to inform future evidence-based models of follow-up care for men with prostate cancer.

British Journal of Cancer (2009) **100,** 1852 – 1860. doi:10.1038/sj.bjc.6605080 www.bjcancer.com
Published online 12 May 2009

Keywords: prostate cancer; follow-up; guidelines; systematic review

What might f-u look like?

- NICE – *no SRs
- Individualized discussion, explain adverse effects
- Watchful wait – primary care, PSA at least annually
- PSA f-u for radical treatment – 6/52, 6m for 2yrs, annually
- Rectal examination not recommended when PSA baseline.
- After 2 yrs, men with stable PSA back to primary care
- Direct access

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Primary care oncology

- We define primary care oncology as '… first contact, continuous, comprehensive and co-ordinating care..' with particular regard for cancer.
    - Starfield B 1994 Lancet

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RA Lewis, RD Neal, NH Williams, et al

Follow-up of cancer in primary care versus secondary care: systematic review

Ruth A Lewis, Richard D Neal, Nefyn H Williams, Barbara France, Maggie Hendry, Daphne Russell, Dyfrig A Hughes, Ian Russell, Nicholas SA Stuart, David Weller and Clare Wilkinson

ABSTRACT

Background
Cancer follow-up has traditionally been undertaken in secondary care, but there are increasing calls to deliver it in primary care.

Aim
To compare the effectiveness and cost-effectiveness of primary versus secondary care follow-up of cancer patients, determine the effectiveness of the integration of primary care in routine hospital follow-up, and evaluate the impact of patient-initiated follow-up on primary care.

Design of study
Systematic review.

Setting
Primary and secondary care settings.

INTRODUCTION

Following completion of treatment, most cancer patients are followed up regularly in hospital outpatient clinics. The perceived benefit of this is to facilitate diagnosis of recurrent disease, monitor the effectiveness and side-effects of treatment, manage comorbidity, and identify and treat psychosocial problems.[1–4] There is also evidence that patients value the psychological and social support that cancer follow-up provides,[5–8] and find it reassuring.[9–11] Conversely, hospital follow-up might also prompt unnecessary tests, raise anxiety, provide false reassurance, and delay the patient's return to full function. For some cancer sites, such as breast and colorectal cancer, there is good evidence that routine

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Macmillan definition of person-centred care

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- Seamless and integrated care that puts the needs of the person living with cancer at the heart of how services are planned, not the needs of the service providers.
- Treating people with sensitivity and compassion and ensuring that they receive high quality care that is holistic in its planning and delivery.
- Care that goes beyond the clinical to address wider social, financial, emotional, practical, psychological and spiritual concerns.

NHS teams, essential charities

National Cancer Survivorship Initiative

DH Department of Health

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NHS Improvement

Personalised care for cancer follow-up

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- Why is it important?
- What might it look like?
- ***How do we change things to get there?***

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Take a primary care perspective

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In a population of about 800,000 expect:

- ~ 570 incident cases of prostate cancer are expected in the BCUHB region per annum.
- ~602 cases last year.
- ~4000 men living with or beyond prostate cancer.

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Estimated numbers for the North Wales Cancer Network in each phase of Prostate Cancer

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Phase	Number	Setting
Diagnosis and treatment	500	primary care refer to secondary care
Recovery and readjustment	400	secondary care
Watchful wait / Active monitoring 1-2 years	400	secondary care may refer some back to primary care
Initial monitoring 2>or=5 years	1100	primary care
Ongoing monitoring 5>/=10 years	900	primary care
Ongoing monitoring > 10 years	200	primary care
Progressive Care >10 years	300	referred back from primary to secondary care
End of life	200	

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Transformed Pathways of Care: Overview

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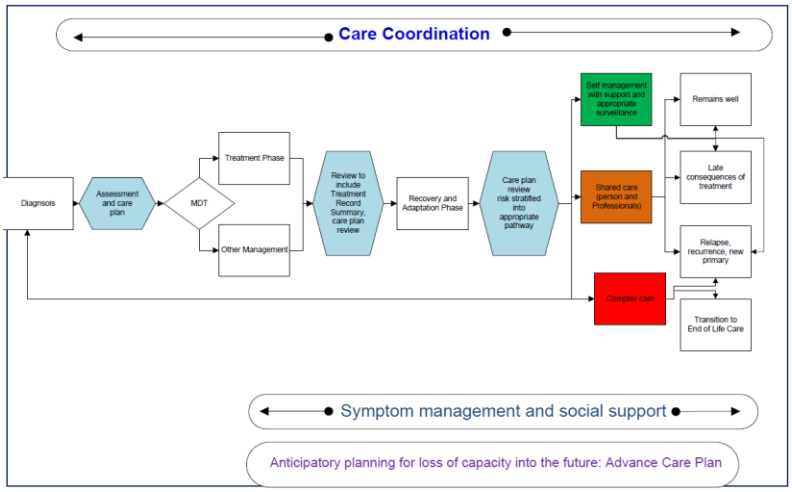

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Risk stratification

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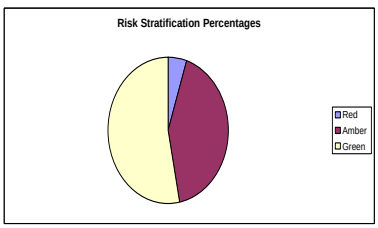
- **Average percentages of follow ups on each pathway:**
- **Colorectal:**
- Red – 5%
- Amber – 42%
- Green – 53%
- **95% of patients moved to an alternative pathway**
- **Prostate:**
- Red – 38%
- Amber – 52%
- Green – 8%
- **60% of patients moved to an alternative pathway**
- **Breast:**
- Red – 2%
- Amber – 4%
- Green – 94%
- **98% of patients moved to an alternative pathway**



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Risk Stratified Prostate Cancer Pathway

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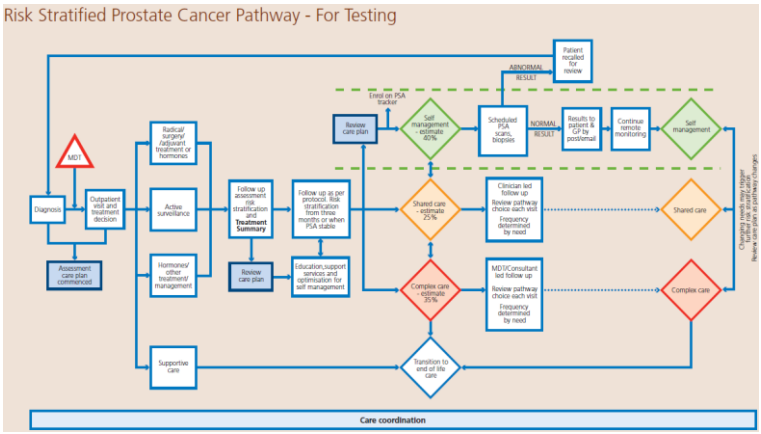

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Criteria for Risk Stratification

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Draft Criteria for Risk Stratification (to be tested)

Pathway	Complex	Shared care	Supported self management	Trigger for re-referral
Curative	All patients for first two years Patients with symptoms (unstable or awaiting treatment).	Those unable to comply with self management.	Potentially all patients once symptoms stable. Follow up with 6 monthly PSA.	Any rise in PSA after surgery Rise above 2 + nadir after RT.
Active monitoring	PSA alone is not an adequate tool. Repeat biopsy schedules are not yet fully defined.			
Watchful waiting		Those unable to comply with self management.	All patients.	Symptoms or PSA rise. Trigger points poorly defined but 2 or 3 consecutive rises is predominant trigger.
High risk (T3/4, or PSA >20 or Gleason >7) no metastases	Increasingly treated with radiotherapy and hormones.	Long term hormones hence cardiovascular risk and bone health monitored in primary care.	Patients with stable symptoms and PSA after 2 years.	Symptoms or 2 or 3 PSA rises if on hormones. Rise above 2 + nadir after RT.
Metastases and hormone therapy	Symptomatic and those with < 90% fall in PSA.	Cardiovascular risk and bone health monitored in primary care.	Patients with 90% fall in PSA who are asymptomatic.	Symptoms or 2 or 3 PSA rises.
Metastases and no immediate treatment	Need careful monitoring. Triggers based on symptoms, marker levels and rate of change.			
Castrate resistant prostate cancer	Managed by MDT but mostly managed by oncologists once 2nd or 3rd line therapy failed.			

British Journal of Cancer (2012) 106, 1 – 5

www.bjcancer.com

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Editorial

Personalised cancer follow-up: risk stratification, needs assessment or both?

EK Watson[*,1], PW Rose[2], RD Neal[3], N Hulbert-Williams[4], P Donnelly[5], G Hubbard[6], J Elliott[7], C Campbell[8], D Weller[8] and C Wilkinson[3]

[1]Faculty of Health and Life Sciences, Oxford Brookes University, Oxford OX3 0FL, UK; [2]Department of Primary Health Care, University of Oxford, Oxford OX1 2ET, UK; [3]North Wales Centre for Primary Care Research, North Wales Clinical School, College of Health & Behavioural Sciences, Bangor University, Wrexham LL13 7YP, UK; [4]Department of Psychology, University of Chester, Chester, CH1 4BJ, UK; [5]Breast Care Directorate, South Devon Healthcare Foundation Trust, Torbay Hospital, Torbay, UK; [6]Cancer Care Research Centre, School of Nursing, Midwifery and Health, University of Stirling, Highland Campus, Inverness, UK; [7]Consultant Research Analyst, National Cancer Survivorship Initiative Consequences of Treatment Programme, Macmillan Cancer Support, 89 Albert Embankment, London SE1 7UQ, UK; [8]School of Clinical Sciences and Community Health, Centre for Population Health Sciences, University of Edinburgh, Edinburgh EH8 9AG, UK

British Journal of Cancer (2012) **106,** 1 – 5. doi:10.1038/bjc.2011.535 www.bjcancer.com

There are approximately 2 million people now living with or beyond cancer in the UK (Maddams *et al*, 2009) and this number is increasing. Cancer survivors can experience physical, psychological and social consequences as a result of the disease and the treatments received (Jefford *et al*, 2008; Foster *et al*, 2009). The effects may be immediate, some of which will resolve and others may persist and become long-term. Late effects can also occur and the interval between the end of treatment and onset can range from a few weeks (e.g. lymphoedema after axillary node removal) to several years (e.g. heart disease following radiotherapy to the chest area). Problems will be individual to each patient due to a unique combination of circumstances including the site and stage of the cancer, the type of treatment(s) given, the age of the patient, genetic factors, concomitant co-morbidities, family and social circumstances, and personality traits.

risk stratification, a topic for which there is already a large body of literature.

DEFINITION OF RISK

We have defined risk stratification as the process of quantifying the probability of a harmful effect to individuals resulting from a range of internal and external factors (e.g., demographic characteristics, genetic make-up, medical treatments). Risk must be differentiated from (healthcare) need, which is the capacity to benefit from health care. A need must be present at the time of assessment, unlike a risk, which implies something that might happen in the future. The assessment of both risk and need are required in the context of cancer survivorship. The categorisation of outcomes presented in Box 1, which we believe may warrant risk

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Long term and late effects following Prostate Cancer

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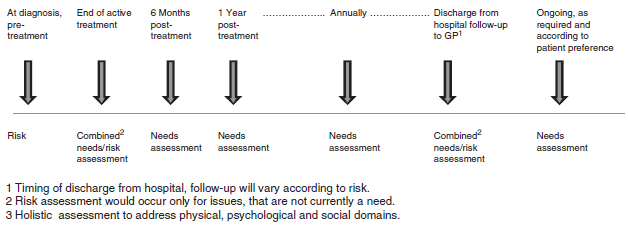
Editorial



1 Timing of discharge from hospital, follow-up will vary according to risk.
2 Risk assessment would occur only for issues, that are not currently a need.
3 Holistic assessment to address physical, psychological and social domains.

Figure 1 A framework for holistic assessment[3] of risks and needs.

RCTs in progress

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- Prospectiv –Prostate Cancer UK (202K) 2012-14
  - PI EW nurse led psychosocial intervention for men with prostate cancer
- TOPCAT-P –Macmillan Cancer Care (297K) 2012-14
  - PI CW Key worker / community MDT approach for men with prostate cancer
- TOPCAT-G – Gynae cancer follow-up – in submission

Diagnose quickly, follow-up safely' programme – BCUHB Charitable funds (293K)

Personalising care along the cancer journey