

Quality care. Everywhere?

An audit of prostate cancer services in the UK



**PROSTATE
CANCER UK**

Foreword

Why should a man who lives in Essex receive worse care and support for prostate cancer than a man who comes from Manchester?

Unfortunately, despite improvements in care, men in the United Kingdom continue to face a postcode lottery when accessing prostate cancer services. Prostate Cancer UK has brought together a report detailing the quality of treatment and care experienced by men across the UK. This report, which is the first of its kind, highlights the variation in the care and support men receive. It also provides a crucial benchmark which will help us in the future to make comparisons between the quality of care and support on offer to men today and in one, five and ten years time.

Each year, 10,000 men die from prostate cancer and there are over a quarter of a million men living with the disease today. Already the most common cancer in men, prostate cancer is predicted to be the most common cancer in the UK by 2030.

Prostate Cancer UK has worked with patients, families, clinicians and policy-makers to develop our Quality Checklist for men with prostate cancer. **A quality checklist: Your standards of care** outlines the quality of care and support men with prostate cancer should expect to receive, no matter where they live. It is evidence based, patient focused and patient driven, and describes the care that men with prostate cancer should receive at each step, from the point of diagnosis through to end of life care.

We hope this report will help commissioners and policy makers see how they are performing compared to other areas in the country and provide a useful starting point to improve the care men receive across the UK. We hope the Quality Checklist will prove to be a useful tool and we urge its adoption.

We look forward to working with policy-makers and health services to take forward this report's recommendations to make sure men get the care they deserve.

More data and the Quality Checklist can be found on our website:
prostatecanceruk.org/qualitycare

Key findings and recommendations

Key findings

All men with prostate cancer have a right to have the best possible care and support regardless of where they live. Unfortunately, there are significant variations in prostate cancer incidence, patient experience, mortality and survival across the UK.

1. Variation in incidence

Wales has the highest prostate cancer incidence rate in the UK, while Scotland has the lowest (see Table 1). There are significant variations in the incidence rate within each country. In England the incidence rate is particularly high in parts of London and Dorset and much lower in the North of England (see Table 2).

2. Patient experience

We currently only have patient experience data for men treated in England. While the experiences of men with prostate cancer have improved significantly over the last decade, substantial variations exist between Cancer Networks. It is clear that the information and support needs of many men with prostate cancer are not being met. While around 9 in 10 men with prostate cancer in the best performing Cancer Networks are given the name of a support group, only just over half of men in some Cancer Networks are given this information (see Table 2). Access to specialist nurses, which we know helps to improve men's overall care experience, is also highly variable. Only 4 in 10 men in some Cancer Networks find it easy to get in touch with their specialist nurse. However, in other Cancer Networks more than 8 in 10 men find it easy to do so.

This report shows that the information and support that men are getting in some Cancer Network areas is of a consistently high quality. The majority of men living in the Greater Manchester and Cheshire Cancer Network area, for example, are getting good support in virtually all of the patient experience topics examined in this report. However, in other areas, such as Arden and 3 Counties - two Cancer Networks in the West Midlands - and also Essex, there is clear room for improvement. Their patient experience scores are at the bottom end of the scale in almost every measure (see Table 2).

3. Survival and Mortality

While prostate cancer survival rates are improving across the UK and mortality rates are broadly falling, there are marked variations between each nation (see Table 1). Wales has the lowest one and five year survival rates but the lowest mortality rate in the UK. While the full picture is unclear, the low mortality rate may show that more low risk prostate cancers are being detected compared to the rest of the UK. However, the low survival rates could mean that men with aggressive disease in Wales may not always be treated in the most effective way.

The highest mortality rate is in England. However, the mortality rate varies significantly across the country (see Table 2). For example, in North London the mortality rate is significantly lower than it is in Merseyside and Cheshire. The same variation can also be seen in England's survival rates. There is a six per cent difference between the one year survival rates in the North Trent Cancer Network and the Yorkshire Cancer Network.

While a direct correlation between survival and mortality rates and service provision cannot be established, it's reasonable to assume that better and more consistent treatment and support could help improve the prospects of better outcomes across the UK.

Recommendations

UK Wide

Urgent action needs to be taken in each nation of the UK to tackle variations in prostate cancer outcomes identified in this report. There are several specific actions that policy makers and other stateholders can take to address these issues.

- To address the UK wide variation in prostate cancer outcomes, Prostate Cancer UK's Quality Checklist should be widely adopted.
- The health service, with support from Prostate Cancer UK and other stakeholders, must ensure that high quality information is available and regularly updated on:
 - men's stage at diagnosis;
 - the uptake of the PSA test and key prostate cancer treatments and drugs;
 - the availability of specialist nurses;
 - patient experience outcomes.This data will help us compare the way in which men are diagnosed, treated and supported in each region and country of the UK.
- We welcome the launch of the National Prostate Cancer Audit for England and Wales. However it's vital that this data is collected routinely across the whole of the UK so that we can compare men's access to new treatments and procedures between each nation.
- We welcome the commissioning of a National Cancer Patient Experience Survey in Wales and Northern Ireland. This means that we will have patient experience outcomes for men with prostate cancer in England, Wales and Northern Ireland. However, it's important that these surveys are repeated at regular intervals in each country - and are also closely aligned - so that we can measure change over time and compare the experiences of men in each country. It will also allow us to compare the outcomes of men with prostate cancer with those of people with other common cancers.
- We have commissioned a Prostate Cancer Patient Experience Survey for Scotland. Our report, which will be published in Spring 2013, will give us valuable data about men's care experiences in Scotland for the first time. However, it's vital that this survey is repeated regularly. We urge the Scottish Government to carry out a National Cancer Patient Experience Survey on similar lines to the ones that have been commissioned in England, Wales and Northern Ireland. It will also allow us to compare the experiences of men with prostate cancer with those of people with other common cancers and measure change over time.
- Regular surveys of the number of specialist nurses – for each tumour type – employed in each country and region of the UK also need to be carried out. This data will help us to identify any regional and national differences in access to specialist nurses.

England

We have combined prostate cancer incidence, survival, mortality and patient experience data across England to get a picture of how services are performing across the country. There are sharp variations in scores with Cancer Networks in the North of England outperforming Cancer Networks in the Midlands and the South East of England.

In particular, different health organisations in England can use available policy levers to drive up the quality of the patient experience and tackle variations. For example:

- NHS Hospital Trusts in areas with high prostate cancer incidence and patient experience outcomes which are lower than the national average should consider including a prostate cancer specific measure in their Commissioning for Quality and Innovation (CQUIN) payment scheme. The CQUIN scheme, which allows Trusts to gain extra income if they meet their identified CQUIN improvement targets, has become an important tool for driving up NHS performance at local level.
- Clinical Commissioning Groups (CCGs) in areas with high prostate cancer incidence should consider including a prostate cancer specific measure in their Quality Premium scheme. The Quality Premium scheme is another key performance improvement tool in the NHS. It works in a similar way as the CQUIN scheme.
- GPs should make sure that our Quality Checklist and relevant Prostate Cancer UK information materials are made available to men during their Cancer Care Review – which should take place six months after diagnosis. The Cancer Care Review is an important opportunity to assess men's information and support needs and to put together a package that's tailored to their needs.

Summary of prostate cancer outcomes

This section contains two tables. Table 1 provides a picture of the level of prostate cancer incidence, mortality and survival across the whole of the UK.

Table 2 focuses on patient experience outcomes of men with prostate cancer in England. This is because we don't yet have patient experience data for Scotland, Wales or Northern Ireland. The table brings together the data from the National Cancer Patient Experience Survey for each Cancer Network in England and also local prostate cancer incidence, mortality and survival data. It also includes a 'score' for each Cancer Network which allows us to produce an overall ranking of Cancer Networks.

A complete set of results can be found on our website prostatecanceruk.org/qualitycare including maps of prostate cancer incidence, survival and mortality in England, Scotland, Wales and Northern Ireland and a series of maps of patient experience outcomes by Cancer Network in England.

Table 1: Prostate Cancer incidence, survival and mortality rates across the UK

	Age-standardised incidence rate per 100,000 men ⁱ	One year survival for prostate cancer (%) ⁱⁱⁱ	Five year survival for prostate cancer (%) ^{iv}	Age-standardised mortality rate per 100,000 men ^v
England	106.4	95	83	23.8
Scotland	82.1	94	80	23.7
Wales	114.0	93	77	22.8
Northern Ireland	96.5	96	83	23.5
UK	104.5	95	82	23.8

ⁱ Department of Health (2012) National Cancer Patient Experience Survey 2011/2012 www.dh.gov.uk/health/2012/08/cancer-experience-survey/

ⁱⁱ Cancer Research UK (2013) Prostate Cancer Incidence Rates per 100,000 population in 2010. Accessed 6 March 2013. Available at <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/incidence/>

ⁱⁱⁱ National Cancer Intelligence Network (2011) 'One-year relative survival estimate, males, ICD10 C61 : Prostate, 2004-2008'. Accessed 10 January 2013. Available here: http://www.ncin.org.uk/cancer_information_tools/eatlas/pct/atlas.html?select=Eav&indicator=i0

^{iv} National Cancer Intelligence Network (2011), Five-year relative survival estimate, males, ICD10 C61 : Prostate, 2004-2008. Accessed 10 January 2013. Available here: http://www.ncin.org.uk/cancer_information_tools/eatlas/pct/atlas.html?select=Eav&indicator=i0

^v Cancer Research UK (2012) Prostate Cancer Mortality Rates per 100,000 population in 2010 <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/mortality/>

Table 2: Prostate Cancer incidence, mortality, survival and patient experience outcomes of Cancer Networks in England

(See next page for explanation of data used in this table)

Cancer Network	Age-standardised incidence rate per 100,000 men ^{vi}	Age-standardised mortality rate per 100,000 men ^{vii}	One year survival estimate (%) ^{viii}	Staff gave complete explanation of purpose of test(s) ^x	Patient given written information about their cancer type	Patient given a choice of different types of treatment	Patient finds it easy to contact their CNS	Hospital staff gave information about support groups	Patient offered written assessment and care plan	Composite score of outcomes
Greater Manchester & Cheshire	98.04	22.78	94.97	91%	83%	95%	75%	88%	22%	5
Anglia	107.44	24.00	96.14	90%	85%	88%	73%	87%	23%	3
Sussex	94.86	24.78	94.62	83%	82%	91%	77%	86%	28%	3
Kent and Medway	98.76	24.82	93.52	89%	84%	91%	76%	91%	31%	2
Mount Vernon	94.12	23.63	95.08	82%	75%	88%	77%	88%	23%	2
North London	118.57	23.75	96.70	93%	81%	97%	68%	80%	22%	2
North Trent	89.16	24.80	91.19	87%	81%	98%	85%	89%	21%	2
Yorkshire Cancer Network	111.32	23.69	97.00	92%	79%	94%	58%	86%	26%	2
Lancashire and South Cumbria	95.79	21.21	95.45	79%	75%	89%	74%	81%	22%	1
North of England	86.31	24.73	95.44	84%	80%	84%	79%	76%	32%	1
Pan Birmingham	108.44	23.74	96.06	84%	81%	96%	69%	82%	29%	1
South West London	106.72	21.77	95.99	89%	80%	92%	65%	82%	26%	1
Surrey, West Sussex and Hampshire	98.08	22.45	94.53	89%	83%	90%	80%	88%	18%	1
Thames Valley	109.62	24.04	94.69	89%	83%	93%	46%	88%	15%	1
Central South Coast	94.39	22.76	94.14	76%	74%	89%	68%	82%	22%	0
Humber and Yorkshire Coast	98.59	23.97	96.11	86%	71%	82%	86%	70%	28%	0
North West London	91.46	20.69	95.50	--	64%	84%	--	--	--	0
Peninsula	99.18	25.80	93.42	87%	74%	85%	77%	90%	26%	0
South East London	115.44	24.46	94.95	88%	79%	92%	61%	87%	37%	0
Avon, Somerset and Wiltshire	111.29	24.57	94.19	88%	79%	92%	80%	85%	25%	-1
Greater Midlands	97.45	24.20	96.23	73%	81%	88%	55%	86%	23%	-1
Merseyside and Cheshire	98.43	27.69	95.43	83%	81%	85%	72%	82%	27%	-1
Dorset	127.58	24.63	96.85	60%	76%	93%	--	78%	18%	-2
East Midlands	99.68	25.65	93.61	87%	79%	88%	70%	78%	24%	-2
North East London	98.88	21.46	94.73	70%	67%	88%	55%	64%	26%	-3
Essex	92.98	23.92	95.56	72%	69%	85%	57%	80%	19%	-4
Arden	102.80	25.33	97.50	70%	61%	71%	52%	65%	19%	-6
3Counties	105.90	25.35	95.86	70%	50%	67%	41%	55%	11%	-7

Explanation to Table 2

Table 2 includes three sets of data:

- The prostate cancer incidence, mortality and survival outcomes from each Cancer Network in England (columns 2-4). In each column the highest and lowest performing 25% of Cancer Networks are highlighted in green and black respectively.
- The results from six key questions in the National Cancer Patient Experience Survey 2011/12 for each Cancer Network in England that directly relate to our Quality Checklist (columns 5-10). In each column the highest and lowest performing 25% of Cancer Networks are highlighted in green and black respectively.
- A combined score (column 11) for each Cancer Network in England which is based on the outcomes in columns 2-10. Each Cancer Network is given a 'plus one' score or a 'minus one' score for each outcome in the highest and lowest performing 25% of Cancer Networks to arrive at a combined score.

Notes

3 Counties Cancer Network covers parts of Worcestershire, Herefordshire and Gloucestershire

Arden Cancer Network covers parts of Warwickshire and Worcestershire

Mount Vernon covers Hertfordshire, Luton and South Bedfordshire

Peninsula Cancer Network covers Devon and Cornwall

Next steps

Our report has focused largely on prostate cancer outcomes in England. This is because we don't yet have patient experience data for Scotland, Wales and Northern Ireland.

We have shown that many men with prostate cancer in England are receiving very good care, information and support. However, our report has also revealed that there are real variations around the country in terms of the care and support on offer to men. Tackling this variation is one of our key priorities. We want to ensure that all men with prostate cancer have access to high quality care and support, regardless of where they live. Over the next few years we will be working closely with NHS Trusts, Clinical Commissioning Groups and Local Authorities across England to ensure that the standards in our Quality Checklist are implemented.

We will also be working with Health Boards in Scotland, Wales and Northern Ireland to ensure our Quality Checklist is implemented. In Scotland we have also commissioned a Prostate Cancer Patient Experience Survey. This report, which will be published in Spring 2013, will give us a better understanding of Scottish men's care and support experiences.

National and local politicians also have an important role to play in tackling the variations we have found across the UK and ensuring that our standards are implemented. We invite politicians of all parties to work with us to ensure that all men get the care and support they deserve. To find out more about our work and to get involved please call our Campaigns Team on **0208 222 7622** or email **campaigns@prostatecanceruk.org**

^{vi} National Cancer Intelligence Network (2011) Cancer incidence rate males, ICD10 C61: Prostate, 2006-2008. Accessed 10 January 2013. Available at http://www.ncin.org.uk/cancer_information_tools/eatlas/network/atlas.html?select=Eav&indicator=i0

^{vii} National Cancer Intelligence Network (2011) One-year relative survival estimate, males, ICD10 C61 : Prostate, 2004-2008. Accessed 10 January 2013. Available at http://www.ncin.org.uk/cancer_information_tools/eatlas/network/atlas.html?select=Eav&indicator=i0

^{viii} National Cancer Intelligence Network (2011) Cancer mortality males, ICD10 C61 : Prostate, 2006-2008. Accessed 10 January 2013. Available at http://www.ncin.org.uk/cancer_information_tools/eatlas/network/atlas.html?select=Eav&indicator=i0

^{ix} Data in columns 5-10 is taken from Department of Health (2012) National Cancer Patient Experience Survey 2011/2012. Available at www.dh.gov.uk/health/2012/08/cancer-experience-survey/

