

# Urology Pathway Board

## Annual Report 2013/14

Pathway Clinical Director: Mr Satish Maddineni

Pathway Manager: James Leighton

## Executive summary

The Urology pathway board has been in existence since its first meeting on 23<sup>rd</sup> April and has met twice more since then. The attached report and work plan reflects this timescale.

The board has been responsive, positive and constructive and will look to build on this work plan with over the next 12 months.

The board has faced a number of challenges in its first 4 months. The board has been constituted at a time when the NW area commissioning team have begun a procurement process for Uro-oncology services.

The board currently has no patient representative. The board are keen that this is resolved in the near future and will work with Manchester cancer to address this issue and then put in place appropriate supportive measures for the patient representative.

However even within this short time frame the board has made progress as outlined below –

- The Board has started to develop a GP educational programme in collaboration with local CCGs.
- Has engaged with commissioners to inform the procurement process.
- Will support the commissioners by agreeing the clinical outcomes to be used to measure the newly commissioned service.
- Will establish sub groups with non-board members from the wider urological stakeholder community to design policy with regard to MRI prostate scanning..
- The board will review and refresh all clinical guidelines
- It will agree and apply a protocol for the active surveillance of prostate cancer patients
- It will agree and apply a protocol for the MRI scanning of prostate patients.
- It has commenced its audit programme
- The board will plan to be a pilot pathway for standardised data entry

As part of the on-going work plan the board will agree the outcome measures or outputs that will be used to assess and monitor the patient and carer experience along the whole pathway. This will be addressed as part of this year's action plan.

As part of this it is also planning to support patients and carers better in living with and beyond their disease by getting a deeper understanding of the non-surgical elements of the pathway and designing appropriate supportive measures. It will also support the agenda of the detection, prevention and awareness cross cutting group.

The board sees this as a key function and one that it looks forward to undertaking.

In the coming year the board has set 5 objectives and these are –

- Optimise data collection to generate outcome measures
- Defining the MR scanning protocols for prostate cancer
- Agree an active surveillance policy for prostate cancer
- Confirming the key clinical outcomes to be measured for bladder, renal and prostate cancer

## Introduction

2013/14 was a transitional year for cancer services in Greater Manchester and East Cheshire. The Greater Manchester and Cheshire Cancer Network ceased to exist in March 2013 when cancer networks nationally were amalgamated into strategic clinical networks as part of the NHS reorganisation. In Greater Manchester this coincided with the creation of Manchester Cancer, an integrated cancer system for Greater Manchester and East Cheshire.

Twenty Manchester Cancer Pathway Clinical Directors were appointed in late 2013 and took up their roles on 1<sup>st</sup> January 2014. They spent the first months in post forming their Pathway Boards, multi-professional clinical groups from across the region. These pathway Boards are now formed and most had their first meeting in April/May of 2014.

As such, this is a transitional annual report. It outlines the current configuration of services, the progress in forming the Pathway Board, the data on outcomes and experience that the Board took into account when setting its objectives, and what those objectives are for 2014/15 and beyond. In July 2015 every Manchester Cancer Pathway Board will publish a full annual report, outlining the work of its first full year and its progress against those objectives.

This annual report is designed to:

- Provide a summary of the work programme, outcomes and progress of the Board – alongside the minutes of its meetings, its action plan and its scorecard it is the key document for the Board.
- Provide an overview to the hospital trust CEOs and other interested parties about the current situation across Manchester Cancer in this particular cancer area
- Meet the requirements of the National Cancer Peer Review Programme
- Be openly published on the external facing website.

## 1. General overview

There are 5 urological cancer types, Bladder, prostate, renal, testes and penile.

Bladder cancer is the seventh most common cancer in the UK (2011), accounting for 3% of all new cases. In males, it is the fourth most common cancer (4% of male total), whilst it is the 13th most common cancer in females (2% of female total).<sup>1-4</sup>

In 2011, there were 10,399 new cases of bladder cancer in the UK 7,452 (72%) in men and 2,947 (28%) in women, giving a male: female ratio of around 2.5:1. The crude incidence rate shows that there are 24 new bladder cancer cases for every 100,000 males in the UK, and 9 for every 100,000 females.

Bladder cancer is the 7th most common cause of cancer death in the UK (2011) accounting for 3% of all deaths from cancer. In men it is the 6th most common cause of cancer death (2011), accounting for 4% of all male deaths from cancer. Amongst women in the UK,

bladder cancer is the 12th most common cause of cancer death (2011), accounting for 2% of all female cancer deaths.

In 2011, there were 5,081 deaths from bladder cancer in the UK 3,408 (67%) in men and 1,673 (33%) in women, giving a male: female ratio of more than 2:1. The crude mortality rate shows that there were 11 cancer deaths for every 100,000 males in the UK, and 5 for every 100,000 females.

**Age-Standardised One, Five and Ten Year Relative Survival Rates, Adults Aged 15-99, England 2005-2009, England and Wales 2007**

	Relative Survival (%)		
	1 Year	5 Year	10 Year
Sex	2005-2009	2005-2009	2007*
Male	78.4	58.2	51.5
Female	68.2	50.2	42.4

\*The ten-year survival rates have been predicted for patients diagnosed in 2007 (using the hybrid approach).

Note: Survival for one and five years is for England only and for ten years is for England and Wales

Prepared by Cancer Research UK

Prostate cancer is the most common cancer in men in the UK (2011), accounting for 25% of all new cases of cancer in males.<sup>1-4</sup> In 1990, both lung and bowel cancers were more common in males than prostate cancer, but by 1998 prostate cancer was the most common cancer in UK males.

In 2011, there were 41,736 new cases of prostate cancer in males in the UK. The crude incidence rate shows that there are 134 new prostate cancer cases for every 100,000 males in the UK.

Prostate cancer is the 4th most common cause of cancer death in the UK (2011), accounting for around 7% of all cancer deaths. It is the second most common cause of cancer death among men (2011) in the UK, accounting for 13% of all male deaths from cancer.

In 2011, there were 10,793 deaths from prostate cancer in the UK. The crude mortality rate shows that there are 35 prostate cancer deaths for every 100,000 males in the UK.

**Age-Standardised One, Five and Ten Year Relative Survival Rates, Adults Aged 15-99, England 2005-2009, England and Wales 2007**

	Relative Survival (%)		
	1 Year	5 Year	10 Year
Sex	2005-2009	2005-2009	2007*
Male	93.5	81.4	68.5

\*The ten-year survival rates have been predicted for patients diagnosed in 2007 (using the hybrid approach).

Note: Survival for one and five years is for England only and for ten years is for England and Wales

Prepared by Cancer Research UK

Renal cancer is the 8th most common cancer in the UK (2011), accounting for around 3% of all new cases. In males, it is the 7th most common cancer (4% of the male total), whilst it is 10th in females (2%).

In 2011, there were 10,144 new cases of renal cancer in the UK, 6,257 (62%) in men and 3,887 (38%) in women, giving a male: female ratio of around 1.6:1. The crude incidence rate shows that there are 20 new renal cancer cases for every 100,000 males in the UK, and 12 for every 100,000 females.

Renal cancer is the 12th most common cause of cancer death in the UK (2011), accounting for 3% of all deaths from cancer. It is the 9th most common cause of cancer death among men in the UK (2011), accounting for 3% of all male deaths from cancer. Among women in the UK, Renal cancer is the 14th most common cause of cancer death (2011), accounting for 2% of all female cancer deaths.

In 2011, there were 4,189 deaths from renal cancer in the UK (**Table 2.1**): 2,572 (61%) in men and 1,617 (39%) in women, giving a male: female ratio of around 16:10. The crude mortality rate shows that there are 8 cancer deaths for every 100,000 males in the UK, and 5 for every 100,000 females.

**Age-Standardised One, Five and Ten Year Relative Survival Rates, Adults Aged 15-99, England 2005-2009, England and Wales 2007**

	Relative Survival (%)		
	1 Year	5 Year	10 Year
Sex	2005-2009	2005-2009	2007*
Male	71.5	53.3	43
Female	71.4	54.8	44.3

\*The ten-year survival rates have been predicted for patients diagnosed in 2007 (using the hybrid approach).

Note: Survival for one and five years is for England only and for ten years is for England and Wales

Prepared by Cancer Research UK

2,207 men in the UK were diagnosed with testicular cancer in 2011. There were 68 deaths from testicular cancer in the UK in 2011 and 97.2% of adult testicular cancer patients in England survived their cancer for five years or more in 2005-2009.

Penile cancer is very rare and there are around 500 cases in the UK every year.

**2. Background to the pathway**

The Urology pathway board replaces what was the Urology Network Site Specific Group (NSSG) of the previously constituted Greater Manchester and Cheshire Cancer network (GMCCN).

The NSSG was a multi-professional group chaired by Mr Maurice Lau, who is a Consultant urology surgeon based at Salford Royal and the Christie NHS Foundation Trusts. He is not a member of the Manchester Cancer pathway board.

The Urology NSSG was a well-established Network group with a consistently high attendance and representation from all MDTs, SMDTs and SnMDTs. The catchment populations of each MDT were clearly defined and referral pathways to SMDTs and SnMDTs were agreed.

However, the network continued to be non-IOG compliant throughout its lifespan. In order to address this and other non-compliant services in Greater Manchester, two cancer summits were organised to agree how to work collaboratively across institutional boundaries to improve patient outcomes and ensure parity of treatments.

An initial agreement appeared to have been reached amongst the senior clinicians in 2012/13. Unfortunately challenges were then tabled by individual Foundation Trusts and as a result the commissioners commenced a formal procurement process in July 2014. The commissioners anticipate that a newly commissioned service will be operational by June 2015.

The purpose of the pathway board is to ensure that services for patients with suspected or diagnosed Urological Cancer (of the Kidney, Prostate, Bladder, or Penis/Testicle) are being delivered in accordance with NICE Improving Outcomes Guidance (IOG) and Peer Review Cancer Quality Measures, as well as the Guidelines for the Management of urological tumours, 2010 (GMCCN) and the current national specifications of the NHS England CRG.

### **3. Configuration of services**

The Manchester Cancer Urology pathway board covers a population of just over 3.2 million and oversees the coordination of services for patients with suspected or diagnosed urological cancer. It will also work collaboratively and have input into the Manchester Cancer cross cutting groups with responsibility for living with and beyond cancer and early detection and prevention of the disease.

This is a large and complex network with a number of treating organisations. As outlined the current configuration of four specialist MDTs (SMDT) with five operating sites is not IOG compliant which is deemed a significant risk. Furthermore it was noted that currently one of the SMDTs has considerably less than the required one million catchment population.

A cancer summit involving all constituent trusts in the network took place in September 2012, where it was agreed that an action plan to deliver an IOG compliant service would be developed and adopted by April 2013. As a result the process to reconfigure the service commenced in mid-2013. However, as described above, this has had to proceed to a formal procurement and tendering process as agreement on the operating sites could not be agreed.

The supra-network configuration for testicular and penile cancer services is IOG compliant with good linkage across organisational and network boundaries. Minimally invasive surgery is offered in most of the SMDT sites. Access to the Da Vinci robot is currently via the Christie NHS Foundation Trust.

There is also a well-established nursing group who meets regularly to share issues and good practice and are actively involved in audit programmes.

The pathway board is covering a population over 3 million served by the following Acute Hospital Trusts:

North West Sector:

Wrightington, Wigan and Leigh NHS Foundation Trust  
 Royal Bolton Hospital NHS Foundation Trust  
 Salford Royal NHS Foundation Trust

North East Sector:

Pennine Acute Hospitals NHS Trust (Bury, North Manchester, Oldham, Rochdale Hospitals)  
 Central Manchester University Hospitals NHS Foundation Trust (including patient flows form Trafford)

South Sector:

Tameside Acute NHS Foundation Trust  
 Stockport NHS Foundation Trust  
 East Cheshire NHS Trust  
 Mid Cheshire NHS Foundation Trust

Second South Sector:

University Hospital of South Manchester NHS Foundation Trust

The Christie Hospital is a Tertiary Referral Centre for the Cancer Network. Radiotherapy is delivered at the Christie Hospital and the satellite radiotherapy units are based at the Royal Oldham Hospital and Salford Royal. Chemotherapy is currently delivered from the Christie Hospital.

The Christie Hospital also hosts the Supra-network MDTs (SnMDTs) for testicular and penile cancers in populations covered by GMCCN and neighbouring network(s). The testicular SnMDT also serves populations from Lancashire and South Cumbria Cancer network (LSCCN), and the penile SnMDT also serves populations of LSCCN and Merseyside and Cheshire Cancer Network (MCCN).

**Table 1 - Specialist Urology Cancer Teams**

Host Trust	Urology SMDT Lead Clinician	Referring local MDTs	Catchment Population *
CMFT	Mr Neeraj Sharma	Pennine	819,720
		CMFT	206,690
		Trafford Healthcare	232,619
		<b>Total</b>	<b>1,259,029</b>
Salford	Mr Satish Maddineni	Wrightington, Wigan & Leigh	315,766
		Salford	233,966
		Bolton	288,341
		<b>Total</b>	<b>838,073</b>

South	Mr Vijay Sangar	UHSM	162,603
		<b>Total</b>	<b>162,603</b>
Stockport	Mr Rick Brough	High Peak (out of Network)	50,000
		Stockport	298,505
		East Cheshire and Mid Cheshire Trusts	470,777
		Tameside	240,079
		<b>Total</b>	<b>1,059,361</b>
		<b>GRAND TOTAL</b>	<b>3,319,066</b>

*\*Figures from NSTS Registered Populations Q3 2010-11*

**Table 2 – Supra Network Penile and Testicular Teams**

<b>Tumour Group</b>	<b>Networks included in Supranetwork MDT</b>	<b>PCT Populations</b>	<b>Supra-network Team Base</b>
Penile	Greater Manchester and Cheshire Cancer Network	3.3m	The Christie NHS FT (operating site at Christie)
	Merseyside and Cheshire Cancer Network	2.3m	
	Lancashire and Cumbria Network	1.7m	
	<b>Total</b>	<b>7,300,000</b>	
Testicular	Greater Manchester and Cheshire Cancer Network	3.3m	The Christie NHS FT
	Lancashire and Cumbria Network	1.7m	
	North Wales	0.6m	
	<b>Total</b>	<b>5,600,000</b>	

## 4. Clinical guidelines

The Pathway Board has only been in place since spring 2014 and has not yet had the opportunity to review its clinical guidelines and patient pathways. As such, the guidelines created by the previous cancer network group have been adopted until such time as they can be reviewed and updated in the coming year.

All of the relevant documentation remains on the legacy website of the old cancer network [www.gmccn.nhs.uk](http://www.gmccn.nhs.uk) and will be migrated to the Manchester Cancer website over the coming months [www.manchestercancer.org](http://www.manchestercancer.org).

A full list of active current guidelines and their renewal dates will be produced for the updated constitution of July 2015.

**Table 3**

Network Agreed Guidelines for the Management of Kidney Cancer
Network Agreed Guidelines for the Management of Bladder Cancer
Network Agreed Guidelines for the Management of Prostate Cancer
Network Agreed Guidelines for the Management of T2, Muscle Invasive Bladder Cancer and Organ-Confined Prostate Cancer <i>(please see Bladder and Prostate Guidelines above, respectively)</i>
Network/Supra-Network Agreed Guidelines for the Management of Testicular Cancer – Diagnosis and Assessment
Specialist Team Referral Guidelines for Testicular Cancer
Network/Supra-Network Agreed Guidelines for the Management of Penile Cancer – Diagnosis and Assessment

The Network Chemotherapy Group has developed chemotherapy treatment algorithms for all tumour groups which can be found using the following link. These algorithms are updated regularly with the most recent version being available on the Christie Hospital intranet site (accessed via N3 (NHS) connections only).

<http://www.christie.nhs.uk/documents/default.aspx?Category=Y&Category1=1>

The user should follow the link above, then under the document database Category Search:

1. Select Policies & Clinical Guidelines
2. From the sub-category 1 drop down menu select Chemotherapy Protocols
3. This gives a selection of potential documents

## 5. Clinical information and outcomes

The specialist urological multi-disciplinary teams (SMDT) will provide specialist care for their referring catchment. Each SMDT are based at named hospitals, and are currently operating on 5 sites, which, as outlined, is non-IOG compliant.

Each of the specialist teams will also provide local care to the catchment for their localities. Specialist surgery and immediate post-operative care will be provided by the specialist teams in the named hospitals.

Members of the UHSM and Salford teams also work in the supra-network team at The Christie. Complex pelvic cancer, robotic assisted prostatectomy, penile cancer and post treatment salvage surgery for testis cancer are currently managed at the Christie.

The Christie currently hosts an inter-disciplinary pelvic surgical team. All radiotherapy is undertaken at The Christie, Christie @Oldham or Christie @Salford.

The specialist surgical teams will undertake the following range of treatments:

### **Bladder cancer**

- Radical surgery (cystectomy)
- Bladder reconstruction
- Surgery for urinary diversion
- Resection of urethral cancer
- Resection of squamous or adenocarcinoma
- Partial cystectomy for cancer

### **Prostate Cancer**

- Radical prostatectomy

### **Kidney Cancer**

- Resection of primary tumours which have or are suspected to have invaded renal vein, vena cava or right atrium
- Resection of metastatic disease
- Resection of both primary and associated metastatic disease
- Resection of bilateral primaries or resection of any primary where it is predicted that the patient will subsequently require dialysis
- Surgical management of patients with von Hippel-Lindau disease or hereditary papillary tumours
- Resection of complex urothelial cancers of the upper urinary tract (bilateral or multi focal disease, cases requiring reconstruction)
- Resection by nephron-sparing surgery
- Resection of non-renal cell kidney cancer treated by nephro-ureterectomy to be discussed at SMDT and decision made on local treatment site.

The information on surgical outcomes is uploaded to the British Association of Urological surgeons (BAUS) by each site.

## **6. Patient experience**

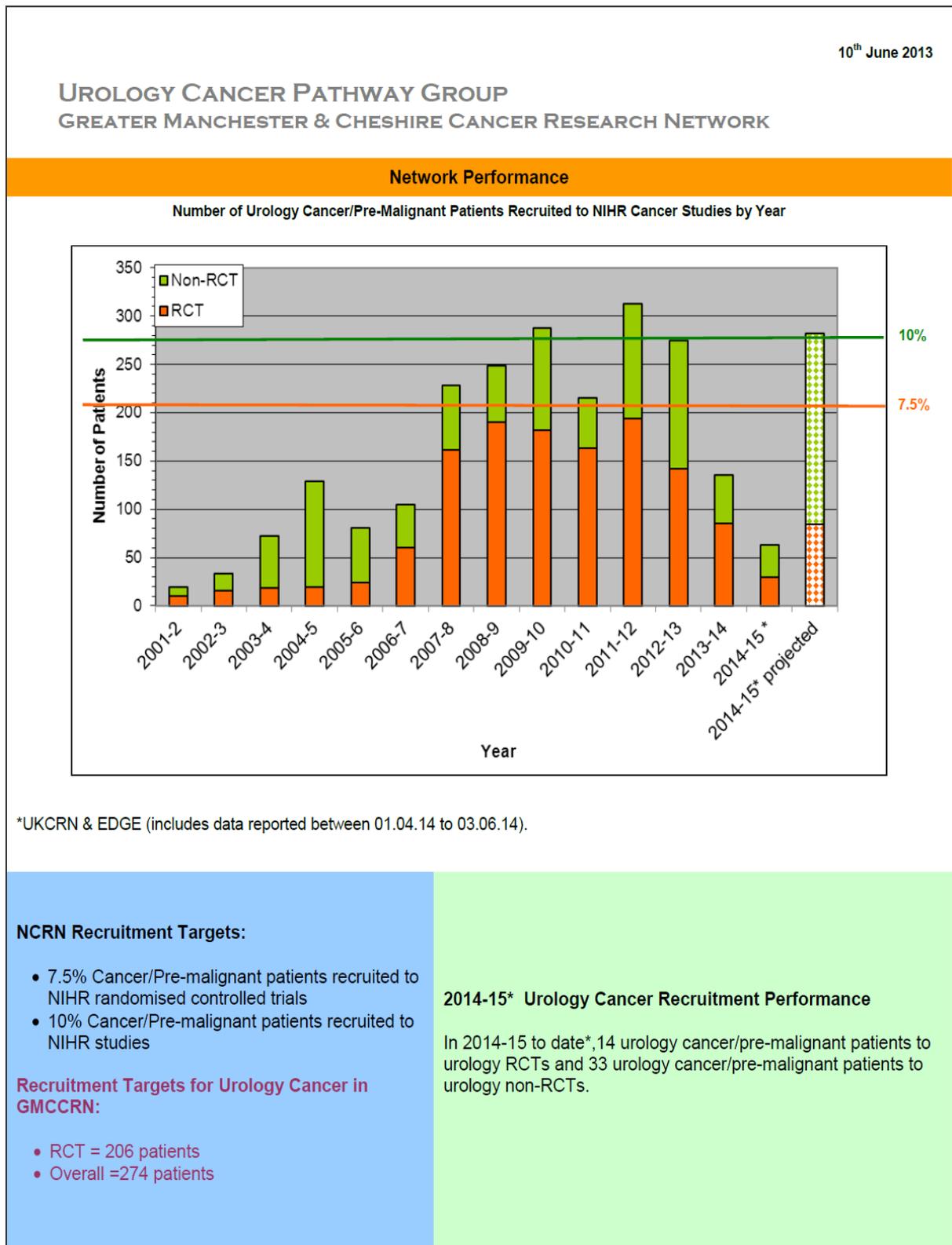
Local MDT's and SMDT's continue to perform patient satisfaction surveys.

The last National Patient Satisfaction survey was published in 2012 and the results for Greater Manchester urology services are on the table below.

		GREATER MANCHESTER & CHESHIRE	GREATER MANCHESTER & CHESHIRE	GREATER MANCHESTER & CHESHIRE	GREATER MANCHESTER & CHESHIRE	GREATER MANCHESTER & CHESHIRE	GREATER MANCHESTER & CHESHIRE	GREATER MANCHESTER & CHESHIRE
		RBV	RM2	RM3	RMC	RRF	RW6	RWJ
		THE CHRISTIE NHS FOUNDATION TRUST	UNIVERSITY HOSPITAL OF SOUTH MANCHESTER NHS FOUNDATION TRUST	SALFORD ROYAL NHS FOUNDATION TRUST	BOLTON NHS FOUNDATION TRUST	WRIGHTINGTON, WIGAN AND LEIGH NHS FOUNDATION TRUST	THE PENNINE ACUTE HOSPITALS NHS TRUST	STOCKPORT NHS FOUNDATION TRUST
		Urological	Urological	Urological	Urological	Urological	Urological	Urological
Question No.	Cancer Type	No of responses						
Q1	Saw GP once/twice before being told had to go to hospital	37	64	38	45	37	102	75
Q2	Patient thought they were seen as soon as necessary	70.0%	70.5%	67.7%	67.5%	85.2%	76.2%	79.0%
Q3	% ans. less than 12 months	80.0%	88.5%	92.1%	90.7%	91.7%	80.2%	96.0%
Q4	Patient's health got better or remained about the same while waiting	94.3%	96.7%	97.3%	97.6%	91.2%	96.0%	97.3%
Q5	% ans. they've had diagnostic tests for cancer in last 12 months	88.5%	76.2%	84.2%	100.0%	88.2%	88.2%	89.2%
Q6	Staff gave complete explanation of purpose of test(s)	91.9%	95.2%	91.4%	100.0%	97.1%	94.8%	98.6%
Q7	Staff explained completely what would be done during test	87.5%	82.6%	90.6%	87.8%	78.6%	76.1%	84.1%
Q8	Staff explained completely what would be done during test	90.6%	89.8%	96.9%	100.0%	83.9%	82.4%	88.9%
Q9	Given complete explanation of test results in understandable way	100.0%	87.0%	88.9%	93.8%	88.0%	84.5%	82.5%
Q10	% ans. that they were first told by a doctor (incl GP) or nurse	72.2%	79.2%	87.5%	85.1%	75.0%	77.2%	79.2%
Q11	% ans. that they were first told by a doctor (incl GP) or nurse	97.1%	98.4%	100.0%	97.6%	94.3%	95.9%	97.2%
Q12	Patient told they could bring a friend when first told they had cancer	69.0%	67.9%	66.7%	69.7%	53.8%	70.0%	55.6%
Q13	Patient felt they were told sensitively that they had cancer	86.5%	89.1%	86.8%	90.7%	80.0%	74.0%	81.3%
Q14	Patient completely understood the explanation of what was wrong	83.3%	78.1%	78.9%	78.6%	80.0%	77.8%	77.3%
Q15	Patient given written information about the type of cancer they had	78.1%	70.4%	77.4%	70.6%	63.0%	66.7%	70.3%
Q16	Patient given a choice of different types of treatment	90.9%	72.0%	87.5%	91.7%	37.5%	86.7%	66.7%
Q17	Patient's views definitely taken into account by doctors and nurses discussing treatment	77.4%	79.2%	82.8%	66.7%	50.0%	55.7%	65.5%
Q18	Possible side effects explained in an understandable way	80.0%	75.0%	75.0%	59.4%	66.7%	60.2%	74.2%
Q19	Patient given written information about side effects	97.1%	71.7%	80.6%	71.4%	45.2%	67.4%	69.1%
Q20	Patient definitely involved in decisions about care and treatment	72.2%	81.0%	73.5%	75.7%	57.1%	60.8%	56.9%
Q21	Patient given the name of the CNS in charge of their care	93.9%	83.9%	87.9%	73.0%	63.6%	70.5%	89.9%
Q22	Patient finds it easy to contact their CNS	86.7%	85.7%	72.7%	72.2%	44.4%	70.7%	74.6%
Q23	CNS definitely listened carefully the last time spoken to	96.8%	94.0%	96.0%	82.6%	88.1%	89.1%	95.1%
Q24	Get understandable answers to important questions all/most of the time	100.0%	95.2%	94.7%	82.4%	69.3%	94.8%	89.3%
Q25	Hospital staff gave information about support groups	81.5%	80.0%	65.0%	76.2%	50.0%	57.1%	60.5%
Q26	Hospital staff gave information on getting financial help	62.5%	33.3%	17.6%	14.3%	10.0%	23.5%	22.6%
Q27	Hospital staff told patient they could get free prescriptions	91.7%	78.9%	86.7%	86.7%	33.3%	54.8%	79.0%
Q28	Taking part in cancer research discussed with patient	42.4%	25.9%	12.6%	10.0%	9.3%	9.3%	24.3%
Q29	Patient would like to have been asked about taking part in cancer research							
Q30	% ans. they've had an operation in last 12 months	72.2%	87.3%	91.9%	90.2%	91.7%	87.0%	92.0%
Q31	Admission date not changed by hospital	96.2%	89.2%	85.3%	81.1%	87.0%	74.7%	84.2%
Q32	Staff gave complete explanation of what would be done	88.0%	88.2%	90.3%	97.2%	78.1%	73.8%	91.2%
Q33	Patient given written information about the operation	83.3%	66.7%	72.4%	68.8%	69.0%	68.8%	80.3%
Q34	Staff explained how operation had gone in understandable way	87.5%	76.4%	69.7%	71.1%	64.9%	64.2%	68.7%
Q35	% ans. they've stayed overnight for cancer care in last 12 months	91.4%	96.9%	92.1%	84.4%	81.1%	87.6%	93.2%
Q36	Got understandable answers to important questions all/most of the time	86.2%	81.9%	92.9%	77.8%	66.7%	70.7%	80.6%
Q37	Patient had confidence and trust in all doctors treating them	93.5%	90.2%	94.3%	86.5%	90.0%	80.9%	87.1%
Q38	Doctors did not talk in front of patient as if they were not there	81.3%	79.0%	85.7%	78.9%	90.0%	69.7%	70.6%
Q39	Patient's family definitely had opportunity to talk to doctor	62.5%	71.4%	67.9%	65.2%	47.6%	57.6%	56.9%
Q40	Got understandable answers to important questions all/most of the time	87.1%	77.4%	82.8%	76.7%	87.0%	63.6%	67.3%
Q41	Patient had confidence and trust in all ward nurses	81.3%	77.4%	77.1%	78.4%	66.7%	67.1%	62.3%
Q42	Nurses did not talk in front of patient as if they were not there	90.6%	87.1%	88.6%	89.5%	93.3%	80.7%	80.0%
Q43	Always / nearly always enough nurses on duty	74.2%	61.7%	62.9%	73.0%	66.7%	55.2%	65.2%
Q44	Patient did not think hospital staff deliberately misled them	93.8%	90.3%	97.1%	83.8%	90.0%	88.8%	91.3%
Q45	Patient never thought they were given conflicting information	87.5%	86.9%	94.3%	86.5%	86.7%	82.0%	81.2%
Q46	All staff asked patient what name they preferred to be called by	56.3%	51.6%	54.3%	73.0%	67.9%	51.7%	36.8%
Q47	Always given enough privacy when discussing condition/treatment	90.6%	82.0%	94.1%	86.8%	96.7%	77.0%	83.8%
Q48	Always given enough privacy when being examined or treated	96.9%	93.5%	97.1%	89.5%	100.0%	87.6%	91.4%
Q49	Patient was able to discuss worries or fears with staff during visit	82.1%	67.3%	76.0%	65.4%	56.3%	55.1%	58.2%
Q50	Hospital staff did everything to help control pain all of the time	87.1%	80.0%	86.2%	69.2%	86.4%	70.8%	78.9%
Q51	Always treated with respect and dignity by staff	90.9%	91.5%	91.4%	84.2%	90.0%	80.9%	78.3%
Q52	Given clear written information about what should / should not do post discharge	93.5%	69.2%	83.9%	80.0%	73.1%	71.8%	75.8%
Q53	Staff told patient who to contact if worried post discharge	100.0%	76.4%	90.6%	81.8%	84.6%	84.1%	83.6%
Q54	Family definitely given all information needed to help care at home	71.4%	45.5%	38.5%	58.3%	36.8%	54.7%	55.3%
Q55	Patient definitely given enough care from health or social services	60.0%	53.3%	90.0%	33.3%	37.5%	47.4%	53.3%
Q56	Staff definitely did everything to control side effects of radiotherapy	100.0%						
Q57	Staff definitely did everything to control side effects of chemotherapy	81.0%	71.4%	81.3%	87.5%	86.7%	75.9%	58.8%
Q58	Staff definitely did everything they could to help control pain	78.9%	80.0%	75.0%	72.2%	71.4%	74.5%	86.5%
Q59	Hospital staff definitely gave patient enough emotional support	82.6%	80.6%	68.4%	78.3%	76.9%	74.6%	66.7%
Q60	% ans. they've had an OP appt with a cancer doctor in last 12 months	97.3%	81.4%	88.9%	81.0%	75.0%	89.8%	78.9%
Q61	Waited no longer than 30 minutes for OP appointment to start	72.7%	71.1%	68.8%	88.2%	84.6%	61.8%	85.7%
Q62	Patient thought doctor spent about the right amount of time with them	91.7%	93.3%	93.8%	97.1%	88.5%	91.5%	91.5%
Q63	Doctor had the right notes and other documentation with them	97.1%	98.0%	96.7%	100.0%	100.0%	92.9%	90.7%
Q64	GP given enough information about patient's condition and treatment	96.9%	96.2%	100.0%	93.8%	96.7%	92.5%	93.2%
Q65	Practice staff definitely did everything they could to support patient	67.9%	67.6%	69.2%	66.7%	78.6%	71.7%	70.8%
Q66	Hospital and community staff always worked well together	62.9%	70.3%	68.6%	68.4%	65.7%	60.0%	64.8%
Q67	Given the right amount of information about condition and treatment	91.7%	92.2%	89.2%	85.7%	91.7%	86.9%	90.5%
Q68	Patient offered written assessment and care plan	7.4%	21.4%	17.2%	17.1%	6.7%	16.5%	27.1%
Q69	Patient did not feel that they were treated as a 'set of cancer symptoms'	80.6%	87.1%	90.9%	85.7%	85.3%	81.8%	81.7%
Q70	Patient's rating of care 'excellent' / 'very good'	88.9%	89.1%	91.7%	90.5%	88.9%	81.8%	90.7%



7. Research and clinical trials



## Peer review papers published by members of the SMDTs in the last 12 months.

Aflibercept versus placebo in combination with docetaxel and prednisone for treatment of men with metastatic castration-resistant prostate cancer (VENICE): a phase 3, double-blind randomised trial. Ian F Tannock, Karim Fizazi, Sergey Ivanov, Camilla Thellenberg Karlsson, Aude Fléchon, Iwona Skoneczna, Francisco Orlandi, Gwenaëlle Gravis, Vsevolod Matveev, Sevil Bavbek, Thierry Gil, Luciano Viana, Osvaldo Arén, Oleg Karyakin, Tony Elliott, Alison Birtle, Emmanuelle Magherini, Laurence Hatteville, Daniel Petrylak, Bertrand Tombal, Mark Rosenthal, on behalf of the VENICE investigators *Lancet Oncol.* 2013 Jul;14(8):760-8. Epub 2013 Jun 4.

Phase II study to assess the efficacy, safety and tolerability of the mitotic spindle kinesin inhibitor AZD4877 in patients with recurrent advanced urothelial cancer. Jones R, Vuky J, Elliott T, Mead G, Arranz JA, Chester J, Chowdhury S, Dudek AZ, Müller-Mattheis V, Grimm MO, Gschwend JE, Wülfing C, Albers P, Li J, Osmukhina A, Skolnik J, Hudes G. *Invest New Drugs.* 2013 Aug; 31(4):1001-7. Epub 2013 Jan 18.

Should centralised histopathological review in penile cancer be the global standard? Tang V, Clarke L, Gall Z, Shanks J, Nonaka D, Parr N, Elliott P, Clarke N, Ramani V, Lau M, Sangar V. *BJU Int.* 2013 Sep 5. doi: 10.1111/bju.12449.

Phase II trial of docetaxel, cisplatin and 5FU chemotherapy in locally advanced and metastatic penis cancer (CRUK/09/001). S Nicholson\*, E Hall, S J Harland, J D Chester, L Pickering, J Barber, T Elliott, A Thomson, S Burnett, C Cruickshank, B Carrington, R Waters and A Bahl. *British Journal of Cancer* (2013) 109, 2554–2559. Published online 29 October 2013

Donaldson SB, Bonington SC, Kershaw LE, Cowan R, Lyons J, Elliott T, et al. Dynamic contrast-enhanced MRI in patients with muscle-invasive transitional cell carcinoma of the bladder can distinguish between residual tumour and post-chemotherapy effect. *Eur. J. Radiol.* Elsevier Ireland Ltd; 2013 Dec; 82(12):2161–8.

*European Journal of Radiology*; 2013; <http://dx.doi.org/10.1016/j.ejrad.2013.08.008> (available as online publication 12 Sept 2013) (accepted manuscript, in press)

Advanced prostate cancer: Advancing patient care. Heather Payne, Chris Parker, Noel Clarke, Chris Farnham, Nimish Shah, Danish Mazhar, Robert Huddart, James Green, Tony Elliott. *Trends in Urology & Men's Health.* Volume 5, Issue 1, pages 40–42, January/February 2014.

Optimisation of an immunohistochemistry method for the determination of androgen receptor expression levels in circulating tumour cells. Jeffrey Cummings, Robert Sloane, Karen Morris, Cong Zhou, Matt Lancashire, David Moore, Tony Elliot, Noel Clarke and Caroline Dive. *BMC Cancer* 2014, 14: 226. Published: 28 March 2014.

Patient-reported Outcomes and Health-related Quality of Life in Prostate Cancer Treated with a Single Fraction of High Dose Rate Brachytherapy Combined with Hypofractionated External Beam Radiotherapy . A. Choudhury, \*C. Arthur, J. Malik, P. Mandall, R. Swindell,

C. Taylor, N. Alam, A. Tran, J. Livsey, T. Elliott, S. Davidson, J.P Logue, J. Wylie. *Clinical Oncology*. Available online 12 July 2014.

Cardiovascular outcomes in patients with locally advanced and metastatic prostate cancer treated with luteinising-hormone-releasing-hormone agonists or transdermal oestrogen: the randomised, phase 2 MRC PATCH trial (PR09)

Langley R, Cafferty L, Alhasso A Rosen , Sundaram SK, Freeman S, Pollock P , Jinks R, Godsland I, Kockelbergh R, Clarke NW, Kynaston H, Parmar MHK, Abel P  
*Lancet Oncology* doi:10.1016/S1470-2045(13)70025-1 March 2013

Prostate Radiotherapy for Men with Metastatic Disease: A New Comparison in the STAMPEDE Trial Parker C, Sydes MR, Mason MD, Clarke NW et al *Clin Oncology*  
<http://dx.doi.org/10.1016/j.clon.2013.01.005> April 2013

Exploring the spectroscopic differences of Caki-2 cells progressing through the cell cycle while proliferating in-vitro Jimenez-Hernandez M, Hughes C, Bassan P, Ball F, Brown M, Clarke NW, Gardner P. *Analyst* 2013, 138 (14), 3957 - 3966

Methylation Profiling and Evaluation of Demethylating Therapy in Renal Cell Carcinoma C Ricketts, M Morris, Gentle D, S Salwati, Brown M, Clarke NW, Wei W, Nathan P, Latif F, Maher E *Clinical Epigenetics* 2013

[A systematic review of neoadjuvant and adjuvant chemotherapy for muscle-invasive bladder cancer.](#) Meeks JJ, Bellmunt J, Bochner BH, Clarke NW, Daneshmand S, Galsky MD, Hahn NM, Lerner SP, Mason M, Powles T, Sternberg CN, Sonpavde G. *Eur Urol*. 2012 Sep;62(3):523-33. doi: 10.1016/j.eururo.2013.05.048.

Nasty or Nice? Findings from a UK Survey to Evaluate the Impact of the National Institute for Health and Clinical Excellence (NICE) Clinical Guidelines on the Management of Prostate Cancer Payne H, Clarke NW, Huddart R, Parker C, Troup J, Graham *Clin Oncology* 2013 Mar;25(3):178-89. doi: 10.1016/j.clon.2012.09.001. Epub 2012 Oct 15

Whole organ cross-section chemical imaging using label-free mega-mosaic FTIR microscopy Bassan P, Sachdeva A, Shanks J, Brown M, Clarke NW, Gardner P, *Analyst*, 2013, DOI: 10.1039/C3AN01674A.

Management of testicular tumours Clarke NW; *Surgery* 2013: 31:10 535-542

Advanced prostate cancer: advancing patient care Payne HA, Parker C, Clarke NW et al *Trends in Urology & Men's Health* 2014: Jan/Feb: 40-42

Arachidonic Acid induction of Rho Mediated Transendothelial Migration in Prostate Cancer Tawadros T, Brown M, Hart C, Clarke NW *Brit J Cancer* 2014

Assessing the challenges of Fourier transform infrared spectroscopic analysis of blood serum Hughes C, Brown M, Clemens G, Henderson A, Monjardez G, Clarke NW, Gardner P Journal of Biophotonics 2014 JBIO.201300167.R1

Optimisation of an Immunohistochemistry Method for the Determination of Androgen Expression Levels in Circulating Tumour Cells Cummings J, Sloane R, Morris K, Zhou C, Lancashire M, Moore D, Elliot T, Clarke NW, Dive C. BMC Cancer 2014

Implementing newer agents for the management of castrate-resistant prostate cancer: what is known and what is needed? N Mottet, S Joniau, NW Clarke, M De Santis BJUI 2014

Quantification of skeletal metastases in castrate-resistant prostate cancer

Predicts progression-free and overall survival

C Tait, D Moore, C Hodgson, M Brown, T Morris, J Growcott, M Malone, A Hughes, A Renehan, N W. Clarke, CDive BJUI April 2014

The Melbourne consensus statement on PSA testing in prostate cancer

D Murphy, M Roobol, P Walsh, W Catalona, NW Clarke, M Cooperberg, T Costello.

BJUI March 2014

## 8. Innovation in clinical practice

Salford Royal – dedicated one stop clinic with on attendance radiology, all forms of urological diagnostic testing allowing rapid diagnosis and treatment planning in one visit.

Stockport - Flurosceine guided laparoscopic partial nephrectomies

Salford and Bolton - A protocol-backed nurse-led abiraterone clinic for patients with metastatic castrate resistant prostate cancer.

Christie (and Salford – soon to launch) - Community based prostate cancer follow up clinic delivered by specialist nurses with care closer to home. This is a pilot running until April 2015 and , if successful, will it may continue long term with a view to developing this across Manchester (via the pathway board).

## 9. The Pathway Board

### 9.1. Formation of the Board

The principle of Manchester Cancer Pathway Boards is that they should be professionally and institutionally representative, yet small and manageable in size. To help Pathway Clinical Directors form institutionally representative Boards the Manchester Cancer central team sought nominations from trusts for their representative(s) on 16 of the 20 Pathway Boards. Nominations were not sought for Children’s, Sarcoma, Palliative Care and Early Diagnosis as alternative arrangements were necessary in these areas.

For each Pathway Board trusts were asked to provide up to three nominations from a range of professions from which the trust representative(s) could be chosen. The team asked that nominations included a brief statement of the individual’s suitability for membership of the relevant Pathway Board.

Nominations were passed to Pathway Clinical Directors who took them into account when forming their Boards. Trusts were informed during this process that Directors would not be obliged to accept all trust nominations but that, if a Pathway Clinical Director wished to appoint a trust representative that had not been nominated by their organisation, then this would be discussed with the Trust Cancer Clinical Lead.

**9.2. Membership**

<b>Trust</b>	<b>Nominee</b>	<b>Profession/ specialty</b>
Bolton	Janet Keegan	CNS
Christie	Prof Noel Clarke	Consultant Surgeon
CMFT	Mr Dan Burke	Consultant Surgeon
Mid Cheshire	Mr Jeremy Oates	Consultant Urologist
East Cheshire	N/A	
Pennine	Mr J Calleary	Urology
SRFT	Mr Kieran O'Flynn	Urological Surgeon
SHH	Mr Stephen Bromage	Consultant urological surgeon
WWL	Mr J Husain	Consultant Urologist
UHSM	Miss Hazel Warburton	Consultant Urologist
Nursing	Jane Booker	Clinical Nurse Specialist
Diagnostics	Maryna Lewinski	Radiologist
Diagnostics	Mike Scott	Pathologist
Prostate care	Helen Johnson	Clinical Nurse Specialist
Clinical trials	Tony Elliot	Oncologist
GP	Steve Elliot	GP
	Cath Briggs	GP
Palliative care	TBC	
Macmillan care	Teresa Karran	
Oncology Nurse	Jeanette Lyons	CNS
Oncologist	Anna Tran	Oncologist

### **9.3. Meetings**

The board has met three times since its first meeting on 23<sup>rd</sup> April 2014. The terms of reference were agreed at this meeting however were amended to reflect a specific quorum number and specific rates of attendance for each member.

The minutes from the first two meetings are in appendix 3.

## **10. Progress and challenges to date**

The board has made good progress in forming and establishing the group. All meetings have been well attended and there has been positive input from all members. It has shown leadership by supporting the commissioning process at a time of service reconfiguration.

However it was also constituted against the background of this service reconfiguration which could have proved a diversion. The challenge of nominating a patient representative remains and is one that the board is keen to address.

## **11. Vision and objectives**

The board has benefitted from the legacy of the excellent work undertaken by the previous Greater Manchester and Cheshire NSSG chaired by Mr Maurice Lau, Uro-oncologist at Salford Royal NHS Foundation Trust and The Christie NHS FT. As a result the pathway has been well managed with clear referral protocols and mechanisms for patients to be reviewed, assessed and treated.

However the board recognises that this was a focus on the surgical element of the pathway. Over the next 12 months the board intends to deepen its knowledge base and understanding of the whole pathway and put in place actions where the patient outcomes, survival rates and experience can be improved and enhanced.

It will also support and actively participate in the work of the prevention, awareness and screening cross cutting group as well as the living with and beyond cancer cross cutting group to deliver these improvements.

It is the intention of the board to identify relevant clinical outcomes and begin measuring these to decide on what appropriate actions need to be put in place as a consequence.

The board intends that urology cancer patients of Greater Manchester will be managed in an IOG compliant service within streamlined and standardised pathways.

## 12. Appendix 1 – Pathway Board Terms of Reference

### Urology Cancer Pathway Board

#### Terms of Reference

These terms of reference were agreed on 23<sup>rd</sup> April 2014 by Mr Satish Maddineni, Pathway Clinical Director for Urology Cancer, and Mr David Shackley, Medical Director of Greater Manchester Cancer Services, on behalf of the Greater Manchester Cancer Services Provider Board. The terms of reference will be subject to future review.

#### 1. The Pathway Board

- 1.1. The Urology Cancer Pathway Board is a cancer care specific board with responsibility to improve cancer outcomes and patient experience for local people across Greater Manchester and areas of Cheshire (a catchment population of 3.2 million). This area is synonymous with the old Greater Manchester and Cheshire Cancer Network area.
- 1.2. The Pathway Board is led by a Pathway Clinical Director and is formed of a multidisciplinary team of clinicians and other staff from all of hospital trusts that are involved in the delivery of Urology cancer care in Greater Manchester. The Pathway Board also has membership and active participation from primary care and patients representatives.
- 1.3. The Urology Cancer Pathway Board reports into and is ultimately governed and held to account by the Greater Manchester Cancer Services Provider Board.

#### 2. Greater Manchester Cancer Services Provider Board

- 2.1. The Greater Manchester Cancer Services Provider Board is responsible for the service and clinical delivery arm of Manchester Cancer, Greater Manchester's integrated cancer system. Manchester Cancer has two other arms: research and education (see appendix for the structure of Manchester Cancer).
- 2.2. The Provider Board is independently chaired and consists of the Chief Executive Officers of the ten acute hospital trusts in the Greater Manchester area:
  - Bolton NHS Foundation Trust
  - Central Manchester University Hospitals NHS Foundation Trust
  - East Cheshire NHS Trust
  - Pennine Acute NHS Trust
  - Salford Royal NHS Foundation Trust
  - Stockport NHS Foundation Trust
  - Tameside Hospital NHS Foundation Trust
  - The Christie NHS Foundation Trust
  - University Hospital of South Manchester NHS Foundation Trust;

- Wrightington, Wigan and Leigh NHS Foundation Trust;

2.3. The Provider Board regularly invites representatives of commissioners, the Strategic Clinical Network, and Manchester Cancer to its meetings.

### 3. Purpose of the Pathway Board

3.1. The purpose of the Pathway Board is to improve cancer care for patients on the Greater Manchester Urology cancer pathway. Specifically, the Pathway Board aims to save more lives, put patients at the centre of care, and improve patient experience. The Board will represent the interests of local people with cancer, respecting their wider needs and concerns. It is the primary source of clinical opinion on this pathway for the Greater Manchester Cancer Services Provider Board and Greater Manchester's cancer commissioners.

3.2. The Pathway Board will gain a robust understanding of the key opportunities to improve outcomes and experience by gathering and reviewing intelligence about the Urology cancer pathway. It will ensure that objectives are set, with a supporting work programme that drives improvements in clinical care and patient experience.

3.3. The Pathway Board will also promote equality of access, choice and quality of care for all patients within Greater Manchester, irrespective of their individual circumstances. The Board will also work with cancer commissioners to provide expert opinion on the design of any commissioning pathways, metrics and specifications.

### 4. Role of the Pathway Board

The role of the Urology Cancer Pathway Board is to:

4.1. Represent the Greater Manchester Cancer Services professional and patient community for Urology cancer.

4.2. Identify specific opportunities for improving outcomes and patient experience and convert these into agreed objectives and a prioritised programme of work.

4.3. Gain approval from Greater Manchester's cancer commissioners and the Greater Manchester Cancer Services Provider Board for the programme of work and provide regular reporting on progress.

4.4. Design and implement new services for patients where these progress the objectives of commissioners and Greater Manchester Cancer Services, can be resourced, and have been shown to provide improvements in outcomes that matter to patients.

4.5. Ensure that diagnosis and treatment guidelines are agreed and followed by all teams in provider trusts, and are annually reviewed.

- 4.6. Ensure that all providers working within the pathway collect the pathway dataset measures to a high standard of data quality and that this data is shared transparently amongst the Pathway Board and beyond.
- 4.7. Promote and develop research and innovation in the pathway, and have agreed objectives in this area.
- 4.8. Monitor performance and improvements in outcomes and patient experience via a pathway scorecard, understanding variation to identify areas for action.
- 4.9. Escalate any clinical concerns through provider trusts.
- 4.10. Highlight any key issues that cannot be resolved within the Pathway Board itself to the Medical Director of Greater Manchester Cancer Services for assistance.
- 4.11. Ensure that decisions, work programmes, and scorecards involve clearly demonstrable patient participation.
- 4.12. Share best practices with other Pathway Boards within Greater Manchester Cancer Services.
- 4.13. Contribute to cross-cutting initiatives (e.g. work streams in living with and beyond cancer and early diagnosis).
- 4.14. Discuss opportunities for improved education and training related to the pathway and implement new educational initiatives.
- 4.15. Develop an annual report of outcomes and patient experience, including an overview of progress, difficulties, peer review data and all relevant key documentation. This report will be published in July of each year and will be the key document for circulation to the Provider Board. A template for this report is available so that all Pathway Boards complete the report in a similar manner.

## 5. Membership principles

- 5.1. All member organisations of Greater Manchester Cancer Services will have at least one representative on the Pathway Board unless they do not wish to be represented.
- 5.2. Provider trusts not part of Greater Manchester Cancer Services can be represented on the Pathway Board if they have links to the Greater Manchester Urology cancer pathway.
- 5.3. All specialties and professions involved in the delivery of the pathway will be represented.
- 5.4. The Board will have at least one patient or carer representative within its membership
- 5.5. One professional member of the Pathway Board will act as a Patient Advocate, offering support to the patient and carer representative(s).

5.6. The Board will have named leads for:

- Early diagnosis
- Pathology
- Radiology
- Surgery
- Oncology
- Specialist nursing
- Living with and beyond cancer ('survivorship')
- Research
- Data collection (clinical outcomes/experience and research input).

5.7. It is possible for an individual to hold more than one of these posts. The Pathway Clinical Director is responsible for their fair appointment and holding them to account.

5.8. These named leads will link with wider Greater Manchester Cancer Services Boards for these areas where they exist.

5.9. All members will be expected to attend regular meetings of the Pathway Board to ensure consistency of discussions and decision-making (meeting dates for the whole year will be set annually to allow members to make arrangements for their attendance).

5.10. It is expected that board members will attend all meetings in a 12 month period. In the instances when board members are unable to attend they may send identified deputies, having informed the Pathway director before the meeting.

5.11. When a board member's attendance is less than 66% in 12 month period, the Pathway Director, in collaboration with Greater Manchester Cancer services Medical Director, reserves the right to terminate their board membership and liaise with the relevant member organisation to submit a new nomination.

## 6. Frequency of meetings

6.1. The Urology Cancer Pathway Board will meet every two months.

## 7. Quorum

7.1. Quorum will be the Pathway Clinical Director(or nominated deputy) plus fifty per cent of the named members of the Pathway Board or their named deputies.

7.2. If the pathway Board meeting is quorate then there will be a voting system implemented for the decision making process. The decision of the board will be made if the majority of the members present agree.

## 8. Communication and engagement

- 8.1. Accurate representative minutes will be taken at all meetings and these will be circulated and then validated at the next meeting of the Board.
- 8.2. All minutes, circulated papers and associated data outputs will be archived and stored by the Pathway Clinical Director and relevant Pathway Manager.
- 8.3. The Pathway Board will design, organise and host at least one open meeting per year for the wider clinical community and local people. This meeting or meetings will include:
  - An annual engagement event to account for its progress against its work programme objectives and to obtain input and feedback from the local professional community
  - An annual educational event for wider pathway professionals and interested others to allow new developments and learning to be disseminated across the system
- 8.4. Representatives from all sections of the Greater Manchester Cancer Services professional body will be invited to these events, as well as patient and public representatives and voluntary sector partners.
- 8.5. An annual report will be created and circulated to the Medical Director of the Greater Manchester Cancer Services Provider Board by 31<sup>st</sup> July of each calendar year.
- 8.6. The agendas, minutes and work programmes of the Pathway Board, as well as copies of papers from educational and engagement events, will be made available to all in an open and transparent manner through the Greater Manchester Cancer Services website once this has been developed.

## **9. Administrative support**

- 9.1. Administrative support will be provided by the relevant Pathway Manager with the support of the Greater Manchester Cancer Services core team. Over the course of a year, an average of one day per week administrative support will be provided.

## 13. Appendix 2 – Pathway Board meeting attendance

### ATTENDANCE - PATHWAY BOARD MEETING

#### UROLOGY

NAME	ROLE	TRUST	23rd April 14	10th June 14
Janet Keegan	CNS	Bolton	Attended	<b>Apologies</b>
Prof Noel Clarke	Consultant Surgeon	Christie	Attended	Attended
Mr Dan Burke	Consultant Surgeon	CMFT	Attended	Attended
Mr Jeremy Oates	Consultant Urologist	Mid Cheshire	<b>Apologies</b>	Attended
N/A		East Cheshire		
Mr J Calleary	Urology	Pennine	Attended	Delayed
Mr Kieran O'Flynn	Urological Surgeon	SRFT	Attended	Attended
Mr Satish Maddineni	Pathway director	Manchester Cancer	Attended	Attended
Mr Stephen Bromage	Consultant urological surgeon	SHH	Attended	Attended
Mr J Husain	Consultant Urologist	WWL	Attended	Attended
Miss Hazel Warburton	Consultant Urologist	UHSM	<b>Apologies Mr le Chow in attendance</b>	Attended
Jane Booker	Clinical Nurse Specialist	Nursing	<b>Apologies</b>	Attended
Maryna Lewinski	Radiologist	Diagnostics	Attended	Attended
Mike Scott	Pathologist	Diagnostics	Attended	Attended
Helen Johnson	Clinical Nurse Specialist	Prostate care	Attended	<b>Apologies</b>
Tony Elliott	Oncologist	Clinical trials	Attended	Attended
Steve Elliot	GP	GP	<b>Apologies</b>	Attended
Cath Briggs	GP		<b>Apologies</b>	Attended
TBC		Palliative care		
Teresa Karran		Macmillan care	<b>Apologies</b>	Attended
Jeanette Lyons	CNS	Oncology Nurse	<b>Apologies</b>	<b>Apologies</b>
Anna Tran	Oncologist	Oncologist	Attended	Attended

## 14. Appendix 3 – Pathway Board minutes to 31<sup>st</sup> July 2014 UROLOGY PATHWAY BOARD MEETING

### MINUTES

DATE: 23/04/2014

#### Member's attendance

Mr Maddineni	(Chair)	Mr Husain	WWL
Janet Keegan	Bolton	Mr Chow	UHSM
Prof Clarke	Christie	Dr Lewinski	Stockport
Mr Burke	CMFT	Dr Scott	UHSM
Mr Calleary	Pennine	Helen Johnson	Christie
Mr O'Flynn	SRFT	Dr Elliott	Christie
Mr Bromage	Stockport	Dr Tran	Christie

#### Apologies

Mr Oates	Mid-Cheshire	Miss Warburton	UHSM
Jane Booker	Christie	Teresa Karan	Macmillan care
Dr Elliot	Salford CCG	Jeanette Lyons	Christie
Dr Briggs	Stockport CCG		

- **Introductions and apologies**

Mr Maddineni (SM) welcomed all to the meeting and noted the apologies received.

- **Introduction to Manchester cancer**

SM outlined the purpose of the pathway board and clarified the only role of members is in reviewing the whole pathway as a stakeholder in improving the outcomes for patients. He stressed that the priority would be to create and maintain an efficient and effective pathway.

- **Board member introductions**

The board members present introduced themselves to the meeting. James Leighton (JL) explained that there would be a patient representative on the board; however their participation would occur after an engagement event to be held in conjunction with Macmillan cancer.

*(Since the board meeting the engagement event is now confirmed to take place on 23<sup>rd</sup> June)*

The board also suggested a need for a finance representative to join the board. The board also suggested other possible membership to come from the cancer managers, university education and from the peer review process. This will be kept under review as the work schedule of the board develops.

- **Terms of reference**

The terms of reference were discussed and a paragraph on the voting process was proposed - *7.2 If the Pathway Board meeting is quorate then there will be a voting system implemented for the decision making process. The decision of the Board will be made if the majority of members present agree.*

Following a short discussion this was agreed and adopted into the terms of reference. The board also asked that the required attendance was amended to 66%. This was agreed.

**Action – JL to make agreed amendments to the board’s terms of reference.**

- **Discussion of board objectives**

In a round table discussion the work of the board and it’s intended objectives were discussed –

- Improved data collection
  - Identifying what data needs to be collected
  - Resources required
  - Local input/BAUS data
  - Standardisation across the area
- Development of pathway board work plan
- Design and deployment of services that will meet the needs of the patients
- Identify opportunities for change
- Maintain the guidelines for urological cancer

There was a consensus formed that the level of intelligence currently available may not be of a sufficient standard to allow for proper analysis of the pathway and that new data collection processes may be needed.

There was discussion on the use of the Christie database as a vehicle to gather such data. This was considered as an option and SM agreed to meet with Dr Livesey, (Outcomes project lead) from the Christie to review the potential of this.

**Action - SM to meet with Dr Livesey and review the Christie database and report back to next board meeting.**

The board also identified the need to review the guidance sent out by the previous cancer network. This was as a means of reviewing how standardised the processes of the pathway are. It was also to discuss if there was a need to map out the pathway within each provider.

**Action - JL to obtain and distribute all cancer guidelines from GMCCN**

**Action – Mr O’Flynn to review the bladder guidelines**

**Action - Mr Calleary to review the renal guidelines**

**Action - Dr Elliott to review the Bladder Radiotherapy /non-surgical treatment guidelines**

**Action - All clinical colleagues to review existing guidelines to discuss at next meeting**

A further discussion on improving participation in clinical trials took place. The need for further data on this was identified.

**Action - Dr Elliott agreed to discuss this with Sue Dyde.**

- **Board roles**

It was agreed that the following will undertake a leadership function on behalf of the board –

- Audit Miss Warburton
- Data collection Mr Bromage & Mr Oates
- Guidelines All members (The review of guidelines will be distributed to members of the Board when they require updating)
- Pathology Dr Scott
- Oncology Dr Tran
- LWB Helen Johnson & Janet Keegan
- Specialist nursing Janet Keegan & Jane Booker
- Research Prof Clarke & Dr Elliott
- Surgery Mr Burke
- Education Professor Clarke

- **Future meetings**

The meeting dates for the remainder of the calendar year were agreed and that all meetings would be held at Salford Royal. The dates are –

June 10<sup>th</sup> – 14.00hrs

July 24<sup>th</sup> – 14.00hrs

September 5<sup>th</sup> – 14.00hrs

November 11<sup>th</sup> – 14.00hrs

- **Educational event**

Board members were asked to consider holding an educational event on urological cancer. Members agreed to consider both the topic of the meeting and the target audience. This is to be discussed at the next board meeting.

**Action - JL to put on agenda of next board meeting.**

- **Proposed service re-configuration**

A wide ranging discussion took place on the proposed service re-configuration in Greater Manchester. SM outlined his recent discussion with NHS England on this and the board discussed the possible models of service provision and the implications of each.

The board agreed that they were keen to work with and support the work of the commissioners and hope that they could help inform the process. To this end it was agreed that SM should write to the commissioners to express the board's concern about having a service established on sites solely specialising in upper and lower tract conditions. The Board voted upon the best model that would be suitable for Manchester and unanimously agreed that the sites (regardless of the final number commissioned by NHS England) should be comprehensive sites performing both upper and lower tract urological oncology procedures.

**Action – SM to write to NHS England**

- **Any other business**

There was no other business discussed

- **Date & Venues for Future Meetings**

The next meeting of the board will be on Tuesday 10<sup>th</sup> June 14.00 hrs.

## UROLOGY PATHWAY BOARD MEETING

### MINUTES

**DATE: 10/06/2014**

#### Member's attendance

Mr Maddineni	(Chair)	Mr Husain	WWL
Miss Warburton	UHSM	Mr Oates	Mid-Cheshire
Prof Clarke	Christie	Dr Lewinski	Stockport
Mr Burke	CMFT	Dr Scott	UHSM
Mr Calleary	Pennine	Teresa Karan	Macmillan care
Mr O'Flynn	SRFT	Dr Elliott	Christie
Mr Bromage	Stockport	Dr Tran	Christie
Dr Elliot	Salford CCG	Jane Booker	Christie
Dr Briggs	Stockport CCG		

#### Apologies

Jeanette Lyons	Christie	Janet Keegan	Bolton
Helen Johnson	Christie		

- **Introductions and apologies**

Mr Maddineni (SM) welcomed all to the meeting and noted the apologies received.

- **Minutes of the meeting held on 23 April 2014**

The board reviewed the minutes of the previous meeting.

Prof Clarke queried the minute on service reconfiguration. He asked whether it was correct to say that the Board members at that meeting were unanimous in expressing a view on having two centres, with one for upper tract conditions and one for lower tract conditions.

There followed a round table and wider discussion on the potential for site-specific tumour group subspecialisation. Prof Clarke felt that there was a need to have a formal consideration of the evidence base before confirming the position of the Board on the issue regarding a stand-alone prostate cancer site. It was noted that the discussion at the last meeting pertained to a kidney versus pelvic centre model only.

There was a proposal to reword the minute to suggest that there was a "consensus" agreement of the Board regarding the issue of a separate upper and lower tract centre as opposed to an "unanimous" agreement (i.e. the Board felt that a separate kidney vs pelvic centre would not be in the best interests of Manchester urological cancer).

However upon reviewing the digital audio tape of the meeting the tabled minute does accurately reflect the discussions at the April meeting. Further correspondence has been issued to all members of the Board regarding these discussions.

Dr Lewinski corrected the Board roles that were listed as radiology had not been included. This will be amended accordingly.

## Action JL to revise list of Board roles

Jane Booker confirmed that she would take on the specialised nursing role on behalf of the Board.

- **Matters arising not on agenda**

- Reply from NHS England about service configuration

The Board noted the letter from NHS England in response to the letter sent from the Board from the April meeting. SM then confirmed that the procurement process will be started at a meeting called by NHS England on July 3<sup>rd</sup>.

- Meeting with Dr Livesey re data input system

Mr Bromage (SB) then fed back on a meeting he had with Dr Livesey at the Christie with regard to the data input system.

- **Data collection**

SB outlined the system currently being used at the Christie, which collects a wide variety of data. He reported that this could be bespoke to collect the data that the Board felt would be necessary for urological cancers. He then drew a comparison with the BAUS database and displayed what data was available for the region on BAUS with regard to nephrectomies, as an example.

SB also relayed to the Board what other metrics are available for surgical outcomes. There followed a discussion on the Somerset database, its uses and limitations. The main drawback of Somerset being that there is no linkage between Trusts.

With the Christie system there would be an integrated single database. The data is entered by the clinician which is a change from the current process. The other benefit is that the Christie database would gather information on the patient's entire pathway.

**Action SB to invite Dr Livesey to board meeting in July to demonstrate the Christie database SB to liaise with BAUS and the Christie data system managers regarding the feasibility of uploading Christie data to the BAUS database to prevent duplication of data collection.**

- **Guidelines review**

Mr O'Flynn (KoF) started a discussion on the function and purpose of the pathway tumour specific guidelines. He outlined that before revision he felt he required direction from the board.

A discussion followed on how the guidelines could be used. The Board felt that the guidelines should reflect the local processes and pathways. Dr Steven Elliot (SE) pointed out that there were no guidelines for primary care management of the patient and that the existing guidelines were secondary care focussed.

There was agreement that future revisions need to reflect the whole pathway. This would be put into the Board's action plan.

Dr Tony Elliott (TE) suggested an amendment to the timescale for the first cystoscopy post Radiotherapy. Other issues included the type and timing of imaging on various urological pathways. Dr Lewinski expressed the need to have consistent imaging protocols, performed at the same level across the conurbation.

There was a subsequent discussion on standardisation of the G2 bladder cancer grade reporting and management. The Board agreed that a time limited group is likely to be needed to develop the wider pathway guidance on behalf of the Board.

The Board noted the reviewed renal cancer guidelines tabled by Mr Calleary.

**Action** The discussion of the renal cancer guidelines to be deferred until the July meeting

- Nice guidelines on prostate cancer Jan 14 – Active surveillance

The Board then reviewed the recently released active surveillance guidance from NICE. The Board felt that there was a need to map out the current imaging capacity for MR scanning of the prostate. It was felt that a statement be developed by the Board on MR imaging of the prostate.

Prof Clarke explained that there were a number of protocols for AS currently published. He felt that the Board should review these, agree which one to adopt and standardise the protocol and MR imaging.

**Action** To form a working party to review AS guidelines (to be discussed at July meeting)

- **Pathway audit set**

Miss Warburton (HW) tabled a paper on her thoughts on how to deliver the Board's audit programme. She asked the Board to consider what to audit, the structure for the audit process and the resources that may be required and how it would be published and circulated.

She suggested two potential initial audits:

- The process by which patients were discussed at the SMDTs across the network
- How patients were referred in from primary care.

KoF expressed the view that an audit programme should move towards also being a quality improvement programme. He suggested it should be one where an objective is set, a structured change is put in place and this change is then assessed. He suggested one of the early issues the programme might want to look at are the Bosniak 2F/3 renal cysts and develop a protocol for looking at these at MDT.

TE proposed an audit of the timing of cystoscopy following radical radiotherapy of the bladder.

The Board felt that the audit programme needed to support the complete patient pathway and not just surgical outcomes. At this stage the pathway had not yet been sufficiently implemented and standardised to allow the assessment of any implemented change.

**Action** The Board agreed to audit the timing of cystoscopy examination of patients post bladder radiotherapy (TE and HW to liaise to progress this).

- **Educational event**

James Leighton (JL) asked that the Board to give consideration to the planned educational event(s) in terms of the target audience and the content. He explained that this was an objective of the Board. SM noted that an educational event aimed at CCG cancer leads would be a useful first step with regards primary care education.

**Action** Board to review strategy at next meeting

- **Annual report**

JL informed the Board that the annual report will be drafted over the next few months and as this is constructed it will be circulated to the board for comment and agreement prior to submission to the Provider Board.

- **Cancer performance**

The cancer performance figures for Q4 13/14 were tabled and noted by the Board. There were no issues raised.

- **Any other business**

TE tabled the NIHR report on clinical trial participation; this was noted and reviewed by the Board. There was no other business for discussion.

- **Date & Venues for Future Meetings**

The next meeting of the Board will be on **Thursday 24<sup>th</sup> July 14.00 hrs.**

## Appendix 4 – Pathway Board Annual Plan 2014/15

### Urology Pathway Board Annual Plan 2014-15

<b>Pathway Clinical Director:</b>	Mr Satish Maddineni
<b>Pathway Board Members:</b>	
<b>Pathway Manager:</b>	James Leighton
<b>Date agreed by Pathway Board:</b>	24 <sup>th</sup> July 2014
<b>Date agreed by Medical Director:</b>	
<b>Review date:</b>	June 2015

### Summary of objectives

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No	Objective	Alignment with Provider Board objectives
1	Optimise data collection to generate outcome measures	Generation of robust outcome data including 1 year survival
2	Defining the MR scanning protocols for prostate cancer	Improve 1 and 2 year survival Improve patient experience by offering best care
3	Agreeing an active surveillance policy for prostate cancer	Improve 1 and 2 year survival Improve patient experience by offering best care
4	Confirming the key clinical outcomes to be measured for bladder, renal and prostate cancer	Generation of robust outcome data including 1 year survival

## Objective 1: Optimise data collection to generate outcome measures

<b>Objective:</b>	To optimise data collection to allow the generation of meaningful outcome measures, scrutiny of the data collected to enable the sustainable generation of outcome measures.
<b>Rationale:</b>	The Board wishes to be able to reliably record patient data so that there is only one record of the patient's journey through the pathway. This will also generate meaningful outcome data, to facilitate service, national and international comparison. This will ensure that the patient care delivered compares favourably with other centres and identify areas where care might be improved.
<b>By (date):</b>	31/3/15
<b>Board measure(s):</b>	The ability to generate outcome figures for 1 and 2 year survivals without additional task-specific audit
<b>Risks to success:</b>	Time and other commitments of involved personnel eg MDT lead clinicians, MDT co-ordinators, data managers, doctors, clinical nurse specialists. Mitigation: Aim for an efficient, unified, sustainable approach
<b>Support required:</b>	Recognition and protection of the vital role of existing data managers. Reflection in job-planning and appraisal of the effort and commitment of MDT clinicians in generating this data

Work programme		
Action	Resp.	By (date)
Dr Livesy, head of Clinical Outcomes Unit, The Christie NHS FT to present to Pathway Board	SM	5 9 14
Urology services agreed as first wave site	Man Can	17 10 14
Final list of outcome measures agreed	All	3/12/14
Full commencement of routine data collection	All	1/1/15
Audit of completeness of data collected	All	31/3/15

## **Objective 2: Defining the MR scanning protocols for prostate cancer**

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<b>Objective:</b>	To standardise the MR scanning protocol for diagnosed prostate patients across the Manchester cancer area.
<b>Rationale:</b>	Following the publication of NICE guidance the Board felt that there was a need to map out the current imaging capacity for MR scanning of the prostate. It was felt that a statement be developed by the Board on MR imaging of the prostate to ensure that all patients accessed the same and highest level of care.
<b>By (date):</b>	31 03 15
<b>Board measure(s):</b>	An agreed MR prostate scanning protocol
<b>Risks to success:</b>	Lack of agreement between sites – mitigated by using a structured and supportive consultation process
<b>Support required:</b>	Support at executive level for the change management process

<b>Work programme</b>		
<b>Action</b>	<b>Resp.</b>	<b>By (date)</b>
Complete site audit	ML / JL	31 Aug 14
Establish working party to review	SM/ML	30 Sep 14
Draft protocol tabled at November board	ML	11 Nov 14
Implementation	All	31 Mar 15

## Objective 3: Agreeing an active surveillance policy for prostate cancer

<b>Objective:</b>	To develop and agree a policy for the active surveillance for men diagnosed with raised PSA but who are non-symptomatic.
<b>Rationale:</b>	Following the publication of NICE guidance in Jan 14 the Board felt that there was a need to support primary and secondary care by outlining a policy for the active surveillance of non-symptomatic men diagnosed with raised PSA. It was felt that a policy be developed by the Board in response to the guidance to ensure that all patients accessed the same and highest level of care.
<b>By (date):</b>	31 3 15
<b>Board measure(s):</b>	Policy on active surveillance for prostate cancer
<b>Risks to success:</b>	Time and other commitments of involved personnel. Mitigation: Aim for an efficient, unified, sustainable approach
<b>Support required:</b>	Support at executive level for the change management and consultation processes

Work programme		
Action	Resp.	By (date)
Review existing literature and policies	SB/JO/DB, NWC	31 Aug 14
Establish working party to review	Board	30 Sep 14
Draft policy tabled at November board	ML	11 Nov 14
Implementation	All	31 Mar 15

**Objective 4:** Confirming the key clinical outcomes to be measured for bladder, renal and prostate cancer

<b>Objective:</b>	Confirming the key clinical outcomes to be measured for bladder, renal and prostate cancer
<b>Rationale:</b>	The generation of meaningful outcome measures to facilitate national and international comparison, and year on year comparison of our own outcomes. This will ensure that the patient care delivered compares favourably with other centres and identify areas where care might be improved.
<b>By (date):</b>	31/3/15
<b>Board measure(s):</b>	The ability to generate outcome figures for 1 and 2 year survivals without additional task-specific audit
<b>Risks to success:</b>	Time and other commitments of involved personnel Mitigation: Aim for an efficient, unified, sustainable approach
<b>Support required:</b>	Recognition and protection of the vital role of existing data managers. Reflection in job-planning and appraisal of the effort and commitment of clinicians in generating this data

Work programme		
Action	Resp.	By (date)
Draft list of outcome measures tabled at board meeting	Board	5 9 14
Final list of outcome measures agreed		7/11/14
Full commencement of routine data collection		1/1/15
Audit of completeness of data collected		31/3/15