

Life & Bladder Cancer - The Yorkshire Survey

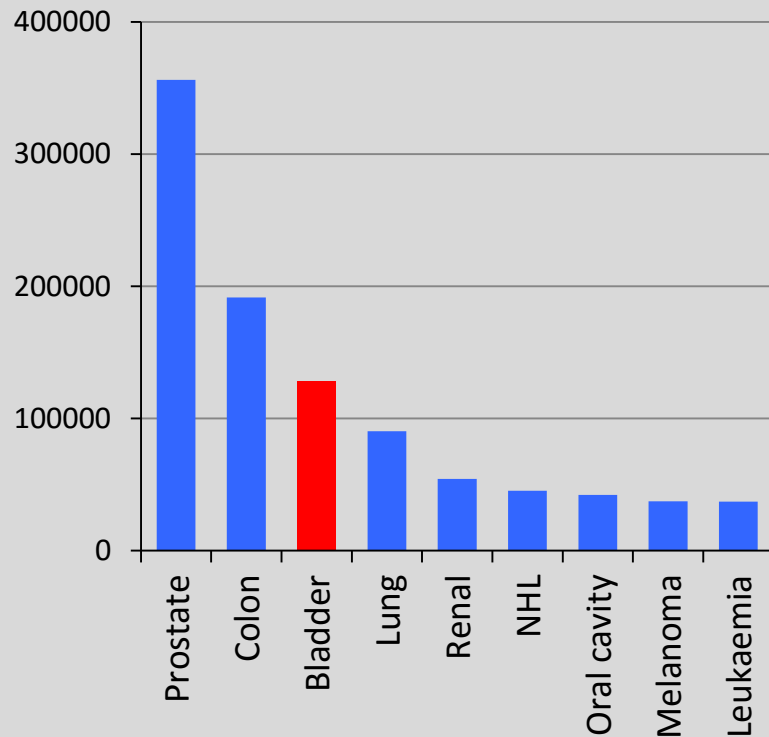
Prof. James Catto
University of Sheffield



The
University
Of
Sheffield.

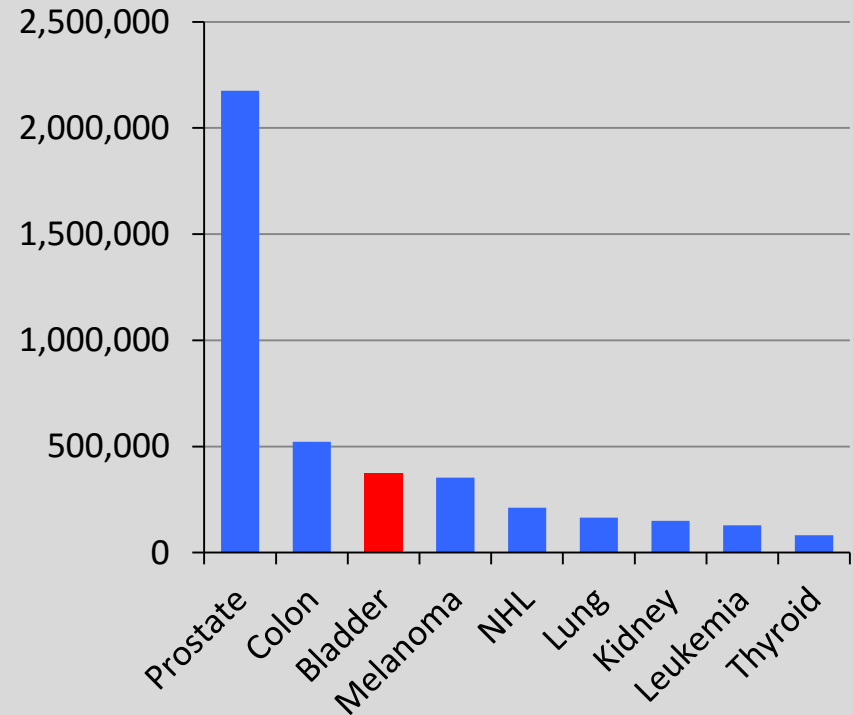
Bladder Cancer - Prevalence

5 Yr Worldwide Prevalence



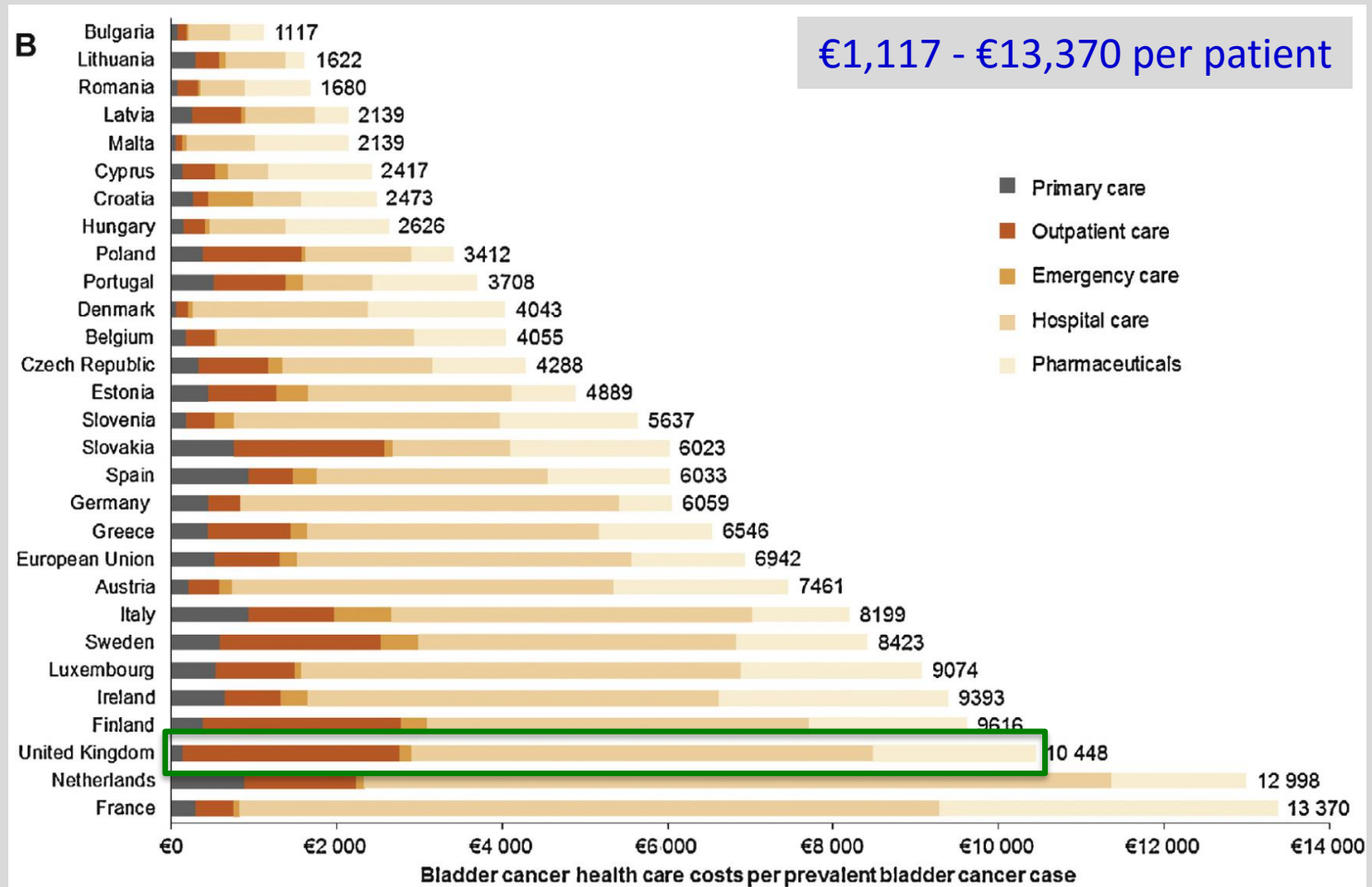
- 3rd most prevalent cancer
- 120,000 cases

30 Year USA Prevalence



- 3rd most prevalent cancer
- 376,000 Cases at 30 years

Bladder cancer - Costs



Economic Burden of Bladder Cancer Across
the European Union
Leal et al. European Urology

Bladder cancer - QOL

Low grade
NMI

High grade
NMI

Invasive

Metastatic

Tools:

EORTC NMIBC 24

EORTC QLQ-BLM30
FACT-VCI

Bladder Cancer Index

SF-36
EORCT-QLQ-C30

Outcomes:

Various NMI BC outcomes

IC Vs.
Reconstruction

21st Century Healthcare: Value

Value = Patient health outcome / Cost

Porter NEJM 2010

Define the right outcomes: What is success?

Results that matter for patients
conditions *not* procedures
conditions *not* specialties
conditions *not* hospital sites nor care sites

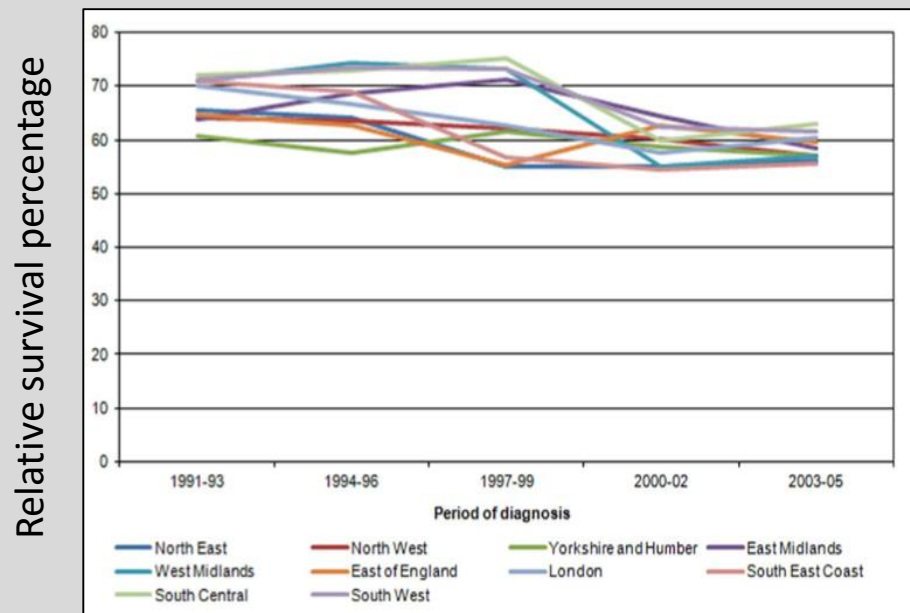
Results *not* patient experience
not compliance with practice guidelines
not clinical indicators

21st Century Healthcare: Outcomes

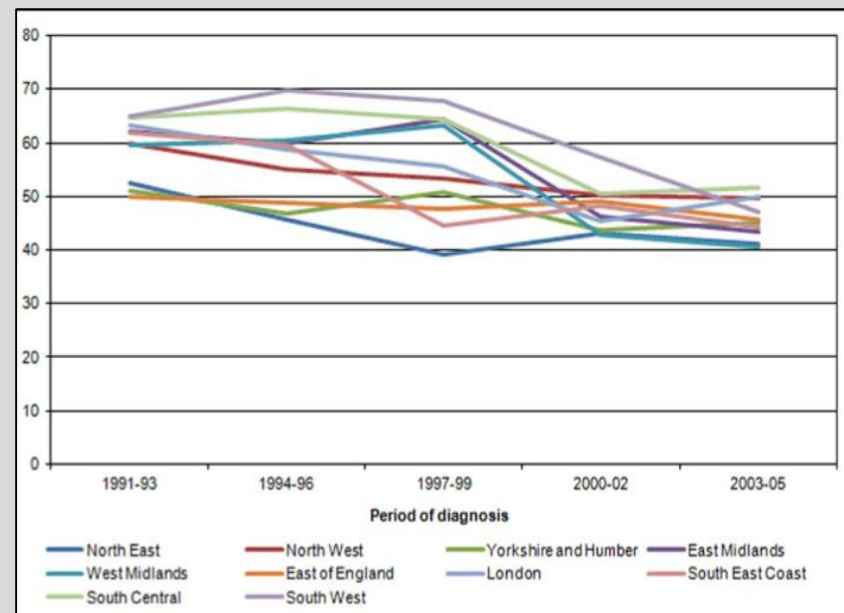
<i>Question</i>	<i>Data</i>	<i>Process</i>
Will I survive?	<i>Mortality Stats</i>	<i>NCRAS</i>

Survival: No Little change

Males



Females

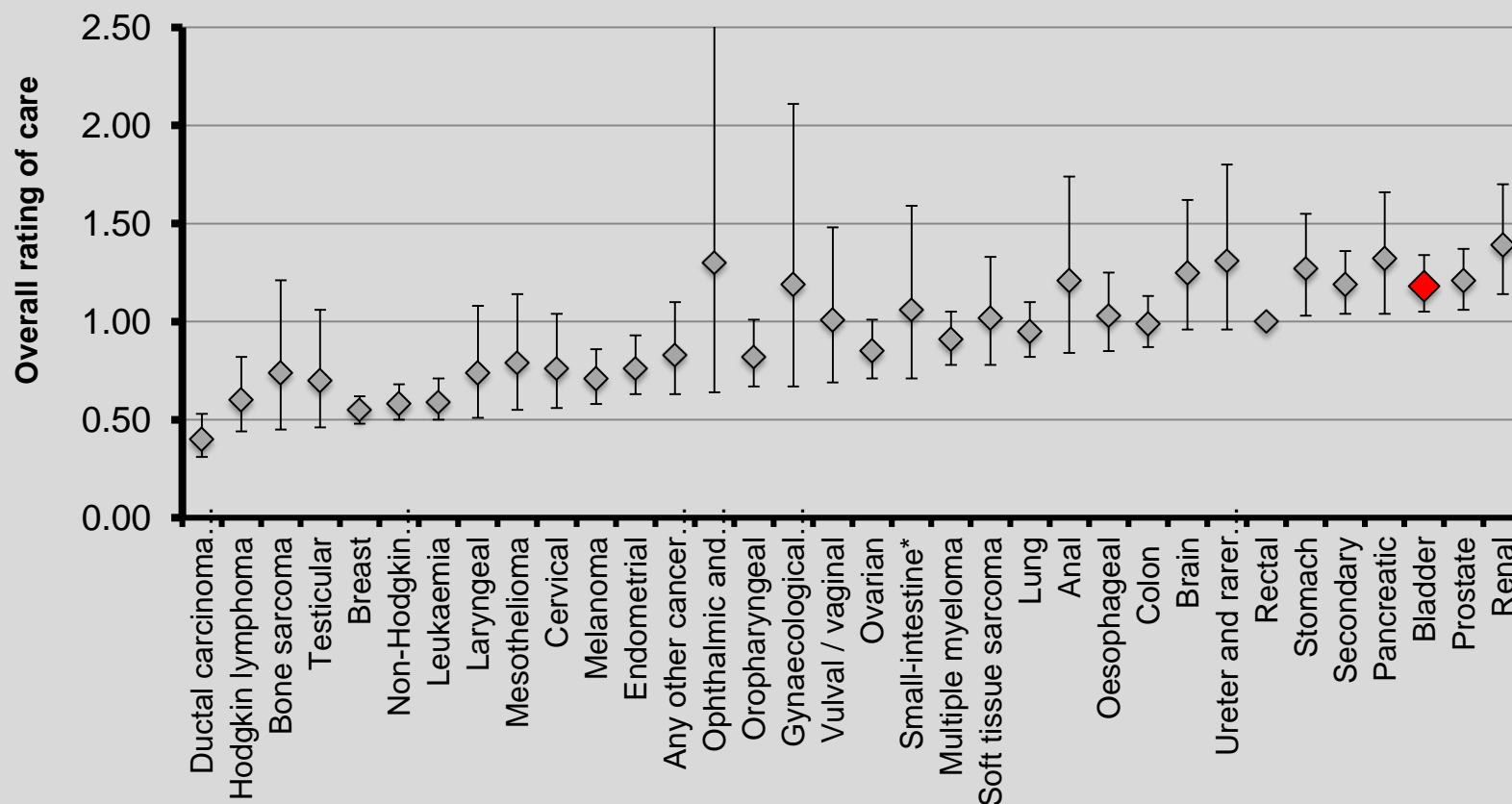


1990 to 2009: Falling bladder cancer incidence is not producing mortality improvements
Eylert et al. J Clin Urol 2014

21st Century Healthcare: Outcomes

<i>Question</i>	<i>Data</i>	<i>Process</i>
Will I survive?	<i>Mortality Stats</i>	<i>NCRAS</i>
How well was I looked after?	<i>Patient experience</i>	<i>NCPES</i>

The English Cancer Patient Experience Survey

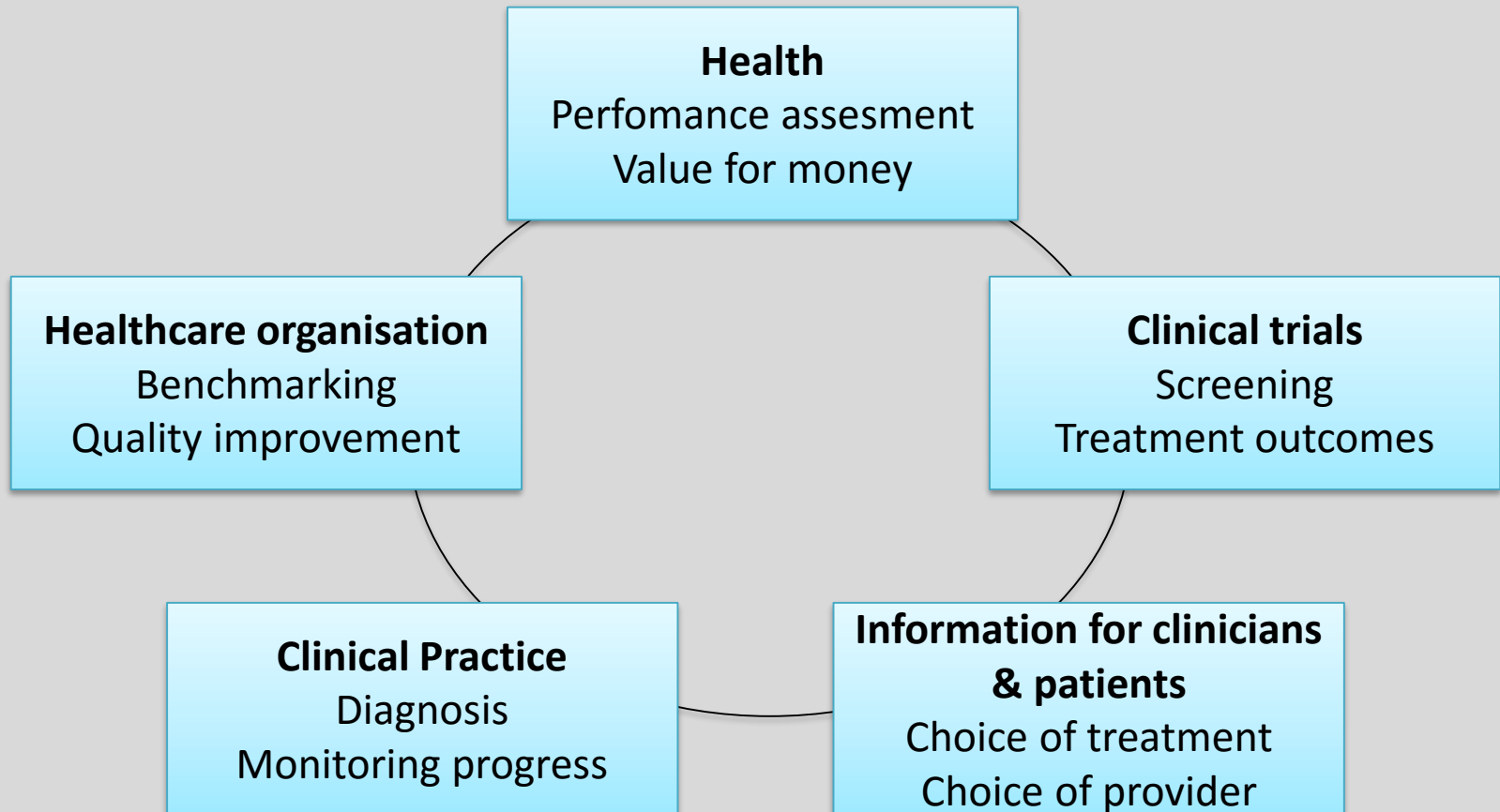


Risk of negative health care experience. Patients with BC (red) were amongst those with the lowest satisfaction and highest rates of negative experiences of all common cancers (odds ratio of negative experience plotted).

21st Century Healthcare: Outcomes

<i>Question</i>	<i>Data</i>	<i>Process</i>
Will I survive?	<i>Mortality Stats</i>	<i>NCRAS</i>
How well was I looked after?	<i>Patient experience</i>	<i>NCPES</i>
What will I be like?	Quality of survival	PROMs

PROMs: Patient Reported Outcome Measures



Black, N. (2013).

Patient reported outcome measures could help transform healthcare.

British Medical Journal 346

National Cancer Survivorship Initiative

2010: National Cancer PROMS Programme

DH PROMs & Cancer Policy Teams

Originally

NHS England

Now

National Cancer PROMs Programme: **Objectives**

- **Embed routine collection of PROMS within core business of the NHS cancer programme alongside survival data**
- Utilise PROMS to
 - describe the quality of survival
 - identify consequences of survival and impact on function
 - identify factors that impact on outcome, including Tx
 - enable provision of appropriate health & social care
 - compare outcomes by service provider organisations

National Cancer PROMs Programme: **Progress**

- 2011 Pilot:
 - 4 Tumour sites n=5,000 66% response
- 2012 Longitudinal survey:
 - Respondents to 2011 pilot >80% response
- 2013 National Survey:
 - Colorectal n=35,000 63% response
- 2014 Pilot:
 - Gynaecological cancers and bladder cancer
- 2015
 - LAPCD: Prostate cancer

Bladder Cancer PROMs Pilot Cohort

- 1,252 patients surveyed = 662 replies (53%)
 - 500 males (72% response)
 - 162 females (24% response)
 - 97% White British, 91% Heterosexual

Age	Number	% of total
under 40	3	0%
40-49	20	2%
50-59	61	5%
60-69	213	17%
70-79	224	18%
80+	123	10%



Public Health
England

Bladder Cancer PROMs Pilot

Self reported Treatment

- 77% reported 'Telescope/Endoscope bladder tumour surgery'
- 20% reported 'Radical cystectomy'
- 30% reported 'Chemotherapy into the bladder'
- 12% reported 'Intravenous chemotherapy (into the vein)'
- 16% report 'Radiotherapy'

Bladder Cancer PROMs Pilot

Mobility

Unable to walk/severe/moderate mobility problems	% of total
Male	21%
Female	23%
Telescopic/endoscopic bladder tumour surgery	22%
Cystectomy	15%
Chemotherapy into the bladder	16%
Intravenous chemotherapy	22%
Radiotherapy	35%

Bladder Cancer PROMs Pilot

Pain

Extreme/severe/moderate pain (cf. none/slight)	% of total
Male	15%
Female	14%
Telescopic/endoscopic bladder tumour surgery	14%
Cystectomy	14%
Chemotherapy into the bladder	14%
Intravenous chemotherapy	14%
Radiotherapy	20%



Public Health
England

Bladder Cancer PROMs Pilot

‘I am bothered by the side effects of treatment’

Very much/quite a bit (cf. not at all/a little bit)	% of total
Male	6%
Female	5%
Telescopic/endoscopic bladder tumour surgery	5%
Cystectomy	9%
Chemotherapy into the bladder	4%
Intravenous chemotherapy	12%
Radiotherapy	10%



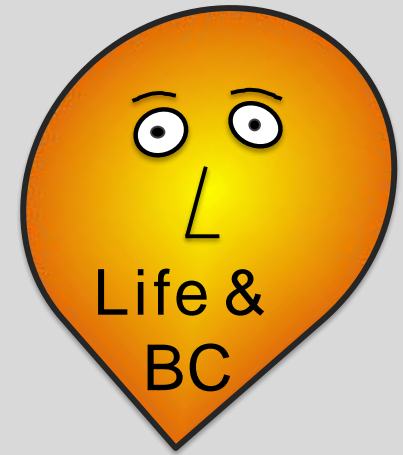
Public Health
England

Bladder Cancer PROMs Pilot

'I am satisfied with my sex life'

Very much/quite a bit (cf. not at all/a little bit)

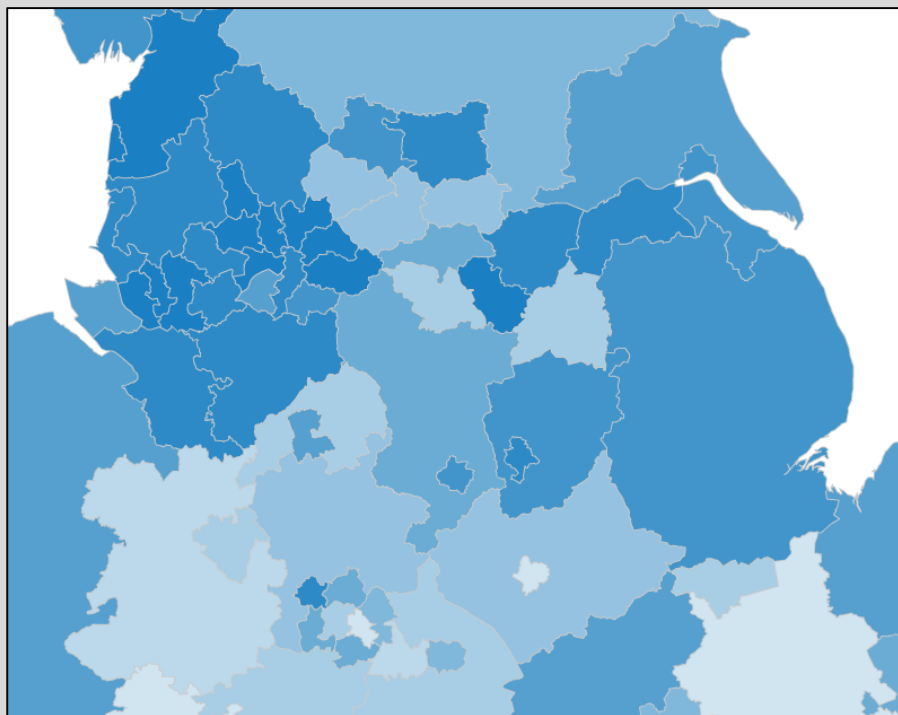
	% of total
Under 40	67%
40-49	60%
50-59	36%
60-69	17%
70-79	14%
80+	10%
Telescopic/endoscopic bladder tumour surgery	20%
Cystectomy	8%
Chemotherapy into the bladder	21%
Intravenous chemotherapy	16%
Radiotherapy	11%



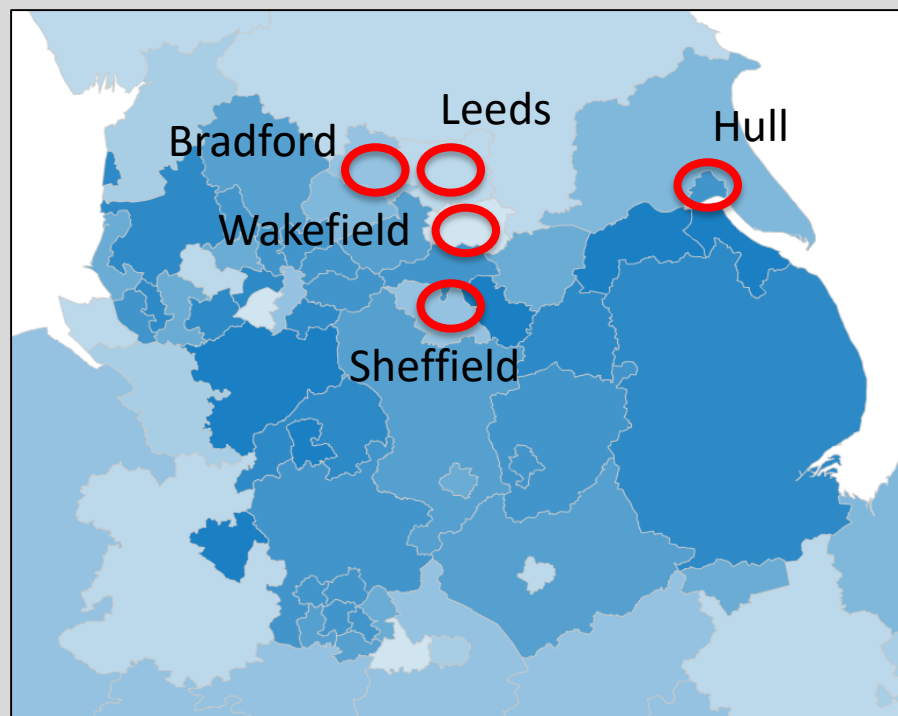
Life & Bladder Cancer - The Yorkshire Survey



Regional patterns: Yorkshire

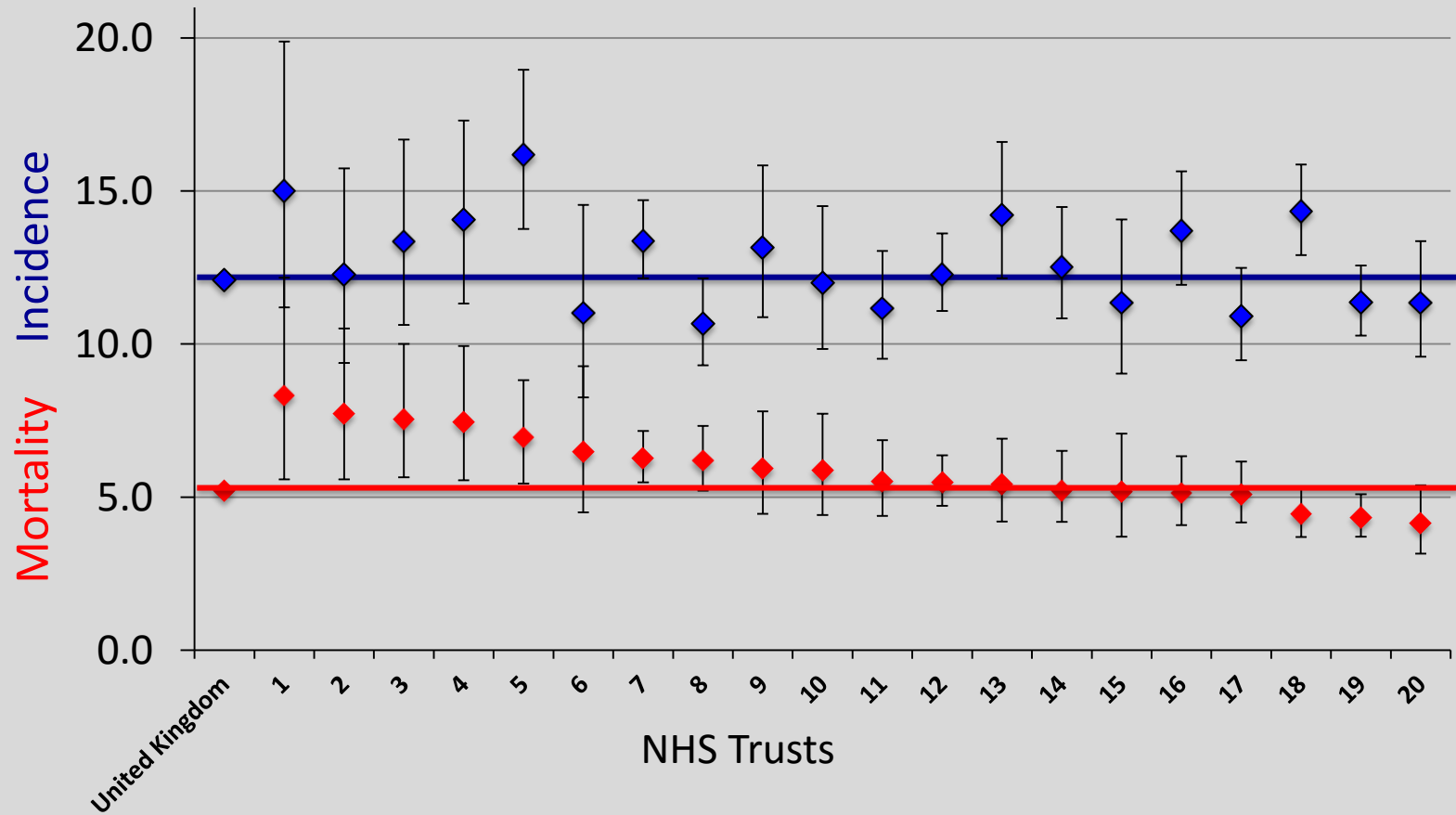


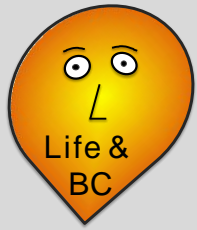
Incidence



Mortality

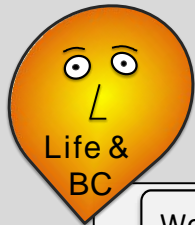
Regional patterns: Yorkshire



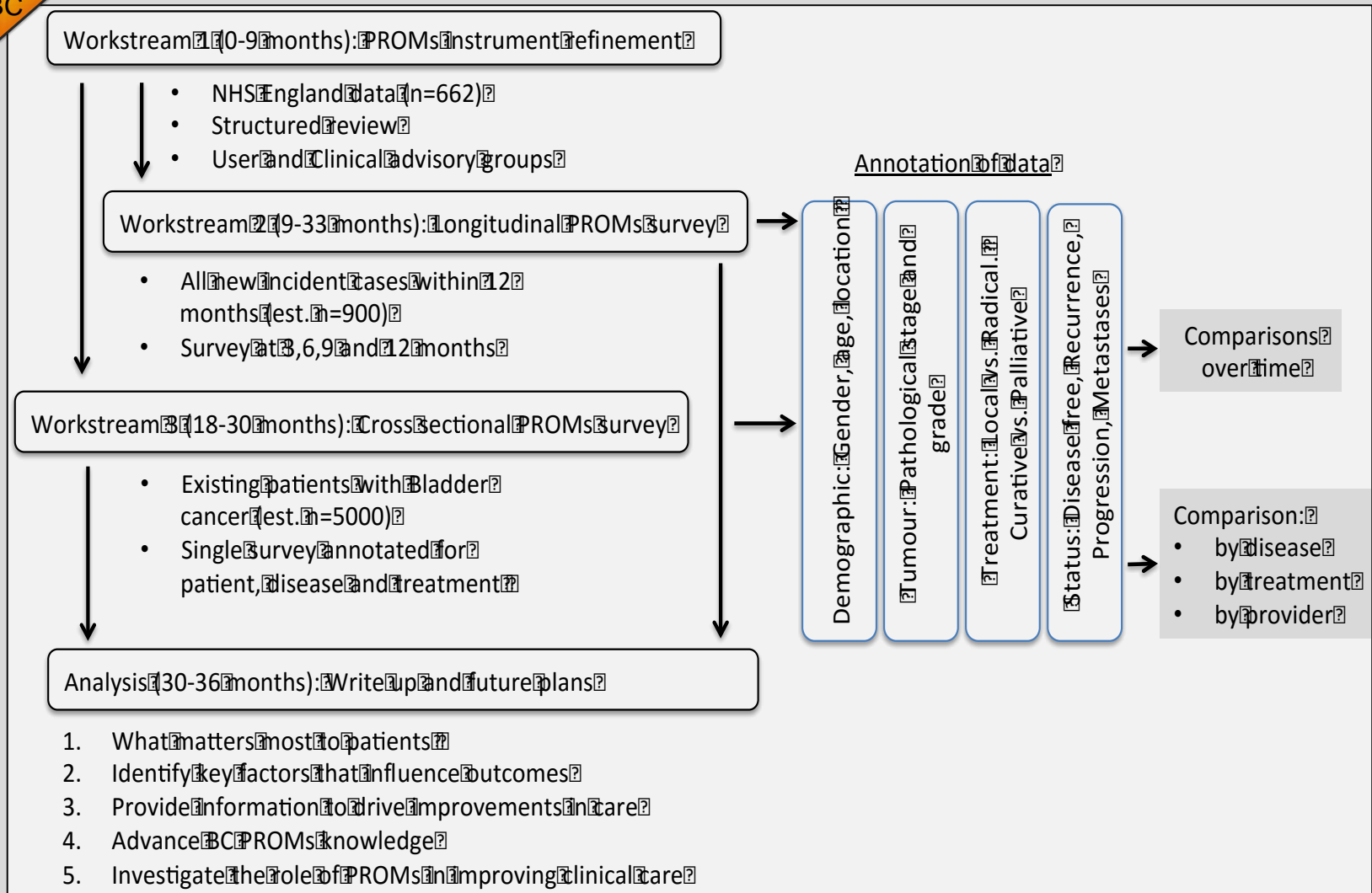


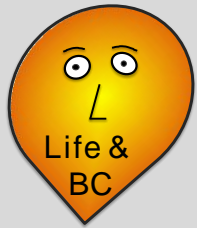
LABC: OBJECTIVES

1. Advance knowledge of how best to collect and use PROM data to inform clinical care
2. Comprehensively assess HRQOL following BC diagnosis and treatment.
3. Understand outcomes that matter most to people living with and beyond BC diagnosis.
4. Identify gaps in care and barriers to improvements



LABC: Design





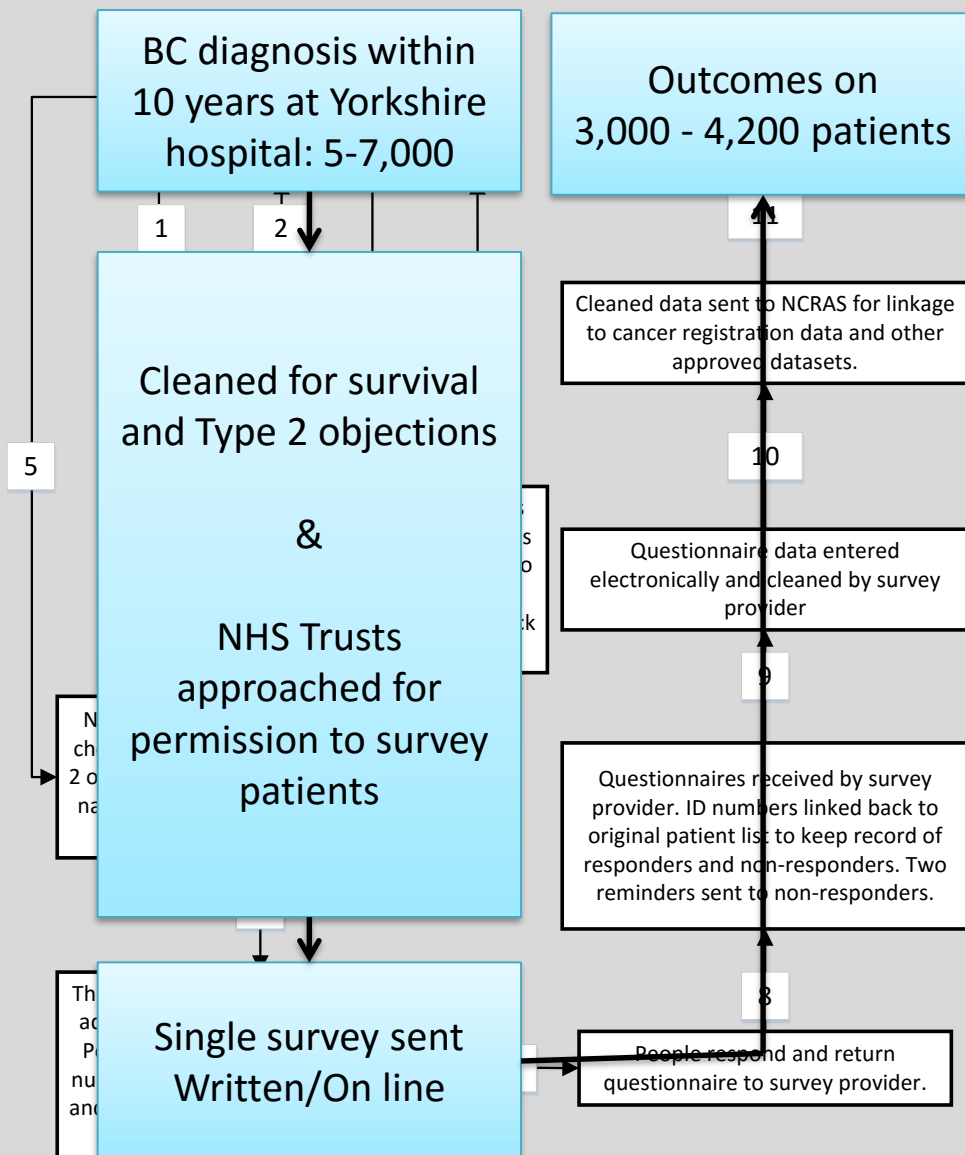
Cross sectional survey

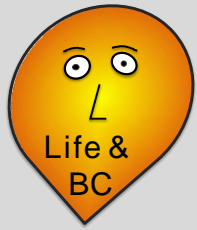
BC Prevalence: 7,400

Years diagnosis after	Men	Women
<1 year	616	224
1-2 years	500	172
2-3 years	474	158
3-4 years	384	152
4-5 years	393	143
5-10 years	1,403	517
10-15 years	947	369
15-20 years	531	206
20+ years	185	71



Cross sectional survey





Longitudinal survey

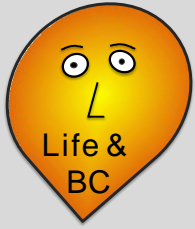
BC Incidence: 1,807 per year

	At diagnosis			At one year after diagnosis		
	Total	Male	Female	Total	Male	Female
Leeds	228	156	72	153	110	43
Bradford	76	56	20	52	40	12
Mid Yorks	200	134	66	134	95	39
York	204	149	55	138	105	33
Calderdale	128	89	39	86	63	23
Sheffield	188	133	55	127	94	33
Doncaster	159	110	49	107	78	29
Rotherham	92	69	23	62	49	14
Airedale	89	63	26	60	45	15
Harrogate	79	63	16	54	45	10
Hull and East Yorks	208	154	54	141	109	32
NL and Goole	156	111	45	105	78	27
Total	1807	1287	520	1219	911	310



Longitudinal survey

Domains	Questionnaires/items	Time points			
		T1	T2	T3	T4
Your overall health	EQ-5D-5L	Yes	Yes	Yes	Yes
Your treatment	Treatment item	Yes	Yes	Yes	Yes
	Decision Regret Scale	No	No	No	Yes
How things are for you now	EORTC-QLQ-C30	Yes	Yes	No	Yes
	EORTC merged Bladder Cancer modules (NMIBC24 and BLM30)	Yes	Yes	No	Yes
	Bladder Utility Symptom Scale (BUSS)	No	No	Yes	No
Your everyday life	Social Difficulties Inventory (SDI)	Yes	Yes	No	Yes
Your care needs	Supportive Care Needs Survey (SCNS34)	No	No	Yes	No
Your emotional wellbeing	SWEMWBS	Yes	Yes	No	Yes
Your exercise habits	Godin Leisure-Time Exercise Questionnaire (prior to diagnosis)	Yes	No	No	No
	Godin Leisure-Time Exercise Questionnaire (current)	No	No	No	Yes
Smoking	Cigarette smoking	Yes	No	No	Yes
	e-cigarette smoking	Yes	No	No	Yes
	Passive smoking	Yes	No	No	Yes
About you	Age	Yes	No	No	No
	Marital Status	Yes	No	No	Yes
	Ethnicity	Yes	No	No	No
	Other conditions (co-morbidities)	Yes	Yes	Yes	Yes
	Height	Yes	No	No	No
	Weight	Yes	Yes	Yes	Yes
	Support for mental health or alcohol/drugs	Yes	No	No	No
	Carer	Yes	No	No	No
Your employment status	Employment (prior to diagnosis)	Yes	No	No	No
	Employment (current)	Yes	Yes	Yes	Yes
	Sick leave and sick pay	Yes	Yes	Yes	Yes
Total number of questions:		114	101	56	108



LABC: Organisational structure

- **PIs**

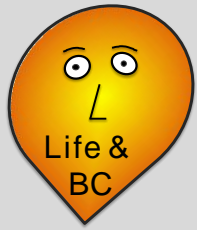
- Jim Catto Sheffield University
- Adam Glaser University of Leeds

- **Workstream Leads**

1. Penny Wright University of Leeds
2. Jim Catto Sheffield University
3. Amy Downing University of Leeds

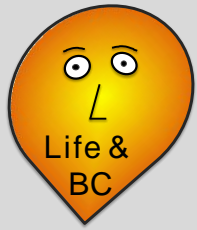
- **Research team**

- Project Manager Sarah Bottomley, Sheffield
- Researcher Assistant Sam Mason, Leeds



LABC: Governance

- **Sponsor:** Sheffield University
- **Oversight**
 - Clinical & Scientific Advisory Group
- **Clinical/Scientific Advisory Group**
 - Linda Sharp – Chair
- **User Advisory Group**
 - *Andrew Winterbottom, FBC*



Project Outcomes

1. Knowledge

- Of long term outcomes
 - Per treatment
 - Per patient (gender/age....)
- Of longitudinal changes
 - Per treatment

2. Local patterns of PROMS


3. An applicable tool for national review?

National datasets

Professionals
MyBAUS

BAUS Data & Audit Project

The information previously on the BAUS Data & Audit page has been moved to the "Professionals" section, under "BAUS Business"

With the transparency that is an essential element of the **Consultant Outcomes Publication (COP)**  project, we believe that audit information from the BAUS Cancer Registry, the BAUS Complex Operations Audit & summary data from the Consultant Outcomes Publication project should be available to everyone, and not restricted to members only.

All data in these reports are anonymised and are now freely available to individuals who are not members of BAUS.

Individual Consultant and unit data has not moved and can be found under "**Surgical Outcomes Audit**" in the "Patients" section.



[Click here](#) or on the image above to view the Data & Audit pages