

National Report: Patient Experience of the Cystectomy Treatment Pathway for Bladder Cancer

33 of 49 centers participated in the audit. In total 1714/2093 (81.8%) patients who underwent cystectomy between 1st Jan 2021 to 31st July 2022 (inc) were alive at the snapshot study time point and eligible for inclusion. The questionnaire response rate was 1081/1714 (63%) across the participating centers.

	National Figures	
Demographics		
Median age at cystectomy	71	
Male/Female ratio	M: 779 F: 255	75.30% 24.70%
Diagnosis leading to cystectomy		
MIBC	554	54.30%
NMIBC	314	30.80%
Recurrent NMIBC	152	14.90%
Neo-adjuvant chemotherapy		
Yes	276	26.70%
No	758	73.30%
Salvage cystectomy		
Yes	51	4.90%
No	981	95.10%
Surgical method of performing cystectomy		
Open	398	38.50%
Laparoscopic	4	0.40%
Robotic	631	61.10%
Urinary diversion		
Conduit	982	95.10%
Neobladder	35	3.40%
Other diversion	16	1.50%
Source of first referral to bladder cancer		
2ww	585	59.90%
Emergency Admissions	44	4.50%
Already under surveillance for upper tract TCC	68	7%
Other	280	28.70%
C-PAT Response Demographic		
How many months ago did you receive your surgery to remove the bladder?		
0-3 months	8	0.70%
4-6 months	58	5.40%
7-11 months	289	26.90%
Longer than 12 months	721	67.00%
Hospital for initial test/scan and final surgery?		
Same	448	41.50%
Different	632	58.50%
Were you given the name and telephone number of a cancer nurse specialist who you could contact if needed?	IQR (No): 3.6 - 12 Full Range (No): 0 - 50	
Yes, it was easy to contact them	743	70.20%
Yes, but it was difficult to contact them	81	7.60%
Yes, but I did not need to contact them	134	12.70%
No, I was not assigned a clinical nurse specialist	101	9.50%
C-PAT Perception of delay		
Was there a delay from when you first saw your GP, until you were referred to your local hospital?	IQR (Yes): 15.3 - 23.5 Full Range (Yes): 0 - 55.6	
Yes	189	18.20%

No	848	81.80%
Was there a delay from when your GP said they had referred you, until you were seen at your local hospital?	IQR (Yes): 5.1 - 14.7 Full Range (Yes): 0 - 50	
Yes	97	9.40%
No	930	90.60%
Was there a delay from when you had your first tests and scans, until you received the results?	IQR (Yes): 4.5 - 12 Full Range (Yes): 0 - 50	
Yes	108	10.20%
No	955	89.80%
After the decision was made to remove your bladder, was there a delay before you received the operation?	IQR (Yes): 3.7 - 13.1 Full Range (Yes): 0 - 38.2	
Yes	110	10.40%
No	953	89.70%
C-PAT Perception of post operative care		
Do you feel like the hospital prepared you for what to expect after your operation?	IQR (Yes): 80 - 92 Full Range (Yes): 71.4 - 100	
Yes	901	85.20%
No	157	14.80%
After you left hospital, was there a delay before you received an appointment or phone-call to discuss any future follow-up?	IQR (Yes): 4 - 12.1 Full Range (Yes): 0 - 40	
Yes	121	11.50%
No	935	88.50%
After you left hospital, do you feel like you had enough support to manage with your new stoma or new bladder at home?	IQR (Yes): 82.7 - 92.1 Full Range (Yes): 62.9 - 100	
Yes	912	86.10%
No	147	13.90%
In the first three months after your operation to remove the bladder...Did you have any complications that required further treatment with a local or general anaesthetic at the hospital?	IQR (Yes): 6.7 - 16.7 Full Range (Yes): 0 - 33.3	
Yes	132	12.40%
No	929	87.60%
C-PAT assessment of satisfaction		
How would you rate the care you received whilst in hospital for the operation to remove your bladder?		
Excellent	776	72.90%
Good	227	21.30%
Average	46	4.30%
Poor	13	1.20%
Extremely poor	3	0.30%
Overall, how likely would you be to recommend the hospital where you had your bladder removed to friends or family, if they needed similar care or treatment?		
Extremely likely	845	79.00%
Likely	172	16.10%
Neither likely nor unlikely	34	3.2%
Unlikely	8	0.70%
Extremely unlikely	11	1.00%
Overall, how would you rate all of the care that you have received?		
Excellent	766	71.50%
Good	262	24.50%
Average	26	2.40%
Poor	14	1.30%
Extremely poor	3	0.30%

Contributing Centers

Aberdeen Royal Infirmary
Addenbrooke's Hospital, Cambridge
Southmead Hospital, Bristol
University Hospital of Wales, Cardiff
Castle Hill Hospital, Hull
Christie Hospital, Manchester
Churchill Hospital, Oxford
East and North Hertfordshire NHS Trust
East Kent Hospitals University Foundation Trust
East Sussex Healthcare NHS Trust
Gloucestershire Hospitals NHS Foundation Trust
James Cook University Hospital, Middlesbrough
Manchester Royal Infirmary
New Cross Hospital, Wolverhampton
Newcastle (Freeman Hospital)
Norfolk & Norwich University Hospital
Nottingham City Hospital
Royal Berkshire Hospital, Reading
Royal Bournemouth General Hospital
Royal Devon & Exeter Hospital
Royal Hallamshire Hospital, Sheffield
Royal Liverpool University Hospital
Royal Preston Hospital (Lancashire Teaching Hospital)
Royal Surrey County Hospital, Guildford
Southampton
Southend University Hospital
Stepping Hill Hospital, Stockport
University College Hospital, London
University Hospitals Coventry and Warwickshire NHS Trust
University Hospitals of Leicester
University Hospitals Plymouth NHS Trust
Western General Hospital, Edinburgh
Ysbyty Gwynedd Hospital, Bangor

