### Muscle-Invasive Bladder Cancer

Consensus statement report

ע<sup>ווו</sup> Bristol Myers Squibb™

This white paper consensus statement report was produced by HSJ and was initiated and fully funded by Bristol Myers Squibb



Wilmington Healthcare

### Introduction

**FOREWORD** 

### Foreword

Bladder cancer is the fifth most common cancer in Europe<sup>1</sup>. The high prevalence consequent to recurrence and the added co-morbidities that patients present with make it a complex and expensive condition<sup>2</sup>.

The lack of general awareness and research funding have also resulted in bladder cancer lagging behind other major cancers, such as prostate and breast, leaving significant gaps and un-answered research questions.

The 10-year overall survival from bladder cancer in the UK is below 50% and has remained so for over three decades. We still have a large proportion of patients, particularly female, who present with advanced and metastatic disease.

An effective and efficient pathway that begins with public awareness through to rapid and tailored patient-centred care is urgently needed to shift the diagnostic and treatment paradigm in bladder cancer. These evidence-based, highly practical recommendations from a group of experts in muscle-invasive bladder cancer (MIBC) are intended to bolster existing GIRFT guidelines on the diagnosis and treatment of bladder cancer, and to highlight the specific need for rapid diagnosis and treatment of the MIBC patient cohort.

Cancer networks, cancer alliances, commissioners and service leads should use this guidance to plan and implement services which include appropriate measures to optimise the chances of a good outcome for patients with MIBC.

Redesigned pathways for bladder cancer can save lives and improve the patient and carer experience in the NHS.



**Professor Param Mariappan** 

Consultant Urological Surgeon, Edinburgh Bladder Cancer Surgery (EBCS), The University of Edinburgh, Western General Hospital, Edinburgh, UK.



#### **BACKGROUND**

### Background

Recently published best practice guidance and reports in urological cancer have lacked a focus on people with muscle-invasive bladder cancer (MIBC).

Both the January 2022 Getting it Right First Time (GIRFT) *Urology report*<sup>5</sup> which covered bladder cancer, and the May 2021 *Exemplar Research Report* by Flight Bladder Cancer<sup>6</sup> appear to miss detail on people with MIBC. This is despite around a quarter of all newly diagnosed bladder cancers being muscle-invasive in nature<sup>7,8</sup>.

MIBC is associated with a low survival rate, and rapid diagnosis and treatment is particularly important. However, the pathway for diagnosing MIBC is complex and consequently has many associated delays<sup>9</sup>.

In April 2023 a panel of healthcare professionals with expertise in MIBC met at a peer-to-peer roundtable, initiated, supported and funded by Bristol Myers Squibb. Patient representatives attended along with representatives from the charity, Fight Bladder Cancer.

The aim was to discuss attendees' own analysis of the pathway, share local best practice projects and resolve some of the shortcomings in the current bladder cancer pathway for the benefit of MIBC patients.

The report has been written by HSJ, reflecting the views of the expert group. Bristol Myers Squibb has reviewed the report for accuracy.

### How to use this report

**HOW TO USE THIS REPORT** 

This interactive report, focused on the outcomes of a roundtable event of healthcare professionals with expertise in MIBC, provides insights, guidance and recommendations for action to improve the pathway for MIBC cancer patients.

Shortcomings in the current care pathway in the NHS landscape are discussed and pathway exemplars are highlighted to display examples of best practice.

Use the interactive menus in the top and side bars to explore different topics which include:

- Introduction
- Existing and Edinburgh bladder cancer pathway
- Cystoscopy and imaging
- Effective triage
- Multi-disciplinary team
- Consensus statement
- Recommendations to GIRFT
- Adapted bladder cancer pathway.

The following colour coding is used within this document:

Existing and Edinburgh bladder cancer pathway

Step 3: Cystoscopy and imaging

**Step 4: Effective triage** 

Step 5: Multidisciplinary team (MDT)

Consensus and recommendations

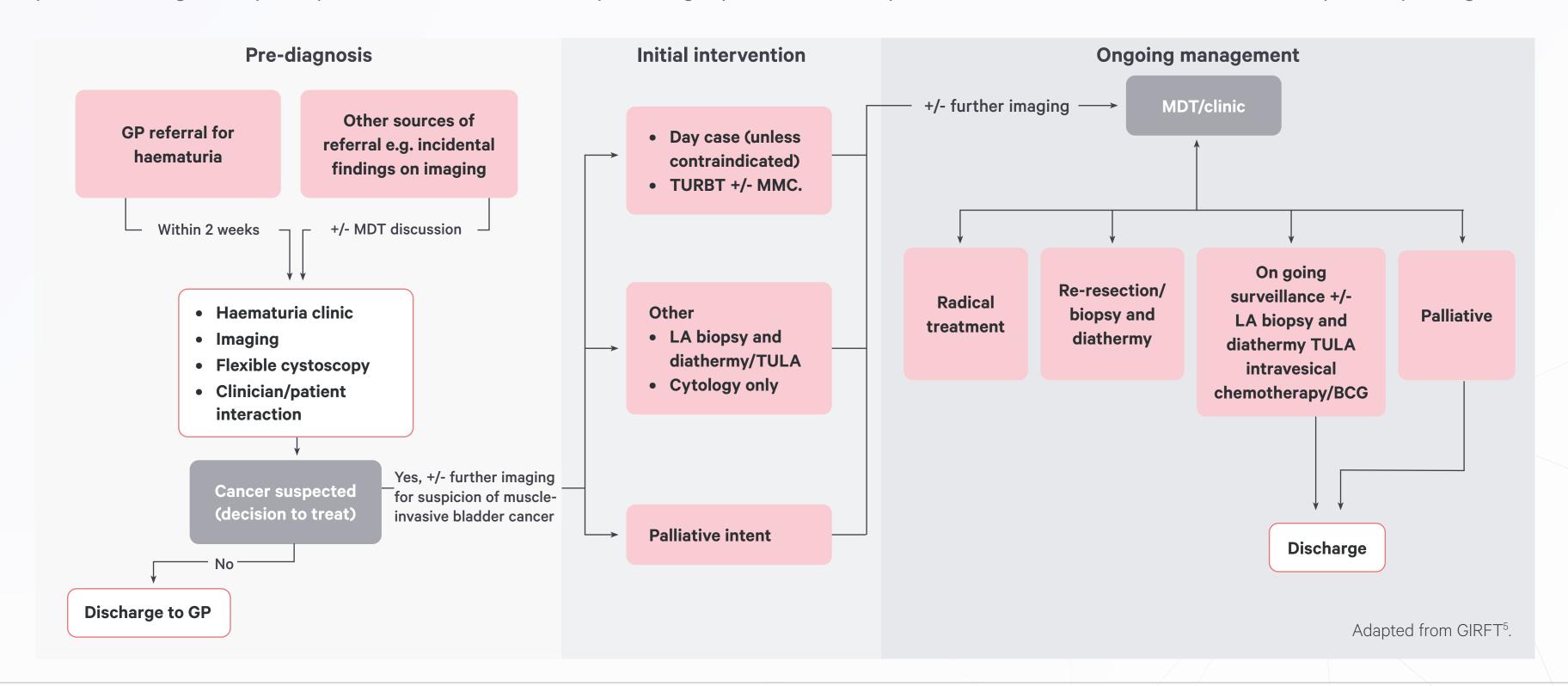
# Existing GIRFT bladder cancer pathway and the Edinburgh bladder cancer pathway



EXISTING GIRFT BLADDER
CANCER PATHWAY

### Existing GIRFT bladder cancer pathway

The current bladder cancer pathway (pictured below) featured in the GIRFT report considers three stages: pre-diagnosis, initial intervention, and ongoing management, with recommended actions attached to each stage<sup>5</sup>. Clear management plans must be formulated through shared decision-making with the patient and agreed upon by all the clinicians who are providing input, so that the patient and clinicians are clear about the pathway being followed.



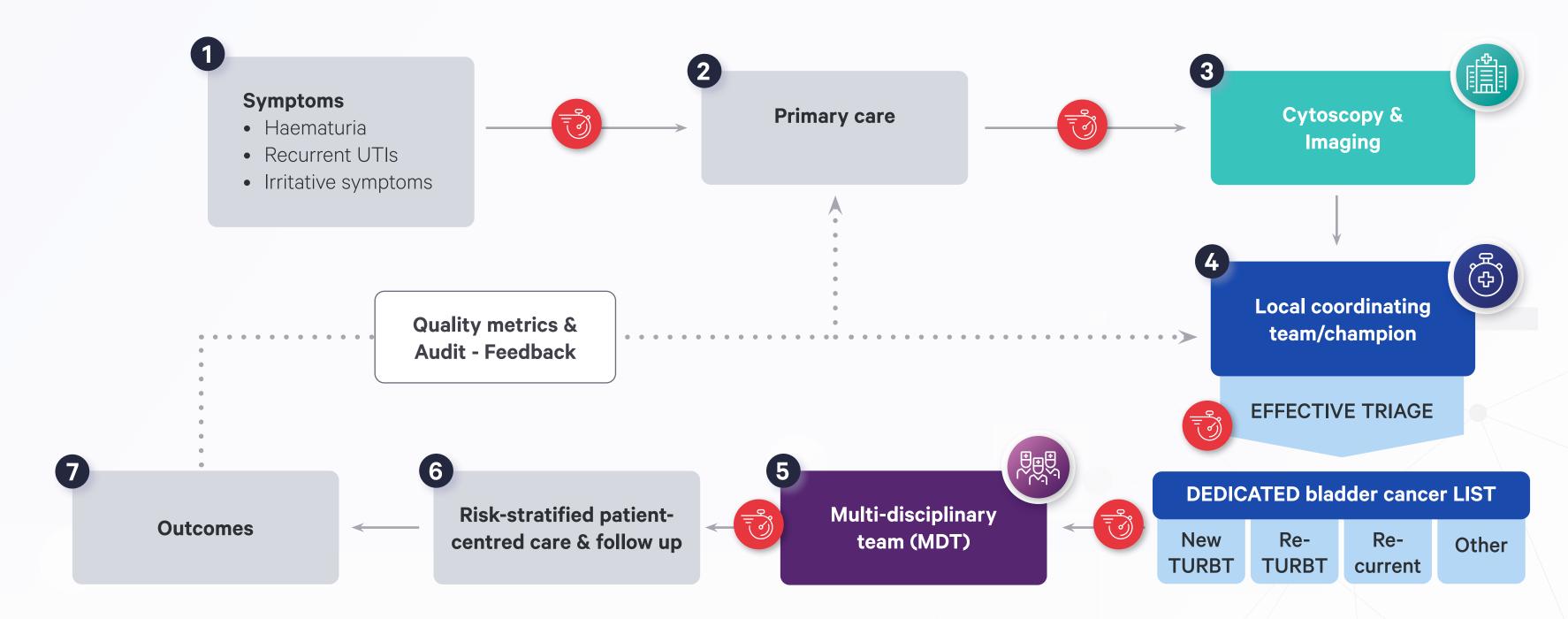


#### EDINBURGH BLADDER CANCER PATHWAY

### Edinburgh bladder cancer pathway (1)

The group considered a variant 'Edinburgh' pathway with seven steps, based on the experience of the roundtable chair<sup>10</sup>. This pathway has been in use at the Western General Hospital for several years, and was developed to fast-track high risk patients.

In this iteration the pathway is divided into:



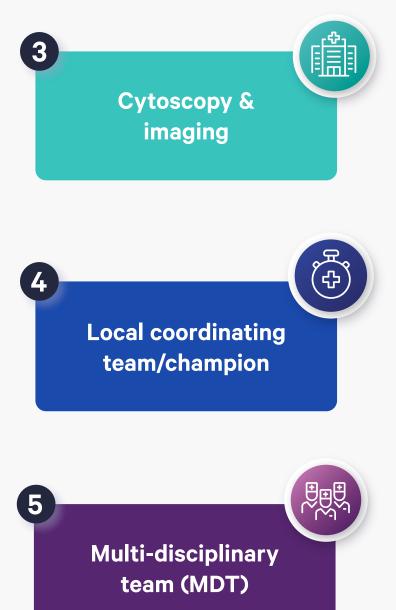


### EDINBURGH BLADDER CANCER PATHWAY

### Edinburgh bladder cancer pathway<sup>10</sup> (2)



As steps 1 and 2 were beyond the scope of the roundtable and not within the remit of the faculty, the group focused on discussion of steps 3, 4 and 5 of the pathway: cystoscopy and imaging, effective triage, and the multi-disciplinary team step.



# Step 3: Cystoscopy and imaging



CYSTOSCOPY AND IMAGING

### Cystoscopy and imaging

The first step to be considered in detail was step 3, around the effective and efficient management of bladder cancer diagnostics.

Although best practice on this stage of the pathway was generally considered to be good, several areas for improvement were discussed by the group.

Patients' representatives argued for a **one-stop shop on diagnostics**, covering haematurias and all other necessary tests at this stage. An integrated diagnostic process is currently being tested via 92 community diagnostics centres in England, but there is scope for more of this nationwide. However, 47 of the community diagnostic centres have actually been constructed on current hospital sites. Only around one in five community diagnostic centres are situated within the community, such as shopping centres, instead of the usual healthcare sites. There exists a discrepancy between what is promised – convenient care closer to home – and what is actually being provided, primarily consisting of diagnostic services delivered in traditional NHS settings. The group raised further concerns that staffing pressures would provide a challenge to this.

Participants asserted that there were **big disparities in provision**, often connected with socioeconomically disadvantaged groups.



#### Cystoscopy

During a cystoscopy, a urologist uses a scope to view the inside of the bladder and urethra. Doctors use cystoscopy to diagnose and treat a variety of problems, including bladder control issues, enlarged prostates and urinary tract infections, as well as bladder cancer.



VISUAL INSPECTION OF TUMOUR

### Visual Inspection of tumour

#### Three bottlenecks were identified:



At initial cystoscopy and haematuria diagnostics: services' aims are often to 'get through the volume' rather than identify the priority/high-risk patients, or patients with MIBC.

**Visual inspection can be of benefit here**, this technique is reasonably good at picking up muscle-invasive diagnoses at the flexible cystoscopy (FC) stage, although additional diagnostics are required to tell if the tumour is high or low grade. A study published in 2017 found that new muscle-invasive bladder cancers were predicted accurately in 85.2% of patients by urologists, who were also able to clinically differentiate between low- and high-grade tumours with clinically reasonable accuracy<sup>11</sup>.

One member of the group advised that cases at the FC stage of the pathway could have their notes amended with stickers marked 'potential MI'. These have assisted the Cornwall team to identify MI patients earlier.



After resection, histological diagnosis must take place, which can delay the process. This is covered later under step 4: effective triage.



At the MDT stage, better tumour staging information is required to enable definitive treatment. This is covered later under step 5: MDT.



### Local co-ordination/champion

LOCAL CO-ORDINATION/ CHAMPION Views were raised in the roundtable discussion that junior registrars who were carrying out cystoscopies often lacked the nuanced understanding and visual inspection skills to identify MIBC. It was commented that more experienced clinicians should carry these out – and have access to digital images to determine urgency - assisted in the future by artificial intelligence (AI) as this technology develops.

MIBC sits in a sea of non-MIBC diagnostics. Although diagnostic quality needs to be good across the board in bladder cancer, strong ownership of muscle-invasive diagnoses, with the right staffing, is paramount.

The group agreed that 'champions' are important to systems at the cystoscopy and imaging stage to help identify, triage and flag up patients with MIBC. These champions could be consultants or clinical nurse specialists (CNSs) – the exact staffing could be adapted to suit local circumstances and resources.





### Challenges to effective implementation

A number of challenges to the implementation of this model were discussed.

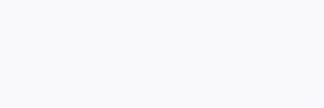
These included:

- The dearth of available nurses
- The lack of urology nurses that specialise in bladder cancer (as opposed to, for example, prostate cancer)
- Even though it was possible to use a less experienced nurse co-ordinator or administrator (for example, at band 4), a greater level of clinical expertise would be required to be a champion.

The group resolved that staffing by a consultant and/or CNS assisted by an administrator or co-ordinator was an optimal ambition for this step of the pathway.

CNSs or consultants can triage referrals. Administrators cannot triage but must track referrals and book appointments or patients cases onto MDT to ensure pathways are followed and patients are not lost.





**CHALLENGES TO EFFECTIVE** 

**IMPLEMENTATION** 



### High levels of patient communication

It was noted that changes to a pathway in terms of 'time taken' can result in negative repercussions on patient experience, in particular, patients' ability to understand where they are in their treatment pathway, and prepare and plan for the next step.

Once the staffing for this stage is established, they should be trained to communicate effectively as patient and carer communication is particularly vital at this stage.

Considering patient needs and instilling effective communication processes here are thus paramount, and can be positively affected by an MIBC clinical champion figure at all stages of the pathway.

All patients should be given the name of a clinical nurse specialist (CNS) who would support them through their treatment.



HIGH LEVELS OF PATIENT COMMUNICATION



### **Amend NICE and GIRFT**

It is difficult to fit the 'ideal picture' into the current resource available. Recommendations from this group would have to take into account local resource implications.

The MIBC clinical community is not in a position to make best practice universal. The group agreed that the most helpful development in that regard would be recognition for these recommendations by the National Institute for Health and Care Excellence (NICE) guidance, and GIRFT, and subsequent changes to guidelines. Recommendations should be made clear for patient organisations to disperse, too.

**AMEND NICE AND GIRFT** 

An exemplar of how this stage could be best managed from a project in Cornwall was shown to the group, with a positive report of the outcomes: lower waiting times for trans-urethral resection of bladder tumour (TURBT) and faster patient communication times. The details of the study are provided on the next page.





### Exemplar: The Cornwall project9

In 2016, the time from initial referral to referral for definitive treatment for MIBC patients at Royal Cornwall Hospitals NHS Trust (RCHT) was **around 90 days**.

Simulation modelling was used to help the trust identify delays in the pathway and improve referral to treatment times.

Modelling exposed two key bottlenecks in the system:

- 1. A delay between patients being referred and receiving TURBT
- 2. A delay for the nurse specialist to contact the patients to discuss their diagnosis and treatment options

It predicted that making two key changes of fast-tracking bladder cancer patients with suspected muscle-invasion to TURBT within 14 days and asking the nurse specialist to speak to the patient to discuss options whilst on the ward for their TURBT could reduce referral to treatment time by up to five and a half weeks.

Analysis of data six months later showed patients waiting 25 days less for their TURBT and five weeks less to be contacted to be informed of their diagnosis.





### Step 4: Effective triage



FAST TRACK PATIENTS
AND CNS TRIAGE

### Fast track and CNS triage

#### Group observations on step 4 of a proposed MIBC pathway

The group suggested the triaging stage was where patients with MIBC could be best or most easily identified. The group noted:

- Patients with a lower-grade tumour could be given TURBT within 6-8 weeks in the best possible outcome.
- At this stage co-morbidities and frailty should be taken into account, with a complete geriatric assessment considered.
- Also at this stage, a decision on whether a TURBT is necessary should be made. Higher risk patients can be identified to fast track to surgical intervention.

In the Kingston model (pictured overleaf) there is CNS-led triage as part of a joined-up process where CNSs work closely with consultants. It emerged from the discussion that most services use CNSs in this way. The Kingston model was deemed to be good practice, but the group suggested it would be difficult to scale because of staffing availability.





**EXEMPLAR** 

### Exemplar: Reliable triage to allow fasttrack care for MIBC patients at Kingston Hospital NHS Foundation Trust<sup>5</sup> (1)

Identifying high-risk patients in order to streamline their care pathway:

Aims to identify high-risk patients early in the pathway to minimise time taken to make a diagnosis.

Changed from consultant to CNS-led triage of patients who have been referred to haematuria clinic, enabling the CNS to request risk-based imaging prior to clinic attendance.

Once the imaging date is confirmed, the haematuria clinic attendance is arranged for the following week, so that the clinician has imaging results available.

CNS automatically emailed results by electronic patient record system and can act on the imaging findings in advance of the clinic.



**EXEMPLAR** 

# Exemplar: Reliable triage to allow fast-track care for MIBC patients at Kingston Hospital NHS Foundation Trust<sup>5</sup> (2)

#### **Key points of good practice:**

- Since changes introduced, 95% of patients have imaging prior to haematuria clinic attendance
- Same-day ultrasound is available for the small number of patients who haven't been scanned ahead of haematuria clinic attendance
- Cross-sectional imaging prior to TURBT allows for more accurate staging
- Accurate documentation at flexible cystoscopy

#### **Lessons learned:**

- A CNS (or team of CNSs) with ionising radiation medical exposure regulations (IRMER) training enables appropriate triaging, and improved pathway performance, especially for those with high-risk disease
- An improvement on cancer waiting time performance is required
- Effective working relationships with the radiology department and a reliable system for requesting imaging and receiving notification of results is required
- Contingency plans are required
- The value of bladder cancer-specific CNSs has been demonstrated



CREATE SPECIALIST CNS
ACCREDITATION FOR
BLADDER CANCER

# Create specialist CNS accreditation for bladder cancer

The group was open-minded as to whether triaging should be led by consultants, junior doctors or by a dedicated CNS. Many CNSs are now carrying out this work nationwide.

The staffing of triage will inevitably reflect differences in systems' workforce capabilities. Some find it difficult to retain band 4 nurse co-ordinators. It is important to recruit those with the correct skill set and/or interest rather than a job title.

Specialist accreditation should be made available for bladder cancer. A key area of focus is currently on prostate, and while there is an overall urology framework, there is currently no specific bladder cancer framework. The bladder cancer skill set should be championed, including full knowledge and understanding of MIBC.

Currently CNSs in urology cover five tumour sites (prostate, bladder, renal, testis and penile) across the whole pathway. The group discussed a need to have a specific bladder CNS framework to improve patient care in diagnostics to end of life.





# Improve quality of patient communication to ensure informed consent

IMPROVE QUALITY OF
PATIENT COMMUNICATION
TO ENSURE INFORMED
CONSENT

Patients at the triage stage can find waiting for results extremely stressful.

Consideration should be given to how best to communicate with patients.

A letter may not be the best way and telephone, email or app communication may be better options. Informed consent must be a priority.

Communications should be co-ordinated by the lead CNS and/or a consultant to ensure the patient is being led through the whole process. Patient-reported outcome measures (PROMs) and experience measures (PREMs) should be documented and actioned.

Challenges remain on how to create the correct patient experience without the optimal number and level of experienced nurses available.

Information should be freely available online and in booklet form. Fight Bladder Cancer, Macmillan and Carers UK for cancer carers all provide this.





# Support further use of MRI to bypass some selected TURBTs

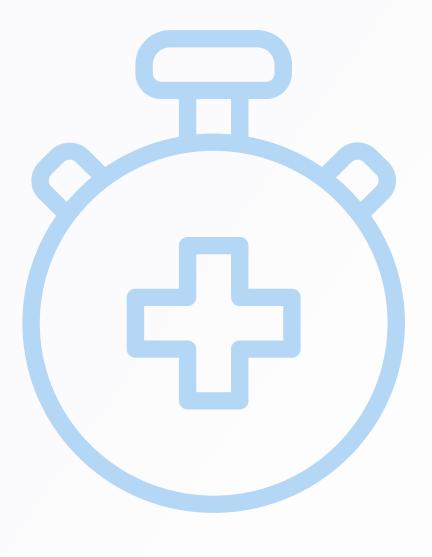
Patients should then be fast tracked to a TURBT by the triage process towards dedicated lists run by surgeons specialising in undertaking high-quality TURBT.

While general urologists can carry out TURBTs, it was noted that procedures on high risk patients may be more appropriately carried out by specialists.

In the future the TURBT step could be bypassed in select patients when MRI becomes more mainstream, guided by the University of Birmingham BladderPath study<sup>12</sup>, which states:

"Those with possible muscle-invasion would proceed to MRI scan and be further separated into MIBC and NMIBC. Patients with no evidence of muscle-invasion would proceed to standard TURBT. Patients with evidence of muscle-invasion will proceed directly to definitive therapy, avoiding TURBT and reducing delay."

SUPPORT FURTHER USE
OF MRI TO BYPASS SOME
SELECTED TURBTS



# Step 5: Multi-disciplinary team (MDT)





AIM FOR ALL RELEVANT
STAFF TO ACHIEVE FAST
CONSENSUS

# Aim for all relevant staff to achieve fast consensus

### Group observations on step 5 of a proposed muscle-invasive bladder cancer pathway.

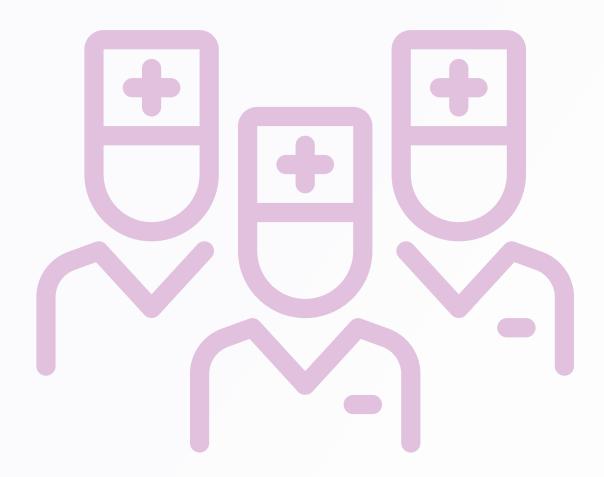
The group felt that in some areas the MDT is 'overdone', and at times, considerable time is spent discussing elements of care where efforts may be best directed elsewhere.

Patients could be selected at this stage where most difference could be made.

The bladder cancer MDT should be the main port of call for nurses to talk through more serious cases, discuss the treatment options and offer a high-level view of the pathway.

At Imperial College Healthcare NHS Trust, the bladder MDT is a separate standalone, involving all those involved with bladder cancer. They offer:

- a full review
- a consensus opinion
- next-day communication with the patient
- rapid achievement of a defined plan.





CREATE RING-FENCED
CLINICAL SPACE

### Create ring-fenced clinical space

### Create ring-fenced clinical space to guide treatment options on MIBC and pre-empt MDT where necessary

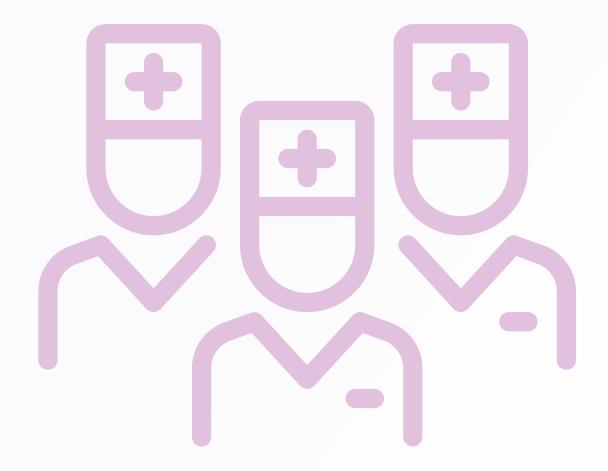
Other areas, such as Newcastle, run a nurse-led MDT where cases are directed to the next stage of the pathway by a more forensic decision-making process on priority patients. Often more information was required by this group, such as staging data.

On average, this added two weeks to the pathway. At Imperial College, after the decision-making has been completed by the ring-fenced, wide-ranging MIBC team, patients could be called to a clinic the next day.

The group agreed there should be a rapidity to the diagnosis being shared with patients and whichever MDT system best allows for this should be in place.

A ring-fenced clinical space is important here, where experienced MIBC clinicians can intervene in the caseload at this step and guide patients to appropriate treatment options. These clinical teams should act pre-emptively – there shouldn't be a need for the MDT to make additional treatment decisions if there is a confirmed diagnosis of MIBC at this stage.

The diagnosis should be communicated to the patient, and the patient should be signposted to bladder cancer peer support organisations.





### Avoid sequential clinical appointments

#### Joint appointment with surgeon and oncologist

Champions should be there proactively for MIBC patients and not rely on the availability and speed of activity of the MDT.

As well as rapidity, reducing the number of appointments at this stage would improve the experience for patients. For example, ideally there should be a joint appointment with a surgeon and an oncologist, so that care can be passed to specialties in a more seamless manner.

Wherever possible 'sequential' clinical appointments should be avoided.

More research is required to establish the optimal minimum and maximum time between the diagnosis and intervention, to cover the period taken by the ring-fenced clinical assessment, clinics with oncologists, surgeons and other members of the MDT, and radical treatment or chemotherapy.

After step 5, quality metrics should be gathered, not only on outcomes but on how well the process is working for patients. **This is vital to improve the pathway.** 





**AVOID SEQUENTIAL** 

**CLINICAL APPOINTMENTS** 



### Consensus statement



**CONSENSUS STATEMENT** 

### Consensus statement

In the NHS there is already a good deal of best practice and work continues to improve outcomes on MIBC, however, there are still several ways to improve this pathway. The exemplars show a way forward, but resources are scarce in the NHS and one model does not fit all systems. However, one could be developed that is widely adaptable to different localities.

For the first stages of the pathway, a raising of awareness in the public is paramount, and the facilitation of early referral via GPs. Screening tests may progress this, and the group supports the study run in Yorkshire<sup>13</sup>, led by Professor James Catto, which pioneers the use of at-home urine self-testing kits to see if bladder cancer can be spotted before it becomes symptomatic.

Once in the hospital, the optimal scenario is to predict which patients are more likely to be muscle invasive at cystoscopy. This requires imaging to be taken and reviewed by experienced clinicians. The future in this aspect may involve artificial intelligence.

Looking at cystoscopy findings will facilitate the next step, the triage, which is then run by clinicians – consultants, CNSs, dedicated coordinators or a combination of these roles. The ideal here includes ensuring ongoing good communication and for this, clinicians need to be trained in the art of

communicating well. Specialist accreditation for CNSs in bladder cancer was also flagged as key to improving care.

Patients should be kept well informed at all stages and their cases should be recorded and evaluated by patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs).

Patients should then be fast tracked to a TURBT following triage, and towards dedicated lists run by surgeons managing MIBC, in order to ensure an efficient pathway. In the future, MIBC patients could bypass the TURBT step when MRI becomes more mainstream, guided by the BladderPath study<sup>12</sup>. This study, which is ongoing, proposes that those with possible muscle-invasion would proceed to MRI scan and be further separated into MIBC and NMIBC. Patients with no evidence of muscle-invasion would proceed to standard TURBT. Patients with evidence of muscle-invasion would proceed directly to definitive therapy, avoiding TURBT and reducing delay.

Following this, patients can then be fast-tracked through to the MDT, taking a more nuanced approach to the fast-tracking, where a relevant and specialist MDT intervenes prior to the main MDT itself.



**CONSENSUS STATEMENT** 

### Consensus statement cont.

The need here includes having a champion to speak on behalf of the patient, and having adequate information to ensure that the process is efficient. All of the options available to the patients should be discussed here, including clinical trials. Patients then come through to a ring-fenced clinic – one that specialises solely with muscle-invasive cases – that would ideally be held jointly with a surgeon and an oncologist.

Throughout the preceding steps, we gain the opportunity to try to fast track the patients through to this ring-fenced clinic as well as radical treatment subsequently through ring-fenced slots.

The quality control step in audit and feedback afterwards is also vital in order to prove that the amendments to the pathway are working in terms of time taken, positive patient experience and observably improved patient outcomes.

Ultimately, recognition from GIRFT for this consensus would be advantageous and would help accelerate the improvements to the pathway that we envisage.



RECOMMENDATIONS TO GIRFT

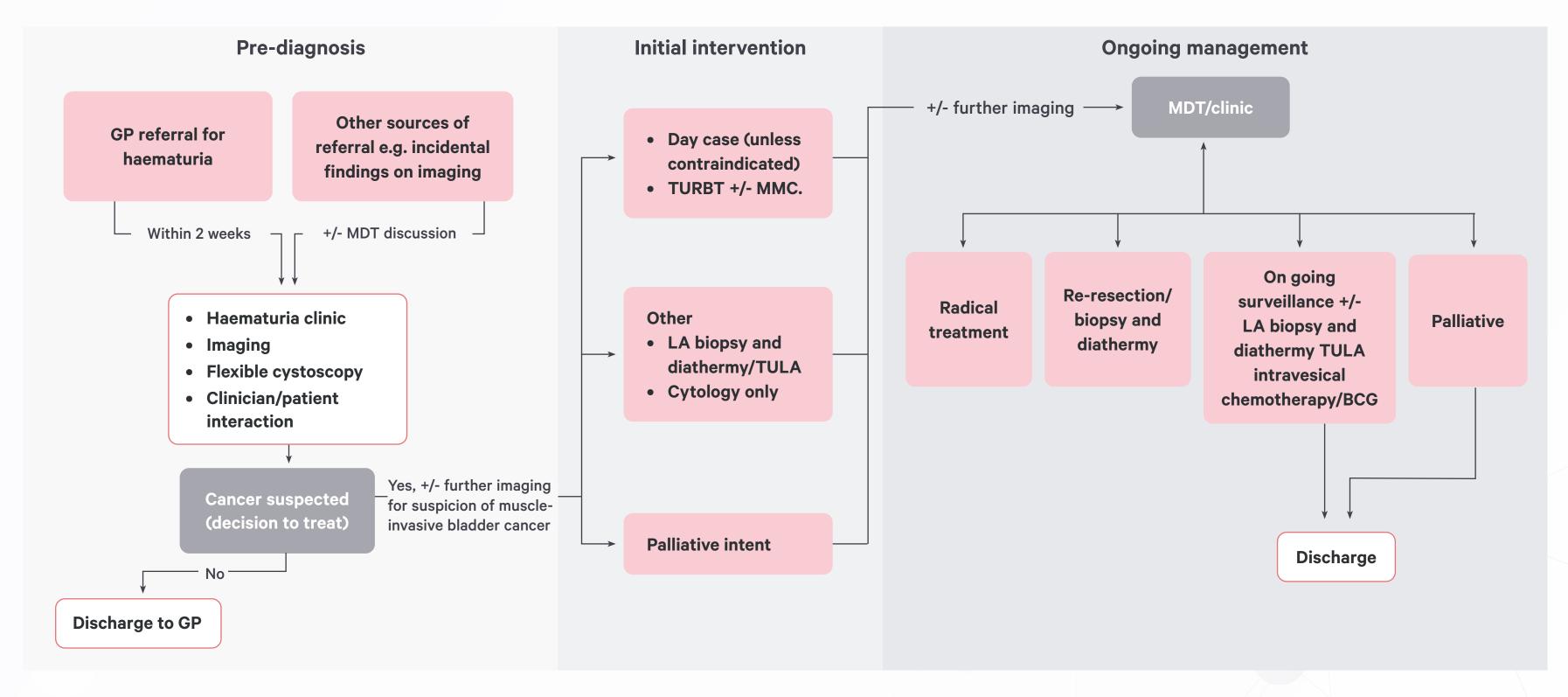
# Recommendations to GIRFT: best practice summary



### Adapted bladder cancer pathway<sup>5</sup>

The consensus recommendations of the expert group are appended to the GIRFT bladder cancer pathway that was referenced on page 7.

ADAPTED BLADDER CANCER PATHWAY



Click the red 'i' button for recommendations.

Adapted from GIRFT<sup>5</sup>.



## Appendices



#### **ABBREVIATIONS**

### Abbreviations

BC Bladder cancer

BCG Bacillus Calmette-Guerin

**CNS** Clinical nurse specialist

FC Flexible cystoscopy

**GIRFT** Getting it right first time

**GP** General practitioner

LA Local anaesthetic

MDT Multi-disciplinary team

MIBC Muscle-invasive bladder cancer

MMC Mitomycin C

MRI Magnetic resonance imaging

NICE National Institute for Health and Care Excellence

NMIBC Non muscle-invasive bladder cancer

PREMs Patient reported experience measures

PROMs Patient reported outcome measures

TULA Trans-urethral laser ablation

TURBT Trans-urethral resection of bladder tumour

**UTI** Urinary tract infection



### Contributors

CONTRIBUTORS

This roundtable event was chaired by Professor Param Mariappan, Consultant Urological Surgeon, Edinburgh.

Paul Midgley, Principal Consultant at Wilmington Healthcare, acted as facilitator.

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# Wilmington Healthcare

With unparalleled NHS expertise and outstanding industry knowledge, Wilmington Healthcare offers data, data visualisation, insight and analysis across the full spectrum of UK healthcare. We deliver sustainable outcomes for NHS suppliers and ultimately patients.

We hope you found this white paper useful. Much of the insight contained in this document is drawn from Wilmington Healthcare's portfolio of data and intelligence solutions, curated by our team of experts and consultants.

For more information or to request a demo of a solution please contact us in any of the following ways:

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