# Who's counting?

The case for urgent action to improve NHS continence care



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### **EXECUTIVE SUMMARY**

Our healthcare system needs to adapt to meet the needs of an ageing society. 80% of the increase in major illness over the next twenty years will come from an older population.<sup>1</sup>

14 million people in England currently have some degree of urinary incontinence.<sup>2</sup> As our population ages, these conditions, such as Overactive Bladder (OAB), where patients get a sudden or compelling need to pass urine and where risks of urinary tract infections, falls and fractures are higher, will increase sharply. Our research – which uses published studies on the age based prevalence of OAB and applies them to the current population of England – estimates that there are 5 million people in England with OAB today and that this is expected to rise to over 7 million by 2035. Most of this increase will be the result of an ageing population – the proportion of those with OAB who are aged 65 and over is expected to rise from 60% to 70% in this period.

Such increases will have knock on impacts on healthcare systems, with more primary care appointments, hospital admissions and demand in social care. We estimate that OAB currently costs the healthcare system in England an estimated £3.7 billion and that this will rise to over £5 billion by 2035.

Urological conditions and continence services are not a healthcare system priority. While some selective and welcome action is being taken through the Women's Health Strategy, these conditions are largely absent from the main national policy documents such as the Government Mandate, NHS Long Term Plan and various other post pandemic recovery service plans.

Despite 400,000 people being on the urology waiting list there is no National Clinical Director in NHS England. There is work on service transformation led by the Getting It Right First Time (GIRFT) team and the National Bowel and Bladder Health project. A new commissioning guide for continence services was published in 2018.<sup>3</sup> However, and understandably, progress on implementing actions on these initiatives has been impacted by the pandemic and health system restructuring. Indeed hospital activity levels for urology have not yet returned to 2012/13 levels and the last ten years can be viewed as a lost decade for delivering service improvements.

<sup>1</sup> Health Foundation. <u>Health in 2040</u>. July 2023. p7 (Accessed on 3 August 2023)

<sup>2</sup> House of Commons Library. <u>Bladder and bowel continence care</u>. June 2023. (Accessed on 3 August 2023) A methodology setting out the methods for the calculations in the report is available on p60

<sup>3</sup> NHS England. Excellence in Continence Care. June 2018. (Accessed on 3 August 2023)

'What gets measured, gets managed' is traced back to Peter Drucker's 1954 book on the 'practice of management'.<sup>4</sup> Whilst there is some data on the performance of urology services such as waiting times data, the lack of up to date integrated data on the demand, quality and provision of such services is a major barrier to progress. Without this knowledge, the ability of the system to improve is greatly reduced. The last national clinical audit was completed in 2009/10.<sup>5</sup> Urology is not included within the list of 28 clinical audits commissioned by NHS England and the Health Quality Improvement Partnership (HQIP).<sup>6</sup> This is despite it being the 11th largest secondary care specialty for hospital admissions.

The commissioning and publication of a new clinical audit can form a baseline from which action to develop and deliver improved services can be taken. NHS England can use the audit to create a urology service dashboard to monitor performance and outcomes more closely on an ongoing basis. A National Clinical Director should be appointed to provide national leadership and roll-out good practice care pathways and 'level-up' urology services. Within Integrated Care Boards (ICBs) and Primary Care Networks (PCNs) a new national audit, leading to a service dashboard can be used to galvanise new action, pioneer innovative community led service models and improve accountability of service delivery.

Urological conditions and continence care are set to be an increasingly important area of health system delivery and management. Policy action in the last decade has been too slow and new and urgent action is now needed to improve services. To do so effectively requires better data on population health needs and service capability. A new clinical audit accompanied by a digital service dashboard would be a good place to start.

<sup>4</sup> P Barnett. <u>If what gets measured gets managed, measuring the wring thing matters</u>. Corporate Finance Review. January/February 2015. (Accessed on 3 August 2023)

<sup>5</sup> Royal College of Physicians. National audit of continence care. 2010. (Accessed on 3 August 2023)

<sup>6</sup> Health Quality Improvement Partnership (HQIP).<u>The National Clinical Audit Programme</u>. (Accessed on 3 August 2023)

### **KEY FINDINGS<sup>7</sup>**

National and regional prevalence and costs

- There are an estimated 5 million people over 40 with OAB in England with an estimated national cost of £3.7 billion per year
- ICBs in the South West record relatively higher rates of OAB in their populations.
   Four of the five ICBs with the highest estimated prevalence rates are in the South West and the five ICBs spending the highest estimated proportion of their budget on OAB are in the region – reflecting older populations in these areas
- Seven ICBs with higher concentrations of urban populations are spending less than 3.5% of their estimated budget on OAB. This includes all London ICBs, along with Birmingham and Solihull ICB and Greater Manchester ICB. East London ICB is spending the lowest estimated proportion of its budget on OAB (2.7%)

#### Primary care

- There are an estimated 317,570 primary care appointments per month for patients with OAB, translating to 3.8 million appointments each year. At an ICB level the number of estimated monthly GP appointments for OAB ranges from 3,277 in Shropshire, Telford and Wrekin ICB to 18,171 in North East and North Cumbria ICB
- Staffordshire and Stoke ICB has the highest estimated proportion, 1.5%, of primary care appointments relating to OAB. Birmingham and Solihull ICB has the lowest estimated proportion (0.85%)

#### Secondary care

- There were over 640,000 Finished Consultant Episodes (FCEs) in 2021-22 for urology, the 11th highest specialty recorded. The amount of FCEs for urology within the NHS remains below 2012-13 levels when 755,146 episodes were recorded. In the ten years since, this level of activity has not been repeated
- When adjusting for population size, North East and Yorkshire and the North West NHS regions record the highest estimated number of hospital admissions for urological conditions with over 1200 FCEs per 100,000 population. The South West and Midlands also record over 1000 estimated admissions per 100,000 population. By contrast, in London the figure is 825 per 100,000
- There are 400,000 people on NHS waiting lists for urological treatment. When adjusting for population size Herefordshire and Worcestershire ICB has the highest number of incomplete pathways per 100,000 population (1,043). South West London ICB has the lowest recorded rate of 477 incomplete pathways per 100,000 population

<sup>7</sup> For full methods, data sources and references please see relevant sections of the report and the methodology in Annex A

- Gloucestershire ICB recorded the highest rate of patients being seen within 18 weeks for urological treatment (84.2%), Birmingham and Solihull ICB recorded the lowest rate of 37.1%
- Studies have shown that people with urinary incontinence are more at risk of falls. There are an estimated 389,722 additional falls each year for those over 65 related to OAB resulting in an estimated 22,604 hospital admissions
- When adjusting for population size, Dorset has the highest estimated number of OAB falls for over 65s per 100,000 population (971), East London recorded the lowest estimated rate (372)
- Lincolnshire ICB records the highest estimated number of OAB related falls for over 65s resulting in hospitalisation as a proportion of overall admissions, 168 per 100,000 population. Eight ICBs have rates below 100 OAB related falls for over 65s resulting in hospitalisation per 100,000 population. This includes the five London ICBs alongside Greater Manchester ICB, Bedfordshire, Luton and Milton Keynes ICB and Birmingham and Solihull ICB
- There is a national estimated cost of £246.7 million resulting from OAB related falls leading to hospitalisation for over 65s each year. Estimated costs range from £14.4 million in North East and North Cumbria ICB to £2.7 million in Shropshire, Telford and Wrekin ICB

#### Social care

 Continence issues are one of the most common reasons alongside dementia and falls for admission to care homes.<sup>8</sup> There are an estimated 36,716 people with urinary incontinence in care homes in England at an estimated cost of £19.8 million. Sussex ICB records the highest rate of people in care homes with urinary continence as a proportion of the population over 75, with a rate of 1676 per 100,000 population. The four lowest rates are in London (North London ICB, South East London ICB, East London ICB and North West London ICB) all of which record rates of below 550 people in care homes with urinary incontinence per 100,000 population over 75

#### Looking ahead: 2035

- There is set to be a 43% increase in the estimated number of people with OAB in England by 2035 linked to the ageing population. Numbers will rise from 5 million today to 7.17 million. This will see costs rise to an estimated £5.24 billion. The majority of this rise is the result of an ageing population
- If no action is taken then direct costs from OAB covering medical consultations, clinical depression and the use of incontinence pads is set to rise by £2bn by 2035. The costs from falls related to OAB resulting in hospitalisation is estimated to increase over three fold to £830m

<sup>8</sup> King's Fund. <u>Making our health and care systems fit for an ageing population</u>. 2014. p43 (Accessed on 3 August 2023)

• Only if a greater than 40% service improvement is achieved will direct and indirect costs from OAB be able to be maintained at 2023 levels. To deliver this health systems need to move towards earlier diagnosis, better support and cost effective treatment in the community for patients with OAB

### SUMMARY OF RECOMMENDATIONS

This report makes recommendations in four areas for improving NHS continence services and the identification, management, support and treatment available for patients.

#### Improving NHS continence service data

 NHS England should commission a new national clinical audit for continence care through the Healthcare Quality Improvement Partnership (HQIP). Conducting the audit should be used to improve clinical coding in relation to continence care and support the development of a urology service dashboard that monitors and tracks health systems against important service performance standards

#### **Prioritising continence services**

- The Major Conditions Strategy should include commitments on delivering more holistic assessments of older people's needs. Continence care should be a central part of such assessments and embedded within relevant care pathways
- Any future Government healthcare prevention strategy should include the better management of continence care as a priority. This should have a leadership role for primary care in delivering an enhanced continence care prevention pathway
- NHS England should appoint a National Clinical Director (NCD) for urological conditions to oversee the improvement of services resulting from a refreshed clinical audit. The NCD should work through a refreshed National Bladder and Bowel Health project to deliver it. Targets for recovering and improving urology services should be included within annual NHS planning guidance
- The National Bladder and Bowel Health Project should use the proposed clinical audit to identify gaps in service provision and work with ICBs and clinical networks to 'level-up' the provision of continence care across the country. ICBs identified as high performing should be paired with areas that are more challenged to share good practice and ways of working. Best practice service delivery case studies should be written-up and highlighted on the FutureNHS portal.<sup>9</sup> Locally ICBs and Trusts should look to identify 'Continence care champions' who can help them in raising the quality and delivery of continence care
- Aligned to the Major Conditions Strategy, the Department of Health and Social Care, NHS England and NICE should use upcoming reforms to the Quality and Outcomes Framework (QOF) to deliver more holistic patient centred assessments. For older patients, the person centred assessment should include an evaluation of continence care issues

Future NHS portal. Available at <u>https://future.nhs.uk/</u>

#### Engaging effectively with patients to tackle stigma and improve selfmanagement

- NHS England should ensure that the NHS App signposts and links to relevant information on symptoms, treatment and care for continence issues for relevant population groups. This should provide a relatively low cost way for engaging with those with or at heightened risk of such conditions. The App should signpost patients to existing effective tools and resources such as the bladder and bowel CONfidence app<sup>10</sup>
- Government should work with healthcare professionals and charities to coordinate a new campaign to tackle stigma and raise awareness relating to continence care issues. This could be done to coincide with World Continence Week in June.<sup>11</sup> ICBs should ensure dedicated helplines for continence care within their localities, so that patients can confidently seek appropriate assistance and support when required

#### Improving the education and training of healthcare professionals

- The General Medical Council (GMC) should ensure that all medical school student curriculums integrate continence care training more extensively into the undergraduate syllabus. The Nursing and Midwifery Council (NMC) and the Health & Care Professions Council (HCPC) could do similar for nursing, physiotherapy and allied healthcare professional degrees. This should include at least a full day's worth of training on both basic bladder and bowel health and ideally one full day on each area.
- Professional Urology Associations, covering the spectrum of the urology workforce, should consider how greater emphasis can be placed on increasing the attractiveness of working in urology and continence care specifically for new graduates
- NHS providers should mandate basic continence training modules to be taken as part of onboarding processes for all clinical staff and as part of ongoing competency assessment processes
- The Health and Care Professions Council (HCPC) responsible for standards in social work – and Care Quality Commission (CQC) should explore appropriate mechanisms to ensure that those working in social care and nursing home settings get sufficient training in the basics of continence care as part of onboarding processes<sup>12</sup>

<sup>10</sup> Expert Self Care. <u>CONfidence App</u>. (Accessed on 3 August 2023)

<sup>11</sup> Awareness Days. World Continence Week. (Accessed on 3 August 2023)

<sup>12</sup> Astellas and Bladder Health UK. Ensuring high quality OAB and continence care in the UK. April 2023

## INTRODUCTION – THE PATIENT IMPACT OF OAB

14 million people in the UK are estimated to be living with bladder problems.

The International Continence Society defines OAB as 'urinary urgency, usually with urinary frequency and nocturia, with or without urgency urinary incontinence.'<sup>13</sup> Patients may experience a sudden and compelling need or desire to pass urine. This sensation is difficult to put off and this can happen at any time during the day or night, often without any warning.<sup>14</sup>

OAB is a common condition in both men and women and has been estimated to affect 12% of the population, with prevalence increasing with age.<sup>15</sup> The majority of patients do not seek medical help for their condition. Shame and embarrassment are barriers to seeking treatment.<sup>16</sup> Many GPs and health professionals are not familiar with the issue.<sup>17</sup>

OAB is usually treated with conservative interventions at first such as:

- Lifestyle changes including changes to drinking habits, including amount and types of fluid
- Pelvic floor muscle training strengthening the pelvic floor
- Bladder training trying to regulate the time it takes to pass urine

If these are unsuccessful then medicines and surgery can be considered.<sup>18</sup>

OAB can have a significant impact on patient quality of life. A study by Stewart et al found that 'OAB with and without urge incontinence was associated with clinically and significantly lower SF-36 quality-of-life scores, higher CES-D depression scores, and poorer quality of sleep than matched controls.<sup>'19</sup>

<sup>13</sup> International Continence Society. Overactive Bladder. June 2018. (Accessed on 3 August 2023)

<sup>14</sup> Royal United Hospitals Bath NHS Foundation Trust. <u>Overactive Bladder Syndrome</u>. (Accessed on 3 August 2023)

<sup>15</sup> Irwin et al. <u>Symptom Bother and Health Care–Seeking Behavior among Individuals with Overactive Bladder</u>. 2008. (Accessed on 3 August 2023)

<sup>16</sup> Irwin et al. <u>Symptom Bother and Health Care–Seeking Behavior among Individuals with Overactive Bladder</u>. 2008. (Accessed on 3 August 2023)

<sup>17</sup> Leron et al. Overactive Bladder Syndrome: Evaluation and Management. 2018.

<sup>18</sup> Royal United Hospitals Bath NHS Foundation Trust. <u>Overactive Bladder Syndrome</u>. (Accessed on 3 August 2023)

<sup>19</sup> Stewart et al. <u>Prevalence and burden of overactive bladder in the United States</u>. 2003. (Accessed on 3 August 2023)

#### My Story: Patient A<sup>20</sup>

I knew the services were poor but I was quite shocked to be told that unless I am fully incontinent 24/7 they will not even speak to me on the phone. I was not given any written resources or directed to any websites.

Bladder Health UK have been brilliant and helpful but I am banging my head against a brick wall at the moment. I have had to accept that there might not be much more treatment-wise that can be offered to me but then when I try to be proactive and access advice on managing as I am, I have just been turned away due to service cut backs. It feels that a lot of the time you are left to try and find solutions yourself and there must be so many people who won't know who to turn to for advice. I want to share my story anonymously as I am likely to soon be complaining to the Trust.

#### My Story: Kelsey Whitehouse<sup>21</sup>

I first experienced debilitating bladder issues when I was just 15. I was diagnosed with Fowlers Syndrome when I was 24, only a year ago. During this time I was in and out of hospital with no answers, constant UTIs, kidney infections and urine infections. I underwent a lot of invasive tests in this time that all came back normal and it made me feel like I was going crazy. I was genuinely so unwell.

For years I felt like I wasn't believed and that my symptoms were "in my head" due to the lack of funding and testing available for Fowlers. It was not until I was transferred to a hospital in London that specialises in diagnosing Fowlers Syndrome that I was believed and diagnosed through an EMG test and urodynamics test which showed my bladder retaining up to 1000ml. They do not know what caused me to have Fowlers Syndrome and it was completely out of the blue. I had no health condition prior to this. My young years as a teenage girl and now woman have been taken away from me due to this awful condition and it affects every part of my life. It has taken nearly 10 years to get diagnosed and I am still awaiting my only treatment option which is sacral nerve stimulation surgery and it may not work.

I have to self catheterise up to five times a day on bad days which causes me agonising pain. There are very limited options for women with Fowlers Syndrome and bladder conditions in general. I feel the funding and waiting times are obscene and ultimately in the end people end up worse off. I am writing my story to spread awareness of this awful disease and try to help other women suffering with bladder issues. The lack of understanding and waiting times are a lot to the point it makes you mentally unwell.

<sup>20</sup> NHS England. <u>Commissioning for Quality and Innovation (CQUIN) scheme for 2023/24</u>. January 2023. (Accessed on 3 August 2023)

<sup>21</sup> HM Government. Major Conditions Strategy: Call for evidence. May 2023. (Accessed on 3 August 2023)

The most recent NHS commissioning guidance for continence care in 2018 noted service challenges, highlighting variations in the adoption of NICE guidance and poorer care for older patients, as areas for particular improvement.<sup>22</sup>

As the population of England ages, issues of urinary incontinence and OAB are likely to significantly increase. However much of the existing data and studies on the condition are now several years old creating a gap in knowledge which will make identifying and supporting patients more challenging. As part of its 2035 health service impact programme, Future Health has set out here to provide up to date estimates on the impact of OAB in England and map out some future scenarios and actions needed.

The approach of this policy research is to draw on a number of published academic studies on OAB and urological conditions more widely and then apply the findings to the latest population and NHS activity data in England to develop new projections on the prevalence, impact and costs of OAB and urological conditions. The age and scope of these existing studies – several are international – creates limitations in the approach and all calculations are clearly labelled as estimates in the report as a result.

One of the objectives of this research is to highlight the lack of current high-quality data, research and evidence in this area of growing importance and seek to stimulate a new discussion about how to better capture and understand the impact of OAB on patients and the health system.

More information on the methods used can be found in Annex A and in relevant sections and references of the report.<sup>23</sup>

Future Health would like to thank all those who kindly contributed their time as part of a set of expert interviews and discussions for the work particularly Jacq Emkes (patient representative, National Bladder and Bowel Health Project), Rachel Skews (Trustee, BAUN), Ann Yates (Director of Continence Services, Cardiff and Vale University Health Board) and Mark Woolcock (Director of 111, NHS Cornwall). Future Health would also like to thank Bladder Health UK for kindly sourcing patient case studies for inclusion in the report.

The views expressed in this report are solely those of Future Health.

<sup>22</sup> NHS England. Excellence in Continence Care. June 2018. (Accessed on 3 August 2023)

<sup>23</sup> Annex A includes the approach to estimating the numbers with OAB and costs, as well as in 2035. Specific studies and associated calculations, for example on healthcare usage and impact are included in the relevant sections of the report

CHAPTER 1: ESTIMATING THE PREVALENCE AND COSTS OF OAB IN ENGLAND A study by Milsom et al, calculated the estimated prevalence of OAB by age group over 40 across six European countries, including the UK. The findings are set out in table 1 below<sup>24</sup>:

Age	Men (%)	Women (%)
40-44	3.4	8.7
45-49	6.0	10.6
50-54	9.8	11.9
55-59	13.2	16.9
60-64	18.9	16.9
65-69	23.7	17.5
70-74	22.3	22.1
75 >	41.9	31.3

Table 1: Prevalence of OAB by age group and sex over 40 in six European countries

By applying these prevalence estimates to current ICB populations it is possible to estimate the number of people with OAB nationally and within each ICB.

When applying these figures to ICB populations, there are an estimated 5 million people with OAB over 40 in England. This represents an increase from a previous UK wide estimate in 2008 of 4.5 million.<sup>25</sup>

Across ICBs numbers range over five fold from 51,742 in Shropshire, Telford and Wrekin ICB to 286,917 in North East and North Cumbria ICB, reflecting different population sizes and ageing demographics.

<sup>24</sup> Milsom et al. <u>How widespread are the symptoms of an overactive bladder and how are they managed?</u> <u>A population-based prevalence study</u>. 2001. (Accessed on 3 August 2023)

<sup>25</sup> Irwin et al. <u>The economic impact of overactive bladder syndrome in six Western countries</u>. 2009. (Accessed on 3 August 2023)



#### Figure 1: Estimated percentage of population over 40 with OAB by ICB<sup>26</sup>

Four of the top five ICBs with estimated population prevalence rates over 40, are in the South West (Dorset, Devon, Somerset and Cornwall and Isles of Scilly). The ICB with the highest estimated prevalence rate is Norfolk and Waveney (19.2%).

By contrast the five ICBs with the lowest estimated prevalence rates are all in London. East London has the lowest estimated prevalence rate of 15.3%. Eight of the ten ICBs with the lowest estimated prevalence rates are in London, South East or East of England. There are two from the North West (Cheshire and Merseyside and Greater Manchester) and none from the Midlands and North East and Yorkshire.

A study by Irwin et al calculated the cost per person with OAB at 515 euros. Adjusting this cost for inflation and converting into Sterling today, leads to an updated cost of £731 per patient.<sup>27</sup>

Nationally this leads to an estimated overall cost of OAB to the NHS of £3.7 billion a year. Costs range from North East and North Cumbria ICB spending an estimated £209.8 million to Shropshire, Telford and Wrekin ICB spending £37.8 million.

<sup>26</sup> The source for all maps in this report is: Office for National Statistics licensed under the Open Government Licence v3.0 Contains OS data. © Crown copyright and database right (2023)

<sup>27</sup> Irwin et al. <u>The economic impact of overactive bladder syndrome in six Western countries</u>. (Accessed on 3 August 2023)



#### Figure 2: Estimated percentage spend on patients with OAB by ICB

Gloucestershire is spending the highest estimated proportion of its budget (5%) on patients with OAB. Ten ICBs are spending an estimated 4.8% or more of their overall budget on patients with OAB. Half of these are in the South West (Gloucestershire, Somerset, Cornwall and the Isles of Scilly, Dorset, Bath and North East Somerset, Swindon and Wiltshire). Three are in the Midlands (Herefordshire and Worcestershire, Lincolnshire and Shropshire, Telford and Wrekin) and two are in the East of England (Norfolk and Waveney and Suffolk and North East Essex).

Seven ICBs with higher concentrations of urban populations are spending less than 3.5% of their estimated budget on OAB. This includes all London ICBs, along with Birmingham and Solihull ICB and Greater Manchester ICB. East London ICB is spending the lowest proportion of its budget (2.7%).

#### Summary

- There are an estimated 5 million people over 40 with OAB in England
- The revised estimated cost of a patient with OAB is £731; with an estimated national cost of £3.7 billion
- ICBs in the South West record relatively higher rates of OAB in their populations. Four of the top five ICBs for estimated prevalence rates over 40 are in the South West, reflecting older populations in these areas
- Half of the top ten ICBs with highest levels of spend on OAB as a proportion of their overall budget are in the South West
- Seven ICBs with higher concentrations of urban populations are spending less than 3.5% of their estimated budget on OAB. This includes all London ICBs, along with Birmingham and Solihull ICB and Greater Manchester ICB. East London ICB is spending the lowest proportion of its budget at 2.7%

## CHAPTER 2: HEALTHCARE SYSTEM IMPACT

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With an estimated 5 million people over 40 in England with OAB the following chapter seeks to map out the impact of the condition across primary care, secondary care and social care. Within secondary care, analysis is included of the wider challenges facing urology services including lengthy waiting lists and associated waiting times for treatment.

#### Primary care

Urological conditions are a significant source of activity in primary care. An estimated 10% of GP referrals to secondary care are for patients with urological conditions.<sup>28</sup>

However many people with OAB do not seek medical help – a report by the Pelvic Floor Society noted that half of patients do not do so.<sup>29</sup>

A 2008 study by Irwin et al estimated that 38% of people with OAB initiate a discussion with a healthcare provider in a six month period.<sup>30</sup> Using this study and the OAB population estimates from the previous chapter, it is possible to estimate the current number of primary care appointments attributable to OAB across England at ICB level.

Across England this level of activity would equate to 317,570 appointments per month for patients with OAB, translating to 3.8 million appointments each year. At an ICB level the number of estimated monthly GP appointments ranges from 3,277 in Shropshire, Telford and Wrekin ICB to 18,171 in North East and North Cumbria ICB.

<sup>28</sup> NHS.UK. Urology. (Accessed on 3 August 2023)

<sup>29</sup> The Pelvic Floor Society. Seizing the opportunity to improve patient care. 2021. (Accessed on 3 August 2023)

<sup>30</sup> Irwin et al. <u>Symptom Bother and Health Care–Seeking Behavior among Individuals with Overactive Bladder</u>. 2008. (Accessed on 3 August 2023)



#### Figure 3: Percentage of GP appointments for OAB over a six month period by ICB



Staffordshire and Stoke ICB has the highest proportion (1.5%) of primary care appointments relating to OAB in a six month period. Seven ICBs record a rate of 1.4% or greater. Two are in the Midlands (Staffordshire and Stoke, Shropshire, Telford and Wrekin), two are from the South East (Surrey, Sussex), two in the South West (Dorset and Somerset) and one in the East of England (Mid and South Essex).

Five ICBs record a rate of 1% or fewer GP appointments relating to OAB over a six month period. Birmingham and Solihull ICB has the lowest number (0.85%). East London ICB, North West London ICB, West Yorkshire ICB and Nottingham and Nottinghamshire ICB also record fewer than 1% of GP appointments for OAB.

The Irwin et al 2008 study of symptom bother and health seeking behaviour, reveals that the majority of patients with OAB do not seek support or advice from a healthcare professional in a six month period. This aligns with previous studies by Ricci et al that 70% of patients with OAB use at least one non-medical measure to cope with their OAB symptoms, such as avoiding social contact and limiting clothing choices that can have negative impacts on patient quality of life.<sup>31</sup>

<sup>31</sup> Ricci JA et al. Coping strategies and health care-seeking behavior in a US national sample of adults with symptoms suggestive of overactive bladder. 2001. Available at: <a href="https://pubmed.ncbi.nlm.nih.gov/11558861/">https://pubmed.ncbi.nlm.nih.gov/11558861/</a> (Accessed on 3 August 2023)

In parts of the country the impact of OAB is therefore likely to be more significant than the estimates above suggest as much demand is 'hidden'. There is a need for better data to identify those patients in need of support and advice and to develop appropriate primary and community care services to meet population health needs.

#### Secondary care

Urological conditions, such as OAB, are one of the largest specialties in secondary care. There were over 640,000 Finished Consultant Episodes (FCEs) in 2021-22, the 11th highest recorded.<sup>32</sup> Urology recorded more FCEs than a number of other important specialties such as respiratory medicine, medical oncology and clinical oncology.



Figure 4: Number of NHS Finished Consultant Episodes by Specialty 2021-22

However activity rates for urology have not yet recovered to pre pandemic levels. For 2020-21 the number of FCEs fell by 226,643 from the previous year. A survey conducted by the Unplanned Admissions Consensus Committee (UACC) found that 70% of continence services were negatively impacted by COVID-19, with a similar number expressing a concern that continence patients will have been left without the required treatment as a result of pandemic disruption.<sup>33</sup>

Activity levels recovered in 2021-22 by 156,250, but this is still 70,393 below pre pandemic levels.

The amount of FCEs for urology within the NHS remains below 2012-13 levels when 755,146 episodes were recorded. In the ten years since this level of activity has not been repeated. Current activity levels are 85% of this.

<sup>32</sup> NHS Digital. Hospital Admitted Patient Care Activity, 2021-22. September 2022. (Accessed on 3 August 2023)

<sup>33</sup> Unplanned Admissions Consensus Committee. <u>The Hidden Cost of COVID19 on Continence (Bladder and Bowel) Care</u>. August 2022. (Accessed on 3 August 2023)



## *Figure 5: Number of Finished Consultant Episodes for Urological Conditions from* 2012-2022<sup>34</sup>

There is widespread variation in the number of admissions for urological conditions by NHS region and NHS Trust. The Midlands records the highest number of admissions (118,155) and North East and Yorkshire the second highest (116,230). The South West has the lowest number of admissions (63,450).

When adjusting for population size, North East and Yorkshire and the North West record the highest with over 1200 FCEs per 100,000 population. The South West and Midlands also record over 1000 per 100,000 population. By contrast in London the figure is 825 per 100,000.



Figure 6: Number of FCEs per 100,000 population for urological conditions by NHS Region<sup>35</sup>

At Trust level, East Kent Hospitals University Foundation Trust recorded the highest number of admissions for urological conditions, 17,060 in 2021-22. But the average number across all Trusts in England is much lower, 3490, and there are number of non-specialist Foundation Trusts who record less than this figure. The reasons for this variation are unclear. The range of procedures and specialist teams available at certain providers is likely to be a driver of increased activity levels. Wider backlog pressures in the system will also be restricting activity in certain trusts.



*Figure 7: Finished Consultant Episodes for urological conditions by NHS Provider Trust* 2021-22<sup>36</sup>

There are 400,000 people on NHS waiting lists for urological treatment.<sup>37</sup> Greater Manchester ICB has the highest number 26,889, Cornwall and Isles of Scilly ICB the lowest 3,034.

<sup>36</sup> NHS Digital. <u>Hospital Admitted Patient Care Activity, 2021-22</u>. September 2022. (Accessed on 3 August 2023)
37 NHS Digital. <u>Referral to Treatment Target data</u>. (Accessed on 3 August 2023)

#### My Story: Patient C<sup>38</sup>

My Urology Consultant spoke to me in October 2022 and said she would refer me to Addenbrookes for treatment for Overactive bladder. I waited until mid April this year, 28 weeks after the referral before I got a text asking me if I wanted to keep the option open to see them. At the time of writing I have now been waiting 43 weeks with no treatment. I have emailed the hospital a couple of times about the NHS 18 week pathway and they just blame the pandemic. Meanwhile my bladder just gets worse and I know it's going to take years to get the treatment I need. I have given up now.

#### My Story: Patient D<sup>39</sup>

I had Interstitial Cystitis diagnosed in 2001. I lived in Devon and had a lovely urologist and once or twice yearly hydrodistentions.

I moved to Hampshire in early 2021 and eventually got a urologist appointment in September 2022 and was told yes I could continue hydrodistentions but the wait would be about three months. Told him it had been two years already as a I was in a lot of pain.

I eventually got through to day case appointments in March 2023 to be told I was only a category four patient and that it would be a six month to one year wait. I even got my GP to write a letter, to which the reply was 'I am sorry she is in pain but we have a significant backlog in elective surgeries.' It is nearly a year now and still nothing. I was diagnosed with diverticulitis in February, had constant flare ups I cannot eat properly, and I feel my angry bladder is not helping. No one seems to care.

<sup>38</sup> Case study supplied by Bladder Health UK

<sup>39</sup> Case study supplied by Bladder Health UK



#### Figure 8: Number of incomplete urology pathways per 100,000 population<sup>40</sup>

When adjusting for population size Herefordshire and Worcestershire ICB has the highest number of incomplete pathways per 100,000 population (1,043). Birmingham and Solihull ICB also records over 1,000 incomplete pathways per 100,000 population for urological conditions. South West London ICB has the lowest recorded rate of 477 incomplete pathways per 100,000 population.

The number of those waiting for treatment represents 62.5% of the current annual treatment volume in the NHS. As a result many patients are waiting longer than the 18 week referral to treatment target. Analysis from Lane, Clark and Peacock reveals over 170,000 patients waiting longer than 18 weeks and nearly 25,000 waiting over a year.<sup>41</sup>

<sup>40</sup> NHS Digital. Referral to Treatment Target data. (Accessed on 3 August 2023)

<sup>41</sup> Analysis of March 2023 data available at: https://waitinglist.health.lcp.com/ (Accessed on 3 August 2023)







In March 2023, Gloucestershire recorded the highest rate of patients being seen within 18 weeks for urological treatment (84.2%), this is 8.7% higher than the second highest figure in South West London, 75.5%.

Reflecting their relative greater waiting lists Birmingham and Solihull ICB and Herefordshire and Worcestershire ICB recorded the lowest rate of patients being seen within 18 weeks for urological treatment of 37.1% and 44.3% respectively. Long waits for treatment make patients more at risk of associated health complications and poorer outcomes.

As in primary care, activity related to OAB specifically is not readily and easily available. Hospital Episode Statistics (HES) do allow for the recording of 'other disorders of the bladder' as a primary diagnosis for admission (ICD-10 code N32).<sup>43</sup> OAB is expected to be classified under ICD-10 code N32.8 ('other specified disorders of bladder'). For 2021-22 there were 25,733 FCEs recorded against this code, with 24,667 admissions. The vast majority of admissions were planned or from the waiting list with only 11.4% of admissions recorded as an emergency.<sup>44</sup>

<sup>42</sup> NHS Digital. Referral to Treatment Target data. (Accessed on 3 August 2023)

<sup>43</sup> NHS Digital. Referral to Treatment Target data. (Accessed on 3 August 2023)

<sup>44</sup> NHS Digital. Hospital Admitted Patient Care Activity, 2021-22. September 2022. (Accessed on 3 August 2023)

The 24,667 admissions recorded would constitute an estimated per patient admission rate nationally of 0.49%. A 2016 study by Ng et al found that 1% of OAB patients were hospitalised as a result of the condition.<sup>45</sup> If these study findings were replicated in England, we would expect to see 50,000 admissions for OAB in a year from the estimated 5 million population. The apparent relative underreporting within HES for OAB related admissions would indicate that coding for OAB is highly variable making it challenging for the NHS to accurately identify the scale of the challenge and to structure services that meets patient needs.

#### OAB and falls - estimating the impact

Studies have shown that people with urinary incontinence are more at risk of falls.<sup>46</sup> 1 in 3 adults over 65 are estimated to fall each year. For those with urinary incontinence, the risk of falling is 26% greater.<sup>47</sup>

Applying this to the OAB population across ICBs enables us to estimate the number of additional falls for over 65s related to OAB.

There are an estimated 389,722 additional falls each year for those over 65 related to OAB. This ranges from 4,252 in Shropshire, Telford and Wrekin ICB to 22,755 in North East and North Cumbria ICB.

<sup>45</sup> Ng et al. <u>Evaluating Outcomes in Patients with Overactive Bladder within an Integrated Healthcare Delivery</u> <u>System Using a Treatment Patterns Analyzer</u>. September 2016. (Accessed on 3 August 2023)

<sup>46</sup> Brown et al. <u>Urinary incontinence: does it increase risk for falls and fractures? Study of Osteoporotic Fractures</u> Research Group. July 200. (Accessed on 3 August 2023)

<sup>47</sup> Brown et al. <u>Urinary incontinence: does it increase risk for falls and fractures? Study of Osteoporotic Fractures</u> <u>Research Group</u>. July 200. (Accessed on 3 August 2023)



#### Figure 10: Estimated number of falls related to OAB per 100,000 population by ICB

When adjusting for population size, Dorset has the highest estimated number of OAB falls for over 65s per 100,000 population (971). Six ICBs have estimated fall rates over 900 per 100,000 people. These include four in the South West (Dorset, Somerset, Cornwall and Isles of Scilly, Devon), one in the East of England (Norfolk and Waveney) and one in the Midlands (Lincolnshire). All five London ICBs have the lowest estimated rates of OAB falls for over 65s per 100,000, with East London recording the lowest estimated rate (372).

The Public Health Outcomes Framework records the number of falls (223,101) requiring emergency admission for over 65s each year.<sup>48</sup> By using this figure as a proportion of the overall estimated number of falls for over 65s (1 in 3) and the additional estimated falls for those with OAB, an estimated 5.8% of falls for over 65s result in hospitalisation.<sup>49</sup>

48 Public Health England. <u>Public health profiles: falls</u>. (Accessed on 3 August 2023)
49 NHS.uk. <u>Falls</u>. (Accessed on 3 August 2023)

For the OAB population over 65, there are an estimated additional 22,604 related admissions to hospital as a result of falls each year. Shropshire, Telford and Wrekin ICB records the lowest estimated rate of 247, North East and North Cumbria ICB, 1320, the highest. The 22,604 figure is 92% of the admissions recorded directly under the 'other specified disorders of bladder' ICD-10 code in 2021-22. Added together the total number of direct and indirect estimated admissions for OAB is 47,721, close to the 50,000 expected on the Ng et al model.<sup>50</sup>

*Figure 11: Estimated OAB related falls for over 65s requiring hospitalisation per 100,000 Finished Consultant Episodes by ICB* 



Lincolnshire ICB records the highest estimated number of OAB related falls for over 65s resulting in hospitalisation as a proportion of overall FCEs, 168 per 100,000 population. Five ICBs in the South West have estimated rates of over 140 OAB related falls resulting in hospitalisation per 100,000 population.

<sup>50</sup> Ng et al. Evaluating Outcomes in Patients with Overactive Bladder within an Integrated Healthcare Delivery System Using a Treatment Patterns Analyzer. September 2016. (Accessed on 3 August 2023)

Eight ICBs have estimated rates below 100 OAB related falls for over 65s resulting in hospitalisation per 100,000 population. This includes the five London ICBs alongside Greater Manchester ICB, Bedfordshire, Luton and Milton Keynes ICB and Birmingham and Solihull ICB.

A 2013 King's Fund study in Torbay found the direct and indirect costs of falls for those over 65 admitted to hospital across 421 patients of £2.9 million, resulting in an average per patient cost of £6888 - this includes hospital care, community care and social care. Adjusting for inflation this results in a direct and indirect cost of a fall being £10,915 today. When applied to the OAB related falls data for over 65s, this leads to an estimated national cost of £246.7 million resulting from OAB related falls for over 65s each year. Estimated costs range from £14.4 million in North East and North Cumbria ICB to £2.7 million in Shropshire, Telford and Wrekin ICB.



Figure 12: Estimated cost of OAB falls for over 65s resulting in hospitalisation by ICB

#### Social care

Milsom et al have demonstrated how the prevalence of urological conditions increases with age.<sup>51</sup> Incontinence was identified as a common cause of care home admissions by the King's Fund in 2014.<sup>52</sup> Prevalence within residential care has been estimated to be 30-80% of residents.<sup>53</sup>

A 2006 study from Morrison and Levy found that urinary incontinence accounted for 10% of male and 6% of female admissions.<sup>54</sup> By applying the findings from this study to the care home population in England it is possible to estimate the number of people admitted to care homes with urinary incontinence, including OAB. This calculation estimates that there are 36,716 people with urinary incontinence admitted to care homes in England. North East and North Cumbria ICB records the largest number 2290, Shropshire, Telford and Wrekin ICB the lowest 379.

<sup>51</sup> Milsom et al. <u>How widespread are the symptoms of an overactive bladder and how are they managed?</u> <u>A population-based prevalence study</u>. 2001. (Accessed on 3 August 2023)

<sup>52</sup> King's Fund. <u>Admission to a nursing home can never become a 'never' event</u>. August 2014. (Accessed on 3 August 2023)

<sup>53</sup> Health Foundation, <u>Care home continence promotion care bundle: improving quality of care and safety</u>. (Accessed on 3 August 2023)

<sup>54</sup> Morrison and Levy. <u>Fraction of Nursing Home Admissions Attributable to Urinary Incontinence</u>. July 2006. (Accessed on 3 August 2023)



## *Figure 13: Estimated number of people admitted to care homes with urinary incontinence per 100,000 population over 75*

When comparing against the overall population over 75 across ICBs, Sussex ICB records the highest rate of people admitted to care homes with urinary continence, with a rate of 1,676 per 100,000 population over 75. The average rate recorded across ICBs is 765. The four lowest rates are in London (North London, South East London, East London and North West London) all of which record rates of below 550 admitted to care homes with urinary incontinence per 100,000 population over 75. North West London has the lowest recorded rate of 460.

The 2008 Irwin et al study estimates that nursing costs for OAB are 381 euros per person. Revising this for inflation and converting to Sterling provides a revised estimated figure of £540 per person. This results in a national estimated cost of £19.8 million of social care costs for people admitted to care homes with urinary incontinence across England. Estimated costs vary from £1.2 million in North East and North Cumbria ICB to £204,000 in Shropshire, Telford and Wrekin ICB.

#### Summary

- There are an estimated 317,570 primary care appointments per month for patients with OAB, translating to 3.8 million appointments each year. At an ICB level the number of estimated monthly GP appointments for OAB ranges from 3,277 in Shropshire, Telford and Wrekin ICB to 18,171 in North East and North Cumbria ICB
- Staffordshire and Stoke ICB has the highest estimated proportion (1.5%) of primary care appointments relating to OAB in a six month period. Birmingham and Solihull ICB has the lowest number 0.85%
- There were over 640,000 Finished Consultant Episodes (FCEs) in 2021-22, the 11th highest recorded. The amount of FCEs for urology within the NHS remains below 2012-13 levels when 755,146 episodes were recorded. In the ten years since this level of activity has not been repeated
- When adjusting for population size, North East and Yorkshire and the North West regions record the highest estimated number of hospital admissions for urological conditions with over 1200 FCEs per 100,000 population. The South West and Midlands also record over 1000 estimated admission per 100,000 population. By contrast in London the figure is 825 per 100,000
- There are 400,000 people on NHS waiting lists for urological treatment. When adjusting for population size Herefordshire and Worcestershire ICB has the highest number of incomplete pathways per 100,000 population (1,043).
   South West London ICB has the lowest recorded rate of 477 incomplete pathways per 100,000 population
- In March 2023 Gloucestershire recorded the highest rate of patients being seen within 18 weeks for urological treatment (84.2%), Birmingham and Solihull ICB recorded the lowest rate of 37.1%
- Studies have shown that people with urinary incontinence are more at risk of falls. There are an estimated 389,722 additional falls each year for those over 65 related to OAB resulting in an estimated 22,604 hospital admissions
- When adjusting for population size, Dorset has the highest estimated number of OAB falls for over 65s per 100,000 population (971), East London recorded the lowest estimated rate (372)
- Lincolnshire ICB records the highest estimated number of OAB related falls resulting in hospitalisation as a proportion of overall FCEs, 168 per 100,000 population. Eight ICBs have rates below 100 OAB related falls for over 65s resulting in hospitalisation per 100,000 population. This includes the five

London ICBs alongside Greater Manchester ICB, Bedfordshire, Luton and Milton Keynes ICB and Birmingham and Solihull ICB

- There is a national estimated cost of £246.7 million resulting from OAB related falls for over 65s each year. Estimated costs range from £14.4 million in North East and North Cumbria ICB to £2.7 million in Shropshire, Telford and Wrekin ICB
- There are an estimated 36,716 people with urinary incontinence admitted to care homes in England at an estimated cost of £19.8 million. Sussex ICB records the highest rate of people admitted to care homes with urinary incontinence as a proportion of the population over 75, with a rate of 1676 per 100,000 population. The four lowest rates are in London (North London, South East London, East London and North West London) all of which record rates of below 550 people admitted to care homes with urinary incontinence per 100,000 population over 75

## CHAPTER 3: EXISTING POLICY AND LOOKING AHEAD TO 2035

With millions of patients affected by OAB and with long immediate waiting lists for urological treatment what policy action has the Government and NHS taken?

The following table sets out major Government and NHS policy frameworks and maps the number of references and actions committed to improving care for people with urological conditions. Documents are labelled:

- Green if there is a reference a specific action or commitment related to urology
- Yellow if there is a reference but no clear action
- Red if there is no reference or commitment

*Figure 14: References and commitments to urology in national Government and NHS policy document and frameworks* 

Organisation	Policy document	Date of publication	Urology/continence/OAB references
HM Government	Major Conditions Strategy	Tbc	Urological conditions not included in the six headline conditions for the strategy
	Mandate to the NHS <sup>55</sup>	Jun-23	None
	Women's Health Strategy <sup>56</sup>	Aug-22	<ul> <li>Several references to continence care including:</li> <li>The pelvic floor health programme for stress urinary continence and pelvic organ prolapse</li> <li>A research of people's experiences of urogynaecology services. This study is examining interactions with clinicians and services covering a range of conditions, including pelvic organ prolapse and incontinence</li> </ul>

<sup>55</sup> HM Government. <u>Mandate to NHS England</u>. June 2023. (Accessed on 3 August 2023)

<sup>56</sup> Hm Government. Women's Health Strategy. August 2022. (Accessed on 3 August 2023)

			<ul> <li>Raising awareness of symptoms that and can prevent women from seeking help – for example, for very painful periods or incontinence following childbirth</li> </ul>
	Integration white paper <sup>57</sup>	Feb-22	None
	Social care white paper <sup>58</sup>	Dec-21	None
	Build back better health and care <sup>59</sup>	Sep-21	None
NHS	Long Term Plan <sup>60</sup>	Jan-19	None
	Elective Recovery Plan <sup>61</sup>	Feb-22	None
	Urgent and Emergency Care Plan <sup>62</sup>	Jan-23	None
	Primary Care Recovery Plan <sup>63</sup>	May-23	None
	Planning guidance <sup>64</sup>	Jan-23	None
	ICB Oversight metrics <sup>65</sup>	Jun-22	None
	NHS Outcomes frameworks <sup>66</sup>	Mar-22	None
	Quality and Outcomes Framework <sup>67</sup>	Mar-23	None

 <sup>57</sup> HM Government. <u>Health and social care integration: joining up care for people, places and populations</u>. February 2022. (Accessed on 3 August 2023)

<sup>58</sup> HM Government. People at the Heart of Care: adult social care reform. March 2022. (Accessed on 3 August 2023)

<sup>59</sup> HM Government. Build back better health and care. March 2022. (Accessed on 3 August 2023)

<sup>60</sup> NHS England. NHS Long Term Plan. January 2019. (Accessed on 3 August 2023)

<sup>61</sup> NHS England. Elective Recovery Plan. February 2022. (Accessed on 3 August 2023)

<sup>62</sup> NHS England. <u>Delivery plan for recovering Urgent and Emergency Care</u>. January 2023. (Accessed on 3 August 2023)

<sup>63</sup> NHS England. Delivery plan for recovering primary care services. May 2023. (Accessed on 3 August 2023)

<sup>64</sup> NHS England. 2023/24 priorities and operational planning guidance. January 2023. (Accessed on 3 August 2023)

<sup>65</sup> NHS England. <u>NHS oversight metrics for 2022/23</u>. June 2022. (Accessed on 3 August 2023)

<sup>66</sup> NHS Digital. NHS Outcomes Framework. March 2022. (Accessed on 3 August 2023)

<sup>67</sup> NHS England. Quality and Outcomes Framework guidance for 2023/24. (Accessed on 3 August 2023)

Pr	rimary Care	Sep-22	None
Er	nhanced Service <sup>68</sup>		
Co fo In (C	ommissioning or Quality and novation CQUIN) <sup>69</sup>	Jan-23	Support patients to drink, eat and mobilise after surgery incentive includes reference to urology

There is very limited reference to urology services and conditions in major national policy documents. The exception is the Women's Health Strategy where research has been commissioned into patient experience of urogynaecology services, there are commitments to raise awareness of incontinence issues relating to child birth and action is being taken through the pelvic floor programme. There is an NHS CQUIN aimed at supporting patients to eat, drink and mobilise after surgery which includes urology patients.<sup>70</sup> But there are no other clear policy commitments or incentives.

Urological conditions have not been included within the forthcoming DHSC Major Conditions Strategy from the Government and were absent from the NHS Long Term Plan.<sup>71</sup> This reflects a general lack of prioritisation over recent years – there were also no references to urological conditions in the 2014 NHS Forward View.<sup>72</sup>

<sup>68</sup> NHS England. Network Contract Directed Enhanced Service. June 2023. (Accessed on 3 August 2023)

<sup>69</sup> NHS England. <u>Commissioning for Quality and Innovation (CQUIN) scheme for 2023/24</u>. January 2023. (Accessed on 3 August 2023)

<sup>70</sup> NHS England. <u>Commissioning for Quality and Innovation (CQUIN) scheme for 2023/24</u>. January 2023. (Accessed on 3 August 2023)

<sup>71</sup> HM Government. Major Conditions Strategy: Call for evidence. May 2023. (Accessed on 3 August 2023)

<sup>72</sup> NHS England. Next steps on the Five Year Forward View. October 2014.

Since 2010, reports from the Royal College of Physicians and the APPG for Continence Care have highlighted gaps in urology service provision, poor outcomes for patients and rising costs.<sup>7374</sup>

A set of actions have been agreed and taken forward within the NHS. In 2018 NHS England issued commissioning guidance for delivering improved continence services.<sup>75</sup> The focus for the guidance was on better patient outcomes, reductions in physical and psychological harm and educational achievement.

The NHS England Getting it Right First Time (GIRFT) programme has also focused on urology. In 2018 a report was published which called for the roll-out of dedicated urological investigation units (UIUs); a greater emphasis on outpatient services and day surgery procedures; and extending the role of specialist nurses.<sup>76</sup> In 2022 the GIRFT urology programme published a series of service guides covering issues such as outpatient transformation, effective bladder cancer treatment, tackling variations in acute stone and bladder outlet obstruction services.<sup>77</sup>

NHS England also leads the National Bladder and Bowel Health Project. The project is focused on developing evidence based patient focused pathways in three areas bowel, bladder and paediatrics and transition. Workstreams are exploring the development of best practice.<sup>78</sup> Much of the work in the bladder workstream has been on responding to the Independent Medicines and Medical Devices Safety Review on improving the care for women considering or who have had surgery for Stress Urinary Incontinence or Pelvic Organ Prolapse using pelvic mesh.<sup>79</sup> A Pelvic Floor Health Oversight Group has been established to oversee this.<sup>80</sup>

<sup>73</sup> Royal College of Physicians. <u>National Audit of Continence Care (NACC) - Pilot Audit Evaluation Report</u>. 2012. (Accessed on 3 August 2023)

<sup>74</sup> All Party Parliamentary Group. <u>Continence Care Services England 2013: Survey Report</u>. 2013. (Accessed on 3 August 2023)

<sup>75</sup> NHS England. Excellence in Continence Care. July 2018. (Accessed on 3 August 2023)

<sup>76</sup> NHS England. Getting it right first time: urology.

<sup>77 &</sup>lt;u>https://gettingitrightfirsttime.co.uk/urology-pathway-delivery-guides-support-trusts-and-networks-to-improve-patient-care/</u> (Accessed on 3 August 2023)

<sup>78</sup> Association for Continence Advice. Research projects of Interest. (Accessed on 3 August 2023)

<sup>79</sup> House of Commons Library. <u>The Independent Medicines and Medical Devices Safety Review</u>. February 2022. (Accessed on 3 August 2023)

<sup>80</sup> NHS England. <u>Patient and Public Voice (PPV) Partner for the Pelvic Health Programme</u>. July 2021. (Accessed on 3 August 2023)

A number of clinical tools and guidelines have also been developed and updated to improve patient care:

- NICE clinical guideline 123 Urinary incontinence and pelvic organ prolapse in women: management (June 2019)<sup>81</sup>
- NICE quality standard 77 Urinary incontinence in women (December 2021)<sup>82</sup>
- NICE clinical knowledge summary Overactive bladder (March 2019)<sup>83</sup>
- NICE clinical knowledge summary Management of a woman with predominantly urgency incontinence (April 2023)<sup>84</sup>

As with many other areas of care, the impact of the pandemic has made these guidelines and policies challenging to implement.

#### Looking ahead: the 2035 challenge

The challenge of urological conditions such as OAB looks set to rise as the population ages. Looking ahead to 2035 the increase in ageing will see a 43% increase in the estimated number of people with OAB in England. Numbers will rise from 5 million today to 7.17 million. This will see costs rise to an estimated £5.24 billion.

By projecting forward it is possible to assess possible increases in OAB by 2035 for each ICB.

<sup>81</sup> NICE. <u>Urinary incontinence and pelvic organ prolapse in women: management</u>. June 2019. (Accessed on 3 August

<sup>82</sup> NICE. <u>Urinary incontinence in women: quality standard</u>. (Accessed on 3 August 2023)

<sup>83</sup> NICE. <u>Scenario: Overactive bladder</u>. March 2019. (Accessed on 3 August 2023)

<sup>84</sup> NICE. <u>Scenario: Scenario: Management of a woman with predominantly urgency incontinence</u>. April 2023. (Accessed on 3 August 2023)



#### Figure 15: Estimated percentage increase in rates of OAB by 2035 by ICB

The average ICB will see an estimated increase of over 50,000 people with OAB by 2035.

ICBs with lower current rates of OAB are expected to see the highest rises in people with OAB by 2035. East London ICB is expected to have an over 80% increase, the highest projected increase recorded. All 5 London ICBs are predicted to have the largest increases.

In reality these numbers will be smaller as London and other urban centres typically lose older populations to more sub-urban and more rural geographies following retirement and during older age. However the overall rise in the numbers of older people across the country will mean that all health systems will need to adapt and develop new ways of working to meet the health needs of older populations including for conditions such as OAB.

In contrast, areas with already higher rates of OAB will see lower overall increases on these projections. Dorset is projected to have the lowest increase. However even here numbers will still increase by 25% or by nearly 22,000 by 2035. In this case numbers may be an under-estimate as ICBs such as Dorset, Norfolk, Somerset and Devon assimilate greater numbers of older people into their geographies through retirement. These systems may already be better placed to meet the needs of older populations, but will still need to think about how to expand capacity to meet the growing demand. With significant expected increases in demand in the coming years, Future Health sought to model different scenarios for delivering service improvement by 2035.

The Irwin et al 2008 economic paper identified a number of component parts to the costs of OAB care as set out in table 2 below.

Excess direct costs	UK costs (euros)	% of direct cost
Prescription medication treatments for urinary symptoms	33	6.4%
Incontinence pad use	48	9.3%
Clinical depression	204	39.6%
Diagnostics	5	1%
Medical consultations	225	43.6%
Total	515	

Table 2: Irwin et al estimated cost per patient with OAB per annum<sup>85</sup>

The three highest areas of spend identified are medical consultations, clinical depression and incontinence pad use, which have a combined 92.5% of total direct costs. This equates to an estimated cost of  $\pm$ 3.4 billion. As set out in the previous chapter the estimated indirect costs from falls related to OAB resulting in hospitalisation is  $\pm$ 246.7 million.

The three scenarios, update the 2008 direct costs for each element from the Irwin et al study in line with inflation to 2023 (and convert to Sterling), and seek to then model the impact to 2035 of (a) no improvement in these areas, (b) a 20% improvement in these areas, (c) a 40% improvement. For indirect costs, Future Health built on the falls analysis from the previous chapter and modelled (a) no improvement in the reduction of falls, (b) a 20% reduction in anticipated falls, (c) a 40% reduction.

Table 3: 2035 increase in total direct and indirect costs for patients with OAB based on different scenarios of cost reduction

Direct costs from OAB	Scenario 1 (No improvement)	Scenario 2 (20% improvement)	Scenario 3 (40% improvement)
Medical consultations	£2.3bn	£1.8bn	£1.4bn
Clinical depression	£2.1bn	£1.7bn	£1.2bn

<sup>85</sup> Irwin et al. <u>The economic impact of overactive bladder syndrome in six Western countries</u>. 2009. (Accessed on 3 August 2023)

Incontinence pad use	£487.2m	£389.7m	£292.2m
Total 2035 direct costs from OAB	£4.8bn	£3.9bn	£2.9bn
Total 2035 direct cost vs 2023 direct cost	+£1.4bn	+£0.5bn	£-0.5bn
Indirect costs from OAB			
2035 estimated costs from falls with people with OAB resulting in hospitalisation	£830m	£664m	£498m
Total 2035 indirect vs 2023 indirect costs	£583.3m	£417.3m	£251.3m
Total 2035 direct and indirect costs	£5.6bn	£4.6bn	£3.4bn
Difference in total 2035 direct and indirect costs with 2023 direct and indirect costs	£2bn	£1bn	£O

If there is no improvement on managing direct and indirect costs in these areas then costs from OAB will rise by £2bn by 2035. Indirect costs are set to increase over three-fold as falls and related hospitalisations increase as a result of an older population. Under the 20% improvement scenario, costs will increase at half this rate (£1 billion). Only under the 40% improvement scenario do the direct and indirect come in similar to today.

On direct costs, there is a £1.9 billion difference between the 40% improvement scenario and the no improvement scenario. The gap between the 40% improvement scenario and the 20% improvement scenario is £1 billion.

Under the no improvement scenario direct costs in these areas will increase by  $\pm$ 1.4 billion. In the 20% scenario costs will rise by an estimated  $\pm$ 500 million. Only in the 40% improvement scenario will direct costs of patients with OAB fall below the estimated cost today.

On the costs of falls, all scenarios see a rise in falls and associated costs. There is a £332 million difference between the no reduction scenario and the 40% reduction scenario.

The above scenarios demonstrate the scale of the challenge facing health services in relation to OAB in the years ahead. The 40% improvement scenario is the only model under which costs will be maintained at the same level as today. Indirect costs in particular look set to rise significantly as the number of people over 65 increases substantially.

Delivering such an improvement will require action on a number of levels, but with a particular focus in primary and community care. There will need to be greater action on earlier risk assessments and the faster identification of patients. Opportunities will need to be unlocked to use the wider primary care workforce including nurses and allied health professionals to support better patient selfmanagement. New digital tools should be used to help patients manage and practice good self-care. This is explored more fully in the next chapter.

Such actions should see a reduction in the core drivers of expenditure relating to OAB including GP consultations (through better self-management and use of the wider primary care workforce), mental health issues (through better patient support and outcomes) and continence pad use (through earlier assessments and better care planning).

With both the Government and Opposition emphasising the importance of building more preventative approaches to healthcare management into the design of the NHS to deliver a more sustainable service with better patient outcomes, improved continence care presents a practical and growing opportunity for delivering this.

One example of such a service is Cornwall's continence cars. The service was an innovation to meet the needs of patients in a county without an out of hours district nursing service. It was set-up at risk by NHS Cornwall with no initial funding. There are now two cars staffed by an experienced driver and an urgent care practitioner (UCP) supporting a range of patients who meet specific criteria (blocked catheters, expected deaths, urinary tract infections and end of life care). This enables other clinicians to focus on the more complex, unwell patients. A CQC assessment found that in a two-month period following its establishment the continence car had responded to 61 urgent non-complex cases, and enabled the service to meet its national quality requirements such as response times in 99% of its cases.<sup>86</sup>

<sup>86</sup> CQC. Cudmore House. 2017. (Accessed on 3 August 2023)

Within social care, in Scotland, NHS Lanarkshire implemented a continence promotion care bundle (CPCB), consisting of five interventions to improve care, within two care homes. The primary aim was reducing the use of high absorbency products by 25% in 12 months, and the secondary aim was reducing the safety risks associated with incontinence. The project demonstrated the following successes:

- A reduction in episodes of incontinence and in pad use, and less distress in residents and families
- A 30% reduction in skin damage
- A 40% 65% reduction in falls
- A 50% reduction in urinary tract infections (UTI)
- A 40% reduction in unplanned hospital admission for falls/UTI
- Improved record keeping and ability to have more time with residents

Economic analysis showed the potential for savings of £250,000 over nine months.87

#### Summary

- There is very limited reference to urology services and conditions such as OAB in major national policy documents. The exception is the Women's Health Strategy which does include some targeted actions
- There is set to be a 43% increase in the estimated number of people with OAB in England by 2035 linked to the ageing population. Numbers will rise from 5 million today to 7.17 million. This will see costs rise in a similar manner, to an estimated £5.24 billion
- The average ICB will see an estimated increase in over 50,000 people with OAB by 2035
- If no action is taken then direct costs from OAB covering medical consultations, clinical depression and the use of incontinence pads is set to rise by £2bn by 2035. The costs from falls related to OAB resulting in hospitalisation is estimated to increase over three fold to £830m
- Only if a 40% improvement is seen will direct and indirect costs from OAB be maintained at 2023 levels. To deliver this health systems need to move towards earlier diagnosis, better support and cost effective treatment in the community for patients with OAB

<sup>87</sup> Health Foundation. <u>Care home continence promotion care bundle: improving quality of care and safety</u>. (Accessed on 3 August 2023)

CHAPTER 4: OPPORTUNITIES AND RECOMMENDATIONS FOR IMPROVING CARE FOR PATIENTS WITH OAB

#### Improving NHS continence data

OAB is a growing issue for the healthcare system. However it is very difficult to ascertain just how significant it is given the lack of good data. The findings of this report seek to map out some high level estimates that capture the potential current and future impact.

A report by the Unplanned Admissions Consensus Committee (UACC) into the hidden costs of COVID-19 on continence care noted that:

"no centralised data collection or monitoring system currently exists in the NHS to track the number of cases, treatment and improvement of continence care. Without this central data collection and analysis, it is impossible to assess the scale of the continence challenge that currently faces the NHS. It is also impossible to gauge the need for, and success of, targeted improvement measures to improve patient continence care and is impossible to hold trusts accountable at a national level for where patient care falls short of what is expected."<sup>88</sup>

The last national clinical audit for continence services was conducted in 2009. It was commissioned by the Health Quality Improvement Partnership (HQIP) and undertaken by the clinical standards team at the Royal College of Physicians (RCP). The full audit was published in September 2010.<sup>89</sup>

The audit concluded that: 'people of all ages, and vulnerable groups in particular (frail older people, younger people with learning disability) continue to suffer unnecessarily and often in silence, with a 'life sentence' of bladder and/or bowel incontinence'.<sup>90</sup>

The audit team noted challenges with case finding and coding, adding that such information gaps meant that 'continence is never high on the agenda for improvement.'<sup>91</sup>

As our research highlights there is still a likely under-reporting of hospital admissions relating to OAB due to issues with the quality of data and coding.

Improving the data in continence services is an important first step to delivering improved care for patients. Without proper identification patients cannot be assessed, referred and supported adequately.

<sup>88</sup> Unplanned Admissions Consensus Committee. <u>The Hidden Cost of COVID19 on Continence (Bladder and Bowel) Care</u>. August 2022. (Accessed on 3 August 2023)

<sup>89</sup> Royal College of Physicians. National audit of continence care. 2010. (Accessed on 3 August 2023)

<sup>90</sup> Royal College of Physicians. National audit of continence care. 2010. (Accessed on 3 August 2023)

<sup>91</sup> Royal College of Physicians. National audit of continence care. 2010. (Accessed on 3 August 2023)

To improve the quality of continence data across the NHS, several important steps should be taken. First, a new national clinical audit for continence care should be commissioned. The new audit presents an opportunity to baseline the needs of the population and the quality of services. There is good evidence that urological services were de-prioritised during the pandemic and many patients did not have access to care. As part of the recovery from COVID-19 now is the time to commission a new audit, to report within 12 months. Despite being the 11th largest specialty for hospital admissions urological care is not covered by the National Clinical Audit Programme. There are currently 28 audits included as part of the programme summarised in Figure 16.<sup>92</sup>

Second and building from the audit data collection, a urology service dashboard should be developed. This should cover a set of core data points which could include:

- Prevalence
- Commissioning practices
- Operational performance (e.g. admissions, waiting times)
- · Awareness of compliance with NICE guidelines
- Patient engagement and feedback<sup>93</sup>

The dashboard should be published alongside the audit, with data regularly updated by NHS ICBs and Trusts to track action and improvement against the audit findings. This work should be incorporated into the planned NHS Federated Data Platform.<sup>94</sup>

<sup>92</sup> Health Quality Improvement Partnership (HQIP). <u>The National Clinical Audit Programme</u>. (Accessed on 3 August 2023)

<sup>93</sup> The framework of metrics within the NHS England GIRFT document: <u>A framework for re-establishing and</u> <u>developing urology services in the COVID-19 era</u> (October 2020) provides a potentially useful starting place for this. (Accessed on 3 August 2023)

<sup>94</sup> NHS England. Digitising, connecting and transforming health and care.

#### Figure 16: The National Clinical Audit Programme

Cancer	Cardiovascular/diabetes/obesity
National Audit of Metastatic Breast Cancer (NAoMe)	National Adult Diabetes Audit (NDA)
National Audit of Primary Breast Cancer (NAoPri)	National Audit of Cardiovascular Disease Prevention in Primary Care
National Bowel Cancer Audit (NBoCA)	National Vascular Registry (NVR)
National Cancer Audit Collaborating Centre	Stroke National Audit Programme
National Kidney Cancer Audit (NKCA)	National Obesity Audit
National Lung Cancer Audit (NLCA)	
National Ovarian Cancer Audit (NOCA)	Surgery
National Pancreatic Cancer Audit (NPaCA)	National Emergency Laparotomy Audit (NELA)
National Prostate Cancer Audit (NPCA)	
National Oesophago-Gastric Cancer Audit (NOGCA)	End of Life
National Non-Hodgkin Lymphoma Audit (NNHLA)	National Audit of Care at the End of Life (NACEL)
Maternity and paedatrics	Falls and Fractures
National Neonatal Audit Programme (NNAP)	Falls and Fragility Fracture Audit (includes the Hip Fracture Database) (FFFAP)
National Maternity and Perinatal Audit (NMPA)	Rheumatology
Paediatric Intensive Care Audit Network (PICANet)	National Early Inflammatory Arthritis Audit (NEIAA)
National Paediatric Diabetes Audit (NPDA)	Respiratory
Mental health and neurological conditions	National Respiratory Audit Programme (NRAP)
National Clinical Audit of Psychosis (NCAP)	
National Epilepsy 12 Audit	
National Audit of Dementia (NAD)	

Third and underpinning both of the processes above is a need to improve the quality of clinical coding in relation to continence care. A study on behalf of the Audit Commission found rates of coding errors of between 8% and 16.4% across inpatient, A&E and outpatient care.<sup>95</sup> A separate study found coding errors at some Trusts as high as 46%, with an average error rate of 7%.<sup>96</sup> The 2009 continence care audit highlighted coding challenges as a major barrier to improvement.<sup>97</sup>

Earlier this year the GIRFT programme published guidance in two relevant areas:

- Male Bladder Outflow Obstruction Surgery Clinician guidance on procedure coding (January 2023)
- Urology Outpatient Procedure Codes (January 2023)<sup>98</sup>

Monitoring the implementation of this guidance will be important, as will the learnings and feedback from NHS systems on the barriers and challenges to implementation. Previous studies have shown the importance of clinicians and coders collaborating closely to improve the quality and depth of the coding captured.<sup>99</sup>

As part of their annual assessment against NHS data and security standards through the Data Security and Protection Toolkit NHS Trusts are required to confirm the quality of their clinical coding.<sup>100</sup> Some Trusts report on the quality of their clinical coding in their annual quality accounts.<sup>101</sup>

As part of NHS efforts to improve clinical coding all Trusts should through their Quality Account publish information on the quality of their clinical coding. NHS England should publish guidance on what information is published so this is standardised across Trusts enabling both comparison between organisations and tracking year on year changes easily.<sup>102</sup>

<sup>95</sup> https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/262027/ pbr\_data\_assurance\_framewrk\_key\_find\_2012-13.pdf (Accessed on 3 August 2023)

<sup>96</sup> Capita. The quality of clinical coding in the NHS. September 2014. (Accessed on 3 August 2023)

<sup>97</sup> Royal College of Physicians. National audit of continence care. 2010. (Accessed on 3 August 2023)

<sup>98</sup> NHS England. Clinical Coding. (Accessed on 3 August 2023)

<sup>99</sup> Abdulla et al. Improving the quality of clinical coding and payments through student doctor-coder

collaboration in a tertiary haematology department. 2019. (Accessed on 3 August 2023)

<sup>100</sup> NHS England. Data Security and Protection Toolkit. (Accessed on 3 August 2023)

<sup>101</sup> North Bristol NHS Trust, <u>Quality Account</u>. 2019/20. (Accessed on 3 August 2023)

<sup>102</sup> HQIP. Quality Account guidance. 2019/20. (Accessed 3 August 2023).

#### Prioritising and championing continence services in the NHS

The audit, dashboard and action on clinical coding will support the greater prioritisation of continence services. ICBs will need to work with Trusts to collect the relevant data and this should make the management of patients with continence conditions a higher priority for systems. ICBs will need to appoint a lead for the audit response improving oversight of services and associated performance.

Nationally NHS England should appoint a NCD to oversee the improvement of services generated through this work and to drive forward good practice. NHS England is currently advertising for 22 NCDs, but there is not one to cover urological conditions, despite the growing impact of these conditions on the health system.

#### NHS National Clinical Director posts being advertised<sup>99</sup>

- Adult Mental Health
- Cancer
- Cardiac Disease
- Cardiovascular Disease Prevention
- Children & Young People
- Critical & Perioperative Care
- Dementia & Older People's Mental Health
- Diabetes
- Elective Care Recovery
- Eye Care
- Infection & Antimicrobial Resistance
- Learning Disabilities & Autism
- Maternity
- Musculoskeletal
- Neonatology
- NHS Impact
- Older People & Integrated Personalised Care
- Palliative & End of Life Care
- Prescribing
- Respiratory
- Stroke
- Urgent & Emergency Care

<sup>103</sup> Health Service Journal. <u>NHSE advertises 22 director roles</u>. (Accessed on 3 August 2023)

The new NCD should work through a refreshed National Bladder and Bowel Health Project and use the clinical audit to identify gaps in service provision to work with ICBs and clinical networks to 'level-up' the provision of continence care across the country. As part of future national budget planning NHS England should reprioritise national resources towards the National Bladder and Bowel Project to deliver this and the programme should publish regular updates on the progress with its work. Targets for recovering and improving urology services should then be included within the annual NHS Planning Guidance. In the more immediate term and before an NCD for urological conditions is appointed, the new National Clinical Director of Older People and Personalised Care should oversee work to ensure continence care is embedded in NHS assessments of older people at greater risk of continence issues.

Healthcare systems identified as high performing should be paired with areas that are more challenged to share good practice and ways of working. Best practice service delivery case studies should be written-up and highlighted on FutureNHS.<sup>104</sup> Locally ICBs and Trusts should look to identify 'Continence care Champions' who can help them in raising the quality and delivery of continence care. The 2018 continence commissioning guide presents a good starting point for monitoring and improving local continence pathways<sup>105</sup>:

- Establishment of case-finding questions e.g. 'Do you ever have problems getting to the toilet on time?'
- Assessment of patients using three simple tests: urine test/ bladder/bowel diary and bladder scan
- Assessment of all people for continence problems, over the age of 75 in primary care, at hospital admission and in the community setting
- The training of the domiciliary sector in simple assessment and the establishment of referral pathways, by community services

Within primary care, potential reforms to the Quality and Outcomes Framework (QOF) create opportunities for conducting more holistic, patient centred assessments.<sup>106</sup> The existing framework is based primarily on a single disease model which is increasingly outdated. Continence issues should be included within a revamped QOF assessment for older patients, that seeks to identify patients at risk or with continence issues earlier and to ensure they have the support and treatment they need. Alternatively efforts should be made to introduce incentives for improved continence care and management within wider primary care practice such as through Primary Care Networks (PCN). The PCN Direct Enhanced Service

<sup>104</sup> Future NHS portal. Available at https://future.nhs.uk/

<sup>105</sup> NHS England. Excellence in Continence Care. July 2018. (Accessed on 3 August 2023)

<sup>106</sup> They work for you. Neil O'Brien MP parliamentary response. June 2023. (Accessed on 3 August 2023)

(DES) contract provides an opportunity to include greater action and commitments on improving the identification and management of patients with continence issues. The Investment and Impact Fund (IIF) incentives within the contract could be used to deliver the necessary prioritisation.<sup>107</sup>

For Government, the Women's Health Strategy includes some welcome commitments on improving support for women's continence care but the Major Conditions Strategy does not include urological conditions as a priority. It is important that the Department of Health and Social Care and NHS England ensure the strategy does not result in a two tier system emerging, with those conditions not directly covered in the strategy seen as lower priority. One way of averting this is to include a section in the strategy on ageing and older people setting out how health systems should adapt and be held to account for the management and outcomes of an ageing population. Such models, including the delivery of whole person care assessments, will be important in improving the identification and support for people with continence conditions.

#### Engaging effectively with patients to tackle stigma and improve selfmanagement

Public education and awareness raising was a core part of the 'what good looks like' continence care toolkit in 2018.<sup>108</sup> As this research highlights, the gaps in care are partly driven by poor data, but they are also the result of patients not coming forward for the treatment and care they need, leading to poorer outcomes. Research highlighted by the Bladder Interest Group highlighted a US study that found that two thirds of people with urinary incontinence were managing their incontinence themselves, with 59% using pads, 38% carrying out pelvic floor exercises, and 16% limiting fluid intake.<sup>109</sup> A separate study from a US-based supplier found that 39% of participants wore at least one incorrect incontinence product during a 24-hour period.<sup>110</sup> Other studies have highlighted anxiety from patients to conceal their incontinence.<sup>111</sup>

<sup>107</sup> NHS England. Network Contract Directed Enhanced Service. June 2023. (Accessed on 3 August 2023)

<sup>108</sup> NHS England. Excellence in Continence Care. July 2018. (Accessed on 3 August 2023)

<sup>109</sup> Bladder Interest Group. The Cost of Poor Bladder Management. 2021. (Accessed on 3 August 2023)

<sup>110</sup> Bladder Interest Group. <u>The Cost of Poor Bladder Management</u>. 2021. (Accessed on 3 August 2023)

<sup>111</sup> Buckley. <u>User perspectives, preferences and priorities relating to products for managing bladder and bowel</u> <u>dysfunctions</u>. 2019. (Accessed on 3 August 2023)

Between 50-54 and 60-64 the estimated prevalence of OAB nearly doubles in men and increases by a third in women. Opportunities are emerging to engage with patients with personalised health messages through new tools such as the NHS App. Whilst such channels may not be appropriate for all patients they are likely to be a growing route. 89% of 55-64 year olds now own a smartphone.<sup>112</sup> Using the NHS App to provide signposting and links to relevant information on symptoms, treatment and care for continence issues for relevant population groups should provide a relatively low cost way for engaging with those with or at heightened risk of such conditions.

Digital tools present new opportunities to engage with patients on the management of their conditions and the prevention of complications and problems. The bladder and bowel CONfidence app provides high quality patient information with the aim of improving self-care and management.<sup>113</sup>

With the projected increase in OAB highlighted in this report there is also a need to tackle the stigma associated with the condition. The Government should work with healthcare professionals and charities to co-ordinate a new campaign to tackle stigma and raise awareness. This could be done to coincide with World Incontinence Week in June next year.<sup>114</sup> Such an approach has been undertaken by other Governments in related areas of care. For example the Scottish Government invested time, money and effort in raising awareness of Crohn's and Colitis in March.<sup>115</sup> Alongside this, ICBs should ensure dedicated helplines for continence care within their localities, so that patients can confidently seek appropriate assistance and support when required.

#### Improving the education and training of healthcare professionals

Awareness and capability in relation to continence care is mixed amongst healthcare professionals. A 2013 survey of 84 UK universities found that the time allocated to undergraduate continence education had not changed in 17 years, with adult nurses receiving an average of 7.3 hours of continencerelated education throughout their undergraduate programme.<sup>116</sup>

<sup>112</sup> Statista. Share of smartphone users in the United Kingdom. 2023. (Accessed on 3 August 2023)

<sup>113</sup> Expert Self Care. <u>CONfidence App</u>. (Accessed on 3 August 2023)

<sup>114</sup> Awareness Days. World Continence Week. (Accessed on 3 August 2023)

<sup>115</sup> Bladder and Bowel Health. <u>Q2 2023</u>. (Accessed on 3 August 2023)

<sup>116</sup> McClurg et al. <u>A multi-professional UK wide survey of undergraduate continence education</u>. 2013. (Accessed on 3 August 2023)

A recent roundtable funded and supported by Astellas in collaboration with Bladder Health UK identified a number of opportunities for improving the training and education of staff in relation to continence issues:

- The General Medical Council (GMC) should ensure that all medical school student curriculums integrate continence care training more extensively into the undergraduate syllabus. The Nursing and Midwifery Council (NMC) and the Health & Care Professions Council (HCPC) could do similar for nursing, physiotherapy and allied healthcare professional degrees. This should include at least a full day's worth of training on both basic bladder and bowel health and ideally one full day on each area.
- Professional Urology Associations, covering the spectrum of the urology workforce, should consider how greater emphasis can be placed on increasing the attractiveness of working in urology and continence care specifically for new graduates
- NHS providers should mandate basic continence training modules to be taken as part of onboarding processes for all clinical staff and as part of ongoing competency assessment processes
- The Health and Care Professions Council (HCPC) responsible for standards in social work – and Care Quality Commission (CQC) should explore appropriate mechanisms to ensure that those working in social care and nursing home settings get sufficient training in the basics of continence care as part of onboarding processes<sup>117</sup>

<sup>117</sup> Astellas and Bladder Health UK. Ensuring high quality OAB and continence care in the UK. April 2023

### CONCLUSION

If a problem is not properly counted how can a healthcare system tackle it effectively? When looking at the issue of OAB and continence care more widely in the NHS the lack of good quality data is a major impediment to progress.

This report has sought to provide an up to date estimate of the impacts of OAB in England. 5 million people in England have the condition and by 2035 as the population ages, we estimate this will rise to over 7 million. Costs are set to grow to over £5 billion, from £3.7 billion today, with growing direct and indirect impacts on healthcare services across primary, secondary and social care.

This has arguably been a lost decade for patients with urological conditions. There is no NCD and the last clinical audit was undertaken in 2009/10. Service activity levels remain below 2012/13 levels and have been further impacted by the pandemic. Patients are waiting longer for treatment with 400,000 now on waiting lists. Many patients themselves are not seeking out medical help and support due to the stigma associated with the conditions. Urology is set to be absent from the Major Conditions Strategy.

There is much operational work underway within the NHS to try and improve services, including the GIRFT programme and the National Bowel and Bladder Project, however progress has inevitably been checked by the pandemic and resource is constrained. With a whole host of other challenges facing the system, the danger is that services for urological conditions continue to fall further behind.

To make progress an updated national clinical audit of services would be an important next step. It would help provide a baseline of continence care service provision and support the development of an up to date and ongoing service dashboard. From this, targeted action can then be taken to tackle variations in services by sharing and rolling out best practice models of care. Targets for improving services could then be included within annual NHS Planning Guidance under a new NCD. The Government's Major Conditions Strategy can be geared towards delivering more holistic assessments of the needs of older people which can include continence care.

Opportunities are also opening up for improved patient engagement through providing more tailored and personalised messages and risk assessments for patients, through the NHS App and structural reforms to the QOF. This should be coupled with Government support for new public health campaigns to tackle stigma associated with continence conditions and new time for these conditions to be assigned within the medical curriculum.

Politicians pursuing healthcare reform and in particular the importance of prevention should make sure continence care is included in any associated, future plans reflecting the ageing population. But to make serious progress will require better data and information on the scale of the problem that requires attention. We hope that this report is a useful addition in efforts to make that happen.

### **ANNEX A: NOTE ON METHODOLOGY**

To calculate the numbers of people with OAB across each ICB in England, Future Health used the Milsom et al age and sex prevalence data and applied it to each CCG mid 2020 population in England to get age-adjusted OAB rates.<sup>118</sup> These were then amalgamated and converted into ICB rates.<sup>119</sup>

To estimate up to date costs Future Health updated the cost per person in the Irwin et al study and adjusted for inflation based on the ONS healthcare inflation market data and converted it to UK Sterling.<sup>120</sup> This resulted in an updated cost of £731 per patient.

Studies have shown that people with urinary incontinence are more at risk of falls.<sup>121</sup> According to NHS estimates 1 in 3 adults over 65 are estimated to fall each year.<sup>122</sup> For those with urinary incontinence, the risk of falling is 26% greater.<sup>123</sup> Future Health applied these figures to estimate (a) the number of falls for over 65s relating to OAB each year, (b) the total estimated number of falls each year for both those with and without OAB, (c) used the Public Health Outcomes Framework data on the number of falls resulting in hospitalisation to calculate the proportion of falls for those over 65 with and without OAB ending in hospitalisation.<sup>124</sup>

For care home admissions for urinary incontinence conditions, Future Health applied an average 8% weighting from the US study to the Public Health England care home admissions for over 75s.<sup>125126</sup>

When projecting forward to calculate the rate of OAB in 2035, Future Health reprofiled each CCG's mid 2020 population by 15 years. Future Health then applied the same Milsom et al prevalence data to secure age and sex adjusted OAB rates. In re-profiling the populations Future Health included only those aged between 40 and 90 in these calculations (those aged 25 and 75 in the 2020 figures) reflecting (a) the age prevalence figures available and (b) the uncertainty of the over 90 population in 15 years time.

<sup>118</sup> Milsom et al. How widespread are the symptoms of an overactive bladder and how are they managed? A population-based prevalence study. 2001. (Accessed on 3 August 2023)

<sup>119</sup> Office for National Statistics. <u>Clinical commissioning groups mid year population estimates</u>. 2020. (Accessed on 3 August 2023)

<sup>120</sup> Office for National Statistics. <u>CPI WEIGHTS 06.2.1/3 Medical services & paramedical services</u>. February 2023. (Accessed on 3 August 2023)

<sup>121</sup> Brown et al. <u>Urinary incontinence: does it increase risk for falls and fractures? Study of Osteoporotic</u> <u>Fractures Research Group</u>. July 2000. (Accessed on 3 August 2023)

<sup>122</sup> NHS.uk. Falls. (Accessed on 3 August 2023)

<sup>123</sup> Brown et al. <u>Urinary incontinence: does it increase risk for falls and fractures? Study of Osteoporotic</u> <u>Fractures Research Group</u>. July 2000. (Accessed on 3 August 2023)

<sup>124</sup> Public Health England. Public health profiles: falls. (Accessed on 3 August 2023)

<sup>125</sup> Morrison and Levy. <u>Fraction of Nursing Home Admissions Attributable to Urinary Incontinence</u>. July 2006. (Accessed on 3 August 2023)

<sup>126</sup> Public Health England. Palliative and end of life care profiles. (Accessed on 3 August 2023)

As highlighted in the text, the future profiling of OAB populations at ICB level does not take into account migration to and from ICBs and these figures should be treated with caution as a result.

When looking at per patient cost breakdowns from the Irwin et al study the projected cost for incontinence pad use is £341m per year for patients in England. It is important to note that this figure does not delineate between individual and health system costs. As a result it is significantly higher than the £80m referred to in the 2018 NHS England Excellence in Continence Care commissioning guide for NHS spend on incontinence pads.<sup>127</sup>

<sup>127</sup> NHS England. Excellence in Continence Care. July 2018. (Accessed on 3 August 2023)



