SEIZING THE OPPORTUNITY TO IMPROVE PATIENT CARE:

Pelvic Floor services in 2021 and beyond

Practical recommendations to address inequalities in care for patients with pelvic floor disorders and to improve services for the future

The Pelvic Floor Society

The Association of Coloproctology of Great Britain & Ireland

The British Association of Urological Surgeons

Bladder Health UK

BOWEL RESEARCH UK.

BSUG British Society of Urogynaecology Registered charity No 1143157

Florence Nightingale Foundation

MASIC Supporting Women with Injuries from Childbirth

PROSTATE CANCER UK

SPEN Scottish Pelvic Floor Network

UKCS United Kingdom Continence Society

WFIPP World Federation of Incontinence and Pelvic Problems

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This report has been endorsed by the Pelvic Floor Society, ACPGBI, BAUS, Bladder Health UK, Bowel Research UK, BSUG, Florence Nightingale Foundation, MASIC, Prostate Cancer UK, the Scottish Pelvic Floor Network, WFIPP and UKCS and is supported by the Royal College of Obstetricians and Gynaecologists.

This document was developed through consensus discussions of a panel of professionals working across urology, urogynaecology and colorectal care. The panel includes representatives from surgical, nursing and patient support specialisms.

Further contributions to the report were received by the Pelvic Obstetric and Gynaecological Physiotherapy group (POGP).

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List of abbreviations used in this document

2WW	Two-week wait referral
AHP	Allied health professional
ASA	American Society of Anaesthesiologists
BMI	Body-mass index
CCG	Clinical Commissioning Group
DVT	Deep-vein thrombosis
EMG	Electromyography
GP	General practitioner
HCP	Healthcare professional
IBD	Inflammatory bowel disease
ICIQSF	International Consultation on Incontinence Questionnaire - Short Form
IV	Intravenous
LA	Local anaesthetic
MDM	Multidisciplinary meeting
MDT	Multidisciplinary team
NHS	National Health Service
NHSI	NHS Improvement
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
OABQ	Overactive Bladder Questionnaire
PFD	Pelvic floor disorder
PNE	Percutaneous nerve evaluation
POPSS	Pelvic Organ Prolapse Symptom Score
PTNS	Percutaneous tibial nerve stimulation
RA	Regional anaesthesia
SNM	Sacral nerve stimulation
Spec	Specialised

Forewords

Rosie Cooper MP
Chair of the All-Party Parliamentary Group for Continence Care

"As this report outlines, continence services are varied across the UK and access to surgery and treatment has traditionally been poor. Most pelvic floor problems can be fixed if patients are able to follow the right care pathway and reach the most appropriate person to care for their condition. Many pelvic floor problems can be managed in the community but it is essential that when problems are more complex these patients are not delayed in reaching expertise or in accessing surgery that can better deal with their condition and help them to return to normal life. In this past year, we have all experienced some degree of isolation and experienced the impact of staying at home due to health reasons. Lots of people with severe incontinence and pelvic floor problems are afraid to leave the house and isolation has been their reality for many years. As we start to emerge from the COVID-19 pandemic and health services begin to return to normal, we need to make sure that we use this opportunity to transform pelvic floor and continence services. We need to ensure that we create a system in which people living with these pelvic floor disorders have timely and consistent access to the care and treatment they deserve that will help them return to a normal life."

Baroness Greengross, OBE
Co-Chair of the All-Party Parliamentary Group for Continence Care

"The APPG for Bladder and Bowel Continence Care is pleased to support this report which has brought together experts from across the UK to examine what needs to be done to improve the delivery of care for people living with pelvic floor disorders in the UK. The patient experiences shared in this report are a snapshot into the significant challenges faced by people living with pelvic floor and incontinence issues. The impact of severe pelvic floor conditions on quality of life is huge and it is shocking that patients can suffer as long as a decade before they reach the right healthcare professional to treat their condition appropriately.
This report includes national and local recommendations that will make a positive difference to how pelvic floor disorders are managed. We urge policy makers, commissioners, ICS representatives, service delivery managers and health professionals to read this report and identify how changes can be made to their services to improve the lives of people living with pelvic floor conditions."

Statement from World Federation of Incontinence and Pelvic Problems (WFIPP)

The WFIPP hereby endorses this much-needed document and congratulates the authors on producing a comprehensive and well-researched all-inclusive Report that is urgent and necessary. The recommendations set out in the Report are designed to fill the gaps that currently exist in the provision of healthcare services in the United Kingdom in matters relating to pelvic health. The recommendations are based on the practical findings outlined in the Report which are totally in line with the recommendations WFIPP is striving to achieve at the international level.

It is most encouraging to see that the healthcare professionals and patient organizations involved in the preparation of the Report seek the same objectives as WFIPP as the international voice for patients and their families, healthcare professionals and institutions on a global basis. We would strongly recommend approval of the recommendations and look forward to seeing them implemented across the United Kingdom.

Please also see the WFIPP Digital Platform 'Support in Continence', which is now available in 7 languages.

Letter from the report authors

Dear Colleague

We are writing this report at a time of unprecedented strain across the NHS as a result of the COVID-19 pandemic. We recognise that the pressures facing the healthcare system are many and varied and that those patients whose concerns are urgent and life-threatening must be prioritised while elective procedures may take a back-seat, particularly during peaks of infections.

However, the issues we are raising in this document are not newly emergent from an unforeseeable global health crisis. Patients with pelvic floor disorders have been neglected since long before humans first encountered SARS-CoV-2. In fact, the current crisis presents us with an opportunity to effect positive change, which is why we are writing to you now.

Pelvic floor services have long been at the back of the queue for funding and prioritisation. Community continence services across the country are under-funded and under-resourced, with patients facing stark inequalities in care, dependent on the region in which they live. A lack of 'joined-up' care of patients with multiple continence issues leads to inefficiencies in the system as well as frustrations for patients. Furthermore, the recent inquiry led by Baroness Cumberlege *(Independent Medicines and Medical Devices Safety Review, 2020)* has highlighted some of the concerning issues of quality and safety of care being faced by this sector as a consequence of under-funding and neglect *(Francis, 2013)*.

For the most severe cases, surgery can fix these problems – but the wait is long. It can take patients 10 years from first presenting to their GP with symptoms until reaching an accurate diagnosis and receiving the surgery they may need to repair their pelvic floor. And it is not uncommon that further pelvic floor care is required in the time after that. Even before this, it may have taken years for some patients to build up the courage – or become desperate enough – to overcome the taboo and trivialisation of continence disorders in order to consult their GP in the first place.

The impact of this wait and lack of timely treatment on patients is severe. In the UK, around 14 million people are estimated to be living with bladder problems, with 6.5 million adults suffering from some form of bowel issue *(NHS England, 2018)*. That makes millions of people, who, as a result of their condition, have been socially isolating since long before COVID-19 led to a government mandate to do so – prevented from leaving their homes for fear of the consequences of their condition and the embarrassment associated with it. This isolation is associated with a significant impact on mental health and wellbeing, yet they face long delays before receiving the specialist care they need. Pelvic floor disorders and obstetric injuries, while life-changing, are often treatable, and our patients deserve timely access to that treatment as well as proactive promotion of self-help options. Patients need to be made aware that their symptoms can, and should, be improved as early as possible with appropriate care and, even when severe, symptoms may be sufficiently reduced with specialist care.

Further, there are broad economic and societal impacts to be considered. Patients suffering from pelvic floor and continence disorders may be unable to work. Incontinence is often a reason for loved ones, particularly the elderly or those with severe health issues, to be admitted into residential care. In addition to the heart-breaking impact on families, this is one of many additional strains introduced to the health and social care system by delayed treatment. Where treatment is delayed it may also need to be more intensive, bringing with it further resource and financial costs *(APPG for Bladder and Bowel Continence Care, 2011)*.

COVID-19 has magnified these pre-existing inequalities, with waiting lists for routine operations soaring across England *(BBC, 2021; COVIDSurg Collaborative, 2020; NHS England and NHS Improvement, 2021)*. Millions of people are enduring long-lasting suffering from life-changing conditions and/or injuries that can and should be fixed.

The good news is that this situation can be improved. The evolution of sustainability and transformation partnerships (STPs) into integrated care systems (ICS) provides a platform for pelvic floor patients to be better treated, providing an opportunity for health promotion and prevention of bladder and bowel problems, maintenance of quality of life in older years and a focus on addressing health inequalities. With the right support, pelvic floor medicine is perfectly positioned to take advantage of the digital revolution currently taking place across healthcare, which could help to find efficiencies to meet resourcing challenges. By actively changing our models of care, we can help meet these challenges and improve outcomes for patients.

Our report considers these opportunities and proposes practical solutions to the challenges faced by patients and healthcare teams. Owing to the availability of data, many of the points raised are focused on England, but we feel they are equally applicable to the devolved UK nations. We can improve the care and quality of life of this often-overlooked population. But we need to act now.

Yours sincerely,

Charles Knowles
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Executive summary

While COVID-19 has worsened patient waiting times across the NHS, patients with pelvic disorders have long been an under-served population experiencing unacceptable delays in care. Pelvic floor disorders are varied and can be complex, but treatment is available. However, patients, particularly those requiring surgery, can wait years from presentation before receiving the treatment they need. Patients with more than one area of the pelvis (compartment) affected may wait even longer while they see multiple specialists to treat their disorder. And all the time they are living with the profound impact of their condition, with some afraid even to leave the house.

WE MUST CHANGE THIS SITUATION AND MAKE SURE THAT IN THE FUTURE, PATIENTS RECEIVE THE CARE THEY NEED IN A TIMELY MANNER.

WE PROPOSE CHANGES IN SIX KEY AREAS:

- **Empowering and educating patients and beyond**
- **Making use of technology**
- **Integrating expertise**
- **Looking again at surgical procedures**
- **Making the most of our teams**
- **Considering collaborations**

Each area is addressed with its own chapter, but a brief summary is provided below.

Empowering and educating patients and beyond

A national, well-funded campaign is needed to raise awareness of the options for treatment

The taboo surrounding pelvic floor disorders is a major barrier to treatment; also, some patients do not realise that treatments may be available. A national, well-funded campaign is needed to break down this taboo and raise awareness of the options for treatment; it should also offer education on maintenance of bladder and bowel health.

Patients must be encouraged and empowered to present for treatment and to refer themselves if necessary – this requires the provision of adequate and accessible information, support and services. Early intervention can address the problem before it progresses to the stage that invasive therapies are required: it is important that patients are aware that conservative (non-surgical) interventions exist at an early stage of their disorder, as fear of invasive procedures can be another barrier.

It can take years for patients to present or to reach the right specialist. More needs to be done to ensure that when they do seek help from a healthcare professional (HCP), whatever the stage of their journey, they are taken seriously and are signposted to someone who can help them. Improved education for midwives and HCPs in primary care, particularly GPs and nurses, can help ensure patients receive the support and understanding they need when they present and that they are able to access the right specialist services for their condition.

Making use of technology

COVID-19 has accelerated the adoption of digital platforms to communicate with patients and colleagues. People living with pelvic floor disorders face barriers to attending in-person appointments, particularly in relation to travelling. A choice of telemedicine and in-person consultations is recommended based on patient and physician needs, such as for physical examination. We must make particular efforts to make consultation and treatment accessible to hard-to-reach communities. Online questionnaires allow accurate patient histories to be collected in advance, making clinics more efficient.

Accessibility of and sign-posting to high-quality supportive patient information and resources is important. Patients may benefit from the use of apps or websites to take ownership of their condition and find additional support; however, as it stands, online resources are often challenging for patients to find; further, they may not know which sources are evidence-based, and not all patients have access to the internet.

Technology can also improve clinicians' daily work experience and education. Virtual multidisciplinary team (MDT) meetings have increased attendance, allowing participants to join from different sites, as well as allowing patients from a local MDT to be discussed with the regional teams. Technology allows for improved access to HCP education and e-learning is increasingly accepted following the tectonic shifts brought about by COVID-19.

Integrating expertise

Many pelvic floor problems do not require hospital care. Seeing patients in their own home can be beneficial

There is an inequality of access to pelvic floor services across the UK, with expertise dispersed around the country and funding and manpower shortages in community care in some areas. The importance of community continence care cannot be overstated, and adequate funding is essential. Many pelvic floor problems can be dealt with efficiently in the community without requiring the resources associated with hospital visits.

In order to better identify patients who truly need hospital care along with those whose condition can be managed in the community, triaging systems that are already used in some centres can help to prioritise patients who require more specialist support.

A hub-and-spoke approach could make the most of available expertise and this should be tailored by region accepting that some will have 'spokes' with specialist expertise, capacity or facilities. This approach will ensure the experts of the future are adequately trained, providing centres with a high concentration of cases and expertise for trainees to learn from.

Such approaches should tie in with full UK adoption of regional MDT working. The Pelvic Floor Society offers a system of voluntary accreditation, making a standardised approach and high standards achievable across the country.

Looking again at surgical procedures

A key road-block for surgical procedures is the long waiting time for theatre availability – worsened by the COVID-19 crisis. However, not all surgery needs to take place in the operating theatre under general anaesthesia. Transitioning appropriate procedures to local or regional anaesthetic in clean rooms or day-case theatres will free up space and help reduce waiting times.

Some centres are already making this change for specific procedures e.g. sacral neuromodulation or Botox injections. Concomitant changes in facilities and training require investment to ensure safety and quality.

Making the most of our teams

Trained nurses and other AHPs, such as physiotherapists, can conduct some protocol-driven procedures to free up specialists for other work. Botox administration and sacral neuromodulation (SNM) are nurse-led in some centres, resulting in reduced waiting times.

MDTs enable regions to make the most of expertise and availability. NICE guidelines recommend both local and regional MDTs, with local meetings reviewing treatments for primary stress urinary incontinence, overactive bladder or primary prolapse, and regional meetings to cover multi-compartmental prolapse and mesh-related problems.

Maintaining a sufficient workforce to meet the needs of patients in the future is an important consideration, particularly given current shortages. While colorectal, urology and urogynaecology specialists may have a primary calling to their own speciality, we should aspire to train future 'pelvic floor' surgeons (and nurse and allied specialists), to firmly consign fragmented and poorly coordinated treatment between pelvic compartments to the past. This is important not least because ignorance of multicompartmental problems can lead to surgery where the opportunity to address two problems at the same time is lost – or, worse still, one problem is made worse by surgery on another. Notably, all stages of medical education, from undergraduate to professional development, should include sufficient emphasis on pelvic floor and continence to ensure that this public health challenge is recognised and addressed.

Considering collaborations

Collaboration with private institutions and premises could help to address specific capacity challenges

With continually growing waiting lists and the ongoing problem of COVID-19, collaborating with private institutions and premises could help to address specific capacity challenges. This is not a new approach: the first wave of COVID-19 made NHS use of private resources necessary, and the experiences gained during this period can offer valuable insights for tackling resourcing challenges moving forward.

Particularly for day cases, the use of private facilities, such as treatment centres, could help to further free up space and reduce the backlog. Potential challenges must be carefully considered, including staff availability, patient selection, quality assurance and follow-up care.

PELVIC FLOOR CONDITIONS: THE BIG PICTURE

An estimated **6.5 million** people live with bowel issues

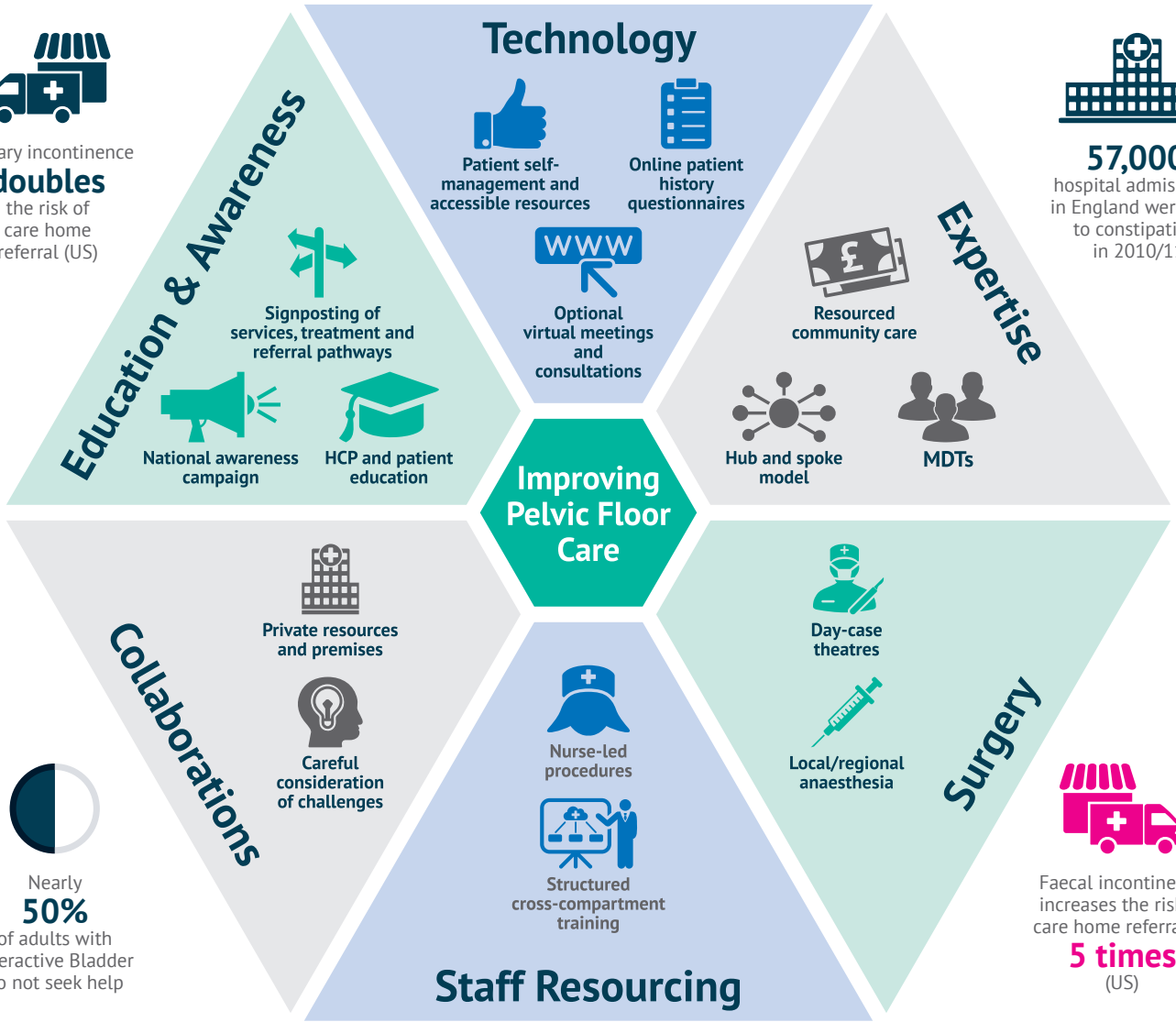
An estimated **14 million** people live with bladder problems

1 in 6 adults over 40 suffers from Overactive Bladder

85% of adults with faecal incontinence haven't told their doctor

Urinary incontinence **doubles** the risk of care home referral (US)

57,000 hospital admissions in England were due to constipation in 2010/11



Nearly **50%** of adults with Overactive Bladder do not seek help

Faecal incontinence increases the risk of care home referral by **5 times** (US)

Over **10%** of people live with symptoms of faecal incontinence

Up to **20%** of people live with constipation symptoms

Full list of recommendations

National recommendations

These recommendations require central action from national health bodies and the Government to make changes which will benefit patients and services nationally.

- Spending priorities must consider pelvic floor disorders, particularly as this area is well-suited to generate large efficiency improvements, and this should be backed by appropriate commissioning (in England; separate systems are in place in Northern Ireland, Scotland and Wales) to help define pathways for treatment
- Improved funding of community continence care services is urgently needed to provide more consistent and efficient referrals for patients who need them and to ensure a minimum national standard of care – this should also improve earlier management, reducing the burden for hospitals and specialist centres
- A national campaign and widespread public education are required to address the taboo associated with pelvic floor disorders, to empower patients to understand the options for care and to present earlier to the right specialists, and to raise awareness of bladder and bowel health among both adults and children
- Signposting to pelvic floor services should be transparent at all levels so that patients and primary care physicians can easily access services without postcode inequalities; this will be of paramount importance as we begin to contend with the legacy of poor outcomes from pelvic floor surgery involving mesh, following the Cumberlege report
- A hub-and-spoke model is recommended to help to optimise available expertise and find regional efficiencies, while also considering how to manage emergency procedures effectively
- Improvements in education are required to guarantee the workforce of tomorrow in the community, primary and specialist care. Changes to medical school and post-registration curricula should ensure that the public health challenge of continence is recognised and addressed from an early stage. E-learning is a viable option, especially since COVID-19 has made this a widespread part of medical life

Locally actionable recommendations

We encourage HCPs and people working in pelvic floor services to consider implementing these recommendations and to ask themselves: what more can I do to improve the situation locally?

- Virtual consultations should be provided as an option for patients, but face-to-face appointments should be available where clinically indicated or requested, and to prevent inequality of access to care
- Questionnaires should be in widespread use to collect a full patient history before consultations, increasing efficiency, and could be provided online, though an alternative approach needs to be available for those with limited internet access or literacy
- Mobile apps or evidence-based information on approved websites could be encouraged to support self-management of patients' conditions, and to provide comprehensive resources and education
- Local / regional MDT meetings should be constituted to meet national guidance; accreditation is available from specialist societies, such as the Pelvic Floor Society and British Society of Urogynaecology (BSUG), to ensure a nationally standardised approach. Virtual meeting technology should be used to optimise attendance
- Local pathways for onward referral between specialties should be made clear, where initial non-surgical management does not resolve the patient's symptoms
- Selected procedures could be transitioned from general to local or regional anaesthesia, allowing them to be performed outside the operating theatre and freeing up space; some protocol-driven procedures could also be performed by nurses rather than doctors
- Local / regional solutions should consider the role of private institutions and premises to improve efficiencies (reduce waiting times) and maintain quality

Introduction: The Reality

Steven Brown, Charles Knowles, Shahab Siddiqi, Carolynne Vaizey, Andrew Williams

What is a pelvic floor disorder?

There is no particularly easy way to exactly define the parameters that constitute a 'pelvic floor disorder'. Rather, the term is used as a catch-all for a number of conditions that primarily affect the bladder, lower bowel (anus and rectum) and vagina, and whose cause (at least in part) derives from a loss of support by the sheet of muscles that forms the pelvic floor itself. It is instructive to consider that the pelvic floor muscles together form a sort of 'basin' or 'hammock' to carry and contain the weight of these organs and maintain their anatomical disposition so that they function normally. While doing so, these organs must pass through openings in the pelvic floor to let things out (such as urine, faeces or babies) or in.

If the pelvic floor becomes weakened, stretched or injured directly, for example at childbirth, this normal support may be lost. This can lead to risk of obvious prolapse (organs visibly falling down), but more commonly to smaller changes in organ position such that these then do not function normally – either not emptying (for example, bladder retention or constipation) or emptying without control (incontinence). Perhaps counterintuitively, a lack of pelvic floor relaxation can also lead to problems such as constipation – this can occur with seemingly no trigger or may be related to conditions such as neuropathic pain, Parkinson's disease or multiple sclerosis. Sexual dysfunction may occur as a result of a weakened or overactive pelvic floor.

Since normal function is a feature of fine nerve and muscle control as well as gross structure, it is no surprise that pelvic floor disorders are common and often hard to treat. Imagine the act of defecation (evacuating the bowel) as an example – something most of us take for granted. This requires filling the rectum (from the colon), us being able to sense when it is full (sensory function) and then being able to push out the contents whilst opening and then closing the anus at an appropriate time. Remarkably, these functions also allow us to discriminate solid, liquid and gas and selectively expel gas from a mixture. This requires functions of the brain and spinal cord as well as the organs themselves.

Some of the main conditions falling within the remit of pelvic floor disorders are shown in the summary box below.

COMMON PELVIC FLOOR DISORDERS

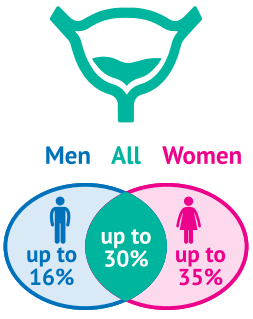
Mainly affecting the bladder	Mainly affecting the vagina	Mainly affecting the bowel
Urinary stress and urgency incontinence	Uterine prolapse	Faecal incontinence
Bladder retention syndromes	Vaginal vault prolapse (if hysterectomy)	Constipation
Anterior compartment vaginal prolapse		Rectal prolapse
	Posterior compartment vaginal prolapse	
Sexual dysfunction		

How many patients are suffering from pelvic floor disorders?

Whatever the cause of their condition, patients with pelvic floor disorders should be considered to be suffering from an invisible disability – and a common one, at that. The summary box shows key figures on how common some pelvic floor problems are – not far behind the common cold *(Royal College of Surgeons, 2017; NICE Single Technology Assessment, 2013; Hunskaar et al., 2004; Downey & Inman, 2019; Boyle et al., 2003; Suares & Ford, 2011; Vos et al., 2012; Perry et al., 2000)*.

PREVALENCE OF MAIN PELVIC FLOOR DISORDERS IN THE UK POPULATION

Urinary stress and urgency incontinence



5%
of adults over 40 have daily urinary incontinence

Faecal incontinence

Adults with some symptoms: approx 10%

1-2%
severe, regular leakage of solid faeces

Constipation

Some symptoms: up to 20%

0.5%
chronic constipation that does not respond to basic treatments

Pelvic organ prolapse

Women worldwide: approx 9%

How are pelvic floor disorders treated?

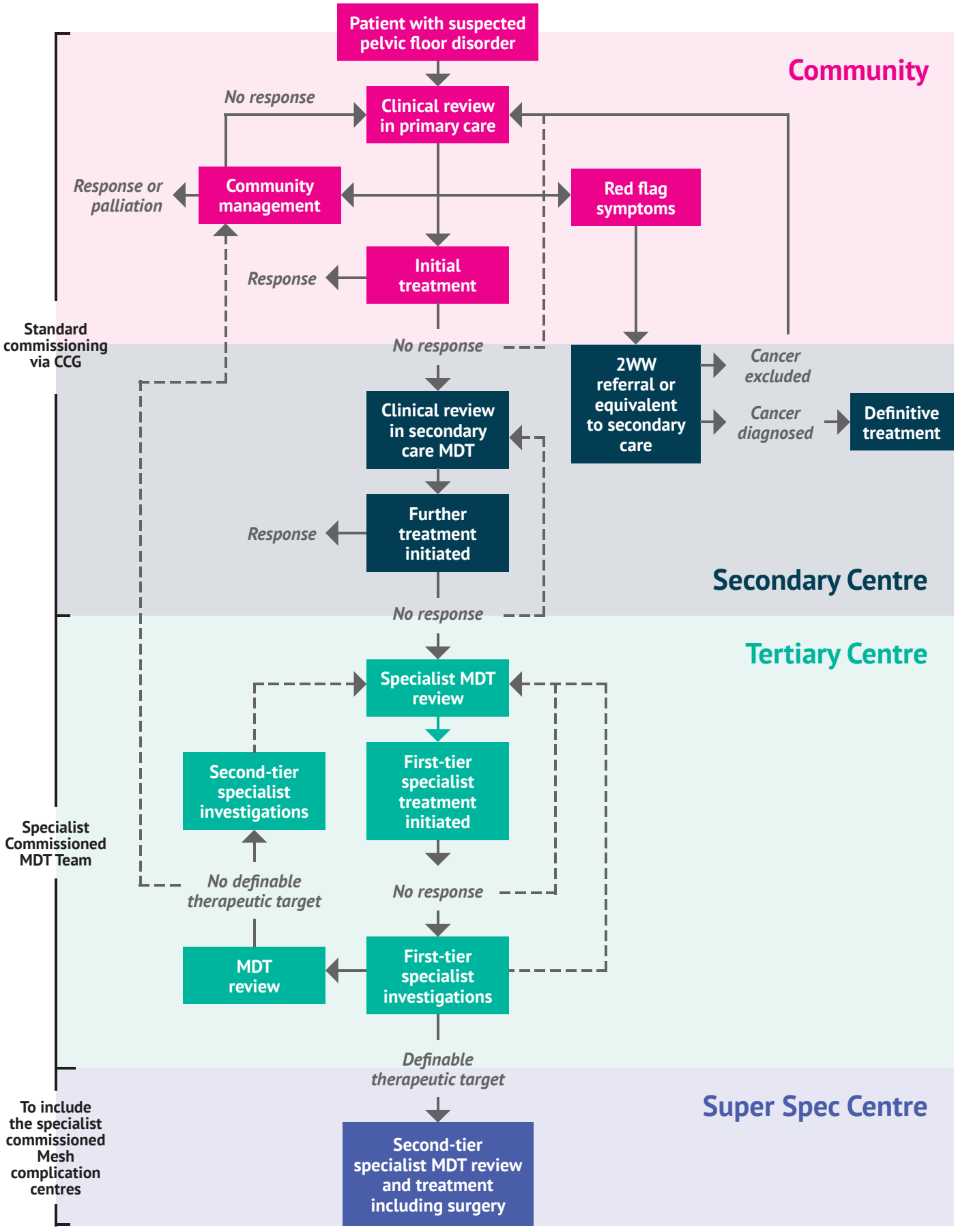
With so many people affected, including both men and women (and around 900,000 children and young people *[NHS England, Excellence in Continence Care, 2018]*), who manages these conditions and what is available? The figure below shows a schematic for a generic pathway of care that holds true for the majority of patients. The figure illustrates the many steps taken to get access to specialist care, and then the steps required once there to obtain and review specialist investigations, trial sequential therapies, and so on.

Given the number of steps involved, it is important to bear in mind that each visit to a hospital can require up to half a day's travel and time at the clinic *(ACPGBI Legacy Working Group, 2020)* – not an easy ask, particularly as many patients are afraid to leave their homes because of their condition.

A wide range of clinical guidance is available on pelvic floor conditions, but there are gaps. There is a lack of clear guidance to support joined-up care between specialties for complex cases: guidelines tend to focus on a single compartment (for example, the NICE guideline on faecal incontinence *[NICE guidelines, 2007]*). The NICE guideline on faecal incontinence further lacks a focus on multidisciplinary team (MDT) working *(NICE guidelines, 2007)*. There is no NICE guidance for constipation in adults or for daytime urinary incontinence in children. Guidance on pelvic floor dysfunction and non-surgical management is, however, in preparation for release in 2021 *(NICE, 2020)* and a revision of international guidance on the prevention and management of incontinence (urinary and faecal) will be available in late 2021 *(International Continence Society, 2020)*.

Updated guidance is important; however, additional steps must be taken to address the challenges faced in implementing that guidance in the current environment. At present, patients face a number of access issues, including problems with obtaining referrals. There is, for some patients, a lack of appreciation by clinicians in primary and secondary care of the complexity of their pelvic floor issues, and this can mean the right questions are not asked in order to take an accurate history *(Vollebregt et al., 2020)*. There is a lack of guidance for patients on experts who can be consulted before going to hospital – for example, specialist pelvic health physiotherapists, continence nurses and other sources of support available in the community – and when patients do reach a hospital, they can find themselves stuck in a 'loop' of repeated assessments by inappropriate specialists.

PATHWAY OF CARE: OVERVIEW



Waiting times for referrals and then for subsequent treatments are long. Some patients have been waiting years for their disorder to be treated. Accurate data are not available but a number of pinch points in the above pathway related to hospital care can be highlighted by data from a survey of the authors.

Data per average NHS Trust	Urinary	Bowel
Wait for first outpatient appointment	3–12 months	9 months
Wait for diagnostics	4 months	6–12 months
Wait for non-surgical therapy e.g. physio, nursing interventions	<6 months to ⩾1 year	6 months
Number of patients waiting	350–500	25–90

These waiting times vary across the country: the services and support available to patients are fragmented across the UK, with occasionally sizeable differences in care in different regions. However, overall the data paint a picture of years rather than months of waiting to access definitive care. This clearly indicates a need for resources to be directed towards developing a larger, suitably skilled workforce, including AHPs and specialist physicians.

Patients with pelvic floor problems, already experiencing high rates of depression and anxiety *(Vrijens et al., 2017)*, have found their situation worsened further by the delays and isolation resulting from COVID-19. Mental health support for these patients is underfunded nationally; however, psychological support is necessary even on a short-term basis until they are able to undergo surgery. There is a national shortage of clinical psychologists *(British Psychological Society, 2019)*, although some Trusts have mental health support available for birth trauma *(Birmingham and Solihull NHS Foundation Trust)*. A clinical psychologist is needed in every unit dealing with benign disorders in line with the NHS Long-Term Plan *(NHS England, 2019)* and CQUIN guidance for 2020/21 *(NHS England and NHS Improvement, 2020)*.

Incontinence in older people *(NHS England, 2018)*

CASE STUDY

JANE'S STORY

Jane suffers from interstitial cystitis, which is a bladder condition that causes long-term pelvic pain and problems with urinating. For over three years, her local hospital Urology team has been administering sodium hyaluronate every six weeks – although she still had flare-ups, the treatment meant that she could keep working and living largely as normal.

After a round of treatment in February, the onset of COVID-19 led to cancellations of her appointments until further notice. With no regular therapy, she found her flare-ups increased in frequency and lasted longer. By September her life had become so heavily impacted that she found it difficult to leave the house, and suffered from tiredness and low mood as a result of nights disturbed by the need to visit the toilet. The pain and burning sensation were persistent. Finally, after a particularly bad night, she found the Bladder Health UK website and phoned their Advice Line. The advice she received led her to contact her Urology Team's secretary, and she found that treatments were recommencing – finally, she was able to restart treatment, but the delay meant her condition had worsened and she now needs four-weekly, instead of six-weekly, treatments.

Jane's symptoms have finally calmed down, but with COVID-19 cases on the increase she is fearful of more cancellations and once again having to endure a recurrence of her symptoms – a physically and emotionally draining situation.

Why should we act now?

Post-COVID-19 waiting times are becoming even worse as patients are de-prioritised further in overloaded health systems *(FSSA, 2020)*. A recently released report from NHS England and NHS Improvement estimated that around 4.5 million people were waiting for non-emergency treatment in November 2020, with almost 200,000 having waited for over a year *(NHS England and NHS Improvement, 2021)*. Patients with continence problems, who have already been isolating for years, now find themselves at the back of an even longer queue.

Although it has made the situation worse in many ways, COVID-19 has also provided evidence that change is possible. Across the NHS, new ways of working have been introduced at unprecedented speed, including movement of services and acceptance of technology and telemedicine *(ACPGBI Legacy Working Group, 2020)*. The pandemic has also exposed some poorly thought-out systems and practices, which we now have an opportunity to improve.

Pelvic floor services are uniquely positioned to take advantage of advances in technology and integrated care organisations owing to the multidisciplinary input required – coordination of multiple specialists has previously caused delays, but telemedicine should in theory make this easier to implement. Technology-enabled care may, in the short term, also help us to address shortages in the workforce and to improve services for patients, including remote assessment and follow-up and even online group support sessions for patients.

> ***"Medicine will never be the same after COVID-19; a lot of us, myself included, are converts to telephone assessment and remote access, whereas I never thought it would be possible to assess a pelvic floor patient over the phone"***
> Andrew Williams, Past President, Pelvic Floor Society

We must acknowledge that our workforce is finite; taking another look at how we assess and treat patients can help to simplify patient pathways and reduce duplication. Integrating pelvic floor care is critical for those patients with multiple compartment issues. In primary care and the community, initial pelvic floor assessment and therapy by a specialist pelvic help physician will address all aspects of bladder and bowel symptoms in a patient-centred programme. This approach could be replicated throughout the patient pathway to ensure joined-up care.

Multi-speciality services and MDTs are critical for patients with complex needs and present another area where technology can help, by connecting expertise. A hub-and-spoke approach with regional pathways will allow regions to make the most of existing expertise and capacity. Further, reconsidering where procedures are performed, and by whom, can free up staff and reduce the backlog. Some procedures can be moved from the operating theatre to a clean room, and protocol-led procedures could allow specialist nurses to take more of a role here. Creative approaches, such as making use of available resource in the private sector, could also help to address capacity issues.

CASE STUDY

MINIMUM STANDARDS FOR CONTINENCE CARE

In 2014, the UK Continence Society published a set of minimum standards for care covering service specification, education and training required to deliver adequate care *(UKCS, 2014)*. This document includes recommendations for multidisciplinary education of HCPs as well as the involvement of multidisciplinary teams for specialist assessment. The aim of this report is not to replace but rather to complement these minimum standards, which in many cases are yet to be met.

It is important to recognise the importance of developing a future workforce: increasing training opportunities and courses is essential to promote career development in pelvic floor disorders, and thus to develop new specialists to replace the current workforce, as needed. Continence care for all ages should be included in the medical school curriculum, yet a recent survey found that 14% of UK higher education institutions with healthcare programmes offered no content at all around incontinence; in those institutions where continence was covered, the number of hours devoted to this ranged from 2.5–7.3 hours, across three years *(McClurg et al., 2013)*. Around 80% of institutions reported no improvement or even a decrease in provision in the prior five years. Only 6% covered continence in a dedicated module *(McClurg et al., 2013)*. Yet education of non-pelvic-health-specialist HCPs, particularly GPs and nurses, is critical to ensure they are aware of the severity of

these conditions and of how to treat, advise and refer patients. Post qualification, specialist training is also under pressure: the loss of biofeedback courses nationally within colorectal care is particularly concerning.

Finally, we need to ensure we empower and educate patients and health professionals so that they are aware that pelvic floor disorders are not a normal part of life and can be treated. Access to treatment should be clearly signposted, including the availability of local services and conservative treatments prior to the last resort of surgery.

The practical proposals in this report address three key gaps highlighted by the NHS Long-Term Plan *(NHS England, 2019)*: funding and efficiency, health and wellbeing, and care and quality. A further consideration is the opportunity for specialist commissioning: it may be possible to take another look at the funding model for the different tiers of treatment. Specific issues with individual procedures, such as mesh insertion, are beyond the scope of this report and have been well covered by the recent inquiry headed by Baroness Cumberlege *(Independent Medicines and Medical Devices Safety Review, 2020)*. However, a revised approach may help to address these further. More information is also available in the recent NICE guidelines on urinary incontinence and pelvic organ prolapse in women *(NICE guidelines, 2019)*.

Ultimately, NHS resource is finite and the difficult job of balancing priorities and funding is a sizeable challenge. In this report, we include a mixture of recommendations, including those that should be actioned at a national level (and therefore require additional or re-allocated funding) as well as a number of practical steps that can be taken by medical colleagues and management teams within Trusts in order to effect positive change quickly. In particular, we hope to highlight ways in which teams are already doing things differently, to inspire and encourage others.

READING THE REPORT

The recommendations in this report are divided across six main themes:

- **Chapter A: Awareness and education**
- **Chapter B: Technology-enabled care**
- **Chapter C: Integration of expertise**
- **Chapter D: Surgery procedures and premises**
- **Chapter E: Utilising human resource**
- **Chapter F: Novel approaches to freeing up resource**

Taken together, we firmly believe that the recommendations in this report will support improvements in care that will transform the lives of patients with pelvic floor disorders. To change lives, we must first change the system. The time to act is now.

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A How to engage and educate patients, healthcare professionals and the public about Pelvic Floor disorders and their treatment

Lesley Booth, Suzanne Evans, Susannah Fraser, Tracy Stewart

Pelvic floor issues leading to bladder and/or bowel incontinence cause a strong sense of taboo and embarrassment, to a greater extent than other medical conditions *(Elenskaia et al., 2011)*. This can dissuade patients, including 50–70% of women, from consulting a doctor *(Medscape, 2019; Leigh et al., 1982)*. While up to 31% of older men may experience urinary incontinence, only around 1 in 5 of those with frequent issues have ever contacted a healthcare professional for help *(Shamliyan et al., 2009)*.

Many patients are unaware that there are options to treat incontinence and that it should not be accepted as a natural part of ageing, an expected consequence of childbirth, or a typical part of delayed development in children and young people. Some members of the large and growing adult incontinence industry *(Nonwovens Industry Magazine, 2019)*, have been accused of normalising incontinence within advertising *(BBC, 2019)*, although since then, banners on TV advertisements have started to suggest that patients seek medical advice. A lack of widespread promotion of bladder and bowel health adds to the problem, with many people unaware that incontinence is not only an adverse medical condition but may also be a symptom of a more serious condition, such as bladder *(Medscape, 2019)* or gastrointestinal *(Adelborg et al., 2019)* cancer, and should always be checked.

Patients experiencing the symptoms of incontinence may be dissuaded from seeking medical help not only from embarrassment, but also from fear of surgical interventions, or that there is nothing that can be done. Or, quite simply, they find that their condition is not taken seriously by their GP, who may not understand the emotional impact of a continence issue.

A lack of education on incontinence and awareness of the availability of conservative treatment options, among both patients and GPs, is contributing to the issue.

The end result is that patients often wait for years to report their problem, and once they do present their pathway to treatment is often not straightforward – leading to years of unnecessary suffering.

KEY POINTS

- **Patients must be empowered, by information and support, to present for treatment and to refer themselves if necessary**
- **Improved education is a must for health professionals in primary care, particularly GPs and nurses**
- **A national, well-funded campaign would help to raise awareness not only of the options available for patients, but of the importance of bladder and bowel health to prevent disease; reducing or removing the taboo is essential. The NHSE-commissioned National Bowel and Bladder Health project will hopefully start to address this**

The empowered patient: signposting the pathway to find help

The patient pathway, the sequence of assessments and therapies undergone by a patient to address their condition, needs to be more clearly communicated and more strongly mandated for pelvic floor disorders and incontinence. Pelvic floor health should be included as standard in the opening discussions of GPs, district nurses, health visitors, and other health professionals with new patients, particularly pregnant women and those most likely to be susceptible (for example, those who have undergone surgery). While continence pads are important, they should not be the end of the discussion for any patient with pelvic floor problems. That said, a postcode lottery in the UK leads to many patients buying their own: some GPs are not allowed to prescribe even pads without a formal diagnosis, which can be hindered by the delays in secondary care.

Patients must be made aware that treatment is available and that a number of conservative and minimally invasive interventions are an option before the last resort of surgery. Early intervention can reduce the chance of long-term conditions requiring invasive treatment, and improve patient outcomes.

If a patient cannot find support in primary care, self-referral is an option. Bladder and bowel community continence services should be made as accessible as possible – or as a minimum, specialist nurses or appropriately trained AHPs should be engaged to serve the local population.

Patients may, however, not be aware of local services and how to reach them: regional listings of services should be made available to ensure they are empowered to take this step. Partnerships with industry could be highly beneficial here: the packaging of incontinence products is an ideal location for information and guidance on how to find support. Manufacturers have made strides in recent years to provide more health information and advice on websites and consumer and healthcare professional materials. A number also run helplines with medical or product advisors.

Once on the treatment pathway, patients can find the journey confusing and frustrating. Reports from multidisciplinary team (MDT) meetings (see **Chapter C**) are not often shared with the patients whose cases were discussed, but this can help them to understand what was suggested, what was agreed and the ultimate outcome – potentially increasing trust as well as understanding.

CASE STUDY

ANDREW'S STORY

Starting at the age of 21, Andrew suffered from faecal urgency – the urgent need to rush to the toilet and vacate his bowels, which became a daily pattern. Over the following 18 years, Irritable Bowel Syndrome was among the diagnoses proposed and doctors suggested diet changes, which Andrew faithfully followed. A number of drugs, including codeine and loperamide, were tried and Andrew underwent countless investigations.

Nothing worked.

For all this time, Andrew lived in fear of unexpected events where he might not have easy access to a toilet. Getting stuck in traffic was terrifying. The associated social isolation and anxiety left him exhausted.

Eventually, after almost two decades, new treatments were tried with great success: percutaneous tibial nerve stimulation (PTNS) and finally sacral neuromodulation (SNM). At last, Andrew can enjoy a walk in the woods and feels he is back in control of his life.

Andrew's story can be read in full, in his own words, at **www.bowelresearchuk.org/stories**.

The educated healthcare professional: provide education and training for GPs and nurses

GPs have a broad educational curriculum, which must include adequate training on pelvic floor disorders and their treatment. GPs should be aware of the appropriate referrals for their patients, as well as the community-based, minimally invasive treatment options available. A listing of regional services, as well as being helpful for patients, would be invaluable to GPs in this regard.

Nurses and carers (particularly those who work in care homes) are a major source of information and support for patients and thus their education should also include the range of treatment options available for incontinence. In addition, ways to support and maintain bladder and bowel health – such as an appropriate diet – should be included in nurses' training in order that they can pass this knowledge on to their patients.

Updated national guidelines are an important tool to improve HCP awareness, as well as supporting joined-up care, and would be welcomed.

An engaged public: a national awareness and education campaign

One of the biggest problems with addressing the issue of incontinence is the associated taboo and embarrassment. A broad, friendly, national campaign, with accessible and memorable branding, can help to start a conversation around pelvic floor disorders and the help available. Such a campaign could perhaps be timed to coincide with World Continence Week (17–23 June in 2021), or a UK-specific Continence Awareness Month could be launched to bring together all the different specialties.

Appropriate use of language, such as describing incontinence as a 'life-limiting' or 'life-changing' condition, can also help to adjust perspectives and attitudes. Industry, as well as government bodies, could be a source of funding for such a campaign, and could also support the campaign through product packaging and advertising to ensure a wide reach.

Incontinence should not be seen as a normal part of life, to be endured rather than addressed. Early and universal education, targeting both children and adults, including those with physical and

CASE STUDY

MOVEMBER

Men have historically been unwilling to discuss their health, particularly with regard to mental health and diseases like prostate and testicular cancer. Founded in 2003, the Movember campaign takes a light-hearted approach to men's health, calling out the stigmas and drawing attention to the health issues affecting men. As well as funding over 1250 health projects in more than 20 countries *(Movember Annual Report, 2020)*, the campaign has reinvigorated the conversation around men's health.

> ***[The closure of public toilets] had a serious impact on where I was able to go. I had to cut short walks in order to get home in time and every trip or activity had to carefully considered to see if [it] was possible. When I did venture out there was a continuous worry that I wouldn't manage ok. This spoiled what should have been an enjoyable and relaxing experience."***
>
> Jane, Patient with interstitial cystitis

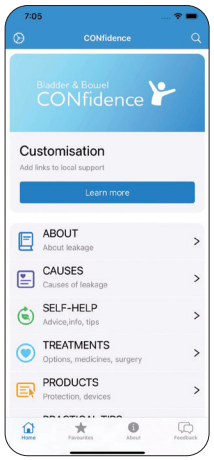
learning disabilities (particularly those undergoing relevant life events such as pregnancy or surgery), can help to ensure people are aware of the steps to take to maintain their bladder and bowel health, key signs to be aware of and the steps to take if they suspect a problem *(Arbuckle et al., 2019)*. Leaflets are not universally permitted in GPs' surgeries: allowing these to be displayed in surgeries throughout the country would be a major step forward.

CASE STUDY

BABCON

In and around Bristol, the Bladder and Bowel CONfidence Health Integration Team (BABCON HIT) aims to promote bladder and bowel continence. This city- and system-wide engagement approach to continence promotion involves academia, healthcare, local authority, patients and the public. The team works to both raise awareness and drive improvements in care, by improving services and undertaking research, for everyone in the local area.

https://www.bristolhealthpartners.org.uk/health-integration-teams/bladder-and-bowel-confidence-babcon/



CONfidence app to be launched at the end of June 2021

Schools, along with school and community nurses, have an important part to play to ensure that children, along with their parents, understand how to maintain bladder and bowel health, and whom to turn to if they have a problem. Incontinence is seen in adolescents and young people *(Arbuckle et al., 2019; Gram & Bø, 2020)*, but many are unaware of the existence of the pelvic floor or of how to train and protect it *(Gram & Bø, 2020; Parden et al., 2016)*. The children's bowel and bladder charity, Eric *(https://www.eric.org.uk/)*, and Bladder & Bowel UK, are heavily involved in raising awareness: this work should be encouraged and continued. The Association for Continence Advice has been heavily involved in producing **videos** and **information sheets**, for example on how to perform pelvic floor exercises, which can help to support young people to maintain their pelvic floor health. This is particularly key for children, as paediatric incontinence is a trigger for domestic violence towards children *(Bennett, 2014)*. Care must be taken, however, to ensure that 'healthy living' is distinguished from serious disorders such as inflammatory bowel disease.

The work of raising awareness and enhancing education is critical to minimise the number of people enduring incontinence as a 'normal' part of life. As well as government and patient support groups, industry has a role to play here: product

packaging and advertising can encourage patients to present to their doctors and to receive the help available, which can greatly improve the issue; in fact, the majority of bladder symptoms can be either entirely remedied or substantially improved via pelvic floor training and lifestyle interventions delivered by specialist pelvic health practitioners *(Johns Hopkins, 2020)*. Action taken now can have an enormous impact on patient wellbeing in the future and ensure that pelvic floor conditions can be treated in a timely and effective way.

CASE STUDY

BOYS NEED BINS!

Boys Need Bins! Similar to the requirement in UK law for female-designated toilets or toilets which may be used by women, sanitary bins should be in male-designated toilet cubicles for disposal of incontinence, stoma, wipes and other personal care products. From a hygiene, dignity and environmental perspective this is an unmet essential need for an underestimated substantial group of the population. Access to sanitary bins is important for anyone who needs to dispose of the used products hygienically, discreetly and correctly.

CASE STUDY

THE NATIONAL BLADDER AND BOWEL HEALTH PROJECT (NBBH)

In 2019, NHS England (NHSE) commissioned the NBBH project *(NHS Supply Chain)* that seeks to address several of the points made in this chapter and those raised by the Excellence in Continence Care (EICC) report in 2018 *(NHS England, 2018)*. At the time of writing, the NBBH project has been delayed by COVID-19 but its objectives are to develop evidence-based and patient-centred bladder and bowel care pathways that can improve outcomes for children, young people, adults, those with learning disabilities, frail elderly people and those with neurological disease. The clinical workstreams are Bladder, Bowel, Paediatrics and Transition.

Specific to this chapter, the NBBH project will develop programmes and educational materials that promote bladder and bowel health to help prevent the onset of bladder and bowel problems in all people. It will also have an important role in improving signposting for patients and improved pathways that provide better continuity of care for patients. Other aspects of the project are covered in relevant chapters.

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B How we can use technology to improve patient care

Nikki Cotterill, Julie Cornish, Tatenda Marunda, Michael Powar

Technology offers a range of advantages and efficiencies. One of the more positive effects of the COVID-19 pandemic has been the widespread adoption of new technologies to support pelvic floor patients and ensure the continued provision of services – where there may have been resistance in the past, necessity has both increased the pace and broadened the scope of change. As part of a long-term 'blended' solution to improve the patient experience, technology can help us to deliver higher quality and more accessible care.

Patients with pelvic floor disorders, and especially those with incontinence issues, face a number of barriers to receiving medical treatment. Travelling to face-to-face appointments, particularly in the case of regional referrals, can be particularly difficult for these patients, who may be afraid to leave the house on a day-to-day basis. Pelvic floor departments are sometimes physically located under 'women's health', providing an additional barrier for men, and the embarrassment associated with continence conditions may also discourage patients from attending in person. Nevertheless, physical examination at an early point in the pathway is required for most of these patients in order to diagnose and guide management.

Prior to the COVID-19 pandemic, patients often struggled to find information around self-management of their condition and psychological support, leading to a feeling of disempowerment and potentially negatively impacting adherence *(Essery et al., 2017)*. This has been magnified during the COVID-19 era, as self-management has been the only option for many.

KEY POINTS

- **Telemedicine, widely implemented during the peak of the COVID-19 crisis, is an important option for patients and offers many opportunities to break barriers; however, a blended approach (offering both virtual and in-person consultations) is likely to be needed**
- **Technology can further empower patients to take ownership of their condition, encouraging them to comply with prescribed regimens and offering opportunities to find support**
- **Patients often struggle to find resources online; online education and information are highly valuable for patients, but care must be taken to ensure accessibility and visibility**

Reaching the potential of telemedicine

The shift towards telemedicine is widely seen as inevitable *(Royal College of Surgeons, 2018)*, particularly given the changes necessitated and implemented during the COVID-19 pandemic *(Clement et al., 2021)*. Feedback from patients on using a virtual clinic approach has been positive from many: it reduces time required for travelling and waiting for appointments, streamlines the process, and has allowed continued health provision despite the challenges of COVID-19. It also makes attendance easier for patients living in rural areas or for those with limited access to transportation *(NHS England, 2019)*. The reduced requirement for travel is particularly beneficial for patients with continence issues, and so the option of virtual attendance should be made available in the long term. Communication via email or text messages could also offer options for appointments in satellite locations to improve accessibility for in-person consultations.

CASE STUDY

ELECTRONIC QUESTIONNAIRES

Gathering a detailed patient history in advance can help to optimise efficiency during both virtual and in-person appointments. Electronic questionnaires are making this possible:

- The ePAQ questionnaire *(ePAQ, 2016)* from Sheffield is recommended by the Pelvic Floor Society, although payment of a licence fee is required
- The ICIQ questionnaires *(ICIQ)*, while not yet available to complete on line, are in the process of becoming electronic – with the aim of ensuring availability online in 2021. The questionnaires are free to access for clinical services and small research projects, though larger funded research (such as NIHR), commercial use and industry-sponsored research incurs a fee

The sometimes-embarrassing nature of pelvic floor conditions does not seem to have hindered virtual appointments. In fact, a reduction in non-attendance has been observed in some centres compared with face-to-face visits. Online availability of information may encourage patients to present earlier or even to undertake self-management, both of which could lead to better outcomes with conservative treatments and a reduction in patients requiring surgery. Further, adequate adherence to conservative measures available in primary care is important to ensure these are truly exhausted by the time a patient reaches secondary care; patients may now be more likely to comply with these treatments, such as pelvic floor exercises.

Technology can provide further support to increase efficiencies, for example in obtaining an accurate patient history prior to consultations. Online questionnaires make it possible for patients to answer questions prior to their appointments, saving time during the consultation itself – and in the case of face-to-face consultations, minimising contact time, a desirable outcome in the face of a pandemic.

Patient consultations are not the only elements of care that can benefit from technology. Multidisciplinary team (MDT) meetings can also be conducted virtually, reducing the time commitment for participants and allowing people to join when they are unable to travel or located in different hospitals. Technology can be a key enabler for MDT working. Acceptance of virtual meetings has greatly

CASE STUDY

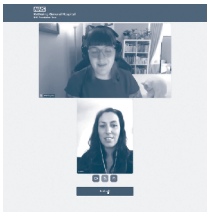
BLENDING THE VIRTUAL AND PHYSICAL

At St Mark's Hospital in London, face-to-face appointments are being reintroduced for initial and final appointments in order to provide reassurance and the opportunity for a physical assessment. Virtual consultations are available to patients for appointments in between.

Biofeedback sessions are being conducted with a mix of face-to-face and telephone consultations. Patient feedback on the approach has so far been positive, with most patients (of 40 surveyed) agreeing they were satisfied. Comments included: "Very good, having time to talk helped me understand my issues. Wonderful service" and "Excellent explanation, very helpful. Now [I] can manage better than before", although some patients have struggled with appointment changes during lockdown.

CASE STUDY

AWARD-WINNING VIRTUAL VISITS



London North-West University Healthcare NHS Trust responded to the onset of the COVID-19 pandemic by rapidly developing software to enable communication between patients and their loved ones, as well as between stretched and often locked-down NHS staff. The open-source software allowed video calls from anywhere in the hospital wards to anywhere in the world, was free to use and collected very little personal data, avoiding privacy of information governance issues. In November 2020, the project was awarded Best Healthcare Project of the Year at the UK IT Awards.

More information about this project is available at **https://www.youtube.com/watch?v=VdLUHccMkzw&feature=emb_title**.

increased since COVID-19 made this the norm, breaking down reluctance. In fact, in our experience, attendance at virtual MDTs has been improved over previous in-person meetings.

While virtual consultations are a valuable option, they are not suitable for everyone and risk excluding some members of society, for example, through digital exclusion and those with communication difficulties – telemedicine cannot be a one-size-fits-all solution *(Clement et al., 2021)*. It is important that any changes in approach do not exacerbate existing health inequalities *(NHS England, 2019)*. As the first wave of COVID-19 lifted, some patients were quick to request face-to-face consultations again. Further, there are situations where face-to-face appointments are necessary. Examination and assessment are limited in a virtual consultation, and nonverbal cues can be harder to pick up. Communication with patients who require translation services may also be more challenging. Performing a physical examination is essential for pelvic organ prolapse even if further diagnostic tests are planned. However, in some instances (for example, rectal prolapse), the greater adoption of digital self-photography and sharing thereof has reduced the problem of trying to reproduce a prolapse in clinic at the time of examination – though challenges relating to secure electronic sharing of potentially sensitive images must be considered, particularly when treating children.

Where virtual consultations are carried out, it is important to adhere rigorously to recognised treatment algorithms: clinicians will need to resist the temptation to over-investigate to compensate for not seeing their patients in person. As virtual consultations become a more frequent part of medical care, it will be important to incorporate these aspects into training *(Clement et al., 2021)*: trainees should be involved in virtual consultations, to help them to appreciate the nuances of this type of review.

Empowering patients to own their care

Patient empowerment is particularly important post COVID-19, reducing the number of unnecessary outpatient appointments but maintaining the

> ***[In the future,] greater access to and sharing of data, widespread availability of new technologies and remote support of experts may reduce inequalities and variation in treatment outcomes between different hospitals"***
> Royal College of Surgeons, 2018. Future of Surgery

patient's ability to come into the hospital or clinic when needed, as well as enabling patient-initiated follow-up. Providing information and support online can help to achieve these goals, with better-informed patients better able to undertake self-management.

Some centres are going one step further and providing mobile applications, which offer the added benefit of outcomes data collection – particularly valuable for pelvic floor care, where data are few and far between. These data can then be fed back into services to make further improvements, supporting the global movement towards personalised medicine *(Royal College of Surgeons, 2018)*. Such technology may also empower seldom-heard patient groups to have their voices heard more.

CASE STUDY

VIRTUAL PATIENT SUPPORT

In Oxford, patient support groups were initially set up on a face-to-face basis with nurses present, in order to allow patients to discuss their concerns and receive advice and support from their peers as well as medical professionals. As a result of COVID-19 restrictions, these meetings have been transitioned successfully to an online meeting platform.

While some patients find it more challenging to build trust with strangers over a screen, others have benefited from the psychological distance and may find it easier to share their feelings. Thanks to the support groups, patients have reported feeling less lonely while awaiting procedures.

CASE STUDY

'LIVING WITH...' PLATFORM

The 'Squeezy' app is supported by the 'Living with...' platform (**https://www.livingwith.health/**) and is currently in use in Cardiff, in collaboration with industry. Once logged in to the app, patients can complete baseline data and record the exercises they have undertaken. Their clinicians can review these data, improving their understanding of patient adherence as well as recording outcomes data at prescribed intervals. The app also allows clinicians to share contact details and appointment information, as well as links to learning resources. While they do not state the number of patients surveyed, the developers report that 90% of patients increased their adherence to exercise regimens after starting to use the app, with 78% noticing an improvement in their condition.

Cost can be a barrier to implementation, particularly with new technology. Partnerships with industry, as seen in Cardiff with the 'Living with...' platform, can provide a short-term opportunity to introduce digital innovations, but it is also important to consider the savings and improvements that can be made in the long term. Continence will need to be considered more within spending priorities – this under-recognised patient group deserves, and needs, more investment.

Breaking barriers to learning with remote education

As part of patient empowerment, it is important to ensure patients are informed. Webinars and online courses can be useful, though care needs to be taken to ensure that content is evidence-led, relevant and pitched at the right level. Webinars can be hosted on social media or on mobile applications as well as on purpose-built websites to improve visibility. Whatever the platform, signposts to charities, patient information websites and online support groups (whether UK-based or international; see **Appendix**) are important to include, as patients often struggle to find resources online. Use of patient-appropriate language and search engine optimisation skills may improve accessibility. A nationally supported continence promotion app, which aims to address this need, is in development and will be included in the NHS apps library.

Finally, technology can also help to improve education among HCPs. Owing to the necessity of online training during COVID-19, health professionals are now more widely accepting of this approach. An example is a certified e-learning programme for catheter training successfully rolled out in Wales. In addition, midwives have access to a peri-partum pelvic floor exercises e-module on the **RCM i-learn platform**, the result of a collaboration between the Chartered Society of Physiotherapy and the RCM, which was written and updated in 2020 by POGP. This approach provides an opportunity to engage more with HCPs' education on the pelvic floor and to reach greater numbers, ultimately improving outcomes for patients.

CASE STUDY

ONLINE LEARNING FOR HCPS

FutureLearn is hosting a number of online training modules for HCPs, including a module on continence promotion and management of bladder and bowel dysfunction *(FutureLearn, 2020)*. This module was developed by the Association for Continence Advice and has had a positive reception from users, with an average rating of 4.9 out of 5 from 20 reviews at the time of writing.

This module is available at **https://www.futurelearn.com/courses/understanding-continence-promotion/1**

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C

How we can ensure that patients consistently receive appropriate and expert care, from the community to the hospital

Mhairi Collie, Graham Mackay, Jon Randall, Arun Sahai, Nikesh Thiruchelvam, Charles Knowles (editor)

Across the UK, patients are presented with an inequality of access to care resulting from the patchy nature of services for continence and functional pelvic conditions. Expertise in assessment and management of pelvic floor disorders is unevenly distributed around the country, presenting challenges for both clinicians and patients in navigating the pathways of care. Further, community continence care is facing funding and manpower shortages in some regions.

Improved support for community care is essential: community-based continence promotion and care services have been shown to improve outcomes for children and adults, as well as reducing the need for incontinence products, hospital and social care and associated costs *(APPG for Bladder and Bowel Continence Care, 2011; Tannenbaum et al., 2019; Stephenson, 2019)*. In addition, implementation of a hub-and-spoke model – with a multidisciplinary team (MDT) at the centre – would help to provide equity of care for patients, no matter their location in the UK. Integrated Care Systems, bringing together local healthcare organisations to create coordinated care plans for the local population, are a key part of the NHS Long-Term Plan *(NHS England, 2019)* and this model would align closely with that ambition.

> ***"[In the future,] greater access to and sharing of data, widespread availability of new technologies and remote support of experts may reduce inequalities and variation in treatment outcomes between different hospitals"***
> Royal College of Surgeons, 2018. Future of Surgery

The variable nature of continence care provision in the UK is reflected across settings. In some areas, community continence services have a low level of service provision or have even been forced to shut temporarily, owing to a lack of funding and a high workload. Additionally, specialist continence nurses and other allied health professionals, trained in continence and pelvic health, who have a key role in assessment and treatment (as identified by the NHS England Excellence in Continence Care report in 2018 *[NHS England, Excellence in Continence Care, 2018]*), are not available to all hospitals, and a large number of community continence advisors are approaching retirement, potentially leading to a sharp drop in available workforce. There are clear disparities in the provision of paediatric bladder and bowel services *(Paediatric Continence Forum, 2017)*.

Referral and self-referral from primary care to community continence services – where those services exist – is often straightforward. However, referral onwards to secondary care can be problematic: which patients should be referred, to where, and by whom? Assessment and treatment in secondary care is often perfunctory with attention focussed on exclusion of cancer rather than addressing patients' primary complaints, as the primary focus becomes achieving cancer exclusion targets. Such patients may or may not be referred on to other secondary specialists with an interest in pelvic disorders, or to tertiary care. In addition, progress through these steps may take years.

KEY POINTS

- **Community continence care is essential and must be adequately funded for all ages, including children and young people; triaging patients ahead of hospital referral can also help to ensure those whose condition is able to be managed in the community or primary care are identified and directed to appropriate support**
- **A hub-and-spoke approach could not only allow regions to make the most of local expertise and capacity, but also provide opportunities for training the workforce of the future**
- **Multidisciplinary teams (MDTs) are critical to ensure patients receive specialist care, but must reach an appropriate standard, as recommended by the All-Party Parliamentary Group for Continence Care; accreditation from the Pelvic Floor Society is available and has been embraced by a number of hospitals in England already**

Supporting community and primary care

Community continence care is a critical base for the service and must be adequately funded. The majority of patients can be managed with non-surgical measures and adequate pre-hospital care can reduce the need for surgery and for complications necessitating admission, such as sepsis from urinary tract infections. In Leicester, an estimated 80% of patients with vaginal prolapse and urinary problems reported improvement with conservative management alone, with high success rates (see case study). Making sure that community continence services are adequately resourced and are able to efficiently triage patients will ensure that the right patients are referred to the right services, should their needs be more complex. A national minimum standard of care and of staffing has previously been recommended for continence care in the community and beyond *(APPG for Bladder and Bowel Continence Care, 2011; NHS England, Excellence in Continence Care, 2018)*, and would help to ensure consistency of services for patients around the country.

REDUCING THE LOAD ON HOSPITALS: TELEPHONE TRIAGE

At St Mark's and Guy's and St Thomas's hospitals in London, patients undergo telephone triage assessment by allied healthcare professionals and are screened for problems potentially requiring specialist management: a large proportion can be managed with advice and conservative measures, allowing specialists to focus on the more complex cases.

When patients enter the system in the primary care setting, they are assigned a code relating to their identified disorder. At present, despite the frequency of overlapping pelvic floor disorders, each code refers to a separate compartment. Ideally, assigning a single code to all pelvic floor disorders would provide a single point of entry for pelvic floor patients, simplifying the pathway and improving the patient's experience.

CASE STUDY: OUTCOMES WITH CONSERVATIVE MANAGEMENT IN LEICESTER

The success rate of conservative therapy for prolapse and urinary leakage in 2019 was investigated using validated outcome measures, and found a high proportion of positive outcomes.

ICIQSF, International Consultation on Incontinence Questionnaire – Short Form; OABQ, Overactive Bladder Questionnaire; POPSS, Pelvic Organ Prolapse Symptom Score.

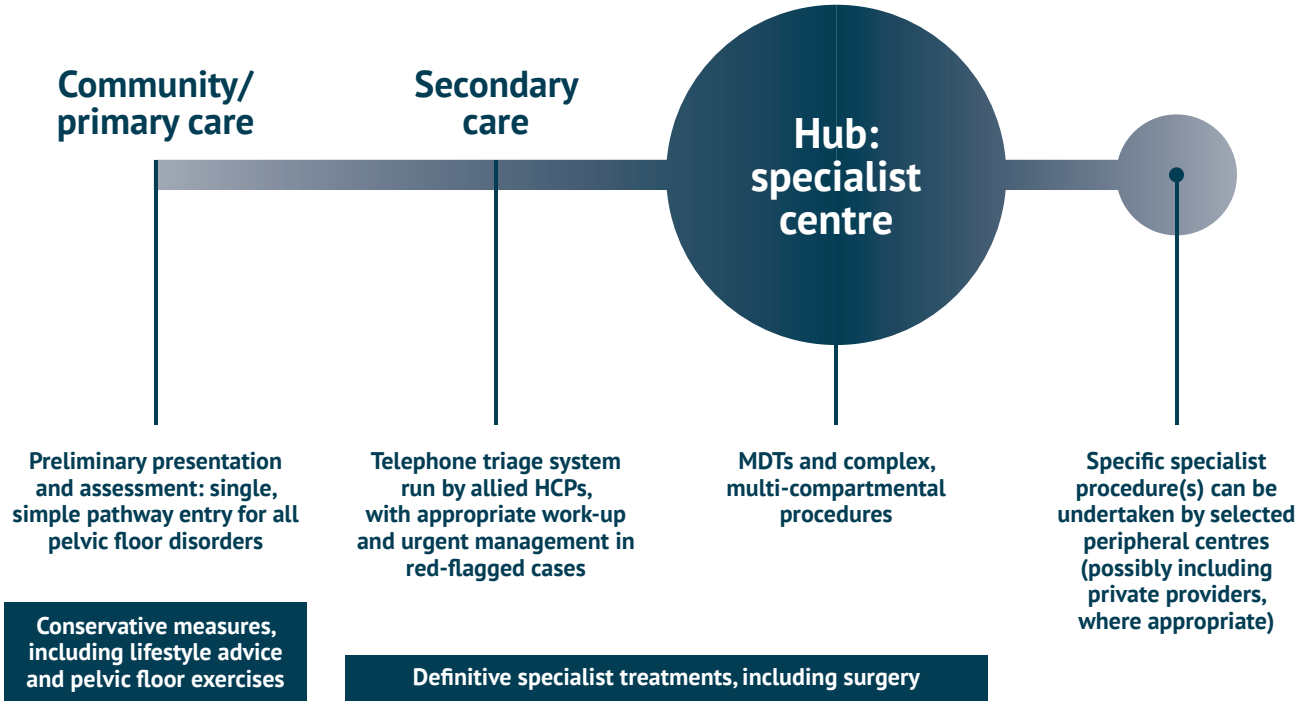
Hub-and-spoke models

A hub-and-spoke approach is already the direction of travel for healthcare, and could allow regions to make the most of existing expertise and capacity. Specialist expertise, capacity or facilities may be available in the spokes, not just the hubs, so it is essential that the right hub/spoke model is set up based on the circumstances of a particular region.

MDTs (see diagram on next page) are a key enabler to make this hub and spoke model work. These can take place largely in the 'hubs', with remote meeting technology allowing experts in the spokes to join the meetings easily and efficiently.

Devolving some expert procedures to smaller units would allow larger specialist centres to focus on highly specialist work, potentially resulting in fewer

HUB-AND-SPOKE MODELS: A PROPOSAL



THE SITUATION IN SCOTLAND

In Scotland, there are separate services for sacral neuromodulation (SNM) for bowel and urinary incontinence. The bowel service is a managed clinical network, with centres including Edinburgh, Glasgow, Aberdeen, Dundee and Inverness offering this service. For urinary incontinence, a Scottish National Service was set up in 2010 but de-designated in 2019 in order to set up 3 regional services; unfortunately, this has led to patchy, unequal service.

In the community setting, there were well-developed services in the West of Scotland for urinary incontinence but limited experience of bowel incontinence until recently: work has been ongoing in the past few years to redress the balance and ensure equity of care.

complications and better outcomes. It may be that some services could be provided by private hospitals or independent treatment centres if local needs require it and adequate integration can be achieved with the NHS MDT. In the oncology field, national-level implementation ensured such a change in approach happened quickly and effectively *(NHS England, Implementing a timed colorectal cancer pathway, 2018)*: this would also be welcomed in the continence and pelvic health field. However, while national-level guidance is awaited, MDT working at a regional level should be implemented to support better outcomes for patients as swiftly as possible.

The provision of adequate training is essential to safeguard the future of pelvic floor medicine, to maintain standards and to ensure outcomes for patients continue to improve (see **Chapter D**). Implementing a hub-and-spoke structure could also help to ensure provision of training opportunities. At present, most trainees struggle to meet the required

number of procedures to qualify in their chosen specialty, for example for prolapse repair: with cases concentrated in dedicated centres, trainees can be offered the opportunity to participate on a more frequent basis.

Where some procedures become increasingly specialised, consideration must also be given to emergency procedures, such as emergency presentation of irreducible prolapse. A plan should be agreed within regional and local teams to define referral pathways and ensure support is available in these cases.

Multi-disciplinary decision making

Developing multispecialty services for pelvic floor procedures is expected to improve outcomes, as well as access, compared with the current approach where procedures are conducted within the individual specialties of coloproctology, gynaecology and urology. Commissioning (in England) is a key step to ensure that defined pathways exist for treatment. A clear map of the location and provision of available services will be important to develop an algorithm to support appropriate referrals in future; a planned initiative to map out available continence services under NHS England is currently on hold as a result of the COVID-19 pandemic, but must not be forgotten.

MDT-based decision making is critical for optimal care for patients' often complex disorders – but it is not yet a universal approach. A survey of colorectal surgeons in 2014 found approximately 50% of respondents used pelvic floor MDT meetings *(Beggs et al., 2014)*. A census of 67 centres in the same year found that 38 (57%) held regular MDT meetings, although only a third did so in conjunction with another unit *(ACPGBI PF census report, 2014)*.

Further, MDTs must reach an appropriate standard in order to be effective. The British Society of Urogynaecology has led accreditation of units specialising in urogynaecology for over 10 years. The Pelvic Floor Society now also offers voluntary accreditation to units with MDTs that meet appropriate criteria, including appropriate attendance and infrastructure and ensuring that mechanisms are in place to identify which patients should be discussed *(The Pelvic Floor Society)*. So far, eight units have been formally accredited in the UK, and a further 35 are accredited by the British Society of Urogynaecology (BSUG). The Pelvic Floor Society is keen to see others sign up to ensure MDT discussion – and thus patient care – are standardised across the country. Learned societies such as the Pelvic Floor Society would support the role of commissioning in driving mandatory accreditation to maintain and improve quality. An achievable and laudable target would be to double the number of accredited centres in the next 12 months.

The Pelvic Floor Society

ACCREDITED UNITS IN THE UK

The following units have received MDT accreditation from the Pelvic Floor Society at the time of writing:

- Guy's and St Thomas's NHS Foundation Trust, London
- Royal London Hospital, Barts Health NHS Trust, London
- St Mark's Hospital, London
- Bristol Cross City, North Bristol and University Hospitals Bristol Trusts
- Manchester University NHS Foundation Trust
- University Hospitals Plymouth NHS Trust, Plymouth
- Royal Hallamshire Hospital, Sheffield Teaching Hospital, Sheffield
- University Hospital Southampton NHS Foundation Trust

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D How taking Pelvic Floor procedures outside the operating theatre can free up capacity

Kim Gorissen, Mahreen Pakzad, Rod Teo, Annabelle Williams

Waiting times for surgery have increased across multiple specialties in the COVID-19 era, but a particular challenge is presented by pelvic floor procedures, which are considered non-urgent and were thus commonly delayed to make room for other, more urgent surgery even before the start of the pandemic. This has resulted in some patients waiting months or even years for life-changing surgery, and COVID-19 has only made things worse.

One of the biggest challenges currently facing the clinical community is access to theatre and capacity for surgical procedures. New approaches are needed to free up space and to increase efficiencies. We will need to ensure these new approaches are introduced sensitively, and they will require training and support – but could form part of a long-term solution for capacity issues overall.

KEY POINTS

- **Transitioning procedures, where appropriate, from general to local or regional anaesthetic in clean rooms or day-case theatres could free up space in operating theatres and help address the backlog of cases**
- **Care must be taken to ensure a sterile environment and technique, as well as to safeguard patient comfort**
- **Implementing a mentoring programme could help to make the switch efficient and smooth, without compromising patient safety or wellbeing**

Going local: could local and/or regional anaesthetic be an option for some procedures?

Transitioning from general to local anaesthetic (LA) for selected procedures may allow them to be performed outside of the operating theatre, in clean rooms (where the only anaesthesia that can be used is local, with the possible addition of some sedation). This would both reduce the wait for operating space for these procedures and potentially increase efficiencies by freeing up theatre space for other procedures. The box below includes examples of procedures that are possible candidates for this approach, and indeed already in use in some centres. Some changes may open the door to others; for example, where the first stage of testing for sacral neuromodulation (termed percutaneous nerve evaluation, PNE) is

well established under LA, the second stage (battery implant) could lend itself to being performed under LA as well *(Thompson et al., 2010)*. In carefully selected and fully counselled patients, tined lead insertion under LA could also be a consideration. Intra-urethral sphincteric Botox injections for voiding dysfunction can be delivered under LA in a clean room, taking them out of the main theatre suite. However, localisation of the sphincter needs to be guided by ultrasound or by concomitant urethral sphincter electromyography (EMG), if available.

Using regional anaesthesia (RA) for some procedures may also be an option to increase theatre capacity, as while this still requires the use of an operating theatre it deceases the interval required between cases – particularly during the COVID-19 era *(Lie et al., 2020)*, where the aerosol generated by a general anaesthetic must be allowed to settle before the next case can commence.

PROCEDURES CURRENTLY POSSIBLE UNDER LOCAL ANAESTHETIC

The following procedures are already performed under a local or regional anaesthetic in some centres, outside the operating theatre, and this approach could be adopted more broadly:

Colorectal	Urology	Urogynaecology
Botox for anal fissure	Botox for detrusor overactivity	
	Botox for urethral sphincter	
Percutaneous nerve evaluation (PNE) for sacral neuromodulation (SNM)		
	Bladder neck injections (for stress incontinence)	
Second-stage SNM		
Anterior and posterior repair*		

**Selected cases as day-case procedures*

There are important considerations to be aware of when considering a transition to local anaesthetic. Operating under local anaesthetic requires a different technique and specialised skills. Using sacral neuromodulation (SNM) as an example, highly experienced implanters are needed to minimise procedural interventions and ensure patient comfort during lead insertion and testing. Indeed, patient comfort should be the central consideration with the patient supported throughout the procedure by staff dedicated to do so.

Where and how can we perform the procedures?

Any clean room should be an option for a procedure under local anaesthetic where, in general, a sterile environment is still needed. A positive-pressure airflow system may be required, dependent on the procedure being performed. Technique should also be sterile to ensure patient safety.

In addition, day-case theatres in separate units might provide an option to move cases from busier centres to perform them under local or regional anaesthetic, freeing up theatre space. An added advantage of a day-case theatre is the reduced risk of being cancelled or delayed, in order to accommodate urgent procedures such as cancer surgery.

Some procedures – such as prolapse operations through the vagina – require as a minimum regional, rather than local, anaesthesia; in these cases, the operating theatre is still required, but the reduction in aerosol generation and the consequent time saved is an important consideration.

Further, some procedures may require general anaesthetic but could still be conducted as day cases. Laparoscopic ventral rectopexy has previously been conducted with same-day discharge with a high success rate – a single-centre UK study found 90% of patients were discharged within a day of the procedure *(Powar et al., 2013)*. This approach could offer another route to reducing the burden on operating theatres.

ENSURING A STERILE ENVIRONMENT FOR LOCAL AND REGIONAL PROCEDURES

The space in which the procedure is conducted must have:

- Appropriate positive-pressure airflow system*,
- Sterile, packaged equipment,
- Available intravenous antibiotics,
- Anaphylaxis kit accessible in the room.

The usual behavioural approaches to ensure sterility must be maintained even outside the operating theatre.

*The number of necessary airflow changes will be procedure dependent.

Consideration should be given to the type of anaesthetic to be used: for example, spinal anaesthetic can cause urinary retention, so it is not appropriate for all patients. There is always a chance that the patient may have to be put under a general anaesthetic, so the patient will still need to be assessed and prepared accordingly. In the current situation patients need to be swabbed for COVID-19 and have a negative test result.

What else should be considered in switching to local or regional anaesthetic?

Provision of anaesthetic team support can be a challenge. Fentanyl is a preferred IV pain relief option for some procedures when procedures are being conducted under local anaesthetic, but must be administered by a trained specialist (for example, a specially trained nurse). In the past,

where sedation was not planned, there have been challenges in securing the assignment of specialist anaesthetic nurses. Such assignments could be beneficial to staff, offering them the chance to gain experience and help to set up new services.

Dialogue with the pharmacy to ensure such medications are available can be lengthy: in order to minimise disruption, these should be prioritised.

A mentoring programme could help to support Trusts and clinicians to make the switch where appropriate, without compromising patient safety or wellbeing. Once the switch has taken place, the service should be audited to ensure patients are comfortable and procedures are being conducted appropriately.

CASE STUDY

EVOLUTION OF APPROACH AT THE BRISTOL UROLOGICAL INSTITUTE

At the Bristol Urological Institute, the urodynamics-dedicated suite, which has its own C-arm and couch, has been used for the last 5 years to perform procedures that have been previously conducted in theatres. For example, the first stage (percutaneous nerve evaluation [PNE]) of sacral neuromodulation (SNM) has traditionally been conducted in theatres, either under sedation or regional/general anaesthesia in the United Kingdom, as it also requires image intensification/ fluoroscopy. Now, however, it is purely being done under local anaesthesia with X-ray guidance, on an outpatient basis, reducing pressure on theatres. Equally, Botox, which used to be done in theatres, is now almost exclusively done in the urodynamics suite under local anaesthesia by a trained nurse practitioner, easing pressure on theatre and also on surgeons.

Injection of urethral bulking agent was also planned to be conducted on an outpatient basis, but the start of this service was halted due to COVID-19 and will now commence in the summer of 2021.

CASE STUDY

MANJIT'S STORY

A 22-year-old nulliparous woman with chronic urinary retention was diagnosed with Fowler's syndrome and a high tone non-relaxing urethral sphincter. She was catheter dependent, and found urethral catheterisation very painful. She was offered all therapeutic options, including insertion of suprapubic catheter, a trial of sacral neuromodulation, a trial of intra-sphincteric botulinum toxin type A and also major reconstructive surgical procedures, such as Mitrofanoff and ileal conduit urinary diversion and stoma bag. She preferred the option of Botox as more of a reversible solution for her. Due to very high body mass index (BMI) and asthma, she was at high risk for general anaesthesia and the potential complications associated with it, e.g. deep vein thrombosis (DVT). In addition, she was surgically prioritised as an NHS England Category 4 patient, as she theoretically could wait at least 6 months, for her procedure and was also at risk of repeated deferment due to low clinical priority. She was offered the intra-sphincteric Botox option under LA and EMG guidance in a "clean room", which she gratefully accepted, with significantly lower waiting time.

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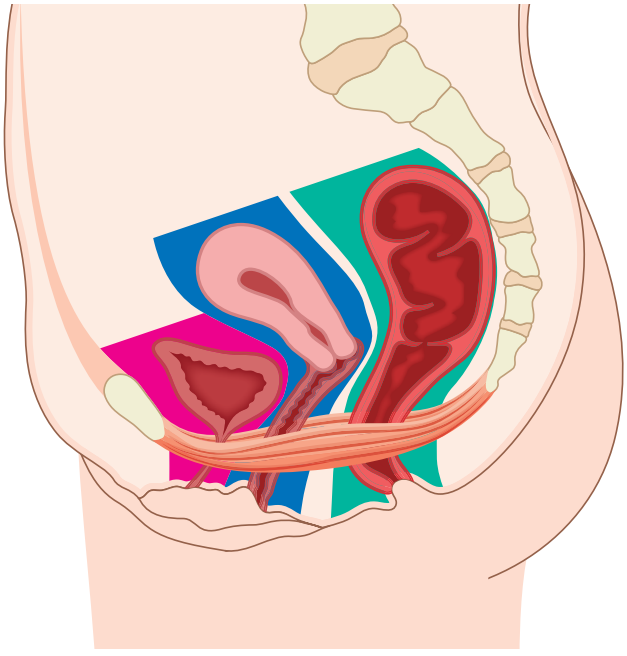
E How combining Pelvic Floor expertise can improve the patient experience

Graeme Conn, Chris Harding, Karen Telford, Karen Ward

The pelvis is considered to have three compartments: anterior, middle and posterior *(Salvador et al., 2019)*, as shown in the figure below. Historically, different surgical specialties (urology, urogynaecology and colorectal) have tended to 'colonise' the pelvis along these lines with each addressing a single compartment. This ignores the basic concept of 'three compartments – one pelvic floor' and can lead to repeated patient visits to different specialists and multiple appointments in order to reach the appropriate diagnosis and to initiate consequent treatment *(Salvador et al., 2008)*. Often there is little crossover between these different consultations. This can not only cause frustration for the patient, but also leads to duplication of work for the clinical teams and may delay important procedures. Further, ignorance of multicompartmental problems can lead to lost opportunities to address multiple problems, or even the risk of making the second problem worse, by conducting surgery on one compartment only.

OVERVIEW OF THE PELVIC FLOOR



Anterior Middle Posterior

This issue is not trivial. According to a survey of women 20 years after childbirth, around one in three presenting with a pelvic floor disorder (PFD) may in fact have two or more PFDs *(Gyhagen et al., 2015)*. Urology, urogynaecology and colorectal surgeons tend to be highly specialised, but patients with such multifactorial pelvic floor disorders require the input of multiple specialities *(Elneil, 2009)*. Primary care and community continence and pelvic health services do not usually distinguish between the compartments, approaching symptom management in a functional and holistic way. Treating all issues together is an approach that should be adopted for the patient referred to secondary and tertiary care following intial non-surgical management and may allow for efficiencies in an increasingly depleted workforce.

KEY POINTS

- **Frequent multidisciplinary team (MDT) meetings are recommended, especially to discuss complex, multi-compartmental cases, featuring subspecialist functional colorectal, urology and urogynaecology team members**
- **Trained nurses and other allied health professionals can conduct selected protocol-driven procedures, freeing up specialist consultants and surgeons to perform other work**
- **In the future, cross-compartmental training is desirable to ensure joined-up care and to create 'three-compartment pelvic floor specialists'**

Optimising collaboration among pelvic floor specialists: the role of the MDT

Patients with PFDs have already had a difficult journey, often taking years to reach a specialist in secondary or tertiary care. It is of paramount importance that the patient feels looked after in a holistic manner and fragmented care and 'silos' should be avoided. Ownership of the problem, with a named responsible clinician in charge of care who liaises with colleagues, can help to avoid patients having to move unnecessarily between specialists.

Joined-up care is particularly essential for our most complex patients, who need a joint evaluation and possibly joint surgery. The optimal approach for these complex cases is the multidisciplinary team (MDT) meeting, featuring a range of specialists to ensure the full spectrum of factors is taken into account when deciding on treatment – an approach recommended by the recent Scottish Independent Review into mesh implants (*Scottish Independent Review, 2017*). Indeed, the MDT is no longer optional and is an essential resource in patient management, and as a minimum standard of care, all patients requiring surgery should be discussed before surgical treatment.

NICE guidelines for urinary incontinence recommend both regional and local MDT meetings *(NICE guidelines, Urinary incontinence and pelvic organ prolapse in women: management, 2019)* and state that local MDTs are appropriate to review proposed treatments for patients with primary stress urinary incontinence, overactive bladder or primary prolapse, whereas regional MDTs should review proposed treatments for patients with complex pelvic floor dysfunction and mesh-related problems. Currently, there are approximately 40 commissioned centres for complex pelvic floor problems (focused largely on urinary incontinence and pelvic organ prolapse) to be established under specialised commissioning. In its current iteration, the service specification relates largely to these symptoms and where they coincide with bowel symptoms, rather than for bowel symptoms alone, leaving people presenting with bowel issues alone uncatered for beyond the pelvic health services in primary and community care.

NICE recommends that local MDTs should feature as a minimum two consultants with expertise in managing urinary incontinence in women and/or pelvic organ prolapse, a urogynaecology, urology or continence specialist nurse and an

JOINT PELVIC FLOOR MDT – BARTS HEALTH NHS TRUST: 'MOVING IN THE RIGHT DIRECTION'

Multi-disciplinary team meetings (MDMs) were started in 2015 with the remit of discussing all colorectal patients under consideration for pelvic floor surgery and Barts was one of the first two centres to achieve accreditation by the Pelvic Floor Society in 2018. The meeting started monthly, then moved to every 2 weeks and is now weekly, discussing 5–10 patients per meeting. The original membership of urogynaecology, colorectal surgery, nursing, clinical physiology (inc. radiology) has expanded to include monthly attendance of urology and neurogastroenterology as well as physiotherapy, research fellows and nurses (for trial recruitment). In addition, the MDM has become regional with the addition of the Homerton University Hospital NHS Foundation Trust (Hackney, London) and Broomfield Hospital Chelmsford.

ADDITIONAL APPROACHES TO OPTIMISE MDT EFFICIENCY

An online questionnaire can be completed prior to remote MDT meetings, offering a standardised approach and a full picture of the patient's issues, symptoms and goals: see **Chapter B**.

accredited *(POGP, 2020)* pelvic floor specialist physiotherapist. Additional optional members listed in the guidelines are a member of the care of the elderly team, an occupational therapist and a colorectal surgeon. However, for regional MDT meetings, the colorectal surgeon is listed as a mandatory attendee, along with a pelvic floor specialist physiotherapist and a radiologist with expertise in pelvic floor imaging. Notably, the older (2007) guidelines for faecal incontinence do not yet include a recommendation for an MDT *(NICE guidelines, Faecal incontinence in adults: management, 2007)*; given the evidence used for these guidelines is still current, the expected timeline for updating these is not yet known, although there is a guideline in progress from the European Society of Coloproctology (ESCP) and United European Gastroenterology (UEG). Further, a guideline on mesh in pelvic colorectal surgery has been submitted to Colorectal Disease at the time of writing. New and updated guidelines should include patient representatives to further improve the relevance and likely uptake of their recommendations.

Better MDT working will help to support the more complex patients, particularly those with multi-compartment disease. The development of MDTs has led in some centres to joint clinics, which are essential to evaluate (in one consultation) the most complex patients. However, since these are a limited and expensive resource, local teams should develop clear vetting procedures and establish strict referral criteria for access to this high-resource clinic. Guidelines in general for MDT referral will be necessary to ensure that all MDTs do not discuss inappropriate cases.

MDTs should be conducted as frequently as required in order to reduce patient waiting times *(Balachandran et al., 2015),* and should be attended by subspecialist functional colorectal, urogynaecology and urology team members. Ideally, two members of each specialist team should be on the MDT group so that one can attend if the other is unavailable *(Balachandran et al., 2015)*. Online meeting technology may allow for more cost- and time-efficient MDT meetings and allow specialists to join and leave as required (see **Chapter B**).

The knowledge and training of specialist nurses is valuable for joined-up pelvic floor care, and the continence resources available from the RCN *(RCN, 2016)* provide a comprehensive overview and support for patient-centred care. One-stop clinics and use of patient navigators, with or without administrators or triage nurses, can help to triage patients according to local guidelines and thereby streamline investigations – these investigations should ideally be conducted prior to clinician review in order to enhance decision making.

Making use of available skills: the case of protocol-driven procedures for nurses

With growing demands on the service, it is time to reconsider which procedures require consultant expertise and which can be performed by appropriately trained nursing or allied healthcare professionals such as Assistant Practitioners. Often acting as leaders in the area of bladder and bowel care, specialist nurses are uniquely placed to step into many procedures in this area. Provision of clear protocols and formal governance arrangements ensures that procedures are standardised, minimising risk to the patient and providing an opportunity for the healthcare practitioner to work towards independent practice. Indeed, many experienced nursing staff can use their expertise and clinical judgement, with the appropriate governance, to conduct procedures. For higher-cost procedures, such as sacral neuromodulation (SNM) implants, procedures can be performed along with a consultant, but with appropriate training procedures under local anaesthetic could also be performed independently, freeing up specialist consultants to perform other procedures.

As part of this approach, a national recruitment drive for specialist nurses is important to ensure sufficient manpower is available – this could ultimately bring about further cost savings.

CASE STUDY

NURSE-LED BOTULINUM TOXIN ADMINISTRATION

A nurse-led service administering botulinum toxin via flexible cystoscopy for overactive bladder the spinal injury setting was launched in 2016 *(Muter P, SCI Nurse Conf 2016 – poster)*. Training was provided via a nationally agreed universal training package from the British Association of Urology Nurses (BAUN) and British Association of Urological Surgeons (BAUS) and a standard operating procedure ensured compliance and consistency in the process.

The outcome: waiting times were reduced and patients were highly satisfied with the service: 100% expressed confidence in their treating clinician *(Muter P, SCI Nurse Conf 2018 – plenary presentation)*.

CASE STUDY

NURSE-LED SNM SERVICE

A nurse-led SNM service launched in 2017 has both reduced waiting times and ensured a consistent point of contact and treatment for patients *(Mullins D, 2019)*. Further training was delivered by a Master's Degree in surgical care practice in general surgery in order to set up the service.

The outcome: waiting times were reduced from 15 weeks to two weeks for test implants and nine for permanent implants; the majority of patients rated the service as outstanding. Consultant time and theatre availability were freed up, resulting in overall efficiency improvements.

The long-term view: training the pelvic floor workforce of the future

Currently there are around 100 unfilled urology posts in the UK, and the shortfall in pelvic floor expertise is expected to increase further. Specifically in surgery, there is a worrying trend of reduced applications for general surgery at Specialty Registrar level, as well as a paucity of people interested in taking up pelvic floor surgery: the recent negative media surrounding mesh may worsen this and create further issues in the future. Functional and incontinence work has always been something of a 'Cinderella' speciality, with cancer and inflammatory bowel disease (IBD) work seen as more challenging and rewarding. However, an improved understanding of pelvic floor conditions has created a pivot point with the perception of this field. Nursing is also under pressure: the previous provision of specialist continence training under the old English National Board (ENB) structure no longer exists and specialist post-graduate continence training is lacking. This reduces the opportunity to specialise in this area of care for adults and for children, and also reduces the visibility of any such career path.

Defining the workforce required to provide evidence-based care is a further stated aim of the NBBH project *(NHS Supply Chain)*. It is essential to attract new trainees to the service – and abandoning the past approach of considering the three pelvic compartments entirely separately may help to do this. With many trainees struggling to meet the required number of procedures to qualify in their chosen specialty, and a large number of senior surgeons now on the brink of retirement, creating a new combined specialty can help to both make the best use of our available resource and attract the pelvic floor specialists of the future.

Colorectal, urology and urogynaecology functional subspecialists all need to be adequately trained in their individual specialties, and then ensure they are able to tackle the often-complex problems encountered in each compartment of the pelvic floor. However, specialist training across the different compartments is a desirable long-term goal to reduce siloed decision making. Equal emphasis in such specialist training should be placed on each aspect of the pelvic floor, with the ultimate aim of creating 'three-compartment pelvic floor specialists'. This may involve, for example, a urogynaecologist training in colorectal for a period, with similar cross-compartmental training for urologists and colorectal specialists. Cross-specialty pelvic floor training fellowships should be encouraged.

Training and education are crucial to improving the quality and availability of pelvic floor services. Future specialists, nurses and allied healthcare professionals need access to structured training programmes and specialist fellowships, as well as modular courses. The hub-and-spoke approach outlined in Chapter B should result in a higher concentration of cases and expertise, thereby maximising training opportunities.

FORTHCOMING PELVIC FLOOR GUIDELINES

NICE are developing a new guideline on the prevention and non-surgical management of pelvic floor dysfunction in women (including young women over the age of 12), which is due to be published in late 2021.

It aims to provide overarching guidance on pelvic floor dysfunction affecting all compartments of the pelvic floor and will include urinary incontinence, faecal incontinence and pelvic organ prolapse as well as other symptoms attributed to pelvic floor dysfunction such as emptying disorders of the bowel and bladder, pain and dyspareunia

It is recognised that there is currently variation in the availability of and access to non-surgical management options, such as pelvic floor muscle training, for women with pelvic floor dysfunction. Women have no clear and effective strategies available to prevent worsening of the condition.

The guideline will focus on community-based pathways that include pelvic floor care and prevention of pelvic floor dysfunction. These pathways are intended to reduce the number of women who go on to develop complex symptoms that would need specialist care (e.g. surgery).

https://www.nice.org.uk/guidance/gid-ng10123/documents/final-scope

A further aspiration for the future could be a focus on 'Pelvic Floor' as a specialism rather than urology, urogynaecology and colorectal all being specialities in their own right *(Beggs et al., 2014; Gash et al., 2015)*: this could help in recruiting and attracting talent to this speciality, securing a high quality of care for the future. Formal accreditation of units is currently offered by the British Society of Urogynaecology (BSUG) and includes a requirement for provision of training, and the Pelvic Floor Society also offers accreditation to pelvic floor MDTs (see **Chapter C**), but a greater emphasis on training standards and broad curricula by professional organisations like the BSUG and British Association of Urological Surgeons (BAUS) would be welcomed in order to help to build momentum for this cross-functional specialism.

Having nurses who can deliver treatment for both urinary and bowel symptoms, as already done by physiotherapists, could shorten the overall patient pathway and may allow some women to avoid surgery – for example, women with small posterior compartment prolapses and defaecatory symptoms who present to gynaecologists may be able to avoid surgery if they have access to appropriate conservative treatment. The protocol-driven procedures conducted by nurses, mentioned above, could also be performed across specialties where appropriate, to reduce duplication of effort and equipment and to maximise efficiencies. Specialist continence training, and a better-promoted career pathway, could also help to safeguard staffing levels in nursing for the future.

In the long run, guidelines should reflect this approach, providing guidance on an agreed, evidence-based national pathway for patients with complex pelvic floor disorders across the spectrum of disease. These guidelines would support primary care clinicians and specialists to ask all the right questions and conduct all appropriate investigations to ensure the best outcome for patients. The recent publication of the UK Clinical Guideline *(POGP and UKCS, 2020)* for best practice in the use of vaginal pessaries for pelvic organ prolapse provides a good example where the patient's needs are potentially met by a range of clinicians with appropriate and shared training as part of the overall management of their pelvic floor

condition. It is encouraging that overarching NICE guidelines for pelvic floor disorders in women are anticipated in 2021 (see box on previous page). It is also important that sufficient workforce is available for the approaches outlined above to ensure that services are not unnecessarily centralised and the travel burden for patients is not excessively high.

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F

How novel approaches and partnerships could help to address capacity issues for Pelvic Floor surgery

Mohammed Belal, Hashim Hashim, Wesley Lai, Charles Maxwell-Armstrong, Charles Knowles (editor)

Waiting lists for pelvic floor procedures, classified as 'benign work', are always lengthy, but have been worsened by the recent COVID-19 crisis. The pandemic led to a hold on all non-urgent procedures (diagnostic and surgical), which has seen waiting lists for pelvic floor procedures grow to 400 – 500 people in some large NHS Trusts. By February 2021, nearly 388,000 patients across all therapy areas in England had been awaiting routine hospital treatment for over a year *(BBC, 2021)*. The numbers of patients waiting for 52 weeks for general surgery and urology surgery in London alone are shown in the table below – these include patients with problems deemed 'less urgent' (including pelvic floor issues).

REFERRAL TO TREATMENT: LONDON COMMISSIONING REGION

Treatment function	Period	Number of patients waiting 52+ weeks	Average (median) waiting time (in weeks)	92nd percentile waiting time (in weeks)
General Surgery	Feb 2020	58	9.2	29.7
	Feb 2021	3,937	13.4	52+
Urology	Feb 2020	2	7.9	24.5
	Feb 2021	1,948	12.7	41.7

Source: NHS England and NHS Improvement, 2021: monthly RTT data collection. Referral to Treatment: London Commissioning Region.

Pressures on benign procedures during the COVID-19 era have come from multiple sources, including the delays to cancer assessment and care, with about 38,000 fewer cancer treatments taking place between March and July 2020 *(Cancer Research UK, 2020)*. This leaves a backlog of potential cancer patients, that needs to be cleared, and will always take priority over benign pelvic floor pathology, even though pelvic floor problems have a significant physical and mental impact on the patient. Other non-oncology departments are also competing for the same limited hospital resources in the post-COVID-19 period, and many, such as trauma patients, may also take priority over pelvic floor patients. Finally, in addition to the normal 'winter pressures' on beds, ring-fencing of 'COVID beds' has further reduced hospital capacity for elective inpatient procedures.

This is likely to increase with further waves of COVID-19. With a lack of surgical space and theatre time for pelvic floor surgery, creative solutions and partnerships with other providers are worthy of consideration.

Public-private initiatives have always been controversial in the NHS in the past, with both positive and negative experiences. The panel does not endorse any particular model, but does feel it is important to look at the pros and cons of different approaches within a fully integrated pelvic floor service.

KEY POINTS

- **Private institutions and premises may be able to support specific challenges, particularly in addressing growing waiting lists**
- **New approaches, whether these are use of private resources or mobile units, could be particularly suited to day cases owing to their use of sedation and short patient stays**
- **The off-site nature of private providers aligns with the concept of pooled regional activity from several trusts**
- **Challenges relating to the private sector must be carefully considered, including care delivered by the same team, patient selection, maintaining quality of care and prevention of conflict of interest issues**

Considering collaboration: a potential new approach

While COVID-19 has contributed to the waiting list challenge for pelvic floor surgery, experience gained during the crisis may also offer insights into ways to tackle this challenge. In fact, public-private collaboration in the pelvic floor sphere had been trialled before the pandemic *(Chard et al., 2011)*, but these became a common feature during the initial COVID-19 peak in the spring and summer of 2020. Private hospitals in many areas have been used for benign and cancer cases since the pandemic began to peak around April, providing 'green sites' for patients vulnerable to infection. However, while there have been positive experiences with these collaborations, in many areas there were also logistical issues and problems with efficiency. Treatment centres may provide an alternative to private hospitals, but consideration must be given to the provision of specialists and specific equipment required.

Private institutions may be able to help with specific challenges. An obvious use would be to address very long waiting times in the NHS for particular procedures. Using private resources, such as theatres, could make the most of available capacity in local private institutions when capacity is at a premium within the NHS. Private facilities could help to reduce waiting lists on the NHS, potentially also offering services during evenings and weekends to further address the backlog.

However, this is only one driver for change. The private sector is also an opportunity to improve quality and patient experience. Some busy acute hospitals make for poor environments to 'squeeze in' elective pelvic floor cases, especially when the mindset of staff is on other priorities.

Pelvic floor procedures that can be performed as day-case surgery are an obvious choice for public/private partnerships. Sacral neuromodulation (SNM) is an example of a procedure that may be suited to a private hospital or treatment centre. SNM cases are day cases, with patients under local anaesthetic (see **Chapter D**), sedation or general anaesthetic and in and out of hospital quickly, and SNM is a minimally invasive approach. Day-case units have been established in multiple NHS Trusts in the past, and could once again be worthy of more attention as a concept.

There is a rationale to pool patients on dedicated lists, run for a single region by one provider with the infrastructure to deliver this without interruption and to adhere to the critical time sequence for the SNM stages (SNM requires two sequenced procedures a few weeks apart). Other procedures that could benefit from this approach include injectables or proctology procedures, such as haemorrhoids or simple fistulae.

An alternative approach for these procedures is mobile units, which can travel around the country to provide extra facilities and specialist equipment. These might provide an additional route to reducing overload, though logistics and requirements may vary from Trust to Trust. A further option could be to locate nurse-led clinics in the private sector but to maintain day cases within the NHS itself, or indeed to develop purpose-built temporary operating theatres – an approach trialled in some places before the pandemic *(BBC, 2019)*.

Anticipating and overcoming challenges

While there are clear potential benefits, the challenges of public-private collaboration must also be considered. For example, more complex procedures that require a large team, overnight stays and detailed follow-up may be problematic if performed at a location miles away from where the experts are located. COVID-19 has highlighted this challenge when individual consultants have on occasion found themselves split across multiple sites, many miles apart, to ensure patients were covered. While this might be achievable during a crisis, it is not sustainable in the long term.

CASE STUDY

NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST COLLABORATION WITH CIRCLE

A collaboration between Nottingham and Circle provided the ability to move the pelvic floor service between sectors, maintaining the service while the NHS was under pressure. The collaboration ended shortly before the onset of COVID-19, with waiting lists reduced to manageability by the collaboration and the NHS now back in control.

CASE STUDY

UNIVERSITY HOSPITALS PLYMOUTH NHS TRUST

The Plymouth Pelvic Unit and UHP have been in ongoing discussion with the local independent sectors with a plan to move some of the pelvic floor procedures such as perineal rectal prolapse repair and SNM to their sites, in order to help with the growing waiting list, especially during the COVID-19 pandemic. In January 2021 NHS Improvement (NHSI) triggered the 'Surge' clause in the national contract, and the pelvic floor team has successfully performed selected pelvic floor procedures such as perineal rectopexy and SNM in the Nuffield hospital Plymouth.

In fact, even for a day-case procedure, patient assessment and follow-up must be considered. These assessments involve a multidisciplinary team of nurse specialists, radiographers and clinical scientists as well as the surgeon. Any public/private partnership needs to consider this complexity, and not simply whether the institution has the surgical space and equipment to perform the procedure. It may be that a blended approach is appropriate – with non-NHS institutions providing the facilities for surgery, but with the pre- and post-care of the patient taking place within NHS outpatient facilities, with decision making passing through regional MDTs (see **Chapter C** and **Chapter E**).

The use of private facilities may be best suited to the fittest (ASA1 and 2) patients, to minimise the risk of complications that would be better handled in an NHS centre. Further, while capacity may be available in the private sector, it is not geared up to handle the numbers of patients passing through the NHS, and consequently private hospitals may be less willing to take on patients in the future outside the current crisis period. We must not ignore that public and healthcare professional (HCP) discomfort, with the idea of private involvement in the NHS, may raise additional barriers.

Maintaining the quality of patient care

Above all, at all times, quality is critical. Whatever the approach taken, a quality agenda will be required to ensure standards are maintained and previous negative experiences of public-private partnerships *(House of Commons Health Committee, 2006; Royal College of Surgeons, 2006; Plumridge, 2008; BBC, 2015; Cumberlege Report, 2020)* are not repeated.

Perhaps looking at public/private partnerships – carefully developed – could be one option to address the large waiting lists that now exist for patients with pelvic floor problems. The COVID-19 experience is teaching us that we are able to find solutions to challenges where there is a will. While there is no single answer to the overload on PF services, an openness to collaboration and new ways of approaching the service may lead the way to identifying more sustainable models in the future.

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Appendix

Guidelines and policy documents referred to in this report

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All-Party Parliamentary Group for Bladder and Bowel Continence Care	Cost-effective Commissioning For Continence Care	2011	http://www.appgcontinence.org.uk/documents/
Baroness Cumberlege	First Do No Harm	2020	https://www.immdsreview.org.uk/Report.html
House of Commons Health Committee	Independent Sector Treatment Centres: Fourth Report of Session 2005–06	2006	https://publications.parliament.uk/pa/cm200506/cmselect/cmhealth/934/934i.pdf
NHS England	Excellence in Continence Care	2018	https://www.england.nhs.uk/publication/excellence-in-continence-care/
NHS England	Implementing a timed colorectal cancer pathway	2018	https://www.england.nhs.uk/wp-content/uploads/2018/04/implementing-timed-colorectal-cancer-diagnostic-pathway.pdf
NHS England	The NHS Long-Term Plan	2019	https://www.longtermplan.nhs.uk/
NHS England and NHS Improvement	Commissioning for Quality and Innovation (CQUIN): Guidance for 2020/2021	2020	https://www.england.nhs.uk/publication/commissioning-for-quality-and-innovation-cquin-guidance-for-2020-2021/
NICE	Faecal incontinence in adults: management. Clinical Guideline CG49	2007	https://www.nice.org.uk/guidance/cg49
NICE	Single Technology Appraisal: Lubiprostone for treating chronic idiopathic constipation: Final scope.	2013	https://www.nice.org.uk/guidance/TA318/documents/constipation-chronic-idiopathic-lubiprostone-final-scope2
NICE	Urinary incontinence and pelvic organ prolapse in women: management. NICE Guideline NG123	2019	https://www.nice.org.uk/guidance/ng123
NICE	Pelvic floor dysfunction: prevention and non-surgical management. In development [GID-NG10123].	2020	https://www.nice.org.uk/guidance/indevelopment/gid-ng10123
Royal College of Surgeons	Commissioning guide: Faecal Incontinence	2017	https://www.rcseng.ac.uk/-/media/files/rcs/standards-and-research/commissioning/commissioning-guide-for-faecal-incontinence-final-january-2014.pdf
Royal College of Surgeons	Future of Surgery	2018	https://futureofsurgery.rcseng.ac.uk/
Scottish Independent Review	Scottish Independent Review of the use, safety and efficacy of transvaginal mesh implants in the treatment of stress urinary incontinence and pelvic organ prolapse in women: Final Report	2017	https://www.gov.scot/publications/scottish-independent-review-use-safety-efficacy-transvaginal-mesh-implants-treatment-9781786528711

List of continence patient organisations and charities in the UK

Bladder & Bowel UK
https://www.bbuk.org.uk/

Bladder Health UK
https://bladderhealthuk.org/

Bowel Research UK
https://www.bowelresearchuk.org/

Continence Product Advisor
https://www.continenceproductadvisor.org/

ERIC
https://www.eric.org.uk/

MASIC (Mothers with Anal Sphincter Injuries in Childbirth)
https://masic.org.uk/

World Federation for Incontinence and Pelvic Problems (WFIPP)
(operates worldwide)
https://wfip.org/
https://www.supportincontinence.org/

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