



Llywodraeth Cymru  
Welsh Government

# Report of the Welsh Task and Finish Group for Faecal Incontinence

“ Sometimes the words we leave unspoken are the most important ones that should have been said.”

**Lets Talk About  
Faecal Incontinence  
#BreaktheTaboo**

# **Executive Summary**

## **Background**

Faecal incontinence (FI) can affect anyone. The largest group is women, both young and old due to the association with pregnancy and obstetric injury. However there are multiple other causes, including surgery for cancer and radiotherapy which affect both men and women. It is estimated that faecal incontinence (FI) may affect 10% of the adult population. The effects of FI can be devastating and is associated with anxiety, depression and a poorer quality of life. The future demand for pelvic floor services is likely to increase with an ageing and increasingly comorbid population.

The Task and Finish Group was commissioned in September 2017 to look at current service provision for FI in Wales and offer solutions for improving outcomes for patients. It convened over a period of 12 months, with members from every Health Board in Wales and from all relevant clinical areas and importantly, patient representatives.

## **Overview**

Faecal Incontinence pathways are outlined by NICE, however, there are inconsistencies in services across health boards in Wales. Organisational surveys carried out as part of the work of the Task and Finish Group demonstrate that services for FI are variable, lack coordination, and the need for cross discipline and inter health board referral can lead to lengthy delays in patient management.

Quality of care for patients across Wales could be improved with an increase in the number of physiotherapists and nurses who have FI pelvic floor training. Currently, a number of health boards lack the relevant health professionals and there are issues of sustainability for those that do. The majority of physiotherapy services for incontinence reside within women's health (urogynaecology) which has led patients presenting with bowel symptoms to have difficulty accessing services and there is limited service provision for men presenting with faecal incontinence. Few patients in Wales are being discussed in a Multi Disciplinary Team (MDT) setting, despite guidelines.. The majority of Health Boards fail to offer in-house or external referrals to psychology, specialist pain or psychosexual services although this is needed by a significant number of patients.

GPs need a defined pathway of referral to reduce barriers to treatment and delays. The group have suggested an all Wales pathway, with standardised treatment, as a model framework alongside improved access to training for GPs and allied health professionals on FI. There is concern that pelvic floor dysfunction is considered low priority, with lack of a coherent strategy. Patients should be initially referred to the continence service (or Bladder and Bowel Health teams). It must be ensured that this is an integrated service with the ability to diagnose / investigate and upgrade patients

in order to rule out serious pathology. This requires an MDT approach, without which there will be no choice for GP's but to refer most patients to secondary care for investigations and a diagnosis. There needs to be a greater collaboration between urogynaecology and colorectal services to allow improved services for those women who develop faecal incontinence after childbirth. More information needs to be given to women in the antenatal and postnatal period about the possibility of developing FI and where to seek help for it.

There needs to be at least one accredited specialist centre in Wales that has the expertise and specialist skills to deal with complex conditions. This does not currently exist and will need to be developed. Health Technology Wales has recommended Sacral Nerve Stimulation (SNS) as a treatment for patients with FI failing conservative management. SNS should be available as a treatment option for FI in Wales but the majority of patients are not able to access this service and the small number that are eventually offered treatment are referred, at significant cost, to England.

Finally, it is important to raise public awareness of the causes, prevalence and symptoms of FI. Lack of awareness of the condition and treatment options acts as a barrier to patients seeking help for a stigmatising condition that impacts so negatively on their quality of life.

### **Recommendations;**

- All patients should be managed using NICE Guidelines for Faecal Incontinence and as part of a Pelvic Floor Multidisciplinary Team
- There needs to be a streamlined referral process between departments and hospitals to avoid the lengthy delays and lack of communication.
- Improved communication between primary and secondary care
- All patients should be able to access the same treatment options as the rest of the UK, irrespective of where you live in Wales (including physiotherapy, continence nurses and sacral neuromodulation)
- There should be at least one accredited pelvic floor unit in Wales to deal with complex patients
- General Practitioners and health professionals need to have a greater awareness of FI and how to manage it
- Women need to have more information on the potential risks of childbirth on pelvic health and continence (antenatal and postnatal)

# **Faecal Incontinence**

The report of the Welsh Task and Finish Group

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## **Forward by the Chair, Welsh Task and Finish Group for Faecal Incontinence**

In September 2017 the then Cabinet Secretary for Health and Social Services in Wales asked for a Welsh Task and Finish Group to review the provision of services for faecal incontinence and pelvic health across Wales and determine the level of services compared to best practice.

Clinical leads from the area of colorectal surgery, urogynaecology, physiotherapy, continence services, midwives, General Practitioners, radiologists, dieticians and psychologists along with patient representatives from MASIC (Mothers with Anal Sphincter Injuries in Childbirth) Foundation and FFTW (Fair Treatment for the Women of Wales) were gathered to undertake the review, with Julie Cornish, Consultant Colorectal Surgeon from Cardiff and Vale University Health Board, as Chair.

From November 2017 to July 2018 we looked at the available research and data evidence, considered the experiences of Welsh patients and undertook an examination of the current care pathway for patients experiencing faecal incontinence.

We are pleased to present the outcome of our work in the form of this report and its associated recommendations. They demonstrate our commitment to improving health and wellbeing of the population of Wales and the quality and safety of the healthcare provided.

### **Key Recommendations:**

- All patients should be managed using NICE Guidelines for Faecal Incontinence and as part of a Pelvic Floor Multidisciplinary Team
- There needs to be a streamlined referral process between departments and hospitals to avoid the lengthy delays and lack of communication.
- Improved communication between primary and secondary care
- All patients should be able to access the same treatment options as the rest of the UK, irrespective of where you live in Wales (including physiotherapy, continence nurses and sacral neuromodulation)
- There should be at least one accredited pelvic floor unit in Wales to deal with complex patients
- General Practitioners and health professionals need to have a greater awareness of FI and how to manage it
- Women need to have more information on the potential risks of childbirth on pelvic health and continence (antenatal and postnatal)

## Background

Faecal incontinence (FI) can affect anyone. The largest group is women, both young and old due to the association with pregnancy and obstetric injury. However there are multiple other causes, including surgery for cancer and radiotherapy which affect both men and women (Whitehead WE 2009). It is estimated that faecal incontinence (FI) may affect 10% of the adult population (Bharucha 2005). The incidence increases with age; with 7% suffering from it in 20-29 age group compared with 22% in the 50-59 year old group (Perry 2002). In nursing homes this rises to around 50% (Edwards N 2001). Its effects can be devastating with a clear association with anxiety, depression and poor quality of life. Aside from the already high prevalence of FI, the future demand for pelvic floor services is likely to increase further driven by public expectation, technological advances, an aging population and increasing prevalence of predisposing factors such as diabetes and obesity. Best estimates indicate a rise in healthcare demand by over 50% in the next 30 years.

There has been a threefold increase in OASI (obstetric related anal sphincter injury) in Wales in the last decade (Ismail S 2014). OASI is reported to occur in approximately 3.7% of vaginal births in the Wales (NMPA report 2017) but this may be as high as 6.1% in first time mothers (Thiagmoorthy 2014). There are approximately 11,000 vaginal deliveries per year in Wales – so at least 600 women per year are affected. This has a significant impact in terms of inability to return to work, social stigma, mental health issues, marital and sexual dysfunction.

The majority of patients with FI can be treated with conservative measures (up to 80%) including: lifestyle and dietary modifications, medication, rectal irrigation, biofeedback and physiotherapy (Norton C 2006). Sacral Neuromodulation is a successful treatment for 70% of patients who fail conservative management but there are no Health Boards in Wales currently offering this service due to funding/commissioning issues.

The management of pelvic floor pathology is a relatively new discipline with evolving working practice between surgical and non-surgical specialties. The need for radical



change in pelvic health services generally has been highlighted with the recent attention on mesh for urinary incontinence in women. This report offers insight and potential solutions to improve the lives of both women and men in Wales who live in silence with faecal incontinence, a condition that is both physically and mentally disabling and significantly impacts on the lives of themselves and their families.

## Chapter 1: Why this review was necessary

It has been recognized amongst clinicians and allied health professionals that faecal incontinence in both men and women is a poorly resourced service, falling outside the traditional remit of womens' health department with urinary incontinence and prolapse. The MASIC (Mothers with Anal Sphincter Injury in Childbirth) Foundation is a U.K. charity that held an event in Wales in 2016 and the evening highlighted the disparity of services for faecal incontinence and the unmet need for a condition that has a profound impact on quality of life for many people. At the same time pelvic health was in the public spotlight due to media coverage of the use of mesh for urinary incontinence and prolapse. As a result of this, three task and finish groups were created to address pelvic floor services across Wales (Pelvic Mesh, Endometriosis and Faecal Incontinence).

Patients have written to the Health Minister and other Assembly Ministers in Wales over the last 10 years to raise their concern about the lack of access to certain treatments (such as SNM; sacral neuromodulation) and outlining their personal experiences;

***“When they told me the only option they could offer me was a bag I didn’t believe it. I’ve had a baby, not cancer.” (female patient – MASIC)***

*“Unfortunately [the surgery] has left me a situation where I go [to the toilet] in the evening...anything up to 15-20 times” (Male patient, LARRIS)*

***“I have faecal and urinary incontinence; faecal is intermittent; urinary is complete. I’ve been offered no input or help whatsoever - no medication, no assessment, no nothing. The only thing they've done is give me nappies” (Female patient aged 32) – FTWW (Fair Treatment for the Women of Wales) report***

*“If I go out for the evening...I have to find where the toilet is and then I need to go 4 or 5 times in the night. So it really is sort’ve something to do with our social life but also it’s it’s just not very nice...yes it does affect how much you do” (Male patient with FI)*

(See Appendix 8-10 for further quotes; FTWW, MASIC, Mumsnet, 4<sup>th</sup> degree tear group)

### **1.1 What patient & patient groups have asked for**

- To have more information on the potential risks of childbirth on pelvic health and continence (antenatal and postnatal)
- For General Practitioners and clinicians to have a greater knowledge of FI and how to manage it
- For better communication between primary and secondary care
- For a more joined up service to avoid the lengthy delays and lack of communication between departments and hospitals
- To be able to access the same treatments as the rest of the UK, irrespective of where you live in Wales

## Chapter 2: Work of the Task and Finish Group

Vaughan Gething, the Cabinet Secretary for Health, Well-being and Sport asked the Women's Health National Specialist Advisory Group (NSAG) to work with Julie Cornish to assess the current situation.

### 2.1 Objectives

The aim of the Task and Finish group was to publish a report which sets out the current services provided for faecal incontinence in Wales and aimed to identify any shortfalls in treatment availability of NICE approved treatment as compared to the rest of the UK.

The report includes:

- The current provision for faecal incontinence in Wales;
- Recommendations for a proposed robust care pathway for the management of safe, sustainable, high quality and cost effective FI care across the whole of Wales including primary, secondary and tertiary care, provided in all settings including remote and rural.
- Suggests measures that should be put in place in primary and secondary care for the management of obstetric anal sphincter injury.
- Agreed Multi-disciplinary Team and investigation protocols for Local Health Boards to implement.
- Proposals for the education and training of health professionals, patients and the public.
- A proposal for future funding for NICE approved services not currently in place in Wales (e.g. Sacral Neuromodulation).

We sought membership to provide multidisciplinary advice on matters relating to faecal incontinence. The total membership of the group reflects the equality and diversity of the NHS and service users, as well as representatives of the public and patient voice. We co-opted additional members for individual meetings from radiology and dietetics to provide appropriate representation. Professional members were encouraged to seek advice from the profession they represent and seek their feedback on matters of policy and practice to inform and support the objectives.

The first meeting on the group was the 9th January 2018, Cardiff. The group met 4 times in total over an 8 month period, following which a report was created and presented to Welsh Government for consideration. The group expects a formal response to this report outlining which of the recommendations the Welsh Government will implement. A copy of the report will be made publicly available.

## 2.2 Governance

The group was chaired by Mrs Julie Cornish, on behalf of the Women's Health NSAG. It has reported to the Women's Health NSAG and to the Cabinet Secretary of Health, Well-being and Sport.

## 2.3 Membership (alphabetical order)

Name	Organisation
Nadia Bhal	Consultant Obstetrics & Urogynaecology (Cwm Taf UHB)
<a href="#">Carole Broad</a>	<a href="#">Senior Physiotherapist (Cardiff and Vale UHB)</a>
Julie Cornish	<a href="#">Consultant Colorectal Surgeon (Cardiff and Vale UHB)</a>
<a href="#">Helen Cottle</a>	<a href="#">Colorectal specialist nurse (Betsi Cadwaladr UHB)</a>
Karen Davies	Joint Lead continence nurse ( <a href="#">Cardiff and Vale UHB</a> )
<a href="#">Mark Dunford</a>	<a href="#">Physiotherapist (Cardiff and Vale UHB)</a>
Rebecca Dixon	Radiologist ( <a href="#">Betsi Cadwaladr UHB</a> )
<a href="#">Karen Edwards</a>	<a href="#">Colorectal specialist nurse (Cardiff and Vale UHB)</a>
Simon Emery	Consultant Urogynaecologist ( <a href="#">Abertawe Bro Morgannwg UHB</a> )
Edgar Gelber	Consultant Colorectal Surgeon ( <a href="#">Betsi Cadwaladr UHB</a> )
<a href="#">Rhiannon Griffiths</a>	<a href="#">Physiotherapist (Aneurin Bevan UHB)</a>
Deborah Hopkins	Cwm Taf Counsellor Maternity (Cwm Taf UHB)

<a href="#">Sharifah Jalil</a>	Consultant Urogynaecologist ( <a href="#">Betsi Cadwaladr UHB</a> )
<a href="#">Julie Jenkins</a>	Head of Midwifery ( <a href="#">Hywel Da UHB</a> )
Rhiannon John	Patient representative (MASIC Foundation)
<a href="#">Maria Lewis</a>	Colorectal specialist nurse ( <a href="#">Cwm Taf UHB</a> , <a href="#">Powys UHB</a> )
<a href="#">Karen Logan</a>	Continence nurse ( <a href="#">Aneurin Bevan UHB</a> )
Amy Marshall	Patient representative (WWTF)
Glynis Morris	( <a href="#">Abertawe Bro Morgannwg UHB</a> )
Carmen Munteanu	GP Partner ( <a href="#">Betsi Cadwaladr UHB</a> )
Heather Payne	Senior Medical Officer Child and Maternal Health, Welsh Government
Darrin Powell	Lead continence nurse ( <a href="#">Cwm Taf UHB</a> )
<a href="#">Angharad Roberts</a>	Physiotherapist ( <a href="#">Betsi Cadwaladr UHB</a> )
Jeanette Starkery	Dietician ( <a href="#">Betsi Cadwaladr UHB</a> )
<a href="#">Michael Thornton</a>	Consultant Colorectal Surgeon ( <a href="#">Betsi Cadwaladr UHB</a> )
<a href="#">Jane Turner</a>	Colorectal specialist nurse ( <a href="#">Cardiff and Vale UHB</a> )
<a href="#">Mair Whittle</a>	Physiotherapist ( <a href="#">Abertawe Bro Morgannwg UHB</a> )
Barbara Williams	Continence Service ( <a href="#">Betsi Cadwaladr UHB</a> )
Holly Williams	Health and Social Services Group, Welsh Government
<a href="#">Jonathan Williams</a>	Head of Womens and Children's Health branch, <a href="#">Welsh Government</a>
<a href="#">Maureen Wolfe</a>	Midwife ( <a href="#">Betsi Cadwaladr UHB</a> )
Monika Vij	Consultant Subspecialist Urogynaecologist ( <a href="#">Abertawe Bro Morgannwg UHB</a> )
Ann Yates	Joint Lead continence nurse ( <a href="#">Cardiff and Vale UHB</a> )

## **Chapter 3: What is the current provision of services for Faecal Incontinence in Wales**

### **3.1 Pathway – Current local service provision**

A survey was sent to all of the Healthboards in Wales in July 2017, to a variety of clinical and allied health professional staff, asking for information on the local provision of pelvic floor services for faecal incontinence, including personnel and access to diagnostics and therapeutic modalities. Seventy two responses were obtained from all 7 Health Boards. These included core members of the MDT; colorectal surgeons, urogynaecologists, specialist nurses and physiotherapists. Additionally, multiple allied professionals responded including; gastroenterologists, geriatricians, urologists, pain physicians and a physiologist. (see Appendix 1 for abstract)

Key findings from the survey:

- Lack of clear pathway for FI patients across all health boards. Seventy six percent reported FI patients were seen in a general surgical/colorectal clinic, with less than a third seeing patients in a specialist pelvic floor clinic (29%).
- Thirty two (44%) of the responders were specialist /continence nurses, encompassing all health boards. Their service was frequently used, easy to refer to and local audits had demonstrated that the nurse clinics reduced consultant waiting times. However, specialist PF nurses were part-time, under pressure, often lacking specialist ‘pelvic floor’ training and without additional resources, were viewed as unsustainable.
- Specialist physiotherapy for faecal incontinence patients was lacking in Cardiff & Vale, Cwm Taf, Hywel Dda and Powys UHBs. Aneurin Bevan, Betsi Cadwaladr and Abertawe Bro Morgannwg UHBs reported some access to physiotherapy for FI patients, though awareness of the service was globally poor throughout all specialities with subsequent under-utilisation for this group of patients.

## **General FI pathway - Organisational Structure**

It is recognised from the organisational survey that we carried out that services for faecal incontinence in Wales are variable (and in some Health Boards non-existent) and that a lack of coordination and the need for cross discipline referrals lead to lengthy delays in patient management. The fact that the majority of physiotherapy services for incontinence reside within womens' health and urogynaecology means that patients presenting with bowel symptoms often have difficulty accessing services and that men presenting with faecal incontinence have little or no service provision.

A proposed care pathway for faecal incontinence was discussed and developed within the group. (See Appendix 2) NICE and ACPGBI (Association of Coloproctology of Great Britain and Ireland) guidelines were used to support this, as well as additional examples from others Hospitals in the UK (Appendix 3)

This is by no means confined only to Wales, although the situation is worse here than the other devolved countries, as both Scotland and Ireland have commissioned sacral nerve stimulation and other specialist management in the last decade. A study by Davis et al (2010) indicated that a combination of external and internal organisational change is needed to change what is perceived as a fragmented, highly variable and poorly integrated approach to pelvic floor services in the UK.

The National Audit of Continence Care (NACC) is the only national audit that examines and promotes quality of continence care in adults aged 18+ across all healthcare settings.

The audit report showed that;

- The great majority of continence services are poorly integrated across acute, medical, surgical, primary, care home and community settings, resulting in disjointed care for patients and carers.
- Provision of training for health care workers to manage bladder and bowel problems was patchy across the nation, and overall occurred in less than 50% of acute hospitals.



- There were gaps in organisational standards for continence care that lead to gaps in clinical care.
- Overall adherence to the national guidance (NICE) for urinary and faecal incontinence was very variable.
- Evidence suggests that healthcare professionals were not consistently asking about incontinence in people who are at risk of the condition (e.g. older people)
- Even where a person is found to have incontinence, diagnosis of causes and therefore curative treatment is often not provided
- A lack of organised treatment planning results in a lack of effective treatment
- Older people received particularly poor care, even though they suffer more from incontinence

*(National audit of continence care (NACC) Pilot audit evaluation report, June 2012)*

The group discussed the FI pathway for men. It was felt that due to the often stigmatised nature of FI, healthcare professionals should actively yet sensitively enquire about symptoms. It was discussed how difficult it can often be to discuss such matters and open up. Physiotherapists advised that there was no designated service for men and often a lack of clarity of services available. It is therefore important to find a mechanism to aid support and encourage people to seek appropriate help.

Faecal incontinence affects function and quality of life, which varies between individuals. It was noted that often there was very little discussions with patients between tests and call for surgery therefore this dialogue needed to improve. The group stressed the importance of patient involvement that would be central to any decision about possible on-going treatment options. Models in other countries have demonstrated improved synchronised care and team working and could be a useful guide to future development in the UK (Ross S 2011, Splete H 2005).

### **Summary of NICE Guidelines (2014) best practice recommendations for the management of patients suffering with FI:**

- That the condition only be managed by those with the appropriate and relevant skills
- At risk groups such as the elderly, multiparous females, those with pelvic floor prolapse, and those with cognitive impairment should be identified and appropriately managed according to their needs;
- Clinical assessment through history and examination was required and that exclusion of RED FLAG / luminal bowel disease was paramount;
- Conservative management strategies were safe and cost effective and should be employed as first line therapy in most cases. This includes optimising stool type, advice on toilet positioning, involving support groups and developing patient centered coping strategies for the patient's particular needs. If these measures fail then introducing medication, the use of plugs, rectal irrigation, bio-feedback and electro-stimulation should be considered;
- Specialist assessment through anorectal physiology, ultra-sound and proctography may be required if the above measures fail to achieve improvement;
- Only surgeons with the appropriate experience and expertise should be involved in the surgery for this condition. These must have open discussion as to the risk and likely outcome from such intervention;
- Surgery that might be considered includes anal sphincter repair and sacral neuromodulation with both considered cost-effective in the appropriately selected cases.

### **Recommendations:**

- The group have suggested an all Wales pathway, with standardised treatment, as a suggested model framework for Wales, in addition to improved access to training for GPs and health professionals on FI.
- Team working. Improving inter-professional referral and streamlining pathways within hospitals. Avoidance of multiple hospital reviews by different specialists leading to frequent duplication of investigation and treatments. A pelvic floor coordinator would allow patients to be more easily referred between colorectal and other services with less delay and improved outcomes for patients.

- Information and research. Patient information leaflets should be made more widely available. There should be standardised data collection and collaborative work between centres delivering this service.
- We recommend that additional funding and investment is urgently needed, as well as a reorganisation of existing services.

### 3.2 Pathway - Regional services

The UK Pelvic Floor Society recently published guidelines defining a pelvic floor unit for bowel dysfunction. (Appendix 4)

It is anticipated that several centres may have or will develop the expertise in the UK to offer a service for the management of more complex problems and a shortlist of 'reference' centres will be developed nationally with the support of The Pelvic Floor Society to facilitate appropriate referral. There is currently no recognised tertiary level service in Wales, but there is the potential to develop this, with collaboration between colorectal, urogynaecology and urology departments.

A tertiary centre would be expected to offer;

- Revisional surgery for complex complications following primary mesh prolapse surgery
- Revision surgery following sacral neuro-modulation
- Anal and perineal reconstructive surgery incorporating tissue transposition
- Antegrade colonic enema (ACE) surgery
- Combined expertise (with gastroenterologists / neurologists) for the assessment of patients with complex primary and secondary neuro-gastroenterological disorders e.g. Hirschsprung's disease, autonomic neuropathies,
- Combined expertise for the management of severe learning or psycho-behavioral disorders
- Transitional care for older children and adolescents

#### **Recommendations:**

- There should be at least one accredited pelvic floor unit in Wales. This does not currently exist and will need to be developed.

### 3.3 General Practice

- There is a need to clearly define the role of GP's in the pathway.
- If the suggested pathways indicates that patients should be initially referred to the continence service (or Bladder and Bowel Health teams), it must be ensured that this is an integrated service who has the ability to diagnose / investigate and upgrade patients in order to rule out serious pathology.
- Need an MDT approach; Without this there will be no choice for GP's but to refer most patients to secondary care for investigations and a diagnosis and refer to the continence services only the patients with 'functional disease'

### 3.4 Continence services

The group discussed the disparity between Health Boards in relation to direct referrals from primary care to appropriate services. The group was in agreement that the current colorectal referral pathway from primary care did not work as well as other departments such as referral system for Urology. A clearly defined pathway was therefore required, which would result in a better link across primary and secondary care.

It was agreed that it was important that patients' symptoms were explored thoroughly at the point of referral. This needs to be through a combination of functional and quality of life scores. There should be an agreement across Wales for the PROMs to be used, to allow assessment of efficacy across the pathway.

The group agreed that clear guidance at the point of referral was also required. This would help identify the most appropriate pathway of referral for patients if through to a colorectal team or physiotherapy.

The group discussed the need for better engagement with the public, e.g. in Cwm Taf UHB, forum talks had been arranged for the over 50's and social media was being used as a mechanism for raising awareness. The group agreed that it was important to raise public awareness of the causes, prevalence and symptoms of FI and raise the profile of the issue going forward. Key to this is awareness of both the physical and emotional impact of the condition.

#### **Recommendations:**

- Improved access and communication between primary and secondary care.
- There should be an agreement across Wales for the PROMs to be used, to allow assessment of efficacy across the pathway (e.g. ICIQ B).
- Raising public health awareness of FI – suggest a campaign on incontinence/pelvic health/ bowel function be developed

### 3.5 Physiotherapy

The range of available services in each health board varies. Only 3 Health boards provide dedicated services for colorectal. It is essential that all potential patients in Wales have the same access to the same services. All physiotherapy departments are working hard to reduce waiting lists, but this is only possible within the available resources.

In Wales there are currently 17 physiotherapists working in women's health. Provision for OASI patients and FI patients in Wales can be found in Appendix 5. All but 2 of the Healthboards have a pathway for OASI patients and due to current provision, Powys UHB do not currently have a pelvic health physiotherapist.

A benchmarking exercise of current physiotherapy services in Wales was undertaken against Aintree hospital, Oxford Hospital, and Poole Hospital. (See Appendix 6) After benchmarking of physiotherapy services for faecal incontinence in 3 hospitals in England, it is evident that the services in Wales are not consistent, and there is a severe lack of access for patients presenting with FI and obstructive defaecation to physiotherapy input. Access for male patients is limited with only one trust able to accept referrals for men in this capacity.

#### **Recommendations:**

- Male and female patients with FI should have access to physiotherapy for specialist Pelvic Floor Muscle Rehabilitation.
- It is recommended that Physiotherapists receive formal training in the management of FI and that there is a designated member of the physiotherapy team who is specialised in bowel management.
- Access to services should be equal for men and women with FI.

### 3.6 Specialist nurses

The group reviewed the continence nurse pathways in Health Boards across Wales. There are clear guidelines from NICE and the ACPGBI on the role of the specialist nurse and when referral from primary to secondary level care should be made.

There is some duplication in the continence and colorectal nurse roles, however the group felt that the patients that were currently being referred to the specialist nurses were usually from in hospital clinicians, rather than primary care directly, and as such were generally more complex and chronic. The ease of access to the surgeon and the MDT allowed discussion if problems arise and reduced delays in management.

## **Recommendations:**

- Need to develop an all Wales guide for nursing management of FI
- Clearer definition of those patients who should be referred to primary care continence team and those that required specialist nurse input.
- Provide training for nursing staff on irrigation and long term management
- Provide training of assessment of red flag symptoms and digital rectal examination

### **3.7 Radiology**

Access to diagnostics (radiology and anorectal physiology) is limited. Those centres that had access to radiology were staffed by a single clinician with the potential disruption to access and lack of sustainability (sickness/retirements). Anorectal physiology was currently available in only 3 Healthboards. It was noted that Glan Clwyd had a good specialist service currently, as did Cardiff and Vale UHB. ABMU and Aneurin Bevan access has been sporadic, with Cwm Taf UHB not having any access to specialist radiology services.

## **Recommendations:**

- Access to anorectal physiology and standard investigations for pelvic floor assessment (including defaecating proctograms and endoanal ultrasounds) should be available to all Healthboards.
- Investigation should be performed when appropriate (i.e. when considering surgical intervention or when it would change management)
- Radiology support is required for Pelvic Floor MDTs

### **3.8 Psychology**

There is very limited access to psychological support in FI patients across all Health Boards in Wales. The group discussed the evidence of long term mental health issues around faecal incontinence; anxiety, depression, psychosexual dysfunction and Post Traumatic Stress Disorder (PTSD).

The support that is available is primarily focused on the women who have undergone recent birth injury. There is little or no support for partners of patients with FI, which can be particularly important for those injuries following childbirth.

ABMUHB have access to psychology for post partum women through the perinatal mental health team, however referrals are only accepted up to 6 months post birth.

There is no service for general FI patients. Cwm Taf UHB has no access to psychology services for FI patients. There is a part time counsellor for women who have birth trauma and can be referred by the midwives in the immediate post partum period. However this is not ongoing service after discharge from obstetric services. There is no specific provision for patients with FI within Aneurin Bevan UHB but there is limited access through psychosexual therapy. Cardiff and Vale do not have access to psychology through either of the colorectal service or the perineal trauma/obstetric services.

Additional psychosexual support is required for some patients and there are only 2 Health Boards currently offering this in Wales. Subsequently there is a long waiting list and difficulty for other Health Boards to access the service

### **Recommendations:**

- There should be a referral pathway for patients with faecal incontinence to access psychological support
- Women with birth trauma and FI may have significant PTSD and ongoing mental health issues following the event. It is recommended that each Health Board has access to a specialist counsellor for this.
- Psychological support should also be potentially be offered to the partner (birth trauma)
- Further development of a psychosexual counselling service within Wales

## **3.9 Dietetics**

Faecal incontinence may be managed through diet and lifestyle alone in some patients. Access to a dietician with an interest in bowel dysfunction has been shown to be effective.

The group was presented with a scheme started in Wrexham - a pilot pathway for (16-45 years) is now working well in one Health Board. A key part of this pathway was that each patient had access to a dietician to explore dietary modification in the first instance. The aim of the pathway was to reduce inappropriate referrals to secondary care and repeat GP appointments. This had been successful and similar programmes could be explored in other Health Boards.

## **3.10 Surgery**

There are clear indications from the Association of Coloproctology on those patients that should be referred directly to a colorectal surgeon.

- Full thickness rectal prolapse.

- Major sphincter pathology
- Trapping rectocele with passive faecal soiling
- Megarectum or megacolon requiring disimpaction
- Reparable external anal sphincter defect and patient opts for surgery. Of note: the majority of patients do not have a reparable defect
- Complex patients such as those with a history of imperforate anus should all be seen by a colorectal surgeon

It is essential that all patients will have had an underlying pathology excluded through the use of investigations as appropriate by their symptoms (typically endoscopy and or imaging).

### **3.11 The Multi Disciplinary Team (MDT)**

Guidelines from the ACPGBI commissioning for Faecal Incontinence (2017) suggest the appropriately staffed multi-disciplinary team consists of:

- 2 Colorectal Surgeons with a specialist interest in Faecal Incontinence
- Specialist nurse or physiotherapist entirely dedicated to functional bowel problems and with a specialist interest in Faecal Incontinence, Ano-rectal physiological testing and endoscopic anal ultrasound
- Radiologist with an interest in pelvic floor imaging
- Urogynaecology support
- Gastroenterology support
- Psychological support



## Chapter 4: Obstetric Anal Sphincter Injuries (OASI)

### 4.1 Antenatal Education and Information

The group reviewed the current information available to expectant mothers in the Bump, Baby and Beyond booklet. The information covers from pregnancy to 4 years after birth. There appeared to be emphasis on mental health issues that could develop within mothers with little or no referral to the potential physical consequences of birth. The group felt there should be further detail on pelvic health within the booklet.

The overall consensus was that there is a lack of information in the antenatal and postnatal chapters on general pelvic health, bladder and bowel incontinence, prolapse, types of childbirth injuries that can occur and their consequences. Additional information on what is and what is not normal in the postnatal period and when and where women should seek help. A more detailed document with specific recommendations will be sent to the Welsh Government from the Task and Finish Group.

- Need to amend 'Bump, Baby and Beyond' to include information on pelvic health
- Education needs to be provided for health professionals who are in contact with mothers on the importance of good pelvic health, what is normal and when women should be advised to seek help.
- Clear referral pathways for health visitors, GPs and midwives for FI services

### 4.2 Incidence of OASI

The NMPA (National Maternity and Perinatal Audit) recorded an incidence of 3.7% for 3rd/4th degree tears across 5 Health Boards in 2017. (See table below)

Health board -3 <sup>RD</sup> /4 <sup>TH</sup> Degree Tear Statistics	2016	2017
CVUHB	1.9% 4 <sup>th</sup> degree is negligible (5 / 5700 births pa)	2.0% 4 <sup>th</sup> degree is negligible (4 / 5700 births pa)
ABMUHB	2.7% combined	2.5% combined
BCUHB	1.97%	2.86
HDUHB	2.3%	1.9%
ABUHB		1.65%

## Recommendations

- All patients who experience an OASI should be advised that physiotherapy following repair of OASIS is recommended
- All patients should be provided with information on the potential long term consequences of OASI, including written information.
- Women who have undergone obstetric anal sphincter repair should be reviewed at a convenient time (usually 6–12 weeks postpartum). Review should be done by a clinician with a special interest in OASI.
- A local pathway should be devised to ensure that all OASI patients are referred to specialist physiotherapy management and beyond as needed.
- Physiotherapists should have a designated clinician (obstetric/colorectal) for patients who fail management.

### 4.3 Care pathways and good practice of OASI (Obstetric Anal Sphincter Injury)

Representatives from all Health Boards were asked to provide local care pathways for third or fourth degree tears. On review it appeared that most of the health board pathways were similar. The group agreed to consider merging the pathways and to provide an All Wales pathway for third or fourth degree tears, but this work will form part of another group.

The standard waiting time to see a physiotherapist was up to 6 weeks and up to 3 months for an appointment with a consultant. Some Health Boards provided additional telephone follow-up appointments with patients, which are dealt with by a clinician who specialises in incontinence.

There is a risk assessment tool which midwives carry out at Cardiff & Vale UHB which generates those who are most at risk and those who would need physiotherapy. The group agreed it would be useful to roll out the tool at all health boards (Appendix 8)

## Recommendations

- **Recognition:** All patients who have a vaginal delivery (even with an intact perineum) should have a rectal examination. Good practice: Two people are required to sign off type and degree of injury.
- **Training:** Training in the recognition and management of all types of perineal trauma, including postnatal care, should be available to all personal involved in maternity care. Good practice: mandatory training every three years with a yearly update.

- **Repair:** OASI should be repaired according to RCOG guidance. Good practice: Every unit should have a standardised repair sheet that is kept up to date with RCOG guidance.
- **Postoperative Management:** Clear patient information leaflets developed through an expert group and based on RCOG and latest evidence.
- All Wales pathway was recommended for 3<sup>rd</sup> and 4<sup>th</sup> degree tears
- **Physiotherapy** teams play a crucial part in the treatment and rehabilitation of the pelvic floor post childbirth. We would recommend the provision of a women's health physiotherapist in all units that provide maternity care in Wales. Good practice: Consider using the post-natal risk assessment tools (currently used in Cardiff and Vale and Cwm Taf UHBs) to identify all patients at risk of pelvic floor disorders post childbirth.

#### 4.4 Information for Primary Care and Mothers

The group discussed how, and when, to ask women about incontinence symptoms. We heard from an affected mother, who described how it took several years for her to openly discuss it. Barriers to this included being told it was 'normal' without an adequate assessment of the symptoms. A variety of patient groups were contacted for patient perspectives on the issue. (See Appendix 8,9,12)

*"A disturbing trend we are noticing in our 4DT Facebook support group, is that women are not being told what to expect during their recovery period. Some of them are not even being told by their doctors that they have a 4DT! These women are being discharged from the hospital in two or three days after birth with little information or resources, and they are not seen again until 6 weeks postpartum. Even then some of them have to ASK to be examined, instead of it being standard procedure." Jem Martell – UK lead for 4DT support group)*

*"Simple advice earlier on would have been really good as I had to find it all myself and it took ages." MASIC mum*

*"The GP was very supportive but didn't know where to send me or how to help me." MASIC mum*

*"They need to understand that we are totally consumed and overwhelmed with a new baby and are not thinking about asking what went wrong, what side effects could be, etc. THEY, as medical professionals, need to take the initiative to tell their patients what to expect, what treatments are available. Saying nothing and leaving a new mum to wonder what the heck is going on to her body weeks or months later is not helpful. Be proactive for your patients, not reactive!"*

*mother from 4DT support group*

Every point of contact with mother and baby/child should be a potential for further information on pelvic health (e.g. health visitor). This should continue to be assessed until 2-4 years post partum as it can take time for a woman to come to terms with the injury and discuss it.

Discussion between the group and General Practitioner representatives revealed that postnatal checks are not mandatory, some practices offer them routinely, in some new mums are invited to make an appointment, some do not offer them at all and mums can make an appointment if they have concerns or advised to do so by the Health Visitor. The potential of identifying some problems relating to continence at 6-8 weeks post delivery are therefore a hit and miss. Maternity discharges become therefore very important as they allow practices to Readcode the information regarding delivery and the baby.

- Suggestion of standardised letter /information for GPs on discharge from obstetricians/midwives. Information to be included in the maternal discharge summary:
  - Type of labour ( NVD, instrumental delivery , C/S)
  - Documentation if 3rd or 4th degree tear identified and if onward referral has been made already
- A point of referral for the patients with complicated deliveries and post delivery continence problems
- Women need to be clearly informed of what has happened. What pelvic floor function is considered normal and when they should seek help and who from. (patient information sheets, patient copy of discharge summary, signposting to support groups)
- The 6 week check of the mother and baby should be treated as a separate event, to allow focus on the mother's physical and mental health
- Every point of contact with mother and baby/child should be a potential for further information on pelvic health

#### **4.5 Perineal trauma clinic and referral to colorectal services**

- There should be a Lead Perineal Trauma clinician in every Trust: The RCOG guidelines recommend that all women with an OASI are seen by a clinician with an interest in perineal trauma at three months post-delivery.
- Good practice: Every maternity unit should identify a clinician with an interest in perineal trauma that would provide consistency in care and be a point of contact for patients and allied health professionals looking after women who have sustained an OASI.
- Colorectal surgeon support: Patients who are identified to have ongoing pain or incontinence at their initial follow up may need to be referred to a Specialist

or Colorectal Surgeon for further investigations as Anal manometry and Endoanal ultrasound.

- Good practice: Identify a Colorectal surgeon locally or centrally to see patients with ongoing issues. Commissioning these services may be required for patients from other health-boards.
- Every unit should have clear and up to date guidelines. Data collection needs to be maintained at a high standard with regular audits and action plans implemented.

## Chapter 5: The Future

### 5.1 Proposals for the education and training of healthcare professionals, patients and the public

The group proposed the development of a Welsh Pelvic Floor Network. This would be a network of interested health professionals. This has been started following on from the membership of the task and finish group and will continue to expand with open access to professionals across Wales.

As part of this it was felt that a national annual event to update on best practice and improve education should be created, with support from relevant national associations (The Pelvic Floor Society, BSUG and the PGOP).

Support should be provided locally for the development of patient support groups with collaboration from charities and organisations (e.g. MASIC Foundation, Tenovus, 4DT, Bowel Cancer UK)

### 5.2 Sacral Nerve Stimulation (SNS)

Health Technology Wales has published its recommendations for Sacral Nerve Stimulation in July 2018.

- HTW advises that the available evidence supports the use of SNS to treat faecal incontinence (only where the condition has not responded to conservative management).

“There is evidence that sacral nerve stimulation has the potential to be cost effective compared with conservative treatment in people who have failed to benefit from conservative treatment. This finding is based on the assumption that the clinical benefit of sacral nerve stimulation is sustained in the long term.”

Currently no Health boards in Wales have commissioned sacral nerve stimulation to patients who have fulfilled the criteria. There are clinicians with the interest and skills to deliver this service within Wales. At least one centre needs to be established in Wales to deliver this treatment. Given the expected number of patients annually that would fulfill the criteria, it suggests that 2-3 centres would be required in the future to deliver this (1 in North Wales and 1-2 in South Wales). A Hub and Spoke model of diagnosis, triage and management was determined by the group to be an effective way to deliver this.

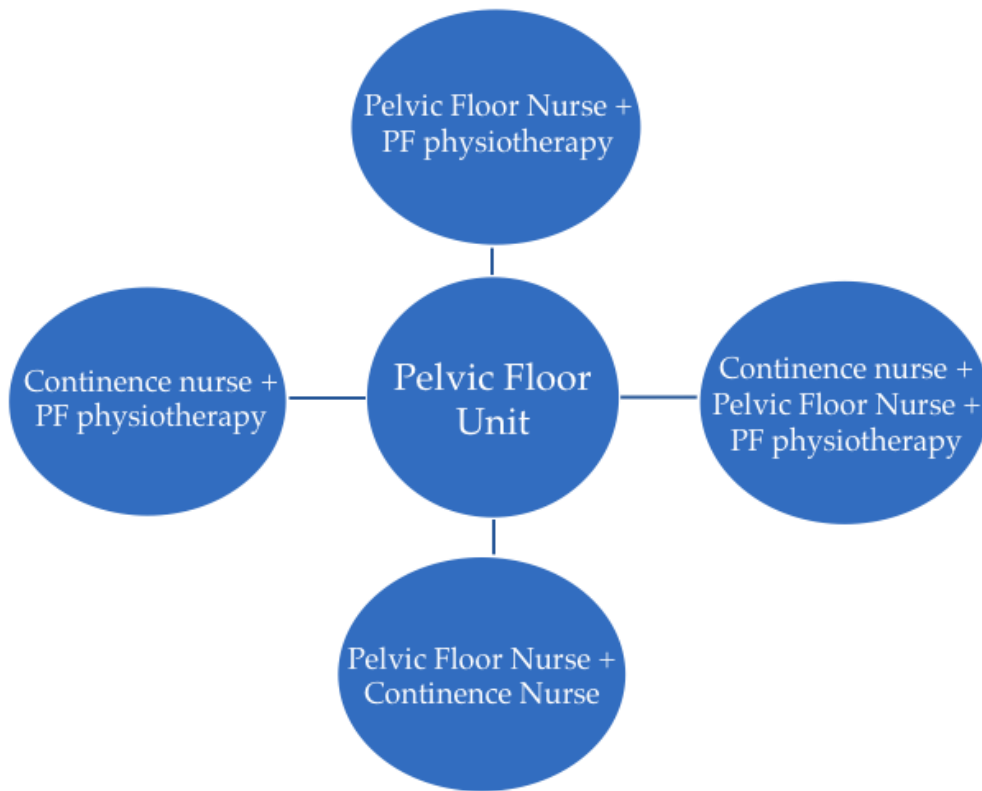


Figure. Proposed Hub and Spoke model with possible combinations of allied health professionals at local units

### 5.3 Pelvic Health Team

The consensus of the group was that it is vital for all disciplines to work together and the formation of a pelvic health team, which would include all relevant disciplines, would improve the speed of diagnosis, access to conservative management and allow a multidisciplinary approach to determine what, if any, surgical approach should be adopted. This would be relevant for urinary incontinence, pelvic organ prolapse and endometriosis.

There is the potential for many of these services to be placed in the community. An example of an obstetric community hub as described in the Better Births report of 2016, could be altered and /or expanded to include urogynaecology, colorectal and urology services as well as physiotherapists, nurses, psychologists and dieticians.

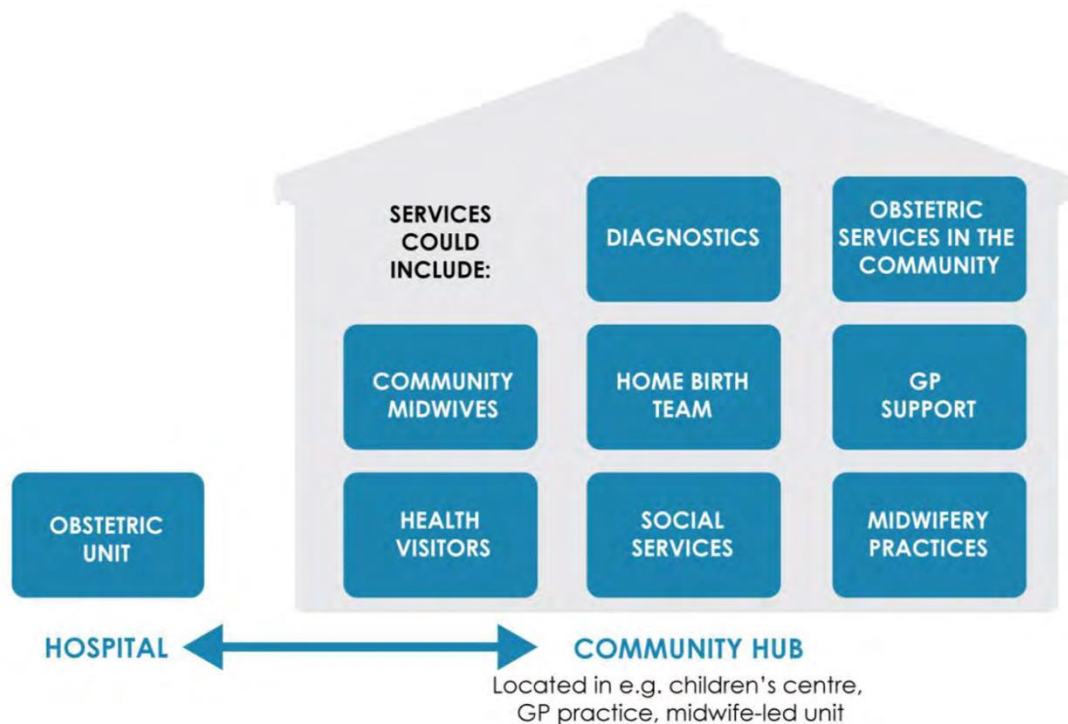


Figure. Community Hub proposal from Better Births Report 2016

(<https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf>)

## Conclusion

This report demonstrates that there are significant deficits in the provision of pelvic floor services for patients with faecal incontinence in Wales. The current workforce of pelvic floor nurses and physiotherapists are insufficient to cope with demand. Primary care need more information on FI and improved signposting for patients to access treatment. A more formalised approach to a multidisciplinary pelvic health team (including colorectal surgeons) should be adopted with improved access to appropriate investigations and treatments which are currently lacking across Wales. This will require reorganisation and prioritisation of existing resources within Health Boards as well as additional investment by Welsh Government.



## Chapter 6: Full List of Recommendations

### What patients have asked for:

- For a more joined up service to avoid the lengthy delays and lack of communication between departments and hospitals
- To be able to access the same treatments as the rest of the UK, irrespective of where you live in Wales
- For General Practitioners and clinicians to have a greater knowledge of FI and how to manage it
- For better communication between primary and secondary care
- To have more information on the potential risks of childbirth on pelvic health and continence (antenatal and postnatal)

### Recommendations for local FI service

- NICE and ACPGBI guidelines should be followed for the management of FI patients.
- GPs need a defined pathway of referral and the group have suggested an all Wales pathway, with standardized treatment, as a suggested model framework for Wales.
- Lead colorectal consultant with an interest in Pelvic Floor to be identified for each Health Board.
- Access and availability of specialist services be increased. There is concern that pelvic floor dysfunction is considered low priority, with lack of a coherent strategy.
- Team working. Improving inter-professional referral and streamlining pathways within hospitals. Avoidance of multiple hospital reviews by different specialists leading to frequent duplication of investigation and treatments. A pelvic floor coordinator would allow patients to be more easily referred between colorectal and other services with less delay and improved outcomes for patients.
- Information and research. Patient information leaflets should be made more widely available. There should be standardised data collection and collaborative work between centres delivering this service.

- We recommend that additional funding and investment is urgently needed, as well as a reorganisation of existing services.

### **Regional Service Recommendations**

- There should be at least one accredited pelvic floor unit in Wales. This does not currently exist and will need to be developed.

### **General Practice**

- There is a need to clearly define the role of GP's in the pathway.
- If the suggested pathways indicates that patients should be initially referred to the continence service (or Bladder and Bowel Health teams), it must be ensured that this is an integrated service who has the ability to diagnose / investigate and upgrade patients in order to rule out serious pathology.
- Need an MDT approach; Without this there will be no choice for GP's but to refer most patients to secondary care for investigations and a diagnosis and refer to the continence services only the patients with 'functional disease'

### **Continence Services**

- Improved access and communication between primary and secondary care.
- There should be an agreement across Wales for the PROMs to be used, to allow assessment of efficacy across the pathway (e.g. ICIQ B).
- Raising public health awareness of FI – suggest a campaign on incontinence/pelvic health/ bowel function be developed

### **Physiotherapy**

- Male and female patients with FI should have access to physiotherapy for specialist Pelvic Floor Muscle Rehabilitation.
- It is recommended that Physiotherapists receive formal training in the management of FI and that there is a designated member of the physiotherapy team who is specialised in bowel management.
- Access to services should be equal for men and women with FI.

### **Specialist nurses**

- Need to develop an all Wales guide for nursing management of FI

- Clearer definition of those patients who should be referred to primary care continence team and those that required specialist nurse input.
- Provide training for nursing staff on irrigation and long term management
- Provide training of assessment of red flag symptoms and digital rectal examination

### **Radiology and investigations**

- Access to anorectal physiology and standard investigations for pelvic floor assessment (including defaecating proctograms and endoanal ultrasounds) should be available to all Health boards.
- Investigation should be performed when appropriate (i.e. when considering surgical intervention or when it would change management)
- Radiology support is required for Pelvic Floor MDTs

### **Psychology Recommendations**

- There should be a referral pathway for patients with faecal incontinence to access psychological support
- Women with birth trauma and FI may have significant PTSD and ongoing mental health issues following the event. It is recommended that each health board has access to a specialist counsellor for this.
- Psychological support should also be potentially be offered to the partner (birth trauma)
- Further development of a psychosexual counselling service within Wales

### **Antenatal information**

- Need to amend 'Bumps, Baby's and Beyond' to include information on pelvic health
- Education needs to be provided for health professionals who are in contact with mothers on the importance of good pelvic health, what is normal and when women should be advised to seek help.
- Clear referral pathways for health visitors, GPs and midwives for FI services

## OASI physiotherapy Recommendations

- All patients who experience an OASI should be advised that physiotherapy following repair of OASIS is recommended
- All patients should be provided with information on the potential long term consequences of OASI, including written information.
- Women who have undergone obstetric anal sphincter repair should be reviewed at a convenient time (usually 6–12 weeks postpartum). Review should be done by a clinician with a special interest in OASI.
- Physiotherapists should have a designated clinician (obstetric/colorectal) for patients who fail management.

## OASI management Recommendations

- **Recognition:** All patients who have a vaginal delivery (even with an intact perineum) should have a rectal examination. An All Wales pathway was recommended for 3<sup>rd</sup> and 4<sup>th</sup> degree tears. Good practice: Two people are required to sign off type and degree of injury.
- **Training:** Training in the recognition and management of all types of perineal trauma, including postnatal care, should be available to all personal involved in maternity care. Good practice: mandatory training every three years with a yearly update.
- **Repair:** OASI should be repaired according to RCOG guidance. Good practice: Every unit should have a standardised repair sheet that is kept up to date with RCOG guidance.
- **Postoperative Management:** Women need to be clearly informed of what has happened. Clear patient information leaflets developed through an expert group and based on RCOG and latest evidence. What pelvic floor function is considered normal and when they should seek help and who from.
- **Physiotherapy** teams play a crucial part in the treatment and rehabilitation of the pelvic floor post childbirth. We would recommend the provision of a women's health physiotherapist in all units that provide maternity care in Wales. Good practice: Consider using the post-natal risk assessment tools (currently used in Cardiff and Vale and Cwm Taf UHBs) to identify all patients at risk of pelvic floor disorders post childbirth.

## GP - OASI Recommendations

- Suggestion of standardised letter /information for GPs on discharge from obstetricians/midwives. Information to be included in the maternal discharge summary; i) type of labour ii) documentation if 3<sup>rd</sup> or 4<sup>th</sup> degree tear identified

and if onward referral has been made already iii) point of referral for the patients with complicated deliveries and post delivery continence problems.

- The 6 week check of the mother and baby should be treated as a separate event, to allow focus on the mother's physical and mental health.
- Every point of contact with mother and baby/child should be a potential for further information on pelvic health

### **Perineal trauma clinic and referral to colorectal services Recommendations**

- There should be a Lead Perineal Trauma clinician in every Trust: The RCOG guidelines recommend that all women with an OASI are seen by a clinician with an interest in perineal trauma at three months post-delivery.
- Colorectal surgeon support: Patients who are identified to have ongoing pain or incontinence at their initial follow up may need to be referred to a Specialist or Colorectal Surgeon for further investigations as Anal manometry and Endoanal ultrasound.
- Every unit should have clear and up to date guidelines. Data collection needs to be maintained at a high standard with regular audits and action plans implemented.

### **Education and training of health professionals, patients and the public - Recommendations**

- A network of interested health professionals should be developed, following on from the membership of the task and finish group, with open access to professionals across Wales.
- A national annual event to update on best practice and improve education should be created, with support from The Pelvic Floor Society, BSUG and the PGOP.
- Support should be provided locally for the development of patient support groups with collaboration from charities and organisations (e.g. MASIC Foundation, Tenovus, 4DT, Bowel Cancer UK)

### **Sacral Neuromodulation (or Sacral Nerve Stimulation (SNS))**

- HTW advises that the available evidence **supports** the use of SNS to treat faecal incontinence (only where the condition has not responded to conservative management).

- There needs to be formal commissioning of Sacral Neuromodulation in at least 1-2 Health Boards in Wales as part of a tertiary level service.

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## Appendix 1. Abstract Summary of Survey of Pelvic Floor Clinicians and Allied Health Professionals in Wales – presented to the Welsh Surgical Society 2017.

James O, Leaman C, Li D, Cornish J. Royal Glamorgan Hospital

**Introduction:** Pelvic floor dysfunction affects >1-2% of the population, with an estimated 150,000 Welsh patients suffering from incontinence. Well resourced, specialist conservative therapy is shown to have >80% patient satisfaction. Despite this, significant disparity exists in the services available, with many Welsh patients unable to access services offered as routine in England. Sacral Nerve Stimulation for example, superior to optimal medical therapy, is not currently funded.

**Methods:** To initiate addressing this issue, an online service evaluation survey (surveymonkey.co.uk) was authored and distributed to pelvic floor networks across Wales.

**Results:** 72 responses were obtained from all 7 Health Boards, from colorectal surgeons, urogynaecologists, specialist nurses, physiotherapists and multiple other allied professionals. 76% reported patients were seen in a colorectal/surgical clinic, with only 29% seen in a specialist pelvic floor clinic.

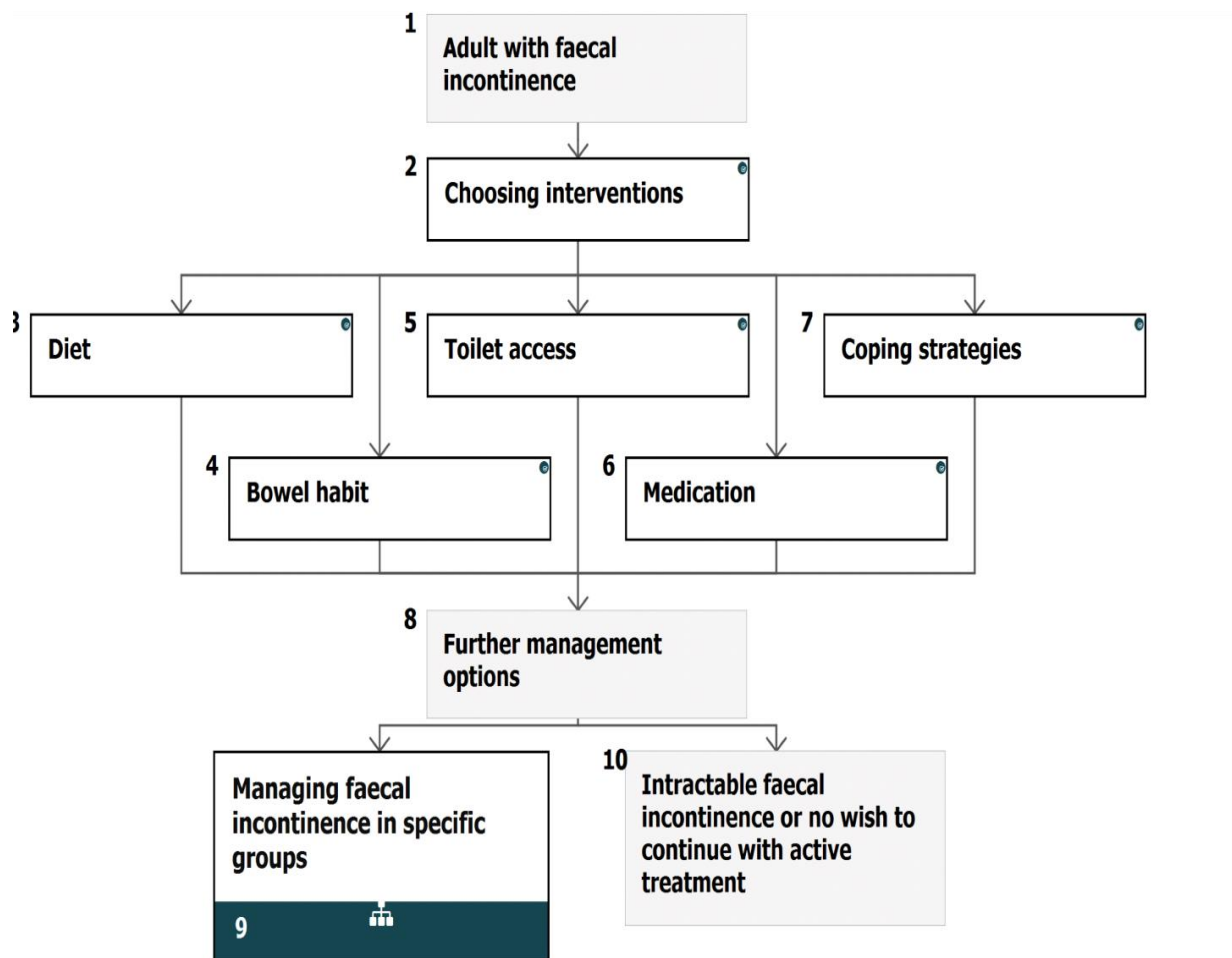
32 responders were specialist nurses, encompassing all health boards. Their service was frequently used, found to be easy to refer to and was audited to demonstrate it reduced consultant waiting times. However, its resources were part-time, under pressure, lacking specialist 'pelvic floor' training and not financially sustainable. Specialist physiotherapy was lacking in Hywel Dda and Powys UHB, with only trial funding in Cwm Taf and Cardiff & Vale UHBs. Aneurin Bevan, Betsi Cadwaladr and ABMU reported seemingly easy access to physiotherapy, though awareness of its existence was globally poor throughout the MDT.

All colorectal surgeons offered Delorme's procedure, 75% an Altemeiers', with others including laparoscopic mesh/sutured rectopexy geographically varied. Crucially, Sacral Nerve Stimulation is not offered anywhere, with patients (almost entirely unsuccessfully) referred to England.

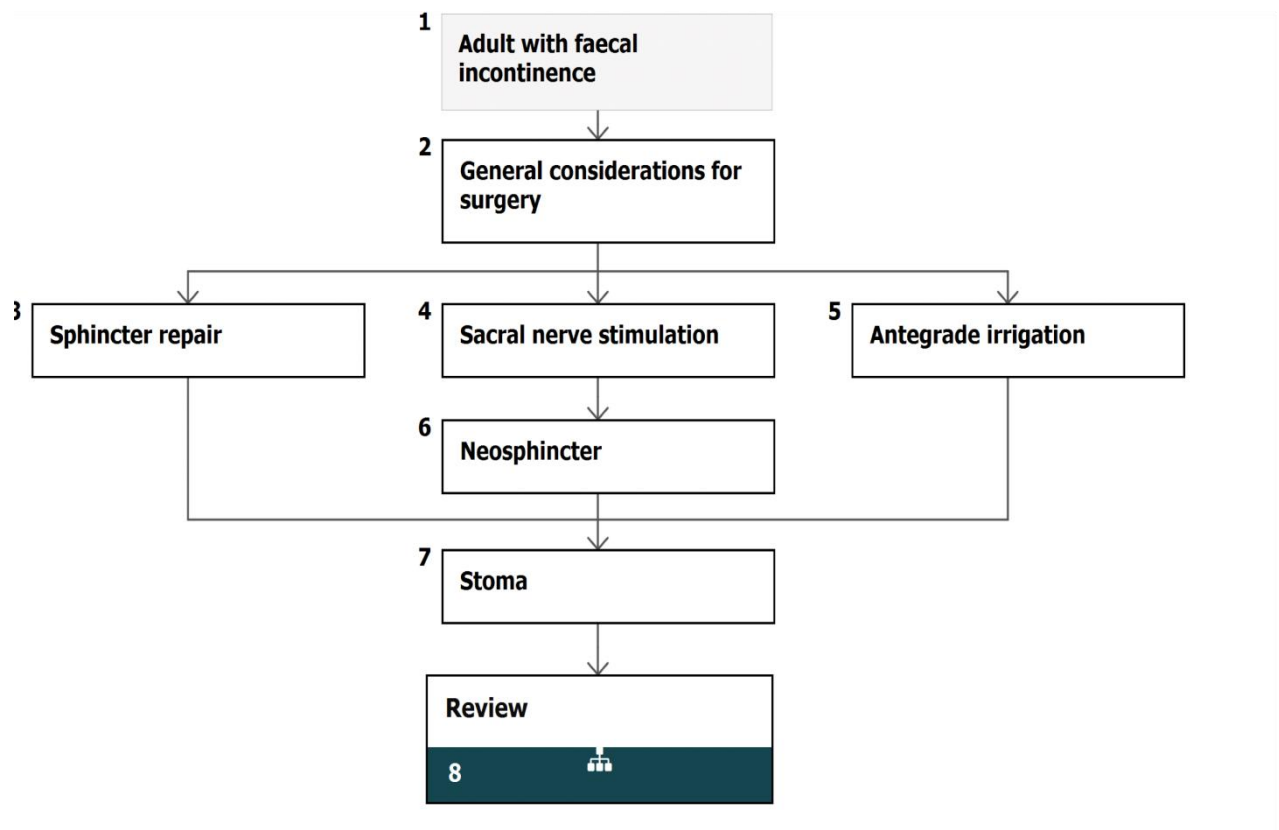
**Conclusion:** A growing network of interested clinicians urge the need for improvement in the availability of a specialist, well-resourced service.

## Appendix 2. Conservative care pathway and Surgical care pathway for faecal incontinence (NICE 2017)

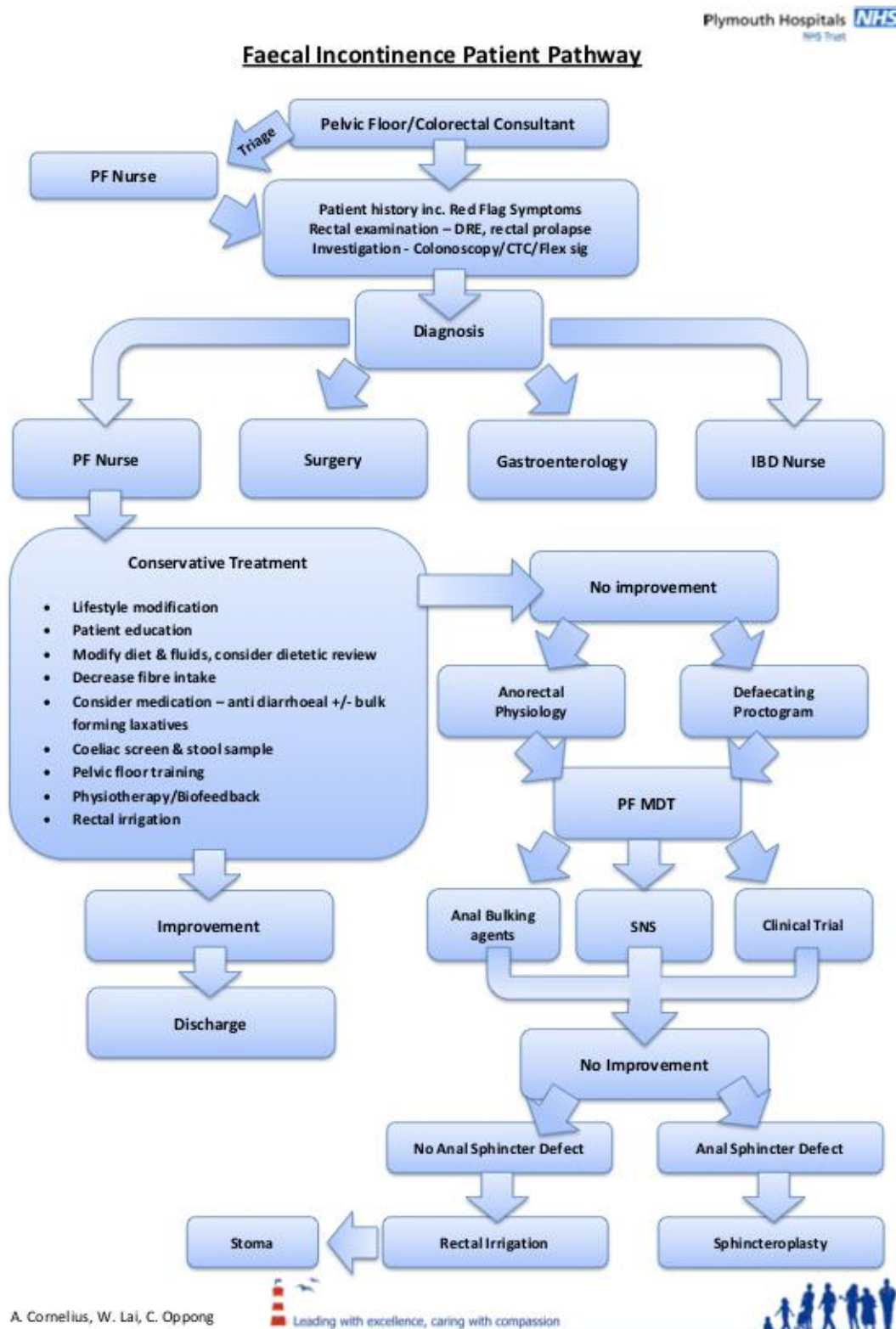
### i) Conservative care pathway for Faecal Incontinence (NICE 2017)



ii) Surgical care pathway for faecal incontinence (NICE 2017)



### Appendix 3. Example of care pathway from Plymouth NHS Trust



## Appendix 4. UK Pelvic Floor Society guidelines defining a pelvic floor unit

### Definition of Pelvic Floor Unit

- Dedicated PF Clinic or equivalent per week including secondary and tertiary referrals as part of a multidisciplinary service.
- Evidence of training in an accredited unit, which provides the full range of investigations and treatments required for training.
- Regular anorectal physiology & urodynamic sessions either personally or in a supervisory capacity.
- Provide three clinical sessions in PF per week.
- A regular & programmed PF MDT meeting a minimum of once/month
- One major procedure associated with pelvic floor dysfunction i.e. incontinence and prolapse per working week per year.
- Full clinical Audit e.g. TPFS or BSUG surgical audit
- Appropriate CME review in PF

### Categorisation of MDT characteristics:

The Team: Members will be considered as core or essential to the running of a pelvic floor service. These core members will include at least one colorectal surgeon who specialises in performing the spectrum of operations that may be needed to treat the conditions. A pelvic floor physiologist and/or a specialist nurse who undertake diagnostic evaluation of pelvic floor abnormalities and introduce and optimize conservative management at an early stage and a urogynaecologist. It will also include a radiologist with an interest in pelvic floor disorders who is able to offer a high quality dynamic defaecography service and interpretation of endoanal ultrasound as well as a member of administrative staff to ensure documentation is accurate and effectively recorded.

Members that can be considered as valuable contributors but not essential (extended members) include:

- A medical gastroenterologists with an interest in dysmotility
- A pain management specialist interested in chronic pelvic pain
- A psychologist and psychiatrist
- A functional urologist
- Alternative therapist specializing in acupuncture/homeopathy.

Attendance:

MDT members (core and extended) should have dedicated time in their job plan to prepare for and attend MDT meetings. The frequency and amount of time dedicated to such meetings should be negotiated locally to reflect the local workload, but should be no less than monthly.

## Appendix 5. Physiotherapy provision for OASI patients and FI patients in Wales

In attempting to assess the need for pelvic physiotherapy provision in Wales the following statistics were considered. As of 2016, the female population in Wales from 16 years old and above was estimated at 1.278 million (Welsh Government, 2017). Statistics suggest that half of the female population will experience symptoms of urinary incontinence during their lives, but only one in five will seek help (Allanda, 2017). This may equate to approximately 639,000 women experiencing symptoms at some point in their lives and 127,800 of these seeking help from their health board in Wales. Approximately one in 12 women living in the community in the UK report the symptoms of pelvic organ prolapse, and of those there is a 12-19% risk of surgical intervention (BMJ, 2016). In Wales this could equate to approximately 200,000 women experiencing symptoms of POP and over 25,000 at risk of surgery at some point in their lives. Although it is impossible to transfer these lifetime statistics to produce a formula for year on year physiotherapy service provision there is clearly a disparity in the funding of physiotherapy compared to the population density covered by each health board.

The range of available services in each health board also varies. All health boards provide outpatient urogynaecology and obstetric services, only 3 health boards provide services for colorectal patients and one health board does not provide a service for pelvic pain. It is essential that all potential patients in Wales have the same access to the same services. All physiotherapy departments are working hard to reduce waiting lists, but this is only possible within the available resources.

In Wales there are currently 17 physiotherapists working in women's health. (The spread of these resources across each health board can be seen in the table below. As can be seen the whole time equivalents in each health board vary greatly even for health boards of a similar population. The affect this has on the waiting list in each area is also clear. Recruitment is also an issue in some areas as is appropriate succession planning. Without adequate succession planning and human resource resilience, retirement and maternity leave or sick-leave are the greatest threats to the current workforce.

All Wales Physiotherapy provision 3rd / 4th degree tears and FI	C&V UHB	AAABUHB	HYWELDDAALHB	PowysTHB	CwmtafUHB	ABMULHB	BCUHB
Do you receive direct referrals from primary care for faecal incontinence?	N	N	N	No service at present	N	N	N
Do you receive direct referrals from secondary care for faecal incontinence?	N	Y	N		Y	Y	Y
Do you see 3 <sup>rd</sup> and 4 <sup>th</sup> degree tears on the maternity wards?	Y	N	N		N	N	N
Do you have a 3 <sup>rd</sup> /4 <sup>th</sup> degree care pathway within your trust?	Y	Y	Y		N	Y	Y
Attendance on maternity ward	Y	N	N		N	N	N
<b>Care package available for patients by Physiotherapist</b>							
<i>Class education</i>	Y	N	N		N	Y	N
<i>1:1 contact</i>	Y	Y	Y		Y	Y	Y
<i>1:1 Assessment (Assessment and treatment)</i>	Y	Y	Y		Y	Y	Y
Access to perineal trauma clinic (consultant led)	Y	Y	Y		N	N	N
Access to reinstate symptomatic patients (post natal)	y	Y	UNSURE		UNSURE	UNSURE	UNSURE
Access to colorectal services for MDT	Y	N			N	N	N
<b>What type of care do you offer to your patients if they have faecal incontinence?</b>							
<i>Specialist DRE, DVE assessment</i>	N	Y	Y		N	Y	Y
<i>Lifestyle advice</i>	N	Y	Y		N	Y	
<i>Specialist physiotherapy treatments</i>	N	Y	N		N	Y	N
Access to functional bowel clinic	N	N	N		Y	N	N
Are you a part of the MDT for faecal incontinence patients?	Y	N	N		N	N	N
Are men included in this service if applicable?	N	Y	N		N	N	N
<b>Copies of your pathway and/or leaflets relating to FI and /or 3<sup>rd</sup> degree tears</b>	Y	Y	N		N	Y	Y
<b>Other patient information leaflets etc.</b>	Y	Y	N		N	Y	Y
<b>Funding issues for developing services</b>	Y	Y	Y		Y	Y	Y

## **Appendix 6. Benchmarking exercise of current physiotherapy services in Wales against Aintree hospital, Oxford Hospital, and Poole Hospital.**

### **Aintree Hospital:**

The unit has a Bowel clinic with MDT members that include physiotherapist and specialist nurses. They have a clear pathway for patients that follows the ACPGBI and NICE guidance.

### **Oxford Hospital:**

All 3<sup>rd</sup>/4<sup>th</sup> degree tear patients are seen on the ward PN by a WH physio (although not currently a 7day services so weekend deliveries may miss IP 1:1).

The current standard in Oxford is that all 3a perineal tears received an invitation letter to book 1:1 Outpatient follow-up at 6-8 weeks postnatal and all 3b-4<sup>th</sup> degree tears are routinely booked into 6-8 week postnatal follow-up with WH physio.

3<sup>rd</sup>/4<sup>th</sup> degree tear patients are also seen by a Consultant Urogynaecologist but are not routinely offered anal manometry/endo-anal u/s.

Female and male faecal incontinent patients are able to routinely be referred to physiotherapy also those with obstructive defaecation and anismus

MDT occurs which is run by colorectal but attended by urogynaecologists. Not all 3<sup>rd</sup>/4<sup>th</sup> degree tear patients are discussed but this is a service for complex patient's complex patients – which may include 3<sup>rd</sup>/4<sup>th</sup> degree.

### **Plymouth Hospital:**

There is no formal funding in place for physiotherapy within the colorectal services. The physio used by urology/colorectal/urogynaecology is based in the main physio team and classed as 'womens health physiotherapy'. Historically the physio workload has come from urogynaecology and urology but as there is a dedicated pelvic floor team in colorectal (2 consultants and CNS) the physio workload has significantly increased and as its all classed as continence, its covered. Due to funding the service is only available to females. A new physiotherapist is starting but this has been industry supported and they will be based in colorectal and doing clinics for bio-feedback, rectal irrigation and pelvic floor.





**GIG**  
CYMRU  
**NHS**  
WALES

Bwrdd Iechyd Prifysgol  
Caerdydd a'r Fro  
Cardiff and Vale  
University Health Board

## Appendix 7. Risk Assessment Tool (Cardiff & Vale UHB) Department of Physiotherapy, Women's Health Continence team

Patient Name _____	GP Name _____
Patient Address _____	GP Address _____
_____	_____
_____ Post Code _____	_____
DOB _____ Hospital Number _____	Is Hospital Transport Required? Y <input type="checkbox"/> N <input type="checkbox"/>
Tel No _____ Mobile _____	Is an Interpreter Required? Y <input type="checkbox"/> N <input type="checkbox"/>
	Language _____

Please could the midwife responsible for this patient complete this risk assessment tool following their vaginal delivery and place in the appropriate location.

Delivery suite: Tray on main reception

MLU: Physiotherapy referral clipboard in main office

**Date of Delivery** .....

### Risk Factors

Large baby > 4kg (8lbs)

Multiparity

Prolonged pushing > 2hrs during labour

Forceps delivery

Episiotomy

3<sup>rd</sup>/ 4<sup>th</sup> Degree tear

Epidural/ Spinal

Multiple pregnancy

Chronic constipation

Obesity

Older primipara (>35)

Incontinence of urine or faeces

Symptoms of Prolapse

### Circle Score

2

2

4

4

3

6\*

2

1

1

1

1

6

4\*

**Total Score =** .....

### Additional Perineal Wound

#### Breakdown Risks:

(Please tick as appropriate)

Extensive oedema ☐

Bruising ☐

Haematoma ☐

Wound contamination ☐

### Low Risk / Medium Risk

0-5 Give one to one instruction on pelvic floor exercise. Give pelvic floor exercise sheet. Inform GP documenting on discharge letter.

### High Risk

6-14 Mandatory referral into physiotherapy. Will be contacted by Women's Health Physiotherapy team and seen in the post natal pelvic floor class @ 4-6 weeks post natal and assessed according to any presenting symptoms.

### Very High Risk

15-23 Mandatory referral into physiotherapy. Will be contacted by Women's Health Physiotherapy team and seen in Perineal trauma class @ 4-6 weeks PN and assessed both vaginally and/or rectally. All 3<sup>rd</sup> /4<sup>th</sup> degree tears will be seen in Perineal Trauma Clinic @ 4 months post natal. Symptomatic patients will be treated as appropriate

**\* Please note that all patients with 3<sup>rd</sup>/4<sup>th</sup> degree tears and/ or symptoms of prolapse should be put in the very high-risk category**

Midwife Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

## Appendix 8. Quotes from MASIC focus group (19<sup>th</sup> May 2015)

"I was naïve...I just thought it was normal..if you'd had a baby"

"The GP fobbed me off....he said "what do you expect?"

"I had to fight to get referred on"

"I didn't know where to go"

"The relief when I found someone to say "I will help you" was immense"

"Its not right that I only found about the support....by accident"

"Nobody talks about it"

"its so ironic that we have pre birth training...but nothing after"

"The GP told me to wait.....then the colorectal surgeon told me....you've left this too late"

"Silence is not helpful"

"Support should start in the hospital...directly after any tear"

"It took them 3 months to diagnose a 4<sup>th</sup> degree tear...the GP's need educating"

"There needs to be more training for diagnosis and management"

"If I was an alcoholic, a drug addict, a sex addict I would have somewhere to go..."

"I knew about the birth trauma association but I just couldn't...bring myself to contact them"

"There should be a red flag system...educating GP'S of what might be happening"

"I felt rejected"

"It's a disability"

" we need adverts..on the backs of toilet doors...you have a captive audience"

"ANY help would be useful!"

" When I was pregnant I read everything....all the books, all the leaflets...**not once...was there any mention of this.** All I needed was one line...urinary incontinence can happen and in rare cases bowel incontinence...you must report these to a GP"

"The GP should ask...the health visitor should ask"

"Mums won't say unless they are asked"

"What frightens me is that I have a voice...what about the women that don't?"

"You don't think about your body...you have your baby to think about"

## Appendix 9. Patient quotes from 4DT (4<sup>th</sup> degree tears) mothers support group (supplied 17.09.2018)

This is a closed facebook support group that has been working with the MASIC foundation.

"A disturbing trend we are noticing in our 4DT Facebook support group, is that women are not being told what to expect during their recovery period. Some of them are not even being told by their doctors that they have a 4DT! These women are being discharged from the hospital in two or three days after birth with little information or resources, and they are not seen again until 6 weeks postpartum. Even then some of them have to ASK to be examined, instead of it being standard procedure.

Here are a few of the responses from the support group when asked what their follow up care was like immediately after the birth;

"My doctor didn't even tell me I had a 4th degree tear or what it was. As they changed shifts, I heard my first nurse telling the second nurse that I had a 4th degree tear. I asked what the worst tear was and she said 4th degree. I had to google what it meant."

"Nobody explained anything to me. Terrible information and follow up."

"All the "doctor" told me was if we wanted more children I would have to have a c section. That's pretty much it."

"I never got any information from anyone about what to expect or a recommendation for PT (physical therapy). I didn't get PT til 5 years later. The first time I mentioned wanting PT to one of my midwives she made a face like I was crazy. I didn't ask again for three or four years. I was so embarrassed. Later I asked a different midwife and she was enthusiastic about the idea. And it helped tremendously. The only thing they did was tell my husband that I'd need a Csection for any future babies."

"No, but was misdiagnosed with 2nd then 3rd and eventually told 4th! Found a private physio myself and have had to do all the research myself "

"Mine didn't inform me what the complications were either! I didn't even understand what it was until 2 days after when one of the nurses explained it to me. I felt stupid for not knowing what to do or where to go for help."

"I knew what a 4th degree tear was (during the birth process) but had no idea of the life long consequences. I felt someone should have come in to at least give us information or a pamphlet that we could store away and read if we did have problems, or after the whole overwhelming newborn phase was over. Not once was pelvic floor physical therapy mentioned to me."

"My doctor told me I had received a 4th degree tear...but nothing more, I too wish I was given the run down and some things to watch for....I've had to self diagnose and reassure."

### **What women want medical professionals to do:**

“They need to understand that we are totally consumed and overwhelmed with a new baby and are not thinking about asking what went wrong, what side effects could be, etc. THEY, as medical professionals, need to take the initiative to tell their patients what to expect, what treatments are available. Saying nothing and leaving a new mum to wonder what the heck is going on to her body weeks or months later is not helpful. Be proactive for your patients, not reactive!”

“I didn’t ask nearly the amount of questions I should have and would have wanted to ask if I weren’t so busy with my baby! I wanted to know what happened, why it happened, and what to expect...I still don’t have the answers to all of those questions and I’m 9 weeks pp.”

“If someone gets a 4th degree tear, they need to be checked out before the typical 6 week check.”

“A random doctor (who ever was on call, not even the one who delivered the baby) should not be the one to just nonchalantly tell a new, young mother that they "could" be incontinent of stool for the rest of her life.”

“There is no standard of care for a 4th degree tear. Ask 10 doctors and you’ll get 10 answers on next steps.”

“When I say I’m having pain during normal activities, don’t tell me “everything is fine” or “that happens with tears; it will get better”. If I’m asking for help, please listen.”

“As a first time mum, I thought what I went through was normal. It wasn’t until my own mum explained it to me that I realized it wasn’t.”

“Please listen when we say something is not okay, take the extra moment to hear us out, we know our own body better than anyone.”

“Explain the support that’s out there. Explain what it’s like to tear. Explain that even a small baby can tear you.”

“Failure to diagnose a 4th degree tear at the time of delivery often means a life of faecal incontinence issues for the mother. Please always do thorough internal examinations after all births, even those that seem low risk.”

Also - please recommend mental health counselling as well as physiotherapy. My trauma contributed to my marriage falling apart. I was depressed, didn’t want any physical affection (not even holding hands), felt broken, and lost my zest for life. I had no idea how to communicate any of this to my husband and feared he’d be grossed out if I shared some of the details.

“Husbands/partners can be traumatised by this too. There’s not much support for them. The nurses and midwives had no hesitation in discussing my very bad situation in front of my husband, but didn’t explain anything. He honestly thought I was going to die during birth. And maybe the baby too.”

## **Appendix 10. Extracts and summary from the Fair Treatment for Women in Wales (FTWW) short report regarding pelvic physiotherapy in Wales (May 2018)**

### **Who we are (FTWW):**

FTWW / Fair Treatment for the Women of Wales is a patient-led third sector organisation dedicated to women's health equality in Wales, established at the end of 2014. We are members of the Wales Council for Voluntary Action, and provide support, information, and advocacy for girls and women in Wales who are suffering a range of health conditions and who are not receiving adequate (or fair) treatment.

### **What is pelvic physio and why do we need it:**

'Women's Health Physiotherapy is the therapeutic treatment of all disorders affecting the pelvis and pelvic floor. From incontinence to prolapse, pelvic pain or constipation, there is growing evidence that physiotherapy can alleviate, and in many cases cure these symptoms'. (<http://www.richmondphysio.co.uk/what-is-womens-health-physiotherapy>)

Following an assessment, treatments for this wide range of disorders may include pelvic floor re-training and stability exercises; provision and training in the use of vaginal dilators, pelvic floor educators / muscle stimulators; internal manual therapy techniques, including trigger point release; myo-fascial stretches, scar massage, neural mobilisations; relaxation and breathing techniques; advice on toileting and positional modifications, as well as support with rectal / colonic irrigation systems, and being an integral part of colorectal teams responsible for the insertion and monitoring of Sacral Nerve Stimulators.

**Symptomatology arising from obstetric or other surgical injury:** Sometimes, giving birth vaginally (even when episiotomy is performed) can result in injury, such as tearing of the perineum – the area between the vagina and anus. Tears can range from small nicks and abrasions to deep lacerations affecting several pelvic floor muscles. The damage caused can result in urinary and / or faecal incontinence. Pelvic physiotherapists should be able to perform a range of interventions to improve these women's quality of life.

It is estimated that 80% of patients with faecal incontinence can be treated with conservative measures including rectal irrigation, bio-feedback and pelvic physiotherapy. However, the lack of specialist pelvic floor colorectal nurses and lack of access to colorectal physiotherapy (outside of trials) within Wales means that patients here are forced to undergo sphincter repair operations with poor outcomes or permanent stoma – both of which procedures have considerable cost and quality of life implications.

In contrast, home-based rectal / colonic irrigation (such as the Peristeen system) and / or Sacral Nerve Stimulation (SNS) are far less radical in nature, less expensive, and can have considerable benefits for patients.

Welsh Government's Prudent Healthcare Principles include 'care closer to home', so

the fact that a clearly efficacious and cost-effective system like Peristeen is not available to patients in Wales (unlike their English counterparts) seems in direct contravention of this principle, resulting in patients here undergoing unnecessary operations in an attempt to rectify the problem, or be on a never-ending cycle of increasingly ineffective chemical laxative preparations.

SNS has been approved by NICE for the treatment of faecal incontinence since 2004. However, unlike England, Scotland, and Northern Ireland, where SNS is now a standard procedure, Wales continues not to offer it as a treatment, despite a pilot in Cardiff demonstrating its success.

To deny patients in Wales access to treatments as these, whilst the rest of the UK offers them routinely is patently unfair and ill-conceived, given that they can reduce on-going costs to health services, whilst also offering considerable potential to improve patients' quality of life.

***“My issues were as a result of giving birth prematurely, and damage from all the surgeries I’ve had...I am currently waiting for a Sacral Nerve Stimulator to be fitted to help with bowel dysfunction...I am under a colorectal surgeon in England (where) I was referred by my gynaecologist (also in England, after having tried) biofeedback therapy which unfortunately was not successful. Treatment such as a Sacral Nerve stimulator should be more known. I’ve had many medical professionals who know very little (or) nothing at all, about that treatment option”. (AC, 24)***

**Prolapse:** With the use of vaginal mesh now under scrutiny as a result of the severe, sometimes permanent, damage caused to a considerable number of women in whom it was inserted, an effective and relatively non-invasive alternative is needed. Easily accessible, specialist pelvic physiotherapy services seem to fit the bill.

In some instances, a focused exercise programme, including bio-feedback, can strengthen pelvic muscles to reduce the impact of prolapse. Specialist physiotherapists would also be able to utilise other remedial devices such as vaginal pessaries / rings.

***“I am now in crippling, chronic pain, all thanks to the multiple mesh surgeries I have had to try to fix pelvic organ prolapse. I take high doses of very strong painkillers just to make it through each day. My children don’t know what it’s like to have a mum who can run and play with them; all they have known is ‘Mummy has to make a long journey to London to have operations to try to fix this mesh mess’! If physiotherapy had been offered before and after my babies’ deliveries, I wouldn’t be in such a state now”. (NM, 33)***

**Sexual dysfunction:** Conditions such as vaginismus (hypertonic vaginal muscles, preventing penetration and gynaecological exams) and vulvodynia (persistent, chronic, unexplained pain in the vulvar area) would potentially benefit from dedicated pelvic physiotherapy.

Currently, the usual treatment modality focuses on counselling services or psychotherapy which only tackle the problem from one angle. This approach fails to

consider the simultaneous physiological issues which may be causing, or arising from, psychological distress and compounding it. Physical therapy would undoubtedly be a useful adjunct to psychological interventions.

***“I was offered counselling but no physio, just given some dilators and sent on my way. I think physio would be helpful in (being able) to have sex, but also in making...smears etc, not torture and...allow me to go for such tests which I generally avoid at the moment. I also think...putting me under general anaesthetic to do basic procedures on me...is not cheap”. (SE, 34)***

### **Why we support the call for more specialist pelvic physiotherapists in Wales:**

Currently, across the whole of Wales, there is the Whole Time Equivalent of 15 personnel working in pelvic physiotherapy in some capacity. This number is totally insufficient to meet patient need.

Not all staff working within this specialism are able to offer the full range of interventions desired. Level and type of provision is inconsistent and does not, on the whole, accommodate the various techniques and therapies explored above. Waiting times vary from health board to health board. Variation and harm is inevitable. Far more specialist training is required, as well as a substantial increase in numbers of personnel able to provide such services.

Further, the existence – and potential usefulness - of pelvic physiotherapy is not widely known or understood. As it stands, in general, the only medical professionals routinely referring to pelvic physiotherapy are urologists and / or uro-gynaecologists – and then, not all of them. This means that those with issues other than those involving the bladder / urinary incontinence are excluded from the service, once again leading to variation and harm being experienced by patients.

In Cardiff & Vale Health Board alone, there are 219 Whole Time Equivalent staff in Adult Physiotherapy services, dealing with, for example, sports-related injuries and low-level back pain. Increasingly, there are moves to provide these services within GP ‘hubs’ or at ‘walk-in centres’. If we compare this level of availability to that of pelvic physiotherapy, it seems unfair, even verging on discriminatory, given that the majority of those requiring the service will be women.

We don’t say this lightly: women make up 52% of the population in Wales. Considerable numbers will have given birth either vaginally or via C-section, had gynaecological interventions, including hysterectomy, or be living with a health condition which causes pelvic pain / organ dysfunction. To neglect their needs is doing women – and their families / communities - a great disservice.

This is not necessarily Welsh Government’s fault; it is a similar picture elsewhere. Ignorance of the impact of pelvic pain / symptomatology is a global issue and is partly as a result of cultural taboos around gynaecology and bowel / bladder dysfunction. We would urge Welsh Government to explore ways in which the impact of such stigma can be reduced, as well as making dedicated services routinely, consistently, and easily accessible.

**We recommend:**

- 1** Welsh Government invest in research into the need, costs, and benefits of pelvic physiotherapy;
- 2** Welsh Government, perhaps via Public Health Wales, considers ways in which the stigma around pelvic well-being and the damaging implications of these taboos, can be combated;
- 3** Welsh Government looks to implement a considerable increase in numbers of specialist pelvic physiotherapists throughout Wales, trained to deliver a range of hands-on techniques to relieve pain and organ dysfunction, including (but not exclusively): internal trigger point release / massage; bio-feedback; myofascial release; visceral manipulation. Numbers recruited should reflect widespread, unmet need, and should be throughout Wales;
- 4** Welsh Government reconsider the availability of both Sacral Nerve Stimulators and home-based colonic irrigation systems on the NHS, with the necessary training for specialist pelvic physiotherapists and nurses to both deliver and support their use;
- 5** Specialist pelvic physiotherapy be easily and routinely accessible to patients, via both the GP and self-referral mechanisms.

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## Appendix 11 . Mumsnet Survey and Campaign for Better Postnatal Care

<b>Mumsnet Better Postnatal Care: Aftercare, Not Afterthought</b>	
Survey taken by 1224 women who had experienced postnatal care in the last 3 years. Survey dates: 3-21 Oct 2016	
<b>If you had an assisted delivery (ventouse or forceps), were you debriefed while staying on the postnatal ward?</b>	
I had an assisted delivery and was debriefed	20 %
I had an assisted delivery and was not debriefed	75 %
Don't know/ can't remember	5 %
<b>If you tore while giving birth, or had another kind of vaginal or genital injury related to the birth, did you feel that you had adequate care for and advice about the injury during the first few weeks after the birth?</b>	
I had a tear/injury and had adequate care and advice	66 %
I had a tear/injury but did not have adequate care and advice	34 %
<b>If you had a caesarean, did you feel that you had adequate care for and advice about the wound during the first few weeks after the birth?</b>	
I had a caesarean and had adequate care and advice	66 %
I had a caesarean but did not have adequate care and advice	34 %
<b>Thinking about AFTER the immediate post-birth period (ie once two or three months had gone by after the birth): did giving birth make sex physically painful or uncomfortable for you? (If sex was already painful or uncomfortable for you before this birth,</b>	
Yes, giving birth made sex painful and/or uncomfortable	36 %
No, giving birth did not make sex painful and/or uncomfortable	51 %
Not sure	13 %
<b>If sex has become physically painful or uncomfortable as a result of giving birth, have you received any medical care focussed on improving things for you?</b>	
I have received great medical care	4 %
I have received adequate medical care	13 %
I have received no medical care and have not asked for any	75 %
I have asked for medical care but have not had any	8 %
<b>Thinking about AFTER the immediate post-birth period (ie once two or three months had gone by after the birth): has giving birth contributed to you being incontinent, or having worse control over your pelvic floor muscles?</b>	
Yes	42 %
No	44 %
Not sure	8 %
Not applicable / No Answer	6 %

<b>If your pelvic floor or continence has been affected as a result of giving birth, have you received any medical care focused on improving things for you?</b>	
I have received great medical care	6 %
I have received adequate medical care	13 %
I have received no medical care and have not asked for any	70 %
I have asked for medical care but not been given it	9 %
Not applicable to me	2 %
<b>In your opinion, which of the following comes closest to describing the institutional attitude of the NHS towards women's long-term sexual and pelvic floor health, post-birth?</b>	
Birth means that women's sex lives get worse and that they can expect to have some mild incontinence: that's just the way it is	15 %
Incontinence and a reduction in quality of sex life is a shame, but so long as the baby's thriving it's a good outcome	17 %
Continence and good sex are important, but the NHS just can't afford to prioritise them	24 %
Continence and good sex are really important, and the NHS should work seriously to make things better for women who are affected	23 %
Birth has no effect on women's sex lives and continence	1 %
Don't know	20 %

## **Mumset Action plan**

### **INFORMATION**

- GPs to be informed (by midwives/hospitals) about birth mode and injuries to the mother
- Midwives to know risk factors and warning signs of PTSD and factor them in to postnatal mental health checks
- Accurate information to be given to women, antenatally, about the risks and long-term effects associated with all kinds of births

### **ENCOURAGE WOMEN TO COME FORWARDS AND PRESS FOR TREATMENT**

- Women to be given more information about which postnatal symptoms aren't 'normal' and where to go if there's a problem. More explicit info about urinary incontinence (including catheter use), faecal incontinence, the symptoms of prolapses, and how to care for tears and injuries.
- Explore an online assessment tool that women could use as an initial self-assessment and print out when seeing their GPs.

### **POSTNATAL PHYSIO AND SPECIALIST CARE**

- GPs to have more training in recognising abnormal postnatal symptoms and warning signs, and be readier to refer to specialists
- Postnatal women to be offered physio as a matter of course
- Self-referral route to specialist centres

### **POSTNATAL MATERNAL CHECKS**

- Mandatory contact points with postnatal women so that GPs or other healthcare professionals can specifically ask about risk factors and symptoms, and signpost/refer on to specialist support where necessary.