Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwasanaethau endosgopi

This response was submitted to the Health and Social Care Committee consultation on Endoscopy Services

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Ymateb gan: | Response from: Cancer Research UK

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Cancer Research UK's response to the Health and Social Care Committee follow up inquiry into endoscopy services in Wales

Background

Endoscopy services play an essential role in investigating suspected bowel and upper gastrointestinal (GI) cancers and positive results from Faecal immunochemical testing (FIT). Bowel cancer is the fourth most common cancer in Wales and causes around 930 deaths per year[1]. However, if found early, it is also one of the most treatable cancers. When diagnosed at the earliest stage, more than 9 in 10 (94%) people with bowel cancer in Wales will survive their disease for five years or more, compared with around 1 in 10 (9%) people when the disease is diagnosed at the latest stage[2]. Endoscopy is also a vital diagnostic tool for upper GI cancers, including oesophageal and stomach cancers which affected over 2,600 people in Wales in 2017-19[1] and cause 698 deaths per year[3,] with the majority diagnosed of people diagnosed at stage IV (39.94% for oesophageal, 42.77% for stomach).[4]

The Endoscopy Action Plan was developed in response to the Health, Social Care and Sport Committee's recommendations following their 2018 inquiry into endoscopy services in Wales. The Endoscopy Action Plan set out a phased improvement plan to support Health Boards to develop sustainable endoscopy services covering 2019-2023. Much of the action of endoscopy improvement falls to the National Endoscopy Programme (NEP), which takes a nationally directed approach to endoscopy service improvement. The board is underpinned by four workstreams, demand and capacity, clinical pathways, workforce training and development, and facilities and infrastructure. The action plan set out a number of immediate, medium- and long-term goals to address some of the issues within endoscopy services in Wales. The plan set out where there was a need for improvement including better data to understand demand, capacity and productivity to feed into plans to address this, greater standardisation of referral pathways, and working toward accreditation of endoscopy sites.

Since 2019 the aims and areas for improvement in endoscopy in Wales remain much the same. Whilst concerted action has taken place and improvements have been made, driven by the NEP, the pandemic has had a detrimental impact and added pressures onto already stretched services. During the pandemic, endoscopy services were severely affected resulting in unavoidable delays for surveillance patients. COVID-19 is mainly spread via droplets and contact, with data supporting airborne spread during aerosol-generating procedures, including endoscopy[5]. In response to the pandemic, most gastroenterology societies, including the British Society of Gastroenterology (BSG) and Joint Advisory Group for Gastrointestinal Endoscopy (JAG), issued guidance advocating for the postponement on non-emergency cases, bowel cancer screening and surveillance[6] which have impacted on the cancer diagnostic pathway. The number of endoscopy procedures in Wales fell by 83.9% during the first three months of the pandemic (March-May 2020) compared to pre-pandemic levels.[7] The infection prevention and control measures put in place during the first phase of the pandemic were effective in reducing endoscopy-related transmission of COVID-19[8], however, they also dramatically reduced the number of procedures taking place, and therefore the number of patients receiving a diagnosis of cancer and other GI conditions. The pandemic also caused knock-on effects on the NEP, with staff being redeployed from frontline endoscopy services and the NEP to focus on the COVID-19 response.

In response to the COVID-19 pandemic and the disruption caused to services, in October 2021, the Minister for Health & Social Services approved the National Endoscopy Recovery Plan. The plan involves creating additional capacity regionally, to sit alongside local and national plans to improve endoscopy workforce availability and capacity. The National Endoscopy Recovery plan is a welcome step - increasing focus on capacity to ensure that patients can access endoscopy promptly and that the system is able to meet demand. Greater focus on increasing capacity as laid out in the recovery plan is encouraging, however, it is important to note that many of the issues existed before the pandemic, and concerted action is needed to continue to drive improvements in endoscopy in Wales.

Waiting times for endoscopy

The pandemic has exacerbated pre-existing challenges in endoscopy waiting times for urgent, routine, surveillance and screening appointments, and the latest waiting times data suggest the situation has seen little improvement. NHS cancer waiting times in September 2022 fell far short of meeting the vital treatment waiting time target of 75% of patients starting treatment within 62 days of being suspected of having cancer. For people with lower GI cancer in September 2022, only 35.1% of people with started their treatment within 62 days of being suspected of having cancer, compared to 37.4% in September 2021. For people with upper GI cancers, 57% of people started treatment within 62 days of being suspected of having cancer, compared to 58.9% in September 2021.[9] The NHS diagnostic waiting times for September 2022 show that over 16,000 people (64.6%) were waiting over 8 weeks for four key diagnostic endoscopy tests[i], far higher than pre-pandemic levels with only 2,888 people in this position in September 2019[10].

There is also significant regional variation between Health Boards in Wales. Cardiff & Vale Local Health Board performed the worst in both upper and lower GI cancer waiting times in the September 2022 cancer waiting times for Wales. Lower GI cancers were notably off-target waiting times across Wales, with Cardiff and Vale and Aneurin Bevan Local Health Boards particularly concerning at 19.0% and 25.0% of patients starting treatment within 62 days of first being suspected of cancer respectively[10]. In terms of NHS diagnostic waiting times for September 2022, Swansea Bay had the highest percentage of patients waiting 8 weeks or more for four key diagnostic endoscopy tests[1] (77%), whilst other Health Boards such as Cardiff and Vale (52.2%) and Betsi Cadwaladr (56.8%) performed significantly better.[11]

From the beginning of October 2022, bowel cancer screening was made available to more people in Wales, and is now open to 55 to 57 year olds, with plans for screening to eventually be made available to all over 50s. This means an additional 172,000 people aged 55 to 57 in Wales will receive FIT kits for home testing[11] by October 2023. The move to bring Wales in line with Scotland and the recommendations of the UK National Screening Committee (UK NSC) was a vital step which will make a significant difference to people with suspected cancer. This will also lead to a greater number of people being referred for endoscopies and adequate planning is required to ensure that there is sufficient capacity to meet the growing need.

Increasing capacity and the workforce to help clear the backlog and meet future demand in endoscopy is essential, however, there are also steps which could be taken on managing capacity and demand. Establishing a capacity and demand plan that includes endoscopy facilities, workforce,

[i] Four key diagnostic endoscopy tests are: colonoscopy, flexi-sigmoidoscopy, cystoscopy and gastroscopy

equipment and utilisation so that is clear what equipment is available, its current condition, and what staff are available to operate it, would allow for better short- and long-term planning.

Additionally, the NHS in Wales should look for innovative alternatives to endoscopy to enable better triage of patients and protect endoscopy services for those who need them, whilst allowing those who don't to receive a diagnosis more rapidly. Examples of alternatives which should be considered include the expansion of CT Colonography as an alternative to endoscopy for appropriate patients, further investigation on the potential of transnasal endoscopy (TNE), the use of Colon Capsule Endoscopy (CCE), and to expand the use of Cytosponge.

Recommendation

- **The Welsh Government and National Endoscopy Programme must ensure that the resources and investment are in place to support Health boards to actively plan and prepare for the increased levels of demand for endoscopy over the next couple of years due to the expansion in screening for bowel cancer**

Increasing capacity in endoscopy services

One of the main aims of the Endoscopy Action Plan is to enable improvement in endoscopy services to be driven at greater pace and with greater ownership by the NHS in Wales. So far, the recovery programme has seen four new endoscopy services go live in Wales, increasing the capacity for endoscopy in Wales and enabling more patients to receive this vital service more quickly.

However, more could be done to widen access and provide additional capacity to deliver diagnostic tests, such as the development of Community Diagnostic Centres (CDCs) which offer diagnostic testing including endoscopy provision outside of usual settings (though with consideration of acute services access in case of serious incident). Currently, there are no CDCs in Wales. This is in contrast to other UK nations, such as England where there has been the rollout of almost 100 such sites.

Wales is well ahead of the rest of the UK in the rollout of Rapid Diagnostic Clinics; however, these do not include endoscopy services suggesting there is scope to roll out a CDC-style initiative in Wales focused on boosting diagnostic capacity within the country including tests such as endoscopy. These services should be placed in areas of high need, including places with high levels of deprivation where they could make a marked difference in cancer diagnosis. Thinking strategically about the placement of sites could also help to reduce some of the current regional variation seen in endoscopy services in Wales.

Wales has also sort to address diagnostic capacity through the widening use of TNE. TNE can be performed non-sedated and be nurse-led as well as being performed in a community or mobile setting[12], these features can help lead to improvements in diagnostic capacity. The procedure has also been shown to be well-tolerated and preferred by patients compared to traditional endoscopy (oesophago-gastroduodenoscopy (OGD))[13,14]. However, the BSG has raised concerns with regards to image quality and diagnostic accuracy in TNE[15]. Since then, technological advances (such as Image enhanced endoscopy or virtual chromoendoscopy) have been found to potentially enhance gastric cancer detection[16,17]. Therefore, whilst TNE has the potential to improve diagnostic capacity and patient comfort, further evaluation considering diagnostic accuracy of TNE in Wales is needed.

Recommendations:

- **Health Boards, supported by the National Endoscopy Programme, must expand capacity for endoscopy, both making better use of existing sites as well as setting up new ones. Locations and service models for new sites should be considered strategically to take into account areas of high need**
- **The National Endoscopy Programme should ensure the use of TNE in Wales is accompanied by evaluation of its uptake by patients, diagnostic accuracy and impact on capacity**

JAG accreditation

Alongside increasing capacity for endoscopy, quality must also be maintained. Accreditation by JAG is a process that promotes quality improvement in endoscopy services by highlighting areas of best practice and areas of change. Services are assessed against four domains: clinical quality, patient experience, workforce and training[18]. Currently, there are only four JAG-accredited sites in Wales, out of a possible 25[19]. Whilst the NEP has rightly placed an emphasis on JAG accreditation, there is a risk that accreditation will not be achieved by all units across Wales. Whilst JAG accreditation is voluntary, it is an important way of ensuring that endoscopy services are continuing to meet quality standards. Maintaining quality of care for patients is vital, and therefore the importance of JAG accreditation should not be underestimated.

COVID-19 and pressures of capacity are having a knock-on effect on progress towards accreditation. Additional demand caused by the pandemic means that many teams feel unable to prioritise the work required for accreditation. Delays to accreditation can also be caused by a lack of support for the infrastructure improvements required to meet the accreditation standards. Ageing equipment and facilities, a lack of capacity to deliver the work required for accreditation due to a lack of staff, as well as a lack of focus by management to push for, and allow staff to prioritise, accreditation all pose barriers and cause delays.

Recommendations:

- **Welsh Government should support greater investment in infrastructure to prevent delays to JAG accreditation**
- **Health Boards should ensure that teams have the space, time and capacity to support the process of accreditation, and this should be built into local JAG action plans**

Bowel Cancer Screening

The UK NSC recommend biennial screening for people aged 50-74 years old, using the highest possible FIT threshold (down to 20µg/g). Wales has recently introduced bowel cancer screening, it is currently available biennially to people aged 55-74 years old, and a 150µg/g FIT sensitivity is used. The test sensitivity used in Wales at present is equivalent to that used in Northern Ireland, however, it is higher than in other nations of the UK, meaning that the test is less sensitive and therefore picking up fewer people for potential referral for further investigation. Scotland is ahead of all other UK nations, having biennial bowel cancer screening available to people aged 50-74, using an 80µg/g FIT sensitivity. England is inviting some people aged 56 and 58, and otherwise invite people aged 60-74, using a 120µg/g FIT sensitivity. Wales initially introduced FIT at a lower sensitivity (150µg/g) as this was felt to be feasible given the capacity of endoscopy at this time. Whilst it is unfortunate that endoscopy capacity is holding back Wales's ability to have a more sensitive test, which would pick up more potential early cancers, the realistic consideration of capacity as well as the ambition to increase the sensitivity of the test is welcome.

The 4-year bowel screening plan in Wales is a phased programme delivered by Public Health Wales which will see all people aged 50-74 years old invited for screening, with different ages invited in a phased approach (currently screening is only available for 55-74 year olds). By the end of 2024, the test sensitivity will also be increased to 80µg/g FIT. This approach is strongly encouraged and has the potential to improve overall bowel cancer outcomes, but the increase in activity must be taken into account in demand and capacity planning.

Consideration must also be given to who is benefiting from bowel cancer screening. The Wales Screening Division Inequalities Report 2020-21 suggests that, across all Health Boards, there is lower uptake in men, those living in more deprived communities, and across most Health Boards, in the youngest age group eligible for screening (60 to 64 years)[20]. It is important to address inequalities in screening and target lower uptake groups with support to help them make an informed decision about taking part in screening. Results from CRUK's awareness-raising campaign for bowel cancer screening show that public health campaign advertising and direct follow-up letters to first-timers and non-responders can increase uptake – with direct mail the most effective in addressing the barriers to uptake felt by first-timers and non-responders. The activity has also been shown to increase uptake in the most deprived groups compared to the least deprived groups for first-timers and previously screened, suggesting accurate, accessible and informative awareness-raising campaigns can help to address inequalities in screening.

Symptomatic FIT

There are two main ways FIT is used in the management of patients with lower GI symptoms: in primary care prior to an urgent referral or alongside an urgent referral, and as a triage test in secondary care to guide the management of patients who have been referred routinely or on an urgent referral pathway. The threshold for determining a positive result is lower than the national bowel cancer screening programme. For symptomatic patients, we recommend FIT is implemented in line with BSG guidance.

Symptomatic FIT is a useful tool for primary care aiding GPs' decision to refer, making it easier to manage a process for repeating FIT, ongoing tests and specialist advice, and referral of patients with a negative FIT result but ongoing clinical suspicion or unresolved symptoms/signs. In secondary care, FIT is a powerful triage test, allowing patients who are symptomatic but have a FIT <10 to be put on patient tracking lists to prevent them from getting lost in the system, and ensuring the specialist has responsibility for following up and acting on the FIT result. To ensure this pathway remains robust and effective there needs to be continued commitment from Health Boards for FIT symptomatic testing, with established business cases, adequate staff capacity and ongoing engagement with primary care.

Younger people

In those eligible for bowel cancer screening, the Wales Screening Division Inequities Report 2020-21 found that people in the youngest age group eligible for screening at the time (60 to 64 years) are less likely to participate in bowel cancer screening[21], and so, targeted awareness raising of screening in this group could be beneficial.

As bowel cancer is less common in younger people (aged under 50), screening for this age group is not recommended. However, it is important to note that bowel cancer rates are increasing in adults aged between 20 and 50[21], and bowel cancer cases increased on average by up to 7.3% each year in 30 to 39 year olds between 2005 and 2014[22]. The overall incidence in people under 50 years old remains very low in absolute terms, and so the benefits of bowel screening currently do not

outweigh the harms in these younger groups. The evidence on this will continue to be kept under review to inform UK NSC recommendations.

The timely recognition and referral of younger people with symptomatic bowel cancer is important. As per BSG guidance, FIT may be used to stratify adult patients aged younger than 50 years old with bowel symptoms suspicious of a diagnosis of colorectal cancer.

Lynch Syndrome

Lynch syndrome is a genetic condition with no known cure which predisposes people to a high risk of colorectal cancer. NICE guidance recommends that all people with colorectal cancer[23] and endometrial cancer[24] are tested for Lynch Syndrome. The BSG guidelines recommend that people with Lynch syndrome should have colonoscopic surveillance every 2 years aiming to reduce their lifetime risk of bowel cancer or detect bowel cancer as early as possible[25].

Currently, genetics teams are responsible for referring people with Lynch Syndrome to symptomatic bowel services for surveillance colonoscopy. From 1 April 2023, people with Lynch Syndrome in England will be included in the NHS Bowel Cancer Screening Programme for surveillance. We recommend that the NHS in Wales consider adopting this approach for people with Lynch Syndrome in Wales as well.

Recommendations:

- **Inequalities in screening must be addressed, Public Health Wales should consider launching an awareness-raising campaign for bowel cancer, specifically targeting lower uptake groups to help them make an informed decision about screening**
- **The NHS in Wales should consider developing a national screening and surveillance programme for people with Lynch Syndrome delivered through Bowel Screening Wales**

Diagnostics workforce

The NHS cancer workforce suffers from chronic shortages, with the most pressing shortages in diagnostic services. The 2021 national census of UK endoscopy services identified a total of 5973 endoscopists employed across services in the UK, with workforce shortages cited as an ongoing issue[26]. Significant growth in the NHS workforce, requiring significant investment, will be needed. Admirable efforts have already been undertaken to boost the recruitment of healthcare professionals, including endoscopists, such as targeted recruitment campaigns. However, increasing the healthcare workforce will take time and more immediate solutions are needed.

Medical education and training

The most important way to meet the growing need for endoscopy services is through long-term investment in medical education and training to increase the number of staff able to perform vital diagnostic tests such as endoscopy.

To support retention and ensure the right balance of skills across the system, Health Boards should also consider providing funding and opportunities to support the workforce to work differently and maximise capacity. For example, funding can be provided which enables staff to lead efforts to work more effectively, provide training for other parts of the workforce, or generally upskill.

The adoption of skill-mix approaches – where roles and responsibilities of a team are designed around the needs of the patient, rather than traditional organisational boundaries – in the diagnostic

workforce can help increase capacity. Health Boards should consider whether they are able to backfill the roles of upskilled staff and, if not, take steps to enable this, for example by recruiting more support workers. Health Education and Improvement Wales should ensure courses are designed with flexibility in mind, aiming to reduce geographical and financial barriers to participation.

Recommendations:

- **Welsh Government must commit to long-term investment in growing the number of healthcare professionals able to perform endoscopy through recruitment, education and training**
- **Health Education and Improvement Wales, national and local health leaders should tackle the barriers to adopting skill-mix approaches**

Workforce plans

The limited data currently available on diagnostic staffing pressures makes it difficult to make informed decisions on current and future workforce planning. The Welsh Government need to take a more strategic approach to workforce planning to address long-term shortages in the diagnostic workforce. In endoscopy specifically, there is a need for a more robust method of collecting data, and better data sharing to effectively feed into an accurate and informed national workforce plan. A more comprehensive understanding of why people are leaving the endoscopy workforce is a prerequisite to an effective plan to reduce this. Both nationally and locally, comprehensive and standardised data on why people leave jobs in the endoscopy workforce should be collected, to feed into future policies that aim to minimise burnout and maximise retention.

Other measures can make a difference in ensuring the current NHS workforce is used most effectively in Wales. Recent studies in England have shown regional variation in both the distribution of the primary care workforce and turnover rates of GPs, with the most deprived areas having fewer GPs and higher turnover rates creating knock-on effects on services.[27, 28] The All-Wales National Nursing Bank has the potential to make a huge difference in the overall efficiency of the workforce, helping to plug gaps and reducing regional staffing disparities. This initiative should be rolled out as soon as possible, with endoscopy flagged as a priority area.

The BSG Workforce Report 2021 found significant regional variation within Wales for population per whole time equivalent (WTE) consultant gastroenterologist/hepatologist, with North Wales the second worst performing region in the UK at 71,004 people per WTE consultant[29]. Whilst the report does not specifically focus on the number of endoscopists per region in Wales, it does indicate a wider issue around geographical variation in the workforce for professions associated with bowel cancer which must be addressed. Better data collection and sharing should help illuminate the real regional variation, whilst workforce sharing arrangements, alongside targeted recruitment and training programmes could help to address some of this disparity.

Recommendations

- **The Welsh Government need to work closely with Health Education and Improvement Wales to take a more strategic approach to workforce planning, with robust data collection and better data sharing**
- **The NHS in Wales need to ensure innovative workforce-sharing arrangements, such as the All-Wales National Nursing Bank, go online as soon as possible, with endoscopy flagged as a priority**

Retention

Even before the pandemic, supporting the wellbeing of and maximising retention in the endoscopy workforce was recognised as vital. COVID-19 has further damaged the wellbeing of a workforce that was already struggling. A survey by Public Health Wales between June and August 2021, found that 71% of nurses, midwives and healthcare support workers in Wales said their mental health had worsened since the beginning of the pandemic, and almost 60% had considered leaving the profession since the pandemic, with the figure even higher for early-career nurses.[30]

A major driver of staff leaving the workforce is concern around work-life balance, demonstrating how a lack of capacity in itself can lead to burnout and harm retention. Allowing staff considering retirement the option of working part-time may aid retention. Healthcare providers should ensure that the option to work less-than-full-time is available to staff, particularly those approaching retirement, while future workforce planning should account for this growing preference when projecting the future supply of staff needed. More generally, healthcare providers should consider modifying the job plans of those nearing retirement – for example by making on-call duties opt-in rather than opt-out.

Recommendations

- **Health Boards should normalise and embed flexible working practices and ensure that the option to work less-than-full-time is available to staff**

Innovation in endoscopy

Innovative technologies have the potential to ease some of the burdens on the endoscopic workforce. Cytosponge, CCE and symptomatic FIT are examples of tools that have been shown to help triage patients based on their risk of having cancer. Whilst some progress has been made in trialling these innovations in Wales, there is still significantly more work to be done before they are utilised to their full potential.

CCE is currently being trialled in four of the seven Welsh Health Boards, in projects led by the NEP. These are key examples of the impact the NEP can have in bringing together clinical and research expertise to improve services and diagnostics for patients in Wales. It's encouraging to note that the project also aims to establish a national reporting pool of trained doctors and nurses who can review the images remotely. Focus should be maintained on these trials, as well as looking to expand access to CCE across Wales.

Cytosponge has seen less adoption, with one trial currently in progress in Wales, supported by the Moondance Cancer Initiative[31]. This is in sharp contrast to other nations within the UK, such as Scotland and England, where the technology is being trialled across multiple trusts. With no need for sedation or local anaesthetic, and requiring less equipment, infrastructure and staffing resource than a diagnostic UGI endoscopy, Cytosponge has the potential to bridge the gap between demand and service provision.

People can be reluctant to visit their doctor with digestive symptoms due to fear of endoscopy[32], however, delaying diagnosis can lead to worse outcomes. Cytosponge and CCE are less invasive and less stressful for patients, potentially making patients feel more comfortable coming forward for testing[33,34]. Given the potential benefits for both triaging patients to ease pressures on endoscopy services and for increasing timelier diagnosis, the NHS in Wales should embrace the potential of

innovative technologies, whilst also giving Health Boards the support to ensure effective implementation.

Recommendation:

- **The National Endoscopy Programme should encourage Health Boards to embrace innovative technologies such as CCE and Cytosponge, expanding trials throughout the country**

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