National Assembly for Wales
Health, Social Care and Sport Committee

Endoscopy services in Wales

April 2019

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About the Committee

The Committee was established on 28 June 2016. Its remit can be found at: www.assembly.wales/SeneddHealth

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Current Committee membership:

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David Rees AM
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The following Members were also members of the Committee during this inquiry.

Julie Morgan AM
Welsh Labour
Cardiff North

Rhianon Passmore AM
Welsh Labour
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1. Background

1. In February 2018, Bowel Cancer UK published its report "A Spotlight on Bowel Cancer in Wales: Early Diagnosis Saves Lives". The report highlights serious delays in diagnosis for bowel cancer in Wales. It also states that bowel cancer outcomes in Wales are amongst the poorest in Europe – Wales ranks 25 of 29 in Europe for five year survival.

2. According to Bowel Cancer UK, the majority of health boards in Wales breach waiting times for tests that can diagnose bowel cancer and an alarmingly low number of eligible people take part in the bowel screening programme. Screening is the best way to diagnose bowel cancer early but between April 2017 and March 2018 only 55.7% of people eligible to take the bowel screening test in Wales actually completed it. For those that need further hospital tests via endoscopy, many will wait much longer than the eight week wait target.

3. From 2019, Wales will replace the current screening test with a simpler and more accurate one called the Faecal Immunochemical Test (FIT), which is expected to increase the uptake of screening, but there are concerns that endoscopy units in Welsh hospitals are already struggling to cope with demand, and so while the new screening test is a positive improvement, it could put more strain on an already overstretched service.

4. The Health, Social Care and Sport Committee (the Committee) therefore agreed to undertake a one day inquiry into endoscopy services in Wales in response to the planned changes to the bowel screening programme and the concerns raised in relation to capacity.

5. The terms of reference for the inquiry were to look at:

- Earlier diagnosis, specifically the introduction of the Faecal Immunochemical Test (FIT) into the bowel screening programme and the recently announced change to age range.
- Diagnostic service capacity and waiting times, including the extent to which capacity constraints are driving the recommendation to set the FIT threshold for its introduction to the bowel screening programme at a relatively insensitive level.
- The long term and sustainable solutions to the challenges that exist within endoscopy services in Wales, including how data on diagnostic

staffing pressures is being used to inform decisions about current and future workforce planning.

- Consideration of other early diagnosis interventions and innovation, such as the introduction of FIT testing by general practitioners in symptomatic patients to reduce referral for diagnostic tests.
- Efforts being taken to increase uptake of the bowel screening programme.

2. Earlier diagnosis

The bowel screening programme

6. Diagnosing bowel cancer early will achieve better survival outcomes for patients. Research shows that the bowel cancer screening programme is one of the best ways to detect bowel cancer early, when it is easier to treat successfully.

7. The bowel screening programme began in Wales in 2008 and invited men and women aged 60 to 69 years to send a stool sample for guaiac faecal occult blood (gFOBt) testing every two years. In November 2012, the programme was expanded to include people aged 60 to 74, the rationale being that the majority of bowel cancers affect those over the age of 60.

Introduction of the Faecal Immunochemical Test (FIT)

8. In November 2015, the UK National Screening Committee (UKNSC) recommended introducing FIT into the bowel screening programme. This new test is more accurate and easier to use. At the time, the UKNSC did not specify a recommended sensitivity level for FIT but recommended as endoscopy capacity grew or screening uptake increased that the programme should adjust the sensitivity level to increase the number of cancers detected.

9. In Wales, it was agreed that FIT would replace the current screening test from January 2019 through a phased roll out. In Scotland, FIT replaced guaiac based FOBt as the test for bowel screening in November 2017. In a study looking at use of FIT in Scotland, it was found that overall uptake was 58.7% for FIT, significantly greater than the 53.9% for gFOBT.

10. The FIT sensitivity threshold planned within the Bowel Cancer Screening Programme in Wales is 150 micograms of haemoglobin per gram of faeces (µg Hb/g), lower than that in Scotland, where it is 80µg Hb/g. In England, the change is expected to happen in Spring/Summer 2019, with a proposed starting sensitivity threshold of 120µg Hb/g.

11. In written evidence to this inquiry, the Welsh Government said that the decision to introduce FIT at a sensitivity of 150 µg Hb/g is based on the associated resource implications for NHS Wales, and is a practical starting point based on existing NHS capacity:

> "The agreed introductory threshold will result in an increased demand for colonoscopy as the participation rate is expected to increase and the test is slightly more sensitive. Modelling provided at the time suggests that implementation at this threshold will result in an additional 350 screening colonoscopies per year across Wales. This will be challenging given the existing pressure on services but is expected to improve the number of cancers detected by 90, which is a 43% increase. Learning from international experience has demonstrated the importance of a phased approach to test modelled assumptions and avoid destabilising services."[1]

12. Further, the new test was due to be implemented from age 60, but in August 2018, the UK National Screening Committee reviewed the optimisation of bowel screening and recommended FIT should be available to people aged 50-74. The test is already being used in Scotland from age 50.

13. Public Health Wales began phased implementation on 31 January 2019 and expect to be sending 1 in 28 people a FIT from 8 February. The sensitivity level for the screening programme will initially be set at 150µg Hb/g with the aim of reducing that level to 80 µg Hb/g by 2023. Sharon Hillier, Director of Screening at Public Health Wales, told us:

> "With the FIT implementation, I think it's just important to explain why it's a phased implementation as well. So, this is going forward on work that we've done in terms of implementing human papillomavirus and cervical screening, where we're doing a phased implementation to see how the programme copes and performs in that way as well, so we can learn around that process, so that when we implement in June, that implementation will go really well."[2]

14. Witnesses to our inquiry welcomed the introduction of FIT but said they would like to see the Welsh Government being more ambitious.

15. Written evidence from Bowel Cancer UK states:

> "Without focus and pace we will continue to fall behind other nations and Welsh patients will be disadvantaged and people will continue to die unnecessarily."[3]

[1] Health, Social Care and Sport Committee, 29 November 2018, Paper 9

[2] RoP, 29 November 2018, paragraph 125

[3] Written evidence, E05

16. Andy Glyde, Cancer Research UK, said:

> "I think the important thing to note there is, if we get to that point by 2023, that's where Scotland is today. So there's a question of ambition there as well: whether or not, actually, we should be going a bit further, thinking that probably Scotland's not going to stand still over the next four years on this and we're still going to be behind the curve, even if we do meet that target."[4]

17. However, Dr Chris Jones, NHS Deputy Chief Medical Officer, Welsh Government, told us:

> "It's a realistic position that we believe to be deliverable, but the intention is to move progressively in terms of the age range and also in terms of the threshold as quickly as possible. We believe, actually, that this commitment will enable us to be relatively well ahead. We've seen in other parts of the UK when a lower threshold has been taken as the starting point that, actually, it's created enormous difficulties with capacity, and that hasn't necessarily been, I think, something that they felt has been helpful. I think this is a proportionate but quite progressive approach."[5]

[4] RoP, 29 November 2018, paragraph 8

[5] RoP, 29 November 2018, paragraph 624

3. Diagnostic service capacity and waiting times

Capacity

18. It is anticipated that the introduction of FIT will lead to an increase in uptake of up to 10% and will impact on the capacity of health boards to carry out endoscopy tests.[6]

19. In 2013, the Welsh Government established an Endoscopy Task and Finish Group to explore concerns regarding endoscopy services across Wales. The group published its report with recommendations to address the challenges around endoscopy capacity in 2014. Amongst the recommendations was the requirement for additional funding, a national strategy for endoscopy services, a systematic drive for improvements in quality and an overall structured approach to the management of capacity and demand. The majority of recommendations have not been implemented, with Bowel Cancer UK accusing the health boards in Wales of failing to get to grips with the challenges identified.

20. Bowel Cancer UK suggest that endoscopy services have become overstretched in Wales, with the Welsh Government's Endoscopy Implementation Group having very little impact in delivering service improvements. Bowel Cancer UK call for "decisive and swift action"[7] from Welsh Government, the Welsh NHS Executive and health boards to address the challenges.

21. In 2015, the Welsh Government committed additional funding to improve waiting times for diagnostic tests, including those waiting for endoscopy procedures following a positive screening result. Additional funding was also provided in in 2016[8] and 2017[9]. However, despite extra funding, the waiting time figures demonstrate that challenges remain.

22. The Welsh Government's approach to tackling issues related to capacity has been described as reactive and short-term. A number of health boards provided details of hospitals contracting with external private providers to provide "insourcing" services to deliver endoscopy procedures within the health board on weekends as

[6] Written evidence, E05

[7] Written evidence, E05

[8] Welsh Government written statement, November 2016

[9] Welsh Government written statement, November 2017

well as "outsourcing", where patients are sent to private providers at sites outside of the health board, to cope with demand.

23. Written evidence from Cardiff and Vale University Health Board (UHB) states:

> "The wider diagnostic endoscopy service in Cardiff and Vale UHB similar to most other health boards in Wales has been facing a severe shortfall in capacity in relation to the existing demand, significant backlog of new and surveillance procedures and an approximate 8-10% annual increase in demand for endoscopy (primarily colonoscopy).
>
> For approximately the last 7 months the UHB has contracted with external private providers to provide 'insourcing' services in endoscopy within Cardiff and Vale on all weekends to deliver on average 50-60 endoscopy procedures on a Saturday and a similar number on Sundays. There was an initial 'outsourcing' contract as well where patients were sent to private providers at sites outside of the health board with several consequent patient safety and quality incidents related to poor quality of procedures, lack of clarity on management and repeat procedures required. 'Outsourcing' is therefore no longer undertaken within Cardiff and Vale UHB though 'insourcing' continues."[10]

24. Evidence from the Welsh Association for Gastroenterology and Endoscopy also states:

> "Many health boards have contracted external private providers to provide 'insourcing' or 'outsourcing' services in endoscopy where patients are either having procedures undertaken by private providers at weekends within the health board sites or sent to private providers at sites outside of the health board. There has been a short term reactive response to the challenges rather than a considered, strategic longer term sustainable one. As a consequence of this there are significant issues with endoscopy capacity in each health board with regard to infrastructure (state of endoscopy rooms, numbers of rooms per 100,000 population as compared to elsewhere in the UK); workforce (numbers of endoscopists particularly nurse endoscopists or colonoscopists currently or potentially available to undertake screening) and capacity planning (often with poor engagement between senior

[10] Written evidence, E03

> health board colleagues and the clinical workforce who deliver screening)."[11]

25. Dr John Green, Chair of the Endoscopy Services Quality Assurance Group at the Joint Advisory Group of Gastrointestinal Endoscopy at Cardiff and Vale UHB, told us "insourcing and outsourcing of activity is endemic across the United Kingdom. It's not a Welsh thing; it's a UK thing".[12]

26. He went on to say:

> "It's not an optimal use of public funding because it's premium rate pay to do so. But it's a solution that the health service across the UK has taken on board to try and improve patient waiting times."[13]

27. When asked to what extent health boards were insourcing and outsourcing services, Dr Chris Jones, NHS Deputy Chief Medical Officer, told us:

> "I don't know the extent in each organisation, because, obviously, these are local decisions that health boards make. But Simon and Andrew will know how much money has been given to the NHS to help them deal with waiting times, and I do know a certain amount of those moneys have been used to outsource and insource to bring endoscopy waiting times down. The endoscopy implementation group was pleased to see improvement in capacity and improvement in waiting times. But we do recognise that not all of that capacity has been delivered through sustainable means. And I think there's a lot of money being spent in this area. If we can be more strategic, with a nationally-directed approach, bringing whole organisations to the table, and demanding, in a sense, that they give this priority, a more sustainable arrangement will follow."[14]

28. Witnesses suggest there is a lack of clear leadership from both the Welsh Government and NHS Executive in providing solutions to the challenges facing endoscopy services in Wales. Written evidence from Bowel Cancer UK states:

> "The Welsh Government and the NHS have been unable to identify a solution to mitigate the tsunami of demand which has been created as a result of an increasingly ageing population, increasing symptom

[11] Written evidence, E04

[12] RoP, 29 November 2018, paragraph 444

[13] RoP, 29 November 2018, paragraph 446

[14] RoP, 29 November 2018, paragraph 687

> awareness and most notably, the change in NICE guidance around referral for suspected cancer and the plans to introduce FIT from January 2019."[15]

29. Dr Jared Torkington, Past President of the Welsh Association for Gastroentology and Endoscopy (WAGE) and a Consultant Colorectal Surgeon at Cardiff and Vale UHB, told us:

> "We do need a radical new approach, because what we're doing is not working. And if you can't get it right in bowel cancer, which is in many ways the most curable of all solid cancers, then you won't be able to get it right in anything else."[16]

> "It does need a radical new approach and, actually, it's no use leaving it to the health boards—it needs some direction from Government."[17]

30. In its written evidence, the Welsh Government accepts that diagnostic endoscopy demand has become out of balance with core capacity. It also states that the NHS Executive Board has considered how to address this issue. The Deputy Chief Executive of NHS Wales and the Deputy Chief Medical Officer are jointly chairing the new nationally directed approach. There will be a national endoscopy programme, supported by the NHS Collaborative, that will be responsible for service planning and supporting incremental increased in capacity for the years ahead.

Waiting times

31. Diagnostic endoscopy is subject to the national eight week diagnostic target. The waiting time is calculated from the date the referral request is received until the date on which the diagnostic test is carried out. Welsh Government statistics show (see Figure 1) that the number of people waiting over eight weeks for diagnostic endoscopy services in December 2018 (latest published figures) was 1,610.[18]

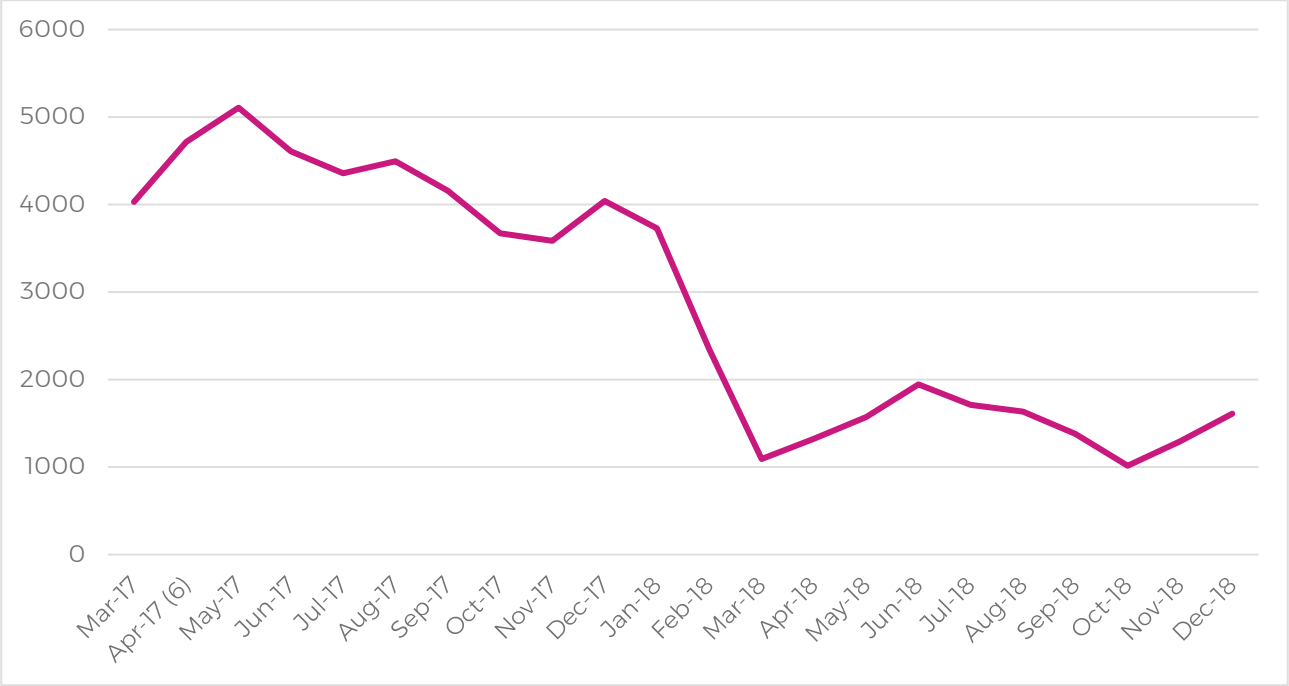
[15] RoP, 29 November 2018, paragraph 687

[16] RoP, 29 November 2018, paragraph 487

[17] RoP, 29 November 2018, paragraph 489

[18] Welsh Government Statistical Briefing – NHS Activity & Performance Summary: December 2018/January 2019

Figure 1: Number of patients waiting over 8 weeks for diagnostic endoscopy, 2017-18



Source: StatsWales

32. There was a sharp decline in waiting time figures between January 2018 and March 2018, but the data presents a worrying picture for patients because waiting times have fluctuated since then, with an increase in recent months. It is evident that demand for diagnostic tests is outstripping capacity. Moreover, it shows that many patients will have potentially been waiting months before a diagnosis and then will have a further wait to start treatment.

33. In November 2018, the Welsh Government announced the introduction of a new single cancer pathway across Wales in 2019. The single cancer pathway will replace the urgent suspected cancer (USC) and non-urgent suspected cancer (nUSC) pathways. The single cancer pathway will measure the wait of patients on the two traditional pathways but importantly, a patient's waiting time will begin from the point of a suspicion of cancer rather than the point of diagnosis. The single pathway is for all cancer patients, whether referred by the GP or identified through an emergency presentation, an incidental finding, screening or during an appointment in secondary care.[19]

34. The Committee received a written response from a bowel cancer patient (stage 3) who wanted to share their personal account and experience of being diagnosed with bowel cancer. The individual describes how their diagnosis was delayed and prognosis worsened as a result.

[19] Welsh Government – Written statement, November 2018

Case Study:

"In the summer of 2014, aged 55, I noticed a change in bowel habit and a number of other unusual symptoms and went to my GP in October 2014. He examined me and took a blood sample but was unable to give a definitive diagnosis. Due to my age and other lifestyle factors, he thought it was very unlikely that I had bowel cancer.

In December 2014, with my symptoms continuing, he referred me to a consultant enterologist.

I was seen by the consultant in March 2015. He thought I should have a colonoscopy and placed me on the waiting list.

My symptoms continued and in August 2015 worsened. In early September, my GP was sufficiently concerned to send me to hospital as an emergency case. I was admitted and given an emergency colonoscopy which revealed a tumour which had grown to block my colon. I underwent surgery and spent 15 days in hospital. My surgeon told me I would not have survived a further 2 or 3 days without intervention.

Two weeks later, while recovering at home – in later September, I received an appointment letter from the endoscopy department of the Royal Gwent Hospital, following the meeting with the consultant the previous March, inviting me to have a colonoscopy – 9 months after being referred by my GP; 6 months after seeing the consultant; a month after undergoing surgery to save my life".

35. The Welsh Government's written evidence acknowledges that pressure at the endoscopy stage of the cancer pathway is one of the most significant factors in potential breaches of the cancer waiting time targets.

36. We are also concerned about waiting times for surveillance procedures for people who are at a higher risk of developing cancers, for example those with Colitis or Crohn's disease, who should be having routine endoscopies. We understand that because of the need to prioritise waiting time requirements, surveillance lists may be being sacrificed because there is no requirement to report to the Welsh Government or the wider NHS on those particular surveillance cases.

37. Written evidence from Cardiff and Vale UHB states:

> "... there are 952 significantly overdue surveillance procedures (mainly colonoscopy) where patients considered as high risk and requiring ongoing surveillance endoscopic procedures that are more than 8

> weeks overdue their planned surveillance. Despite this group being known to have a higher yield of cancer than most other groups and due to the focus on targets being mainly associated with new rather than follow up or surveillance this high risk group has been neglected and we have had several incidents of cancers arising in patients on this surveillance waiting list (potentially avoidable had they been scheduled for their procedure as planned and due to capacity constraints."[20]

38. This was supported by Tenovus Cancer Care, who told us:

> "There is evidence that patients, as a result of having had one or more polyps, are now having their follow-up surveillance endoscopies delayed. This will result in more interval cancers, and could cost lives which should be of concern to all."[21]

[20] Written evidence, E03

[21] Written evidence, E06

4. Long term and sustainable solutions to the challenges that exist within endoscopy services in Wales

39. Clearly, capacity, in terms of staffing and facilities, is a significant challenge facing the service. While short term measures, such as "insourcing" and "outsourcing" have been successful in reducing waiting times to some extent, this has come at considerable cost and is not sustainable for the future.

40. Phedra Dodds, a consultant nurse endoscopist at Powys Teaching Health Board told us:

> "... we need to be using what we've got more efficiently. We need to be doing seven day a week endoscopy, we need to be using the suites for 12 hours at a time, we need to have people in them, not just the endoscopists—we need our nursing support as well to be well trained, and have enough of them; I know that some units are struggling in getting enough nurses. We need to have training, we need to have opportunities to progress, and I think endoscopy needs to be seen as a very important speciality within hospitals and within trusts. It is so important on the diagnostic pathway that it just needs to have a much higher profile."[22]

Leadership

41. As has been stated previously, witnesses told us there is a lack of clear leadership from both the Welsh Government and NHS Executive in providing solutions to the challenges facing endoscopy services in Wales.

42. Written evidence from Cardiff and Vale UHB states:

> "There has been a focus on meeting RTT targets and concentrating on 'breaches' as can be seen from the above but very little engagement from senior colleagues within the UHB on strategic planning and building a sustainable service instead of the short term 'insourcing' and 'outsourcing' approaches outlined above."[23]

[22] RoP, 29 November 2018, paragraph 484

[23] Written evidence, E03

43. The Welsh Association for Gastroenterology and Endoscopy (WAGE) told us:

> "The significant constraints within endoscopy services in Wales are currently still being looked at in a fragmented manner with different approaches and varying levels of engagement between stakeholders within each health board. We feel that given the common themes involving infrastructure, workforce, planning and capacity and the population demographic this may benefit from a centralised approach with delivery and operational elements closely monitored for each health board."

44. It went on to suggest:

> "... solutions may need to involve – a) Establishment of an 'Endoscopy academy' analogous to the 'Radiology academy' recently agreed and implemented by Welsh Government. This would enable intensive and rapid training of the workforce to address workforce capacity constraints in a sustainable manner as well as attract colleagues to work within Wales.; b) Ensuring that each health board has a nominated senior exec lead responsible for the team and for planning and implementation of solutions as described above; c) Applying an all Wales centrally supported approach to planning and implementation of wider endoscopy services with WAGE as an integral part of the new approach (liaising with the Wales Cancer Network, Health Education and Innovation Wales, Public Health Wales and the NHS collaborative)."[24]

Workforce planning

45. Evidence from Cancer Research UK states:

> "...there are currently not enough trained staff to fill current posts, as shown by high levels of vacancies and outsourcing. Workforce planning to date has been based on poor data, and providers stating what they can afford rather than need to deliver clinical best practice. It is also difficult for the service to foresee innovation which may change workforce needs."[25]

[24] Written evidence, E04

[25] Written evidence, E09

46. It was suggested that the National Imaging Academy could provide a model for increasing the endoscopy workforce. Dr Tom Crosby, Medical Director for the Wales Cancer Network and Consultant Oncologist at Velindre Cancer Centre, told us:

> "We look at the National Imaging Academy, and it's probably one of the best things that Wales has done in terms of improving the workforce for diagnostics, and there are some lessons there about how that was developed and how that might work within endoscopy services."[26]

47. A number of witnesses highlighted the need for a more strategic approach to workforce planning in Wales.

48. Dr Sunil Dolwani, President of WAGE and Consultant Gastroentologist and Bowel Cancer Screening Lead at Cardiff and Vale UHB told us:

> "At the moment, we're trying to undertake an exercise whereby we do our workforce planning, which is more centralised, and what we also hope to do from the Welsh Association for Gastroenterology and Endoscopy is to make it really detailed, so that every member of staff who's involved in endoscopy can actually tell us about what their level of participation in endoscopy is, what kind of procedures they do, and what their retirement plans are so that we can actually get a really clear idea for the next five years, not just a snapshot for now. That's something that we hope to know much more about within the next few months, so that we can actually then say, for the first time ever in Wales and in most other areas, 'Here's what we need.' Because leaving it to health boards alone has not resulted in each health board doing this properly at all, and it's been very reactive and very fragmented."[27]

49. Dr Andrew Goodall, Director General for Health and Social Services and Chief Executive of the NHS Wales, said:

> "I would agree that there are some opportunities linked into HEIW about taking a fresh approach to this workforce-planning approach. What I can state is that the chief executive of HEIW was part of the NHS board discussion when we were agreeing our directed national approach, and the workforce is a significant area. Whilst we may need to expand more the clinical teams, as in our medical staff, I think the

[26] RoP, 29 November 2018, paragraph 331

[27] RoP, 29 November 2018, paragraph 449

> real scope to happen is the way in which we oversee and supervise the non-medical staff. I think there's much more we can do there."[28]

50. We also heard of an increased role for non-medical endoscopists in expanding capacity in this area. The Royal College of Nursing's written evidence states:

> "... Advanced Nurse Practitioners (ANPs) and Clinical Nurse Specialists (CNSs) with competencies in the area of endoscopy are able to perform endoscopic procedures without the supervision of other health or medical professionals and can therefore be invaluable in expanding services."[29]

51. We asked Phedra Dodds, a consultant nurse endoscopist at Powys Teaching Health Board, why so few of the nurse endoscopists were able or allowed to do colonoscopy. She told us:

> "Part of it is to do with training. It takes a long time to train to do colonoscopy. It takes a lot longer than to do the other two modalities of endoscopy. Part of it is to do with nurses' experience, part of it is to do with training opportunities, and to be honest, part of it is to do with payment. Some nurses are paid less than some others in Wales to perform endoscopy. And colonoscopy is more risky than other procedures, and it's been difficult to tell health boards that, and to actually get a good payment structure for nurses to do colonoscopy."[30]

52. Written evidence from Powys Teaching Health Board also highlighted a disparity of pay grade for nurse endoscopists in Wales compared to England. It went on to say:

> "In developing a sustainable service, there needs to be an on-going commitment to increasing the number of gastroenterologists and other medical endoscopists but also to developing nurse and other non-medical-endoscopists. We believe that this would benefit significantly from a national approach in support of work at both national and local levels."[31]

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[28] RoP, 29 November 2018, paragraph 647

[29] Written evidence, E08

[30] RoP, 29 November 2018, paragraph 438

[31] Written evidence, E15

53. The Welsh Government acknowledged that the role of non-medical endoscopists was an important aspect of service provision but suggested that "the scope of practice is more limited and requires ongoing mentoring and support from consultants".[32]

Training

54. A number of witnesses drew attention to the lack of a national training programme in Wales.

55. Cancer Research UK suggested that:

> "To address immediate shortages in endoscopy, HEIW should look at ways to better use existing staff including developing a non-medical endoscopy accelerated training programme, making sure they are trained to perform colonoscopies. This should be alongside increasing training places for clinicians who perform endoscopies to ensure there is sufficient capacity in the longer term."[33]

56. Evidence from the Royal College of Physicians Wales states that "investment into a single training facility for nurse and medical endoscopists would be a distinct advantage". It goes on to say:

> "There is no dedicated endoscopy training facility or faculty in Wales. In addition with specialty training being reduced (from 5 to 4 years) in all medical specialties, including gastroenterology, not all future trainees will come out of training able to undertake colonoscopy as it is not a core competency. This has downsides, but it also raises the possibility of organising a post-CCT credentialing school in Wales with a one-year dedicated training programme (potentially with a tie-in to work in Wales). This could use a faculty of trainers that would also provide nurse endoscopist training."[34]

57. While the Royal College of Nursing recommends that HEIW works with health boards and higher education institutions to develop and implement a strategic plan to ensure that sufficient education opportunities are available for those wishing to undertake endoscopy training, ensuring that the funding is

[32] Health, Social Care and Sport Committee, 29 November 2018, paper 9

[33] Written evidence, E09

[34] Written evidence, E10

available for these courses and also that the necessary backfill is available to enable staff to be released to undertake the courses.[35]

58. Written evidence from HEIW states:

> "An investment in training infrastructure for endoscopy is badly needed – no central funding has been given since March 2009. Equipment purchased in 2006 is now outmoded and in some of the original clinical training centres the training environment does not meet JAG quality assurance standards."[36]

Infrastructure

59. We heard that the lack of a strategic approach to tackling issues related to capacity had resulted in "significant issues with endoscopy capacity in each health board with regard to infrastructure (state of endoscopy rooms, numbers of rooms per 100,000 population as compared to elsewhere in the UK)".[37]

60. Written evidence from the Welsh NHS Confederation states:

> "Health Boards also need greater capacity in terms of increasing physical space and equipment to cope with the anticipated additional demand. Where necessary, this needs to underpin workforce plans with significant input from strategy and estate teams."[38]

61. While Dr Sunil Dolwani, President of WAGE and Consultant Gastroentologist and Bowel Cancer Screening Lead at Cardiff and Vale UHB told us:

> "Infrastructure has been a big problem, because there has not been the investment in endoscopy infrastructure that there should have been and that other countries have seen over the past decade or so. Some examples would be—for example, in Betsi Cadwaladr we have seen two units in really poor infrastructure situations, one where the decontamination room has not been refurbished to the standard that it should be, and another where, quite literally, the roof fell in and

[35] Written evidence, E08

[36] Written evidence, E16

[37] Written evidence, E04

[38] Written evidence, E11

endoscopy had to be undertaken in portakabin and mobile van-type situations, which is really unfortunate."[39]

Joint Advisory Group on Gastrointestinal Endoscopy (JAG) Accreditation

62. The current Joint Advisory Group on Gastrointestinal Endoscopy (JAG) accreditation scheme was established in 2005 and, along with the Global Rating Scale (GRS), has supported endoscopy services across the UK to focus on standards and identify areas for development.

63. JAG has been working in Wales for a number of years, supporting endoscopy services to improve the quality of patient care. JAG accreditation provides a framework for services to benchmark their performance against best practice standards, implement improvement, and receive external and independent quality assurance that the best quality of care is delivered to their patients. To become accredited, services must meet a range of standards which drive service efficiency and maximise capacity. Services must meet national waiting time targets, review current and future capacity against predicted demand and proactively manage waiting lists and booking and scheduling arrangements. Services must meet a number of requirements around workforce planning and development, ensuring services have the appropriate workforce to meet the current and future needs of the service. This is in addition to the other JAG standards which cover all aspects of a high quality service including patient experience, quality, safety, environment and training.

64. Currently 6 out of 20 services hold accreditation in Wales. The main barriers for Welsh services include environment as well as meeting waiting time targets.

[39] RoP, 29 November 2018, paragraph 414

5. Consideration of other early diagnosis interventions and innovation

Referral from primary care

65. Alongside the bowel cancer screening programme, there are other interventions and innovations that can be adopted to improve earlier diagnosis of bowel cancer. While screening is the most effective way of detecting bowel cancer early, referral by GP is still the route by which most people are diagnosed. As such, referral through primary care is a particularly important route to diagnosis for those who experience symptoms that could be bowel cancer and those below the age covered by the screening programme. It is important that GPs and practice nurses are able to recognise these symptoms and refer appropriately and promptly.

66. In its written evidence, the British Medical Association (BMA) Wales distinguish between the different groups of patients that will need access to diagnostic endoscopy services. Firstly, there are those patients with clear cut symptoms of urgent suspected cancer who will require a colonoscopy within a very short time span. Secondly, there are patients displaying less clear symptoms who do not meet the threshold for an urgent suspected cancer referral, who the BMA say are "particularly poorly served".[40]

67. Guidelines from the National Institute of Clinical Excellence (NICE) are in place to assist GPs to make referral decisions. The NICE guidelines for suspected cancer,[41] which were updated in July 2017, recommend that FIT is adopted in primary care to guide referral for suspected bowel cancer in people without rectal bleeding who have unexplained symptoms, but do not meet the criteria for a suspected cancer pathway referral. This would help to address the gap identified by the BMA who state that "the variation in waiting times between an Urgent Suspected Cancer referral to colonoscopy and "urgent" referral can be measured in months meaning that some cancers are undiagnosed for some time". The BMA say that this group would be very well served by non-invasive testing, such as a FIT referral directly by the GP.[42]

[40] Written evidence, E12

[41] NICE Guidelines: Suspected cancer: recognition and referral

[42] Written evidence, E12

68. Bowel Cancer UK and Cancer Research UK both refer to pilots being carried out in parts of England and Scotland, looking at the use of the FIT test in the primary care setting as a stratification tool for those with vague symptoms of bowel cancer (though not red flag symptoms as these would immediately be put on the Urgent Suspected cancer pathway).

69. Bowel Cancer UK suggest that some health boards in Wales are wishing to roll out this new approach, but state that "due to a lack of clear leadership within NHS Wales to make wide strategic decisions on the best way to approach introducing the FIT test for use with symptomatic patients, it is yet to be introduced".[43] Cancer Research UK, however, appear to be more cautious, stating that "there are still unanswered questions of how the implementation of FIT in symptomatic patients will work in primary care".[44]

70. Evidence from the Welsh NHS Confederation also suggests that the evidence base for the effectiveness of FIT testing as part of a primary care/secondary care diagnostic pathway in symptomatic patients is not as robust as it could be. For this reason, health boards have been working collaboratively to outline what the baseline data collection and pathway measures need to be to pilot a study of this type. It is hoped that research of this kind will strengthen the evidence base for such an intervention so that it can be used in bowel cancer screening procedures in future.

71. It goes on to say that health boards have engaged in detailed discussions with NHS organisations in Scotland (where a pilot has already taken place) to learn from their experiences, and with organisations in NHS England such as the FIT pioneers' group:

> "It is hoped that through continued engagement with the groups involved in the all-Wales initiative, such as Health Technology Wales and the Welsh Association for Gastroenterology and Endoscopy (WAGE), at least one Welsh Health Board will be well-placed to pilot a systematic and evidence-based roll out of FIT testing for symptomatic patients in 2019. The hope is that having the pilot in place in one Health Board will enable other Health Boards to structure and implement their own services to integrate this into the symptomatic diagnostic pathway."[45]

[43] Written evidence, E05

[44] Written evidence, E09

[45] Written evidence, E11

72. Written evidence from WAGE states

> "The introduction of FIT testing as part of a primary care-secondary care diagnostic pathway in symptomatic patients has some evidence to support its use and NICE DG30 guidelines recently support its use in 'low risk patients'. The introduction of this test is however predicated on there being i) significant endoscopy capacity to perform a diagnostic colonoscopy in those testing positive; ii) there being accurate and real time data to measure and evaluate its impact on direct to test colonoscopy, clinic referrals, GP referral patterns and cost effectiveness of introducing this. Currently none of these requirements are met in most health boards in Wales."[46]

73. Dr Jared Torkington, Past President of WAGE and a Consultant Colorectal Surgeon at Cardiff and Vale UHB, told us:

> "So, the difficulty we have with symptomatic FIT is that it will put more pressure on a system that is failing. I think I speak for the three of us, and, in fact, most of the community that deals with these patients—we all want to see more tests in primary care that can somehow reduce demand and give GPs the confidence not to refer everybody they see, not to feel that they're making the right decisions in terms of that, but we are conscious that the evidence base at the moment is emerging. We think that Wales is perfectly placed to be trialling and collecting evidence to support the widespread introduction of this."[47]

74. Dr Sunil Dolwani, President of WAGE and Consultant Gastroentologist and Bowel Cancer Screening Lead at Cardiff and Vale UHB, supported this, saying:

> "... what we want to do is not give yet another overly complicated pathway to primary care colleagues, in a time-pressured consultation, to have difficulty in referring appropriately. We're trying to simplify it and keep it as evidence based as possible, and what we're trying to do is pilot it and trial it and see the impact of it, because the centre of all this has got to be the patient. A lot of this is not about how it reduces the demand on colonoscopy; it's about how we diagnose cancers earlier and what happens to those patients, because a patient has come to a GP with some symptoms."[48]

[46] Written evidence, E04

[47] RoP, 29 November 2018, paragraph 524

[48] RoP, 29 November 2018, paragraph 527

75. The Welsh Government's written evidence states:

> "It is important the potential for FIT as a triage test is carefully tested, particularly around the safety-netting of referrals that do not proceed to endoscopy. There are also important considerations in terms of the increased histopathology demand and commonality of the standard of testing, as well as the need for close working with primary care. The Welsh Government will monitor health board progress with piloting these approaches and assist with the adoption of learning and common approaches across Wales. Health Technology Wales has also received a topic request from the Wales Association of Gastroenterology and Endoscopy to review the evidence for the use of FIT in the symptomatic population in line with guidance from the National Institute for Health and Care Excellence (NICE) to guide referral for suspected colorectal cancer in people without rectal bleeding who have unexplained symptoms but do not meet the criteria for a suspected cancer pathway referral."[49]

[49] Health, Social Care and Sport Committee, 29 November 2018, paper 9

6. Efforts being taken to increase the uptake of the bowel screening programme

76. The standard for uptake for the bowel screening programme has been set at a UK level of 60% of invited participants returning a used test within six months of invitation. Uptake of bowel screening is below standard across the UK and this is largely attributed to the nature of the test.

77. The latest figures for the period April 2017 to March 2018 show an uptake of 55.7% at an all-Wales level for all of the invited participants.[50] Uptake is higher in females (57.2%) compared to males (54.1%). There is also a strong correlation with deprivation – with uptake in the most deprived areas being 45.6% compared to least deprived areas at 63.3%.

78. A number of witnesses told us that the introduction of the FIT test has the potential to improve the uptake of screening, largely because the new test requires just one (instead of three) samples, as well as an improved detection rate for bowel cancer and advanced pre-cancerous polyps in the bowel.

79. As noted above, take up rates for men are generally lower, and for men from deprived areas even more so. Written evidence from Tenovus Cancer Care states:

> "While it is accepted that men, in general, are a noted hard-to reach group, deprivation is a major driver of poor health outcomes and Tenovus Cancer Care believes that far more effort needs to be paid to focussing attention on more deprived communities. Particular focus should be paid to those identified as experiencing multiple deprivation, as defined in the Wales Index of Multiple Deprivation (WIMD)."[51]

80. It goes on to say that confronting and reducing the undeniable stigma attached to bowel cancer and screening in general should be a key concern:

> "… for example by targeting more community-focussed interventions, such as in rugby clubs and in targeting BAMER communities, including engagement with community and faith leaders."[52]

[50] Public Health Wales: February 2018

[51] Written evidence, E06

[52] *ibid*

81. Hayley Heard, Public Health Wales, made a similar point in oral evidence:

> "We know that the people who are less likely to complete our test kit are men from poorer areas, and the gap between the poorest and the richest in terms of uptake is wider for the bowel screening programme than it is for the other cancer screening programmes, which is a concern, but also quite helpful. We've generated a lot of intelligence over the last few years, so that we now know the people who don't do our test kit, so we're able to target interventions at those cohorts of people."[53]

82. She went on to say that recent work she'd been doing with cancer charities showed that it was now more a question of changing attitudes towards screening than raising awareness about it.

83. Dr Tom Crosby highlighted work going on in other parts of the UK to raise awareness in more deprived areas but emphasised the need for evaluation of its effectiveness before embarking on a similar course of action:

> "Scotland are looking at multi-media messages to deprived communities. So, I think this is an area ripe for research, piloting, evaluation of new practices, but we certainly must recognise that as a really real problem. I think we need to do more research into that area and carefully evaluate. It's very easy to knee jerk to a response of awareness campaigns. They are expensive and we need to do them in an evidence-based way."[54]

84. Dr Chris Jones told us:

> "We are worried about the reach into the population, because we know it's often the more disadvantaged populations who don't take up the screening offer."[55]
>
> "But we do know also that, where third sector organisations make an effort to reach into those communities, actually, they can make a difference, so we want to work particularly closely with them in collaboration."[56]

[53] RoP, 29 November 2018, paragraph 237

[54] RoP, 29 November 2018, paragraph 327

[55] RoP, 29 November 2018, paragraph 629

[56] RoP, 29 November 2018, paragraph 631

85. The Royal College of Nursing Wales' evidence states that it is important for improving the uptake of the bowel screening programme to ensure that the appropriate staff with the right skills are deployed in the right areas to encourage uptake:

> "Many patients will, in the first instance, be seen by a Practice Nurse, and it is essential therefore that the nursing workforce is engaged with and involved in any promotion activities related to screening. Ensuring that staff are engaged with on different initiatives, will help to ensure that patients and the general public have access to the right information, and is likely also to help to dispel some of the stigma around the screening tests and help patients to feel more confident in the process."[57]

86. Earlier this year, Cancer Research UK ran a "Be Clear on Cancer" campaign in Wales which aimed to increase participation in the bowel cancer screening programme. Full evaluation is still ongoing, but Bowel Screening Wales has reported an increase in returned kits during the campaign period.

87. Written evidence from the Welsh NHS Confederation highlighted a number of approaches being taken by its members to address this challenge of increasing uptake. Examples of such interventions include:

> "The dissemination of consistent key messages, pre-invitation letters and primary care pilots with non-responder data. Further examples of ongoing work in this area include analysis of Cancer Research UK's 'Be Clear on Cancer' campaign; the development of further pilots in primary care; collaborative projects with charity organisations to develop community engagement workers; and a review of letters and leaflets using behavioural insight techniques that aim to develop culturally and literacy sensitive material."[58]

88. Written evidence from the Welsh Government states:

> "It must also be acknowledged that screening is voluntary and many people actively choose not to participate. Population screening is not without risks and participants need to be fully informed in order to make an informed choice as to whether it is right for them. PHW has focused on improving uptake and promoting informed choice. Since 2015, pre-invitation letters have been sent to targeted participants to

[57] Written evidence, E08

[58] Written evidence, E11

> improve uptake and reduce inequalities in the programme. Since March 2018 information on non-responders has been shared with GPs. BSW has also worked with CRUK to develop a toolkit to increase knowledge of bowel screening among primary care staff. BSW ran the 'Be Clear on Cancer' campaign in conjunction with CRUK earlier this year which showed a sustained increase in completed test kits returned. The implementation of FIT is expected to increase uptake as has been the experience from pilots in England and the roll out in Scotland."[59]

89. Dr Andrew Goodall, Director General for Health and Social Services and Chief Executive of the NHS Wales, told us:

> "Obviously, one of our reasons for moving to this [FIT test] is to actually try to improve our overall uptake for the scheme, because we're aware that whatever we are technically doing to deal with the capacity within the system, there is something, I think, about both awareness for population and community, but also to make sure that the ease of testing is actually dealt with as well. Certainly we've been very encouraged by looking at some of the outputs from the English pilots talking about an uptake increase of around 8 to 10 per cent. Hopefully we would see that translate into Wales, although I do think there are some specific areas that we do need to target as well."[60]

[59] Health, Social Care and Sport Committee, 29 November 2018, paper 9

[60] RoP, 29 November 2018, paragraph 619

7. Conclusions and recommendation

90. We are in agreement with witnesses that bowel screening reduces a person's risk of dying from bowel cancer. However, we are concerned that capacity is overstretched and despite recommendations made in 2013, little progress has been made in addressing the challenges facing endoscopy services.

91. We are pleased that FIT is being introduced and believe it will help to achieve the aim of reducing the number of people dying from bowel cancer in Wales by 15% by 2020 in the group of people invited for screening.

92. However, if survival rates for bowel cancer are to improve, then efforts to detect bowel cancer early through increased uptake of the screening programme, particularly by men in deprived areas need to be increased.

93. We recognise that demand has to be properly managed, but we are disappointed that the thresholds for FIT testing are lower in Wales, and are concerned that without a clear plan to optimise the programme, Wales will fall further behind its counterparts in other parts of the UK. We would like to see the Welsh Government, through the National Endoscopy Improvement Programme, set out milestones for achieving programme optimisation – age and sensitivity, so that these can be measured and progress monitored, hopefully achieving full optimisation earlier than 2023.

94. Waiting time statistics still give cause for concern, and there needs to be a commitment that health boards will deliver a maximum waiting time for diagnostic tests of eight weeks by the end of the year 2019. Investment is needed to get waiting times under control, but there also needs to be a more sustainable approach as outsourcing and insourcing is expensive and does not deliver a long term solution. There is also a need to look at how surveillance cases are managed, as these delays are unacceptable.

95. Changes to the nature and skills of the current workforce are needed, with commitment to not only increase the number of gastroenterologists and other medical endoscopists, but also to develop nurse and other non-medical-endoscopists. It was therefore disappointing to hear that some nurses are paid less than others in Wales to perform endoscopy – this needs to be addressed.

96. We believe it is now time for progress to be made and strong leadership is needed from the Welsh Government to drive this agenda forward.

Recommendation

97. By October 2019, the Welsh Government should work with the National Endoscopy Improvement Programme to create and publish a national endoscopy action plan that addresses current and future demand for services with clear timescales and targets for improvement, to be overseen by the National Endoscopy Programme Board, and must include details of how and when each of the following issues will be addressed and/or taken forward at pace:

- a timetabled programme for increasing FIT sensitivity and age testing with milestones for optimising the programme so that Wales does not fall further behind its UK counterparts;
- address current capacity issues and provide assurances that health boards will deliver a maximum waiting time for diagnostic tests;
- a more sustainable approach to achievement of the waiting time targets, given the short term nature and cost of insourcing and outsourcing;
- immediate action to review how high risk patients are managed, with the development of a sustainable, national approach to managing those requiring ongoing surveillance endoscopic procedures;
- a national approach to service planning to ensure endoscopy services in Wales are in a position to cope with the anticipated increase in referrals from the Bowel Screening Wales programme, including new models of care to increase the number of endoscopists in Wales;
- options for a non-medical accelerated training programme to expand the endoscopy workforce to meet demand including consideration of an endoscopy academy and details of how the different needs of a mixed workforce will be met;
- support for health boards to work towards JAG accreditation, with an expectation that all endoscopy units in Wales will aim to achieve accreditation in the future, ensuring that endoscopy services are being delivered in line with best clinical practice;
- a decision on how and when FIT should be introduced to primary care;
- a more ambitious target than the current 60% of all eligible participants choosing to take part in the bowel cancer screening programme,

including details of how and when this target will be revised and achieved, and efforts to address health inequalities, particularly to increase uptake among men in deprived areas; and

- build on the "Be Clear on Cancer" public awareness campaign to help improve uptake by raising awareness of the changes to the bowel screening programme.

98. In making this recommendation, the Committee would like assurances that there is sufficient senior clinical buy-in at health board level and at Ministerial level. The National Endoscopy Programme Board must be accountable to the Minister to ensure implementation of the national endoscopy action plan is accelerated and delivered at pace.

99. The Committee expects the national endoscopy action plan to be published within six months, which will address each of the issues set out above. The Committee will follow up progress in implementing the action plan twelve months after publication to ensure there has been a measurable improvement in patient outcomes.