

**THE SINGLE CANCER PATHWAY:
NEXT STEPS TO ACHIEVE EARLIER
DIAGNOSIS IN WALES**

Inquiry into Cancer Waiting Times

Cross Party Group on Cancer

November 2020

CHAIR'S FOREWORD

With 1 in 2 of us likely to develop cancer at some point in lives, there is no one in Wales that has not been touched by this disease. Importantly, survival of cancer has improved over time. But studies continue to show that Wales is behind the pack for cancer survival when compared with other countries.

There are rarely such things as silver bullets. However, the evidence is clear that diagnosing more cancers at an earlier stage, when they are more treatable, offers the best hope of saving more lives. The introduction of the Single Cancer Pathway, as a new way to understand diagnostic pathways and measure waiting times, should be welcomed by all. It provides us with the tools to properly identify those opportunities to get better at diagnosing cancer, and the context through which we can make them a reality.

Of course, it is impossible for any discussion about health and social care today to take place without addressing the elephant in the room. The COVID-19 pandemic is the greatest threat and challenge to our NHS, and cancer has not been immune to this. I have heard many experiences of people whose cancer tests and treatments were in some way affected by COVID-19. It has caused considerable anxiety and, most worryingly, concerns that cancer survival could be negatively affected.

At this point, it is important for me to thank those staff across NHS Wales whose tremendous efforts have sought to maintain cancer services as much as possible in the most difficult of circumstances. The past eight months have been like no other for them and without their hard work, the adverse impact on cancer patients would have been even greater.

I have chaired the Cross Party Group on Cancer for almost two years, and I am pleased to see the contribution it has had in keeping cancer high on the political agenda. This inquiry, when we first started in February 2020, was intended to support conversations on how the Single Cancer Pathway moved from a new cancer waiting time metric to fulfil its true potential in transforming cancer diagnosis. While COVID-19 disrupted our work too, I believe this report offers a roadmap for how the Single Cancer Pathway can achieve what its architects ultimately wanted. Cancer will outlast our fight against COVID-19. My hope is that when we look back in years to come, we will be able to recognise the Single Cancer Pathway as a pivotal moment for cancer care in Wales.

My final thanks go to everyone who contributed to this inquiry. We heard from a range of people, from those working in the health service to third sector organisations, as well as, most importantly, people affected by cancer themselves. Thank you also to Cancer Research UK for their continued support as secretariat of the Cross Party Group and in the running of the inquiry.

We must never lose sight of the importance of improving earlier diagnosis and cancer survival – the prize is simply too great.

David Rees MS

Chair of the Cross Party Group on Cancer



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ABOUT THE CROSS PARTY GROUP ON CANCER

The Cross Party Group on Cancer (CPGC) is a group of Members of the Senedd from across the political spectrum. The Group seeks to facilitate discussion between Members of the Senedd, medical professionals, charities, and those affected by cancer. The CPGC aims to identify ways to improve cancer outcomes and patient experience in Wales, and to campaign for those improvements.

The Chair of the CPG is David Rees MS. The membership of the CPGC includes:

- Dawn Bowden MS
- Angela Burns MS
- Andrew RT Davies MS
- Mike Hedges MS
- Bethan Sayed MS
- Caroline Jones MS
- Dai Lloyd MS
- David Rees MS

Meetings of the CPGC are attended by other stakeholders, including third sector organisations, healthcare professionals, industry, and people affected by cancer. The CPGC is supported by Cancer Research UK, who provide the secretariat to the Group.¹

ABOUT THE INQUIRY

In February 2020, the CPGC launched an inquiry into cancer waiting times in Wales. The purpose was to consider how the new Single Cancer Pathway was being implemented during its first year, as well as develop recommendations to identify next steps for cancer diagnosis in Wales.

With the onset of the COVID-19 pandemic in Wales in March 2020, the CPGC took the decision to pause the inquiry. Many of our stakeholders, both in the NHS and third sectors, were directly impacted by COVID-19, with their response to the pandemic rightly taking priority over their capacity to input into this work. We also recognised that everyone was operating in a fast-moving world where the effect of the pandemic on cancer services in Wales was becoming clearer and more concerning.

Following the first pandemic peak, we relaunched the inquiry at a meeting on 14 July 2020. We revised the initial inquiry terms of reference to expand its scope to understand the impact of the pandemic on cancer diagnosis and treatment. However, it was important to still focus the inquiry on the effect and potential of the Single Cancer Pathway on cancer diagnosis. While the pandemic cannot be divorced from cancer outcomes and patient experience in Wales right now, we hope that the recommendations in this report will be helpful for both the recovery of cancer services post-COVID, as well as the ongoing transformation agenda to radically improve cancer outcomes in Wales.

In order to develop the CPGC's understanding of the Single Cancer Pathway, cancer diagnosis, and the impact of COVID-19, we have undertaken a wide-ranging evidence gathering exercise, including:

- A consultation of our stakeholders and beyond. A list of respondents can be found in Appendix A and the consultation questions in Appendix B;
- Three evidence sessions. Details, including witnesses, can be found in Appendix C;
- A survey to gather patient experiences of cancer diagnosis. This was supported by Cancer Research UK's Patient Involvement Team and promoted by the Wales Cancer Alliance. We received 11 patient experiences which, while not representative of people affected by cancer in Wales, provided important insight of what it is like to be diagnosed with cancer;
- Additional desk-based research.

We are grateful to everyone who contributed to the inquiry, including colleagues from the NHS who are under significant pressure due to the pandemic, third sector organisations who are dealing with their own COVID-related challenges, and especially, the 11 people affected by cancer for sharing their own experiences.

The Inquiry Terms of Reference

- To invite and take evidence from each sector involved in cancer diagnosis and to review their aspirations for the future of cancer care in Wales, including: clinical leads; charities; healthcare professionals; delivery bodies and patients;
- To understand the patient experience of the Single Cancer Pathway;
- To understand how the Single Cancer Pathway can improve cancer waiting times and cancer outcomes for people in Wales;
- To understand both the impact of the COVID-19 pandemic on the Single Cancer Pathway and any opportunities it might present;
- And to make recommendations to Welsh Government based on this evidence.

EXECUTIVE SUMMARY

1. Cancer continues to place a significant burden on Welsh life, with around 19,300 diagnoses² and around 8,800 deaths every year³. There are 170,000 people in Wales today who have been diagnosed with cancer.⁴ With cancer incidence set to rise in part due to an ageing population, it is estimated that the number of people living with cancer in Wales will rise to 200,000 by 2025 and 300,000 by 2040.⁵ While cancer survival has improved in recent decades, Wales still has some way to catch up with the best performing nations.⁶
2. Improving cancer survival will require diagnosing more cancers at an earlier and more treatable stage. Cancer waiting times have been one metric to measure the performance of diagnostic pathways. However, they are not perfect. Traditional cancer waiting time targets have not provided a complete picture with the time from referral to diagnosis not measured, while those on non-urgent pathways are only tracked between their diagnosis and treatment. This makes it difficult for cancer waiting times to be used to full effect – encouraging the health system to diagnose patients in a timely way, as well as identifying bottlenecks where diagnostic pathways can be improved.
3. In November 2018, the Welsh Government took the bold decision to change cancer waiting times and introduce a Single Cancer Pathway.⁷ This new metric sought to include all cancer patients, regardless of their route to diagnosis. It also started the clock at point of suspicion of cancer, rather than only at an urgent referral, up to the start of treatment, making it more ambitious than any other cancer waiting time metric in the UK.
4. The Single Cancer Pathway began in June 2019, with the first data released in August 2020. The early trend has been largely static, with around 75% of patients across Wales starting treatment within 62 days of their cancer being suspected. However, there has been variation between and within health boards over time.⁸
5. While it is admirable to have a more comprehensive and transparent cancer waiting time metric, the Single Cancer Pathway was envisaged to offer more than better reporting. It was to be a lever for change. Diagnosing cancers earlier is a complex problem and a new metric for the start and end of a patient's diagnosis journey would not, on its own, shift overall stage at diagnosis in a meaningful way. However, introducing a new, more ambitious cancer waiting time system would create the environment by which difficult questions can be addressed, such as increasing capacity in diagnostics, workforce, optimising pathways, and data and informatics. If the Single Cancer Pathway is one piece of the puzzle, it is the one that others connect to, in order to build the broader picture.
6. That opportunity was put on hold by the COVID-19 pandemic. Cancer has been severely affected by the pandemic, with significant disruption to diagnostic and treatment services, especially during the peak of the first wave. Reporting against the Single Cancer Pathway was paused in order to relieve as much pressure on the NHS as possible.
7. Since the start of the pandemic, the Welsh Government and NHS Wales have repeated the message that essential services, including cancer diagnosis and treatment, must continue. As health services attempt to recover from the first wave and face the challenge of more COVID-19 cases and forthcoming winter pressures, cancer must remain a key priority going forward. If services experience the same level of disruption through future waves, it could be devastating for cancer patients as their diagnosis and treatment are likely to be delayed. It is critical that cancer services are protected over the coming months.

8. Furthermore, the first pandemic wave created a backlog of cancer cases that have yet to be fully realised. Many of the people who put off seeing their GP for fear of COVID-19 or concern about adding to NHS pressures, will still have those symptoms, which could be cancer. The worry is that when they do present, their diagnosis will be for a later stage, and less treatable, cancer. Reducing this backlog as quickly and safely as possible will add further strain to diagnostic services, with additional capacity and plugging of workforce gaps urgently needed.
9. It is still important to keep sight of the Single Cancer Pathway as an intrinsically positive measure. Resuming Single Cancer Pathway reporting would present an opportunity to restart and reset, particularly for those conversations on where improvements to diagnostic pathways can and should be made. One silver lining of the pandemic has been the accelerated innovation we have seen in parts of the health service as it has tried to manage the most challenging of circumstances. Fostering this spirit will be essential in order to drive transformation in the way we diagnose and treat cancer in Wales.
10. The Cancer Delivery Plan 2016 was due to come to an end in 2020. While the Welsh Government has announced there will be a successor, more detail is needed on what a new cancer strategy could look like. The challenge facing cancer services is immense. There was a clear need to improve cancer diagnosis, treatment and care before the pandemic hit. COVID-19 has set us back further. A new cancer strategy needs to be bold and ambitious in tackling these challenges. Delivering the full potential of the Single Cancer Pathway must be a central component of any strategy. Given the time needed to develop this, the Welsh Government should also commit to a COVID-19 recovery plan for cancer, to address some of the immediate challenges facing diagnostic and cancer services, as well as provide the foundation upon which a comprehensive cancer strategy can be established. The CPGC is keen to work with the Welsh Government to help deliver on this. Many of the recommendations that follow in this report can inform both pieces of work.

SUMMARY OF RECOMMENDATIONS

No.	Theme	Recommendation	Pg.
1	Single Cancer Pathway	The Welsh Government and NHS Wales should urgently commit to developing a new comprehensive cancer strategy to follow the Cancer Delivery Plan. This should include measures to make the Single Cancer Pathway a success in driving the earlier diagnosis of cancer.	17
2	Single Cancer Pathway	The Welsh Government should restart reporting against the Single Cancer Pathway as a matter of urgency. This should include: <ul style="list-style-type: none"> • a performance target for the Single Cancer Pathway for local health boards to comply with. Such a target should be attainable but challenging enough to drive improvement in the NHS; • alongside a 62-day wait target, an additional 28-day point of suspicion to diagnosis target for local health boards to report against; • data on waiting times that is broken down by tumour site, health board, age, and referral route; • the removal of suspensions by local health boards to ensure consistency and accuracy of reporting patient experience in diagnosis; and • regular thematic reports of cancer waiting time breaches produced by local health boards to understand any action that can be taken to improve waiting time performance. 	19
3	COVID-19	The Welsh Government must urgently publish a COVID-19 Cancer Recovery Plan to maintain cancer services and provide reassurance to the public that cancer services are continuing safely during the pandemic. This should also include: <ul style="list-style-type: none"> • a wide-ranging mass-media communications campaign, encouraging anyone with concerning symptoms that may be cancer to seek help from primary care, and provide reassurance that people can be seen and treated safely. This should be targeted to the right population groups to avoid exacerbating health inequalities; and • details on how all local health boards will maintain COVID-secure 'green' sites, with all the robust measures required, to shore up capacity and maintain cancer surgery, as well as endoscopy procedures. 	25
4	Public awareness	NHS Wales and the Welsh Government should consider running a long-term programme of public awareness campaigns on the signs and symptoms of cancer, with an initial focus on lung cancer.	26
5	Primary care	The Wales Cancer Network should monitor the national adoption and implementation of NICE NG12 guidelines for suspected cancer, including increasing GP direct access to diagnostic tests.	27

6	Primary care	Local health boards must ensure that there is good communication between primary and secondary care to ensure consistent urgent cancer referral standards, as well as feedback when a referral is deemed inappropriate. This should include making use of third sector programmes to optimise this interface.	28
7	Primary care	Local health boards and primary care clusters should ensure that there is protected time for cancer related continued professional development, which includes working with third sector organisations for GP and practice staff learning.	28
8	Primary care	Referrers should explain to patients they refer for suspected cancer that they are being placed on a cancer pathway, which could help reduce 'did not attends' (DNAs) in secondary care. This should be done sensitively and with signposting to third sector organisations for patient information and support.	28
9	Cancer screening	The Welsh Government, Public Health Wales, and the cancer screening programmes should agree optimisation plans to improve the effectiveness of cancer screening including increasing informed uptake and reducing inequalities, with particular focus on bowel and cervical screening.	29
10	Cancer screening	The Wales Cancer Network should continue to scope out a national lung screening programme for Wales, including developing pilots to understand how this might work in practice.	30
11	Cancer screening	Public Health Wales should share data on uptake in cancer screening programmes with primary care to enable GPs to support informed uptake.	30
12	Diagnostic capacity	The Welsh Government, Health Education and Improvement Wales and the Wales Cancer Network should develop a fully funded plan to increase capacity in cancer diagnostics, including: <ul style="list-style-type: none"> • a cancer workforce plan, including the diagnostic workforce, to identify short- and longer-term measures to expand the cancer workforce to meet rising demand for cancer diagnosis and treatment; • a national skills mix approach for diagnostic services and identify opportunities to add capacity across Wales; and • an ambitious capital spending programme to increase the number of diagnostic equipment needed, particularly MRI and CT scanners, to ensure adequate capacity to manage rising demand for diagnostic services. 	32
13	Diagnostic capacity	The Welsh Government should publish an update on: <ul style="list-style-type: none"> • the progress of both the Statement of Intent for Diagnostic Imaging Services and the National Imaging Academy, including the contribution they are making to increasing capacity in diagnostic imaging services; 	33

		<ul style="list-style-type: none"> • progress of the National Endoscopy Programme Action Plan, including any divergence from the plan due to the COVID-19 pandemic; and • the progress of the Pathology Statement of Intent to improve capacity in cellular pathology. 	
14	Diagnostic capacity	The Welsh Government should commission a feasibility study into a national pathology academy to support the training, recruitment and retention of cellular pathologists.	33
15	Rapid diagnostic clinics	Local health boards should publish their plans for the development of rapid diagnostic clinics, including timescales and how they could play a role in the wider recovery of diagnostic services from the COVID-19 pandemic.	34
16	National Optimal Pathways	Each local health board should report to the Welsh Government and the Wales Cancer Network how far their existing diagnostic pathways are from meeting the standards within the national optimal pathways, how regional working can maximise capacity, and identify any additional investment required to deliver them.	35
17	Start of treatment	The Wales Cancer Network should establish a standardised approach to pre-habilitation to support local health boards in developing this across their pathways.	36
18	Patient experience	Following the next Cancer Patient Experience Survey, the Wales Cancer Network, supported by the third sector, should develop a plan to ensure every cancer patient has a key worker and receives a holistic needs assessment.	37
19	Data and informatics	<p>The Welsh Government should outline its plan for the future of cancer data and informatics, including:</p> <ul style="list-style-type: none"> • a statement on progress in the development of a replacement for the CaNISC informatics system. This should include the timeframes for when a new system will be operational; and • how the Single Cancer Pathway can maximise opportunities to exploit data to build understanding of patient experience and where improvements can be made across pathways, for example, exploring the feasibility of routine reporting of routes to diagnosis. This should include both health boards and the national cancer registry having sufficient staff to process and analyse data in a timely way. 	38

CANCER IN WALES

11. Every year, around 19,300 people are diagnosed with cancer in Wales.⁹ It remains the biggest killer, resulting in around 8,800 deaths annually.¹⁰ 1 in 2 of people in the UK born after 1960 will develop cancer in their lifetime.¹¹ It has a significant burden on our health service, our society, and for ourselves and our loved ones. There are 170,000 people in Wales today who have been diagnosed with cancer.¹² With cancer incidence set to rise in part due to an ageing population, it is estimated that the number of people living with cancer in Wales will rise to 200,000 by 2025 and 300,000 by 2040.¹³
12. Cancer survival has improved in recent decades and this important progress should be welcomed. Today, around half of cancer patients in England and Wales survive their cancer for ten years or more.¹⁴ However, international studies consistently show comparable countries outperforming Wales for cancer survival.¹⁵ If Wales was able to catch up with the best performing countries, many lives could be saved.
13. Diagnosing cancer at an earlier stage gives the best chances of improved survival. Cancers diagnosed at stage I or II tend to be easier to treat successfully compared to stage III and IV cancers.

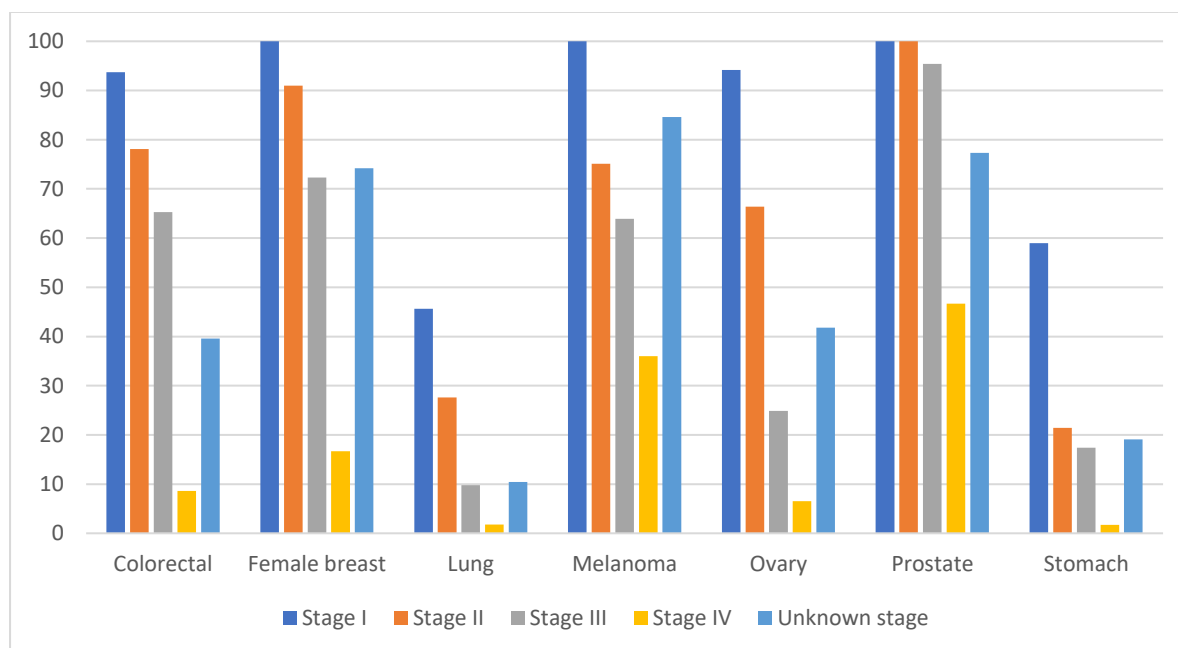


Fig 1. Five-year cancer survival by stage at diagnosis in Wales, 2011-2016¹⁶

14. Currently, only around half of cancers are diagnosed at stage I or II, showing that there is significant improvement to be made. This hides the variation that exists between different cancers, for example skin and female breast cancers having a much higher proportion of stage I and II diagnoses, compared to others, such as lung and pancreatic cancers.

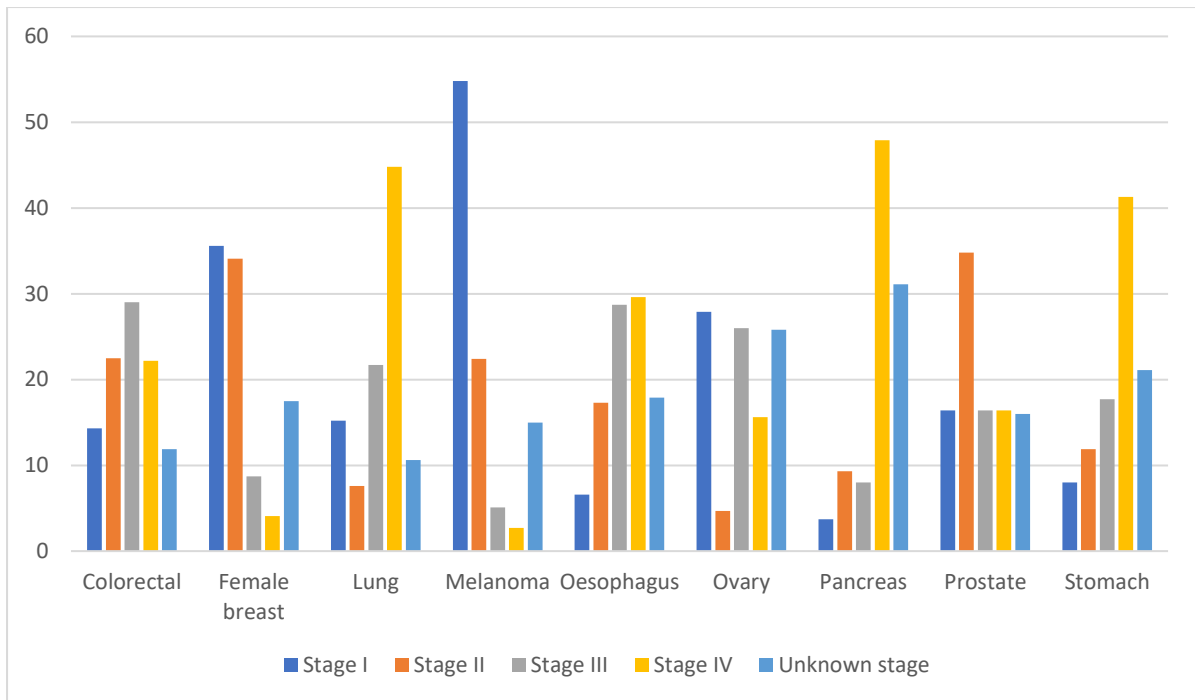


Fig 2. Cancer incidence by stage at diagnosis in Wales, 2011-2017¹⁷

15. Diagnosis of cancer is not a single event but a process, involving a number of steps and different factors. It can be broken down into several intervals when key actions occur.

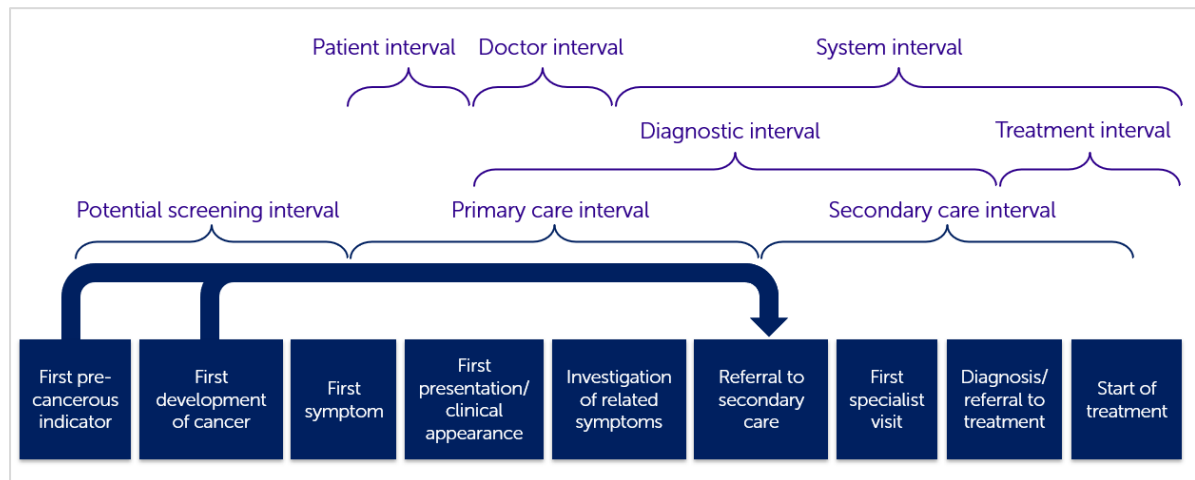


Fig 3. Intervals across the diagnostic pathway¹⁸

16. As such, achieving the earlier diagnosis of cancer is not simple but a complex puzzle. There are opportunities throughout the pathway to speed up processes, remove barriers and bottlenecks, and improve patient experience. The Single Cancer Pathway works across the entire diagnostic pathway and could provide the driver for the improvements needed to diagnose cancers earlier. The following sections of this report will consider where those opportunities might be and offer recommendations accordingly.

THE SINGLE CANCER PATHWAY

17. On 22 November 2018, then Cabinet Secretary for Health and Social Services, Vaughan Gething AM, announced the Welsh Government’s intention to introduce a new Single Cancer Pathway for the diagnosis of cancer. This new approach would begin reporting in June 2019 and include £3 million annual funding to support its implementation.

“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. As well as enabling a more accurate, single measure of waits in the health system, the need to standardise what is being measured has proved to be a unique opportunity to review the quality of pathways and tackle variation in clinical practice across Wales. This is a significant piece of work for the NHS.”

Vaughan Gething AM, Cabinet Secretary for Health and Social Services, 22 November 2018¹⁹

18. The Single Cancer Pathway was to replace the previous cancer waiting time measures:

Pathway	Waiting time	Target wait	Compliance target
Urgent Suspected Cancer (USC)	GP referral to start of treatment	62 days	95%
Non Urgent Suspected Cancer (nUSC)	Diagnosis to start of treatment	31 days	98%

19. USC patients are those who have presented to their GP with red flag symptoms, as described in NICE NG12 guidelines on suspected cancer, such as a persistent cough, lump, change in bowel habits.²⁰ These patients are placed on an urgent pathway for the appropriate diagnostic test(s) and/or specialist appointment. This pathway measures the period of time from the GP referral through to the start of treatment, once diagnosed.

20. Other patients who are diagnosed through a different route are captured through the nUSC pathway. This might include someone referred by a GP for diagnostics for concerning but non-specific symptoms that do not necessarily suggest cancer. This pathway only measures from the point of diagnosis and decision to treat, up to the start of a patient’s treatment for cancer.

21. Both cancer waiting time metrics had high performance targets set against them, which were regularly missed. In May 2019, the final month before the Single Cancer Pathway was introduced:

- 79.6% of patients started their treatment within 62 days of a GP referral onto the USC pathway. The target of 95% was last achieved in August 2010.
- 96.5% of patients started their treatment within 31 days of a cancer diagnosis and decision to treat on a nUSC pathway. The target of 98% last achieved in November 2017.²¹

22. Aside from failing to meet targets, this traditional approach to cancer waiting times did not present a true picture of diagnostic performance and patient experience in two key ways:

- Patients diagnosed through a nUSC route were not monitored through their diagnostic phase, making it difficult to identify the waits they are experiencing. As some of these patients might have presented with non-specific symptoms, it could be that they are bouncing between primary and secondary care for a significant period of time before their diagnosis.

- The USC cancer waiting time only captures the urgent referral and start of treatment, making it difficult to see where the cause(s) for missed targets could be.

23. The Single Cancer Pathway aims to address these issues through a very different approach to cancer waiting times:

Pathway	Waiting time	Target wait	Compliance target
Single Cancer Pathway	Point of suspicion to start of treatment	62 days	N/A

24. The Single Cancer Pathway is unique in its approach to cancer waiting times as it contains the following features:

- It includes all cancer patients regardless of their route to diagnosis
- It begins at the point of suspicion. For some patients, this may still be the point that a GP makes an urgent cancer referral. However, for others, it could be following an outpatient appointment, cancer screening, A&E attendance, or elsewhere.

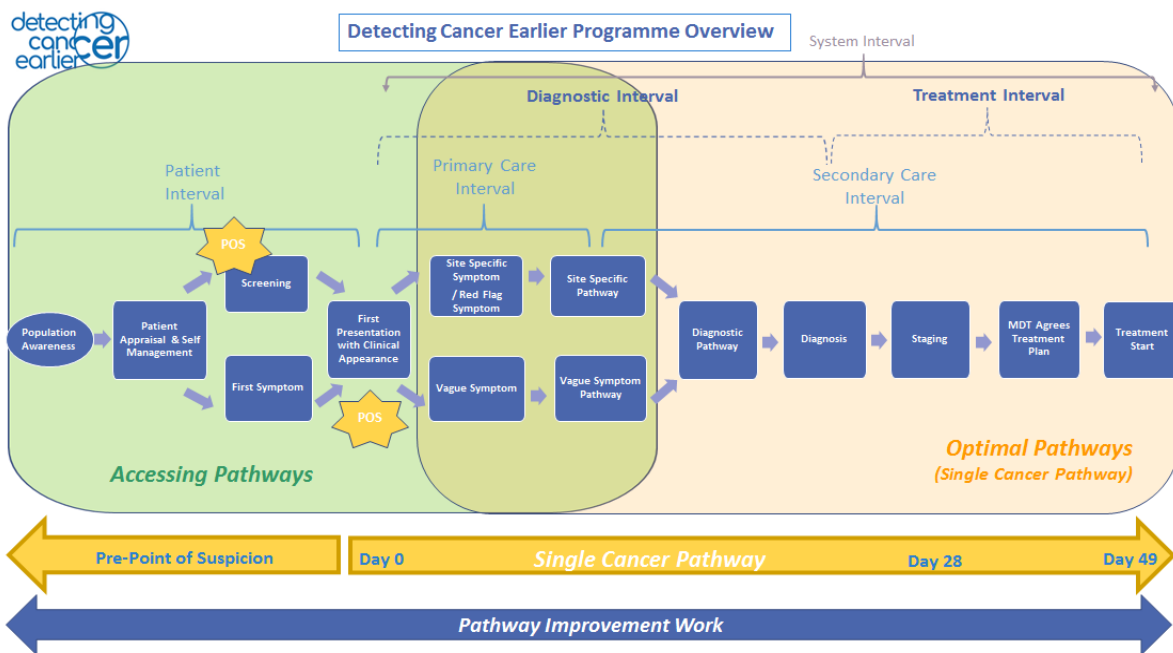


Fig 4. Wales Cancer Network schematic of the Single Cancer Pathway. This sets out a simplified pathway and aspirations to aim for.²²

25. It should be noted that, to date, no target has been set for local health boards on the number of patients who begin cancer treatment within 62 days of the point of suspicion. There are also no further formal targets, such as the number of days a patient should receive a diagnosis following suspicion of cancer.
26. Throughout our inquiry, we have heard near universal support for the implementation of the Single Cancer Pathway and the principles that underpin it. In particular, the opportunity to identify and monitor the diagnostic experience of patients through a nUSC pathway was welcomed by both clinical colleagues and third sector organisations who responded to our inquiry. Many thought it would also offer the chance to examine and improve patient experience

during a cancer diagnosis. Evidence suggests that a timely diagnosis is important for patients, with managed routes to diagnosis associated with better outcomes.²³

27. The true value of the Single Cancer Pathway is whether it can provide the levers to drive the earlier diagnosis of cancer in Wales. A substantial change to ways of working, as proposed through the Single Cancer Pathway, provides the potential for a national conversation and major change in how well our diagnostic pathways operate. In 2018, Cancer Research UK modelled which interventions could increase the proportion of earlier stage cancer diagnoses in England, visualising this in an Early Diagnosis Waterfall. It is easy to see how many of these interventions are relevant in Wales and how the Single Cancer Pathway could act as a driver to deliver such measures.

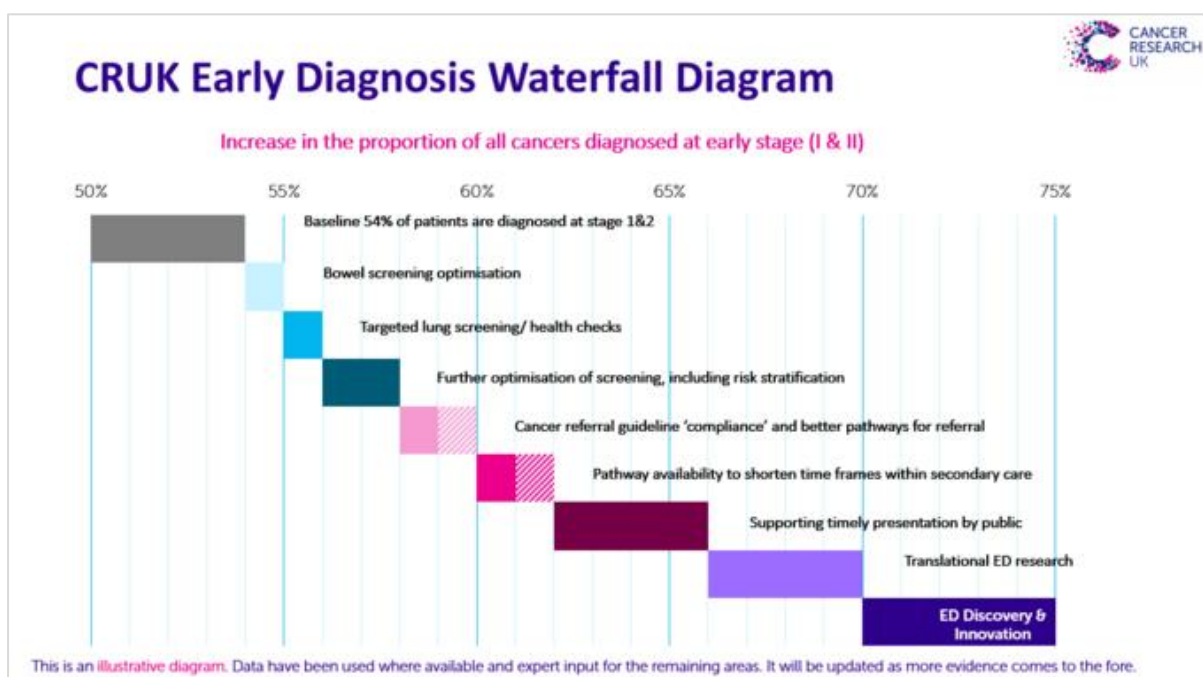


Fig 5. Cancer Research UK early diagnosis waterfall²⁴

28. Many of the interventions set out in this model are relevant to Wales. While they may sit outside the scope of the Single Cancer Pathway, the new cancer waiting time system potentially offers the right environment through which such measures can be explored and implemented in Wales, thereby leading to a change in the distribution of early/late stage cancer diagnoses.
29. Unfortunately, a theme from both third sector and clinical respondents to our inquiry was pessimism about how effective the Single Cancer Pathway would be in achieving this aim, unless additional resource and investment was put into diagnostic services. It was concerning when one clinician told us that the Single Cancer Pathway felt more “aspirational” without a clearer plan for how the target could be achieved.
30. This view is backed up by the early results of the Single Cancer Pathway. From its launch in June 2019 to January 2020, the proportion of patients starting treatment within 62 days of their point of suspicion remained stubbornly flat around the 75% mark:

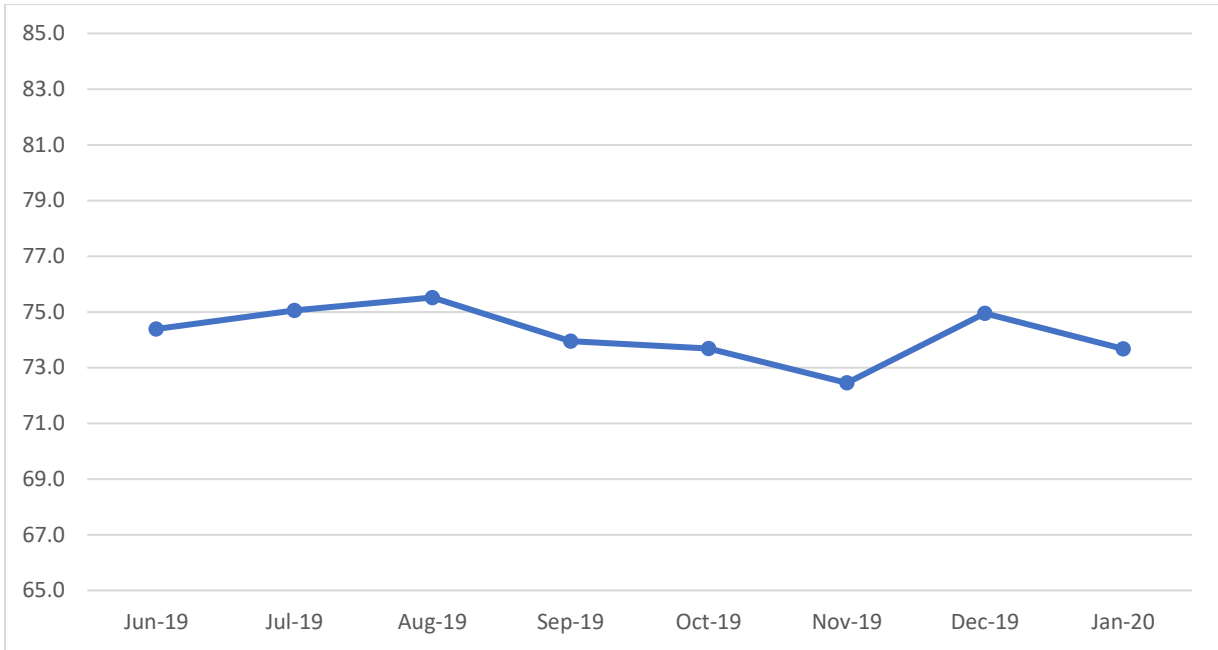


Fig 6. Single Cancer Pathway performance – percentage starting treatment within 62 days of suspicion of cancer (including suspensions)²⁵

31. However, significant variation can be seen, both between local health boards, and even within local health boards from month to month:

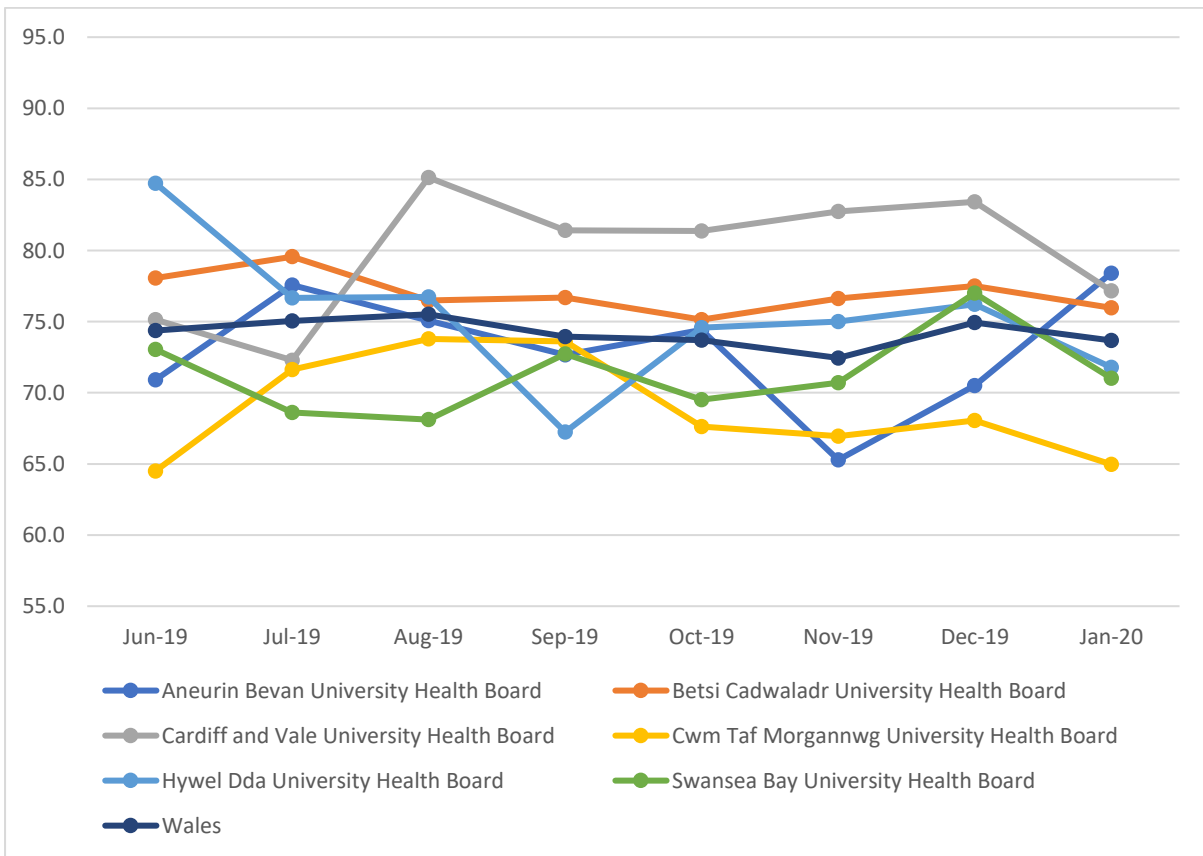


Fig 7. Single Cancer Pathway performance by local health board – percentage starting treatment within 62 days of suspicion of cancer (including suspensions)²⁶

32. These data demonstrate that simply implementing the Single Cancer Pathway is insufficient to improve waiting times, nor would it likely be enough to diagnose cancers earlier. While additional work alongside the Single Cancer Pathway is underway, as will be detailed throughout this report, it is clear that more is needed. For the Single Cancer Pathway to be more than a new way to measure waiting times, a national, fully funded plan is required.

33. The World Health Organisation recommends that every country has a cancer strategy, “no matter what resource constraints [it] faces,” and it is internationally recognised that a comprehensive cancer strategy with clear, measurable ambitions is key to improving outcomes.²⁷ The Cancer Delivery Plan 2016-2020 is due to come to an end soon. On 11 March 2020, Deputy Minister for Health and Social Services, Julie Morgan MS, announced:

“Members will be aware that we’ve had a cancer delivery plan in place since 2014. This has a significant focus on earlier detection, and we have for some time met the World Health Organisation’s call for its members to have in place a cancer control programme. But you will be aware ... that a number of national disease-specific plans are due to come to an end in December this year, and we’ve been giving significant attention to what should replace them. So, I am pleased to confirm today, perhaps somewhat earlier than intended, that the Minister has asked officials to press ahead with developing a successor approach to the cancer delivery plan [and] ... that a one-year extension is granted in order that we can phase in successor arrangements..”²⁸

34. While no further details have been announced on what a “successor approach” to the Cancer Delivery Plan might be, there is an urgent need for Wales to set a new comprehensive cancer strategy.

35. The Single Cancer Pathway could serve as a centrepiece of a new cancer strategy, acting as a vehicle to drive transformation in the diagnosis of cancer. A strategy is needed to also ensure that cancer services right across the pathway see transformation to guarantee they are fit for the future, where rising demand can be met, and the best outcomes achieved. Many of the following recommendations in this report should form the basis of this new strategy. It is also important to recognise that, without adequate investment, resource and leadership, it will be impossible to make transformation a reality – either through the Single Cancer Pathway, or in other areas of cancer services.

RECOMMENDATION 1: The Welsh Government and NHS Wales should urgently commit to developing a new comprehensive cancer strategy to follow the Cancer Delivery Plan. This should include measures to make the Single Cancer Pathway a success in driving the earlier diagnosis of cancer.

36. On 13 March 2020, Vaughan Gething MS announced that NHS performance targets, including cancer waiting times would be relaxed to relieve pressure on the health service as the pandemic took hold in Wales.²⁹ This means that the most recent Single Cancer Pathway data is January 2020. Since then, data has been limited to the number of people entering the pathway and starting treatment. This makes it difficult to understand the full impact the pandemic has had on cancer diagnosis in Wales. As cancer services are now in a recovery phase after the initial shock of the pandemic, it is imperative that reporting against the Single Cancer Pathway is restarted urgently so the public can have more confidence that diagnostic and cancer services are operating despite COVID-19.

37. Since June 2019, local health boards have been asked to report the Single Cancer Pathway alongside the previous USC and nUSC waiting times. Now that the Single Cancer Pathway has

been established, moving to a system where it is only necessary for health boards to report against the Single Cancer Pathway would reduce some of the administrative burden on them at this time. The Health Minister has indicated that when Single Cancer Pathway reporting resumes, both USC and nUSC waiting times will no longer be reported.³⁰ It is however important that we do not lose some of the valuable insight from the previous system, for example, the number of people urgently referred by their GP for suspected cancer.

38. With no Single Cancer Pathway performance target for local health boards and NHS Wales to collectively achieve, it is difficult to judge how well cancer diagnostic services are performing, or for health boards to know what standard they are being judged against. Given both the impact of COVID-19, and that the Single Cancer Pathway is a more ambitious metric than the previous system, it may not be appropriate to set the same target as the USC pathway. However, it is important that an achievable, yet challenging, target is set to provide the incentive for improvement in diagnostic services.
39. During the inquiry we also heard from clinicians and stakeholders that the approach to waiting times under the Single Cancer Pathway is flawed in two ways. Firstly, the only measurement is from point of suspicion to start of cancer treatment and therefore lacks the granularity required to deliver meaningful analysis and improvements. However, we heard from health boards that across Wales, the process of starting treatment following a diagnosis works relatively well. This is backed up by the fact that treatment waiting times for nUSC patients tend to be closer to hitting the overall target. Within current reporting, the period from GP referral/point of suspicion to a cancer diagnosis lacks clarity. It is this period that the Single Cancer Pathway seeks to improve and where the greatest gains for earlier diagnosis and cancer survival can be made. National guidance for the Single Cancer Pathway indicates that a diagnosis should be made within 28 days of the point of suspicion in order for the Single Cancer Pathway to be achieved.³¹ This would be similar to the Faster Diagnostic Standard being pursued in England.³² We believe that this should be made a formal performance target. This will make it easier to assess the impact of the Single Cancer Pathway, while indicating to health boards that this is a priority.
40. The second flaw in the current approach to the Single Cancer Pathway is that the data are only reported in total for each local health board. In comparison, waiting times for both the USC and nUSC can be broken down by tumour site, giving a much richer insight into which patients are experiencing longer waits. The data quality of the Single Cancer Pathway must be improved to include different tumour sites, as well as for children, teenagers and young adults (CTYA), while taking into account all of the usual safeguards against patient identification in published statistics.
41. Finally, the Single Cancer Pathway currently allows for suspensions of patient waits in some circumstances. This might be if a patient regularly fails to attend appointments or is uncontactable, or for medical reasons, such as pregnancy or another cancer diagnosis meaning that treatment is paused. However, this prevents a full and undistorted insight into cancer waiting times, particularly if the approach to suspensions is inconsistent between local health boards. Similarly, it does not allow for understanding and learning of why patients might not complete the Single Cancer Pathway, and identify potential action that could remedy this, such as improved patient information. Suspensions should be removed, while any target for the Single Cancer Pathway allowing for some slippage so that local health boards are not unfairly penalised for issues outside of their control.

RECOMMENDATION 2: The Welsh Government should restart reporting against the Single Cancer Pathway as a matter of urgency. This should include:

- *a performance target for the Single Cancer Pathway for local health boards to comply with. Such a target should be attainable but challenging enough to drive improvement in the NHS;*
- *alongside a 62-day wait target, an additional 28-day point of suspicion to diagnosis target for local health boards to report against;*
- *data on waiting times that is broken down by tumour site, health board, age, and referral route;*
- *the removal of suspensions by local health boards to ensure consistency and accuracy of reporting patient experience in diagnosis; and*
- *regular thematic reports of cancer waiting time breaches produced by local health boards to understand any action that can be taken to improve waiting time performance.*

IMPACT OF COVID-19 ON CANCER DIAGNOSIS AND TREATMENT

42. Like many aspects of society, the economy, and the health service, cancer has been severely affected by the impact of the COVID-19 pandemic in Wales. During the first peak of the pandemic, cancer and diagnostic services experienced major disruption, while the number of people entering the Single Cancer Pathway dropped significantly. Cancer Research UK's Cancer Patient Experience Survey in May 2020 found 40% of Welsh respondents reporting that cancer testing they would usually expect was delayed, cancelled, or altered; while 27% said that their cancer treatment was affected.³³
43. While the Welsh Government and NHS Wales sought to prioritise cancer services as an "essential service" to continue despite the pandemic,³⁴ there can be no doubt that COVID-19 will set Wales back with regards to cancer outcomes and survival.
44. For the Single Cancer Pathway, the COVID-19 pandemic has, for all intents and purposes, shut down the process of reporting against the new system and using the insights it offers to better understand the diagnostic pathway, patient experience and opportunities for improvement. As one health board told us, the pandemic could not have hit at a worse time for the Single Cancer Pathway.
45. From March 2020 to August 2020, there were around 18,200 fewer urgent referrals for suspected cancer from GPs in Wales. The biggest fall in urgent referrals occurred in April, at the height of lockdown, when the number of referrals was 63% lower than in April 2019. The latest available data, for August 2020, show that urgent referrals were still down by 9% compared to August 2019. Lung cancer has been the slowest to recover during this period, from a 72% drop in April to still down by 26% in August. Suspected skin, urological, and lower gastrointestinal cancers have been the next slowest to recover so far.³⁵
46. The consensus we heard both in our evidence sessions and in written submissions was that fewer people contacted their GP during this period, accounting for much of this drop in urgent referrals. The central public message to stay at home may have put some people off from seeking help from their GP if they experienced concerning symptoms, because of fear of catching COVID-19 or a concern of burdening an NHS very publicly under strain. Some respondents noted that some Welsh communities are already stoic in their attitudes towards health and would be less likely to seek help for health concerns in normal times. The pandemic has exacerbated many of these barriers. In a Health, Social Care and Sport Committee evidence session on 16 July 2020, Dr Andrew Goodall, Director General of Health and Social Services at the Welsh Government and Chief Executive of NHS Wales, said that primary care had experienced a drop of 30 to 35% in attendances during the pandemic.³⁶ This was despite the change in how primary care has operated with increased provision of remote telephone and video appointments to avoid patients having to attend appointments in person, noting that this approach could itself be a barrier for some people's ability to access primary care.
47. This effect was felt further through the diagnostic pathway too. Some health boards reported an increase in the number of 'Did Not Attends' (DNAs) for appointments in hospital, assumed to be because of concern about the risk of COVID-19 in hospital settings. At a time when capacity has been stretched by the pandemic, DNAs only add to the pressure facing diagnostic services right now.

"I attended clinic once during lockdown. I discovered a new lump and was given an appointment to attend clinic 3 working days after phoning the breast care team. I was

amazed at the speed. I noticed however that the clinic was much quieter than usual. I was seen on time - usually I expect to wait an hour or more. I've no idea if women are choosing not to attend or are not being offered appointments."

Diagnosed breast cancer, 2015

48. The Welsh Government and NHS Wales have sought to reassure the public that health services are available, and people can access care safely during this time, both in its regular press conferences and through wider traditional and social media.³⁷ Urgent cancer referrals have yet to reach pre-pandemic levels, when they would be expected to exceed them as the backlog of cancer cases starts to come through the system. That this has not happened suggests that further communication campaigns are necessary to reassure and encourage people to contact their GP if they experience concerning symptoms. The Welsh Government also needs to carefully consider its message for accessing the NHS during the winter. Previous years' campaigns, such as Choose Well, which have advised people to not use NHS services inappropriately, may have the unintended consequence of putting off people with genuine needs from accessing the care they need.
49. The impact of the pandemic has meant that there are people in Wales who have concerning symptoms but have yet to be diagnosed for cancer. The concern from so many who inputted into our inquiry is the effect this will have on cancer survival. Those cancers that have gone undiagnosed during the pandemic may progress past the point at which they can be treated successfully. When the NHS fully recovers from the first wave of COVID-19, it could find another crisis coming, this time of later stage cancers, which will be more difficult to treat. It is essential that additional capacity is found to conduct the extra cancer tests needed to deal with backlogs as quickly and safely as possible, to increase each person's chance of an early diagnosis.

"I attended my 3-year review just prior to lockdown. I had my blood test and a bowel screening test both of which were OK, but I should have had my CT scan and sigmoidoscopy within about 6 weeks. I'm still waiting for those."

Diagnosed bowel cancer, 2017

"[Partner's] diagnosis took a while due to COVID and it was given over the phone by a doctor not known to us. Very traumatic."

Partner diagnosed head and neck cancer, 2020

50. This issue has been exacerbated by the effect of the pandemic on NHS workforce absences. Even pre-pandemic, there were chronic shortages in the diagnostic workforce which were impacting on capacity for cancer tests.³⁸ However, staff illness and requirements to self-isolate have added to this pressure. In week of 14 April to 20 April 2020, 2.5% of the total NHS workforce were absent due to COVID-19, while a further 5.0% were self-isolating.³⁹ Furthermore, we are aware of some staff across the NHS in Wales, including those involved in cancer care and clinical trials, being redeployed to assist with treatment and care of COVID-19 as hospitalisations increased. There is now the additional risk of burnout among NHS staff through both future pandemic waves and winter pressures that could see this situation made worse in future.

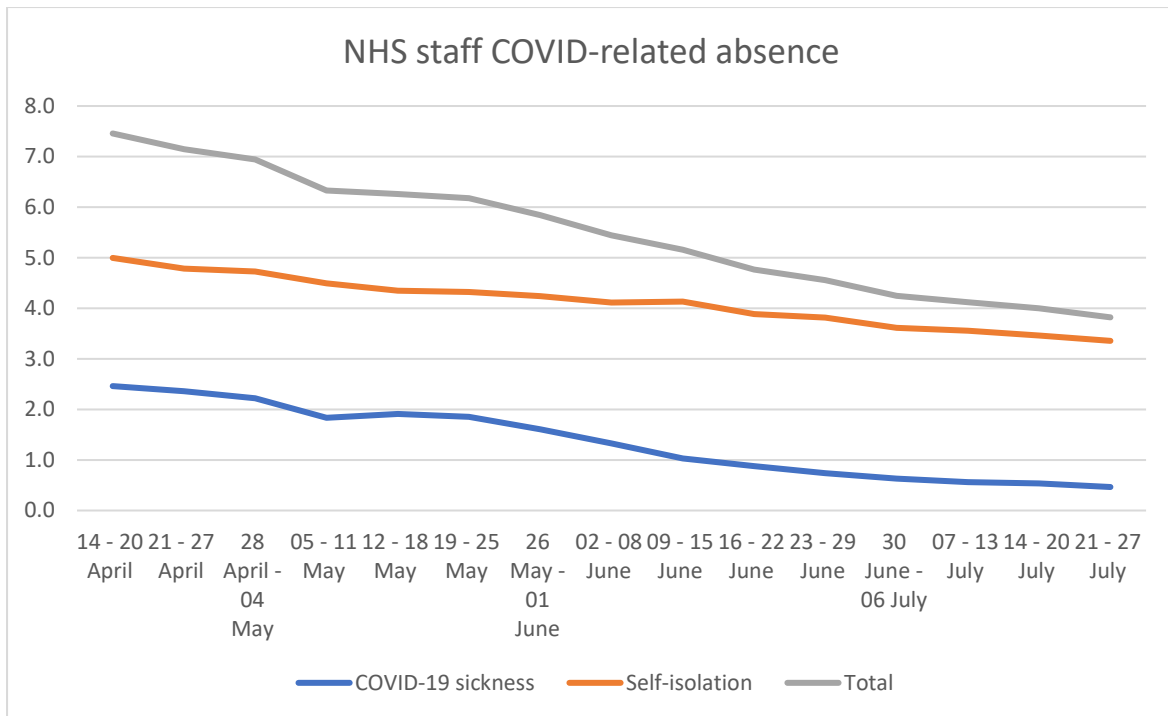


Fig 8. NHS staff COVID-related absences 14 April – 27 July 2020⁴⁰

51. Endoscopy services were the hardest hit of all diagnostics, following initial advice from the British Society of Gastroenterology (BSG) that stated that all but emergency endoscopy procedures should be paused, given the increased risk of COVID-19 due to the aerosol-generating nature of such procedures.⁴¹ During the first wave of the pandemic, the number of people waiting for a diagnostic endoscopy increased from around 11,900 at the end of March to around 15,700 at the end of July.⁴² This will not be helped by the reduction in capacity caused by enhanced infection control measures, such as the additional PPE and extra equipment cleaning requirements, which is impacting imaging services too.
52. Cancer screening programmes were officially paused on 20 March 2020, meaning that no invitations for bowel, breast or cervical screening were sent to eligible participants for several months.⁴³ Modelling by Cancer Research UK suggests that every month, 55,600 people would normally be invited to take part in one of the three cancer screening programmes in Wales, leading to the diagnosis of at least 80 cancers, plus additional pre-cancerous changes detected and treated.⁴⁴ Many of these would likely be very early stage and treatable cancers. While screening programmes were paused to protect the public and NHS staff, this has only added to the backlog of cancer diagnoses that need to be addressed. We are pleased that all three cancer screening programmes have now restarted. However, clearing this backlog will take months and require additional capacity in diagnostic services to manage the flow of participants requiring further tests.
53. One silver lining of the pandemic has been the fast pace of innovation that has been found throughout the NHS since March. Through the need to work differently and introduce change urgently, we have heard of several innovations in diagnostics that have improved care and patient experience, including:

- The acceleration of the introduction of faecal immunochemical testing (FIT) for patients presenting with bowel symptoms, to help triage patients who need further diagnostic testing.
- Remote telephone and video appointments in both primary and secondary care, meaning fewer patients need to enter GP practices or hospitals, reducing the risk of COVID-19 transmission. However, it is important to note the limitations of this approach, including the potential for exacerbating inequalities, and ensure patients who need and want to be seen face-to-face can do so safely.
- Development of rapid diagnostic clinics has been accelerated in some health boards.
- New cancer support telephone lines were set up in some health boards to provide patients with information and assurance about any changes they were facing to their treatment and care as a result of COVID-19.
- One health board has used a cancer decision tool in primary care to proactively contact patients not engaging with primary care but may be at higher risk of cancer.
- New and more efficient ways of working for MDTs, including virtual meetings.
- A shift from transrectal biopsy to local anaesthetic transperineal biopsy in prostate cancer, both to remove a higher COVID-19 risk procedure, as well as lower the risk of sepsis and readmission.

54. Many of these innovations were either initiated or expedited as a result of the pandemic but will continue beyond it. Just as important, we must not lose the culture and mindset that has enabled this rapid innovation to take place. It should not require a global pandemic for innovations that improve patient care and experience to be implemented at pace. Support and infrastructure should be put in place to enable innovations to become reality. It is also important that accelerated innovations are still based on evidence and receive proper evaluation to ensure they have the desired impact on cancer outcomes.

55. While this inquiry on the Single Cancer Pathway has been primarily focused on the diagnosis of cancer, it is important to note the full impact of the COVID-19 pandemic on the rest of cancer treatment and care. We heard from multiple sources of treatment plans changing during the peak of the pandemic, including delays to/cancellation of surgery, as well as alternative, and potentially less effective, treatments being offered. This was down to both concern of COVID-19 transmission in hospitals, as well as ICU capacity being stretched by COVID-19 patients. This has had the potential to have a further alarming impact on cancer outcomes. After early diagnosis, access to the most effective treatments is critical to improving cancer survival. We were told of a few positive examples of changes to patient treatment leading to more personalised, timely treatments that early results are showing could be leading to better outcomes. However, for others not receiving their surgery as soon as possible or switching to a different treatment would have generated anxiety about whether their cancer could be properly treated. Health boards have reassured us that the vast majority of their treatment backlog from the pandemic peak has been dealt with, whilst the systems they have in place and better knowledge of the virus mean that there are far fewer treatment plan changes happening now.

“I’ve been lucky. The pandemic hasn’t affected any active treatment for me. A routine follow up for the lung cancer was deferred until after my CT scan in December, which made sense. A routine lymphoma appointment became a phone appointment, which was useful, and I have had a face to face appointment because the consultant had some concerns since then.”
Diagnosed lymphoma, 2017; diagnosed lung cancer, 2019

56. In June 2020, the Wales Cancer Network issued “A Framework for the Reinstatement of Cancer Services in Wales during COVID-19” to provide guidance to local health boards on how cancer services could be run as safely as possible during the pandemic.⁴⁵ We heard from health boards of their efforts to maintain COVID-secure or “green” sites or areas where some procedures are able to take place while reducing the risk of COVID-19 transmission. The principles needed to maintain COVID green sites include:
- Separate sites or areas of existing hospital estates from where COVID-19 patients are treated
 - Testing of patients before admission, ideally with a period of self-isolation before the procedure
 - Regular testing of staff, even if asymptomatic
 - Robust processes for infection control and PPE supply
57. COVID green sites are needed to enable cancer surgery, as well as some diagnostic procedures, such as colonoscopy, to take place in a way that reduces the risk of COVID-19 and maintains public confidence that they can access services safely. Cancer Research UK has found strong public support for such measures, with 87% of Welsh respondents to their Cancer Patient Experience Survey agreeing that the Welsh Government should, “offer a safe environment, such as a COVID-19 free zone, for cancer patients to be treated.”⁴⁶ Now more than ever, as COVID-19 cases in hospitals rise, it is vital that COVID green sites are maintained through the second pandemic wave to prevent disruption to cancer services like that seen earlier in the pandemic. These may require use of the independent sector, which should be transparent. Green sites should provide equitable services across Wales, and therefore may require regional working between health boards to deliver them.
58. The Welsh Government recently issued guidance to support local health boards develop their operating frameworks for Q3 and Q4 of this financial year. This included the restated importance of cancer as an essential service that must be maintained during the pandemic, identifying, “urgent cancer treatments, including access to urgent diagnostics and related rehabilitation”.⁴⁷
59. A further impact has been on cancer research. Many labs conducting discovery science were closed as a result of lockdown, while clinical trials were disrupted. New clinical trials were not able to set up, except for COVID-19 trials. Recruitment to existing trials was halted. For patients already on a trial, changes were made to protect them from COVID-19, such as delivery of medication by post or in hospital car parks, remote consultations, and new protocols that meant any adverse effects resulted in a trial patient ceasing participation. Some staff, such as research nurses, were also redeployed, either to COVID-19 care or trials. For some patients, particularly those with later stage cancers, this would have restricted access to a clinical trial, which could have been a final treatment option. While new guidance is in place to reopen clinical trials, the top priority has been given to COVID-19 trials, meaning that cancer trials, which could have equal or greater benefit, are finding it difficult to get up and running again.
60. Finally, outside of the health service, the third sector has seen its income adversely affected as the pandemic has forced the cancellation of fundraising events and temporary closure of charity shops. Cancer charities play an important role in care and support for people affected by cancer, through their information and advice, funding of programmes and posts to support the NHS, holistic support provision, and in funding of important cancer research. Any reduction in the size or scope of the cancer charity sector will have a negative effect on cancer care in Wales.

61. The recovery of cancer and diagnostic services must continue to be a top priority for the Welsh Government, the Wales Cancer Network and local health boards. A national cancer recovery plan is necessary to set out how the backlog of cancer patients will be managed as quickly and safely as possible, as well as how services will be maintained through future pandemic waves and during winter pressures. As well as driving efforts to reduce the cancer backlog, it would provide assurance that a consistent approach is being taken across Wales and build public confidence that anyone affected by cancer will receive the best possible diagnosis, treatment and care during this difficult time. It would also lay the foundations for transformation that should be developed further in a new cancer strategy. The Scottish Government is currently developing a cancer recovery plan⁴⁸ and we strongly urge the Welsh Government to take a similar approach. Such a plan should be fully funded, with clear timelines, accountability, national and board-level leadership, as well as include the following measures:

- Plans for local health boards to maintain COVID-secure green sites, with necessary capacity for cancer surgery and other procedures to continue with far less disruption.
- Arrangements for the required COVID-19 testing capacity for relevant NHS staff and patients to keep services running smoothly and COVID-secure.
- Arrangements for adequate PPE provision for cancer services.
- Plans for how local health boards will quickly and safely deal with backlogs for cancer diagnoses and treatment, including for screening.
- Monthly reporting of the number of cancer patients waiting for diagnostics and treatment, in order to understand how the backlog is being reduced.
- Support for recent innovations, including evaluation and sharing of best practice, as well as how to foster this innovative spirit in future months and years.
- A requirement for local health boards to work across regional borders to support each other with demand and capacity management, as necessary.

RECOMMENDATION 3: The Welsh Government must urgently publish a COVID-19 Cancer Recovery Plan to maintain cancer services and provide reassurance to the public that cancer services are continuing safely during the pandemic. This should also include:

- *a wide-ranging mass-media communications campaign, encouraging anyone with concerning symptoms that may be cancer to seek help from primary care, and provide reassurance that people can be seen and treated safely. This should be targeted to the right population groups to avoid exacerbating health inequalities; and*
- *details on how all local health boards will maintain COVID-secure 'green' sites, with all the robust measures required, to shore up capacity and maintain cancer surgery, as well as endoscopy procedures.*

PUBLIC AWARENESS OF CANCER

62. Through the inquiry, we heard broad consensus for the need to improve public awareness of the signs and symptoms of cancer, even before the impact of COVID-19 is considered. Having the most effective and efficient diagnostic pathways will make little difference to cancer survival if people do not present to their GP with concerning symptoms in a timely way. While the patient interval is technically outside the scope of the Single Cancer Pathway, measures to improve public awareness and encourage help seeking behaviour will be integral to the overall impact the Single Cancer Pathway might have.
63. It has already been noted that awareness and attitudes in some parts of Wales, and among certain communities, can be stoic and fatalistic. People may put off seeing their GP if they have concerning symptoms, either through fear of cancer or a worry about bothering the GP.⁴⁹ Concerns about the risk of COVID-19 may have exacerbated these barriers, with 56% of Welsh respondents to Cancer Research UK's Cancer Patient Experience Survey agreeing that they would be concerned about COVID-19 if they were to go to hospital for cancer screening tests or treatment, with 30% saying they would delay attending such appointments.⁵⁰
64. Cancer awareness campaigns can take different forms. They can be large, national mass-media campaigns, such as the various iterations of Be Clear on Cancer. While these have been successful in raising population awareness, they can work better among higher income groups and not reach every community.⁵¹ Alternatively, campaigns can be smaller, more targeted interventions, such as Cardiff University's ABACus health checks. This study is testing a community-based intervention, where participants complete a health questionnaire with a trained lay advisor. This has been shown to have a positive influence on awareness of cancer symptoms.⁵²
65. The most recent Be Clear on Cancer campaign to run in Wales took place in 2017 and focused on signs and symptoms associated with lung cancer, most notably a cough that last three weeks or more. Unfortunately, an evaluation of the campaign in Wales found that while more people presented to their GP for a cough during this time, this did not translate into improved outcomes during the period of the campaign or immediately afterwards. The study concluded that the campaign was resourced well enough to be effective.⁵³ Any future campaigns run in Wales must bear this in mind. The value of an awareness campaign must focus on its ability to improve cancer survival and save lives.

"Having a stronger awareness of any changes in my body would have prompted me to see the GP earlier."

Diagnosed lung cancer, 2017

66. As noted previously, urgent referrals for lung cancer have been the slowest to recover since the first peak of the pandemic. Given that a cough is one of the principal symptoms of COVID-19, it may be more difficult for people to associate a cough with cancer. An awareness campaign could help explain the difference between a cough for COVID-19 and lung cancer by encouraging people to see their GP if their cough has lasted a long time. As urological, skin, and gastrointestinal cancers have also been slower to recover, the value of public awareness campaigns should be investigated here too.

RECOMMENDATION 4: NHS Wales and the Welsh Government should consider running a long-term programme of public awareness campaigns on the signs and symptoms of cancer, with an initial focus on lung cancer.

PRIMARY CARE

67. GPs act as the gatekeepers to secondary care in the NHS. They therefore play an important role in efforts to diagnose cancers early, as long as they recognise the signs and symptoms of cancer and refer onto an appropriate pathway in a timely way. However, it is important to recognise the difficulty GPs face. They may only see a handful of cancers diagnosed among their patients every year and, in the case of rarer cancers, one or two over their entire career. Support is needed to help GPs identify those patients that need to be referred for urgent cancer tests.

68. NICE guidelines on suspected cancer (NG12) provide details on when patients with certain signs and symptoms should be referred by a GP, as well as guidance on safety-netting and when to investigate within primary care. They include a number of principles to give GPs more flexibility to refer patients in order to help diagnose cancers earlier:

- A threshold of a 3% risk or higher that symptoms might suggest cancer should be referred.
- A lower threshold for children and young adults
- Guidance is organised by signs and symptoms, rather than cancer type to better reflect how patients present to primary care
- Guidance on when GPs should refer patients directly for tests, such as CT scans and endoscopies for a number of symptoms
- The inclusion of “very urgent” referrals for some symptoms, where someone should be seen within 48 hours.⁵⁴

69. However, we consistently heard from consultation respondents that NG12 is not being applied uniformly across Wales.

“I think early referral is paramount. I feel that if I had been referred sooner things would have been a lot different.”

Diagnosed bowel cancer, 2017

70. The reasons for this are multifaceted. One academic told us that GP awareness of NG12 is not universal, which can lead to variation in its application. We also heard that NG12 can divide some GPs between those who find it helpful to have clear guidelines on when to refer, while others feel it can be a restrictive tick box exercise that does not allow enough for referrals on gut instinct. There is also variation in which diagnostic tests GPs have direct access to as required by NG12, such as a chest X-ray for suspected lung cancer or a CT scan for a suspected brain cancer.

“Despite several visits to the GP, I wasn’t referred for a long time.”

Diagnosed bowel cancer, 2017

“The GP practice was useless. Three visits and never diagnosed. They said it was a blocked tear gland.”

Diagnosed head and neck cancer, 2018

RECOMMENDATION 5: *The Wales Cancer Network should monitor the national adoption and implementation of NICE NG12 guidelines for suspected cancer, including increasing GP direct access to diagnostic tests.*

71. Once a GP referral is made, this would be assessed in secondary care before a patient is accepted onto an urgent cancer pathway. Several health boards spoke of the importance that GP referrals are of a high quality in order to make this process as smooth as possible. Inappropriate or incomplete referrals may be sent back to primary care. It is important that, in these

circumstances, GPs receive clear feedback, both to address the issue for that patient but also provide learning and development to improve future referrals.

72. To enable this, it is critical that there is good communication between primary and secondary care. In some cases, local health boards told us how they have, or are seeking to, improve their systems to enable better communication, such as electronic referrals or cancer decision tools. The third sector also plays an active role in this area. The Macmillan Primary Care Framework for Cancer offers continued professional development (CPD) for GP practices and their staff on several modules, including recognition and referral of cancer.⁵⁵ Cancer Research UK's Facilitator Programme works with primary care in a similar way, including non-clinical staff members in GP practices.⁵⁶ The WICKED programme, run out of Bangor University, is developing a ThinkCancer! educational intervention to support primary care and cancer safety netting planning.⁵⁷ However, we have heard that protected time for CPD in primary care has been under strain recently and it is important that this is supported in the future.

RECOMMENDATION 6: Local health boards must ensure that there is good communication between primary and secondary care to ensure consistent urgent cancer referral standards, as well as feedback when a referral is deemed inappropriate. This should include making use of third sector programmes to optimise this interface.

RECOMMENDATION 7: Local health boards and primary care clusters should ensure that there is protected time for cancer related continued professional development, which includes working with third sector organisations for GP and practice staff learning.

73. Health boards stressed to the inquiry of the importance of patients attending appointments in secondary care, including for cancer tests, when they are booked. DNAs can cause delays to a patient's waiting time for diagnosis, as well as add additional pressure on diagnostic services by taking up much needed capacity. One solution offered was to ensure that patients were made explicitly aware that they are being referred onto a cancer pathway to emphasise the importance of further investigation. This would help patients understand the urgency of their appointments, especially when appointments may occur at less convenient times or require additional travel. The flipside of this, particularly when considering that the vast majority of patients referred for suspected cancer are not then diagnosed with cancer, is an increase in patient anxiety up until the point either a diagnosis or all-clear is given. To help with this, appropriate signposting to third sector organisations for high quality patient information could support people during a difficult time.

RECOMMENDATION 8: Referrers should explain to patients they refer for suspected cancer that they are being placed on a cancer pathway, which could help reduce DNAs in secondary care. This should be done sensitively and with signposting to third sector organisations for patient information and support.

CANCER SCREENING

74. The three cancer screening programmes for bowel, breast and cervical cancers fall outside of the Single Cancer Pathway and are the responsibility of Public Health Wales. However, patients who receive a screening result that requires further tests and investigations will enter the Single Cancer Pathway at that point. As such, it is within the scope of this inquiry to consider how any opportunities to improve cancer screening to save more lives, particularly as screening tends to pick up earlier stage and more treatable cancers.

“Unfortunately, I was level 4 before I knew I had cancer. I had not done the postal check [bowel screening] because I found it too repulsive. I would willingly have gone to doctors or hospital for the check - but I couldn't do it.”

Diagnosed bowel cancer, 2016

75. Programmes should seek to find ways to optimise how they operate in order to secure higher informed uptake rates. Recently, the introduction of FIT in bowel screening in Wales has meant that an easier and more sensitive test is now used. However, bowel screening starts at the age of 60 in Wales when the UK National Screening Committee (UKNSC) recommends the starting age to be 50. The threshold for when further tests are required is set when a test produces a result of 150 micrograms (ug) of blood per gram (g) of faeces, a decision that was made to manage demand into endoscopy services with limited capacity. In Scotland, this threshold is set at 80ug/g, meaning that more early bowel cancers are likely to be picked up. The Welsh Government had agreed to a bowel screening optimisation plan that would see the starting age reduce to 50 years old, the sensitivity increase to 80ug/g, by April 2023.⁵⁸ However, COVID-19 has delayed the first milestones of this plan. The Welsh Government, working with Bowel Screening Wales, should urgently confirm a new optimisation plan, ideally to adhere to the original target date of April 2023. Following this, further planning should take place to understand how bowel screening can be made more sensitive, in line with UKNSC advice, which recommends a threshold of 20ug/g once capacity allows.⁵⁹

76. For cervical cancer, Wales led the UK in introducing human papillomavirus (HPV) testing as the primary test in cervical screening, reducing the number of smear tests needed. Modelling to understand when HPV-negative women can be moved to a longer five-year screening cycle would inform how capacity can be released and enable some existing resources to target communities that are less likely to participate in the programme. Across the UK, trials are underway to see the impact that self-sampling might have to improve uptake of cervical screening.⁶⁰ Public Health Wales should closely monitor the evidence emerging from these studies so that Wales can implement this change at pace, if deemed effective.

RECOMMENDATION 9: The Welsh Government, Public Health Wales, and the cancer screening programmes should agree optimisation plans to improve the effectiveness of cancer screening including increasing informed uptake and reducing inequalities, with particular focus on bowel and cervical screening.

77. Lung screening or health checks have been gaining traction in recent years, with broad support also indicated by both health boards and third sector organisations during our inquiry. The NELSON trial concluded earlier this year that lung screening could reduce mortality.⁶¹ In England, Targeted Lung Health Check pilots have been set up, albeit since disrupted by COVID-19, to understand the feasibility and cost-effectiveness of running such a programme as a targeted intervention.⁶² Normally this would involve identifying people at a high risk of lung cancer due to

their smoking history, based on their GP record, and inviting them to a lung health check. Those who are determined to be at a higher risk of lung cancer using risk algorithms will be offered a lung screening using low-dose CT scans. The Wales Cancer Network has begun a scoping exercise on whether a lung screening pilot should be introduced to understand how this might work in Wales. The UKNSC is currently considering whether to recommend a national lung screening programme. If it returns a positive recommendation, Wales must be prepared to safely and effectively implement this at pace across the entire pathway.

RECOMMENDATION 10: The Wales Cancer Network should continue to scope out a national lung screening programme for Wales, including developing pilots to understand how this might work in practice.

78. With the exception of cervical screening, cancer screening programmes happen outside of primary care. However, there is an opportunity for GPs to support efforts to increase uptake of cancer screening. Data on eligible patients who haven't participated in bowel screening have been shared with GP practices. This enables GPs to have a conversation with their patient about completing their bowel screening kit. We heard from GPs in this inquiry that this was welcome, and they would like to see it extended to include data for other cancer screening programmes.

RECOMMENDATION 11: Public Health Wales should share data on uptake in cancer screening programmes with primary care to enable GPs to support informed uptake.

CAPACITY IN DIAGNOSTIC SERVICES

79. A key theme that emerged throughout our inquiry was the need to address issues of capacity in diagnostic services for the Single Cancer Pathway to have an impact on cancer outcomes. There was broad recognition that demand for cancer diagnostics has increased in recent years and will continue to do so. Part of this is down to the projected increase in cancer incidence that would be expected with an ageing population.

80. Furthermore, efforts to improve earlier diagnosis of cancer will require additional cancer tests to be performed, for example if NG12 guidelines on suspected cancer were universally applied across Wales. This would require both the equipment for the necessary tests, such as MRI and CT scanners, as well as the right workforce in place to run them and report results. Unfortunately, many contributors to the inquiry made it clear that Wales is experiencing significant gaps in both diagnostic equipment and workforce.

“Long delay between seeing GP and referral to hospital. The impact of wasting a month from seeing the GP to seeing the diagnostic clinic was traumatic. My cancer had already spread, and I can't help thinking this may not have happened if that month was saved.”
Diagnosed breast cancer, 2015

81. On 22 October 2020, Health Education and Improvement Wales and Social Care Wales published a new health and social care workforce strategy. This included an ambition that, “by 2030, we will have a sustainable workforce in sufficient numbers to meet the health and social care needs of our population.”⁶³ One action in the strategy was for the development of plans for key workforce groups. A workforce plan for cancer and diagnostics must be a top priority for the Single Cancer Pathway to operate as intended.

82. Imaging services conduct scans of patients to detect and diagnose cancer. Depending on the suspected cancer, this can include X-ray, CT, MRI, ultrasound or PET/CT. In some cases, one clinician may conduct the test, e.g. a radiographer, while another interprets the results, e.g. a radiologist. Demand for imaging has been increasing approximately 10% per year.⁶⁴ However, Cancer Research UK identified in 2019 that in Wales, there was a 10% vacancy rate in radiology and 9% in radiography.⁶⁵ This may mask the true gap in the workforce, as vacancy rates only include the posts that local health boards are able to recruit to, not the true workforce need for those specialties. Just as concerning, in 2018, almost 30% of consultant radiologists were expected to retire by 2021.⁶⁶ An Auditor General for Wales report has also found that all but one health board has struggled to recruit and retain radiographers.⁶⁷

83. Compounding this is a lack of imaging equipment in Wales. OECD data shows that the UK has 7 MRI units and 9 CT scanners per million people, much lower than the OECD average of 17 MRI units and 27 CT scanners.⁶⁸ This gap will make it difficult to manage rising demand for diagnostic imaging, not just for cancer but a range of diseases, particularly in light of the backlog caused by the COVID-19 pandemic.

RECOMMENDATION 12: The Welsh Government, Health Education and Improvement Wales and the Wales Cancer Network should develop a fully funded plan to increase capacity in cancer diagnostics, including:

- a cancer workforce plan, including the diagnostic workforce, to identify short- and longer-term measures to expand the cancer workforce to meet rising demand for cancer diagnosis and treatment;*
- a national skills mix approach for diagnostic services and identify opportunities to add capacity across Wales; and*
- an ambitious capital spending programme to increase the number of diagnostic equipment needed, particularly MRI and CT scanners, to ensure adequate capacity to manage rising demand for diagnostic services.*

84. It is important to recognise the work that has already begun in this area. In March 2018, the Welsh Government published a Statement of Intent for Diagnostic Imaging Services, which included actions on a national training strategy for imaging, as well as developing a sustainable capital replacement programme.⁶⁹ There has however, been no update from the Welsh Government on progress made against the Statement of Intent to date.

85. Also in 2018, the National Imaging Academy for Wales was set up, with £3.4m investment by the Welsh Government, to provide a new innovative training programme for radiologists and other imaging professionals.⁷⁰ In August 2019, the Academy had 59 radiologist trainees,⁷¹ although some respondents to our consultation queried whether the Imaging Academy would be able to do more than just replace future retirees, rather than adding to the overall radiology workforce.

86. Endoscopy is another key diagnostic service that has found itself under strain through a lack of capacity. This is particularly important for upper and lower GI cancers, including oesophageal, stomach and bowel cancers. Participants of bowel screening who are referred for further testing receive a colonoscopy, which can detect cancerous and pre-cancerous polyps, as well as removing them in some cases, contributing to cancer prevention.

87. Cancer Research UK's 2019 investigation of the diagnostic workforce found that while demand for endoscopy in Wales is increasing by 8-10% per year, around 11% of endoscopy nurse posts are vacant. Data for gastroenterologists are not available.⁷²

88. Furthermore, endoscopy has been hardest hit by the COVID-19 pandemic following advice from the BSG that all non-emergency endoscopy procedures should be halted.⁷³ Health boards have since restarted endoscopy, albeit at far reduced capacity with increased PPE and infection control measures. Some health boards reported to us that their endoscopy capacity is down to just 40%, at the same time as trying to manage the backlog that has built up since March.

89. In September 2018, the Welsh Government announced a National Endoscopy Programme.⁷⁴ This was to be a centrally directed programme aimed at increasing endoscopy capacity, including addressing workforce issues. Following a short inquiry by the Health, Social Care and Sport Committee,⁷⁵ in October 2019 the National Endoscopy Programme launched an Action Plan, which by 2023, sought to increase endoscopy, eradicate endoscopy waiting time breaches, and ensure all endoscopy units are JAG accredited.⁷⁶

90. Cellular pathology is the service that examines cells and tissue to diagnose cancer and advise on treatment. Cancer Research UK identified in 2019 that approximately 30% of consultant histopathologist posts are vacant and a further 36% of the consultant workforce due to retire in the next five years. This is against a backdrop of a decrease in headcount of 36.8% since 2015,

equivalent to the loss of 21 consultants.⁷⁷ Our consultation also found concern about differences between pathology contracts in Wales and England, which are making it more difficult to recruit and retain histopathologists in Wales.

91. The Welsh Government published a Pathology Statement of Intent in April 2019, addressing similar challenges in workforce and equipment as the Imaging Statement of Intent.⁷⁸ Again, there has been no update on the progress of the work.

RECOMMENDATION 13: The Welsh Government should publish an update on:

- *the progress of both the Statement of Intent for Diagnostic Imaging Services and the National Imaging Academy, including the contribution they are making to increasing capacity in diagnostic imaging services;*
- *progress of the National Endoscopy Programme Action Plan, including any divergence from the plan due to the COVID-19 pandemic; and*
- *the progress of the Pathology Statement of Intent to improve capacity in cellular pathology.*

92. Some of the respondents to our inquiry considered the opportunities that adopting a similar model to the National Imaging Academy could have for pathology. A national pathology academy could provide an innovative approach to pathology training, which may improve recruitment and retention.

RECOMMENDATION 14: The Welsh Government should commission a feasibility study into a national pathology academy to support the training, recruitment and retention of cellular pathologists.

93. Workforce issues are not simple to resolve. Wales is not the only country facing problems recruiting and retaining diagnostic staff. While the Welsh Government's 'Train. Work. Live.' campaign has been successful in attracting more GPs and nurses to Wales,⁷⁹ it may be more difficult to use such an approach for specialist diagnostic staff. Furthermore, while increasing training places for diagnostic staff should be a central component of any workforce plan, the number of years needed to train for imaging, endoscopy or pathology specialties mean this is a longer-term solution. Innovative approaches are needed to provide additional short-term capacity. Skills mix approaches offer an opportunity to maximise the use of the diagnostic workforce through upskilling existing staff to take on roles that can free up capacity. For example, reporting radiographers can free up consultant radiologists, nurse endoscopists can free up gastroenterologists and surgeons, and biomedical scientists can dissect specimens to free up consultant histopathologist time. A national skills mix approach, led by Health Education and Improvement Wales could help add capacity to the diagnostic workforce while additional trainees are recruited.

RAPID DIAGNOSTIC CLINICS

94. The concept of Rapid Diagnostic Clinics (RDCs) has been building momentum across the UK. In 2017, the Wales Cancer Network funded two pilots – in Cwm Taf Morgannwg University Health Board and Swansea Bay University Health Board – to test this model in Wales. RDCs in Wales are intended for people who present with vague or non-specific but concerning symptoms, such as fatigue, weight loss, abdominal pain, etc. Such symptoms can indicate several different conditions, including cancer, and so it can be difficult for GPs to know which pathway to refer a patient onto. People with non-specific symptoms who are diagnosed with cancer can often be diagnosed at a later stage, when their cancer is less treatable. Furthermore, their experience through diagnosis can be poor, as patients may be passed from one test to another, taking a long time moving between primary and secondary care.
95. RDCs can play an important role within the Single Cancer Pathway, as they aim to reduce this time to diagnosis for a cohort of patients without a clear pathway. For a patient with non-specific symptoms, they attend a clinic where they receive several diagnostic tests in the same day. The aim is that, by the end of the clinic, one of three outcomes will be achieved; a diagnosis of cancer or another condition, a referral for further diagnostic testing, or an all-clear and return to primary care. RDCs are being implemented across England, following on from multi-disciplinary diagnostic centre (MDC) pilots implemented within the ACE programme.⁸⁰
96. The two South Wales pilots have seen positive results. They have diagnosed cancers and non-cancer diseases, significantly decreasing the time to diagnosis to a matter of days in some cases. Patient experience has been reported to be good, with patients liking being able to receive several tests at the same time. GPs have also appreciated having a pathway for patients they previously found difficult to refer. A study into the Swansea Bay pilot concluded that the model was cost effective.⁸¹
97. However, RDCs cannot be treated as a panacea for earlier diagnosis. Most of the cancers diagnosed through the pilot sites were late stage, however the RDC may have provided a more timely and managed diagnosis, including enabling treatment to begin earlier, in some cases palliative, than they otherwise would. RDCs are also designed for a very specific cohort of patients. There are currently no plans to open out the model to a wider group than those presenting with vague symptoms. In addition, RDCs require specific capacity in diagnostic services, particularly from imaging. If a health board has no extra capacity to direct to an RDC, it must consider where this capacity is taken from routine diagnostics, which could have an impact on other patients' waiting times.
98. Nevertheless, the results from the two RDC pilots have indicated that there is a role for RDCs across Wales. On 30 September 2020, it was announced that the Wales Cancer Network would fund other health boards to develop their own RDCs.⁸² One health board, Aneurin Bevan University Health Board has already commenced its first RDC. Its development began some time ago before the COVID-19 pandemic sped the process up. Other health boards are still in the early stages of development. It is important that there is equitable access to RDCs across Wales as soon as possible.

RECOMMENDATION 15: Local health boards should publish their plans, for the development of rapid diagnostic clinics, including timescales and how they could play a role in the wider recovery of diagnostic services from the COVID-19 pandemic.

NATIONAL OPTIMAL PATHWAYS

99. To support the implementation of the Single Cancer Pathway, the Wales Cancer Network has developed a series of national optimal pathways for most cancer sites. These set out a best practice pathway with ambitious targets for timings for each step of the pathway. For example, the national optimal pathway for colorectal cancer explains that a patient should receive their first diagnostic tests within 7 days of point of suspicion, with results of all diagnostic and staging tests for discussion by a multi-disciplinary team (MDT) no later than day 21.⁸³
100. There was broad agreement from those who responded to our consultation that the national optimal pathways were a positive development. They present what good should look like within the Single Cancer Pathway, as well as provide an opportunity to reduce regional variation in practice. However, there was also a sense that the national optimal pathways are aspirational rather than achievable. Some of the changes required to meet the standards within the national optimal pathways are not cost or workforce neutral. As a result, additional investment is required to support local health boards to improve their diagnostic pathways along the national optimal pathways.
101. One health board told us that they are conducting a review to understand how close their current practice is to some of the national optimal pathways. This will lead to an action plan to drive improvements in those pathways.

RECOMMENDATION 16: Each local health board should report to the Welsh Government and the Wales Cancer Network how far their existing diagnostic pathways are from meeting the standards within the national optimal pathways, how regional working can maximise capacity, and identify any additional investment required to deliver them.

START OF TREATMENT

102. It was acknowledged in some of the responses we received to this inquiry that the treatment interval – from the point of diagnosis and decision to treat, to the start of cancer treatment – generally operated quite well across health boards. This is supported by the cancer waiting time data for nUSC patients, which measures the number who start treatment within 31 days of their diagnosis.

“Once referred my testing and diagnosis was pretty quick and I was admitted quite quickly for surgery. The waiting period is extremely stressful and, personally, once diagnosed, I wanted to get things sorted out ASAP!”

Diagnosed bowel cancer, 2017

103. However, workforce challenges persist in the cancer treatment workforce too. The Royal College of Radiologists recently reported that Wales has seen the slowest growth in the clinical oncologist workforce among the UK nations.⁸⁴

104. The treatment modality hit most by the COVID-19 pandemic has been cancer surgery. Following emerging evidence about the risk of COVID-19 post-surgery, as well as the need to redeploy ICU capacity towards COVID-19 patients, health boards saw a significant reduction in all but the most urgent surgical procedures. All health boards have now recommenced cancer surgery and most reported to us that the backlogs caused during the first pandemic wave have been addressed. However, it is critical that cancer surgery is supported to avoid the same level of disruption in future pandemic waves, particularly as delays to surgery could lead to some patients’ cancers progressing and becoming less treatable. Several organisations, including the Royal College of Surgeons for England, have called for COVID ‘green’ sites to be established and maintained to enable cancer surgery to run smoothly and safely.⁸⁵ This should be a priority for the Welsh Government, Wales Cancer Network and local health boards in the coming months through the second pandemic wave and winter pressures.

“It was several weeks longer to treatment than pathway stated.”

Diagnosed head and neck cancer, 2020

105. Another component of this interval is pre-habilitation. This is where patients are encouraged and supported to make lifestyle changes in order to improve the chances that they can withstand treatment, recover more quickly from treatment, and potentially improve their outcomes. This might involve losing weight, quitting smoking, or another change. Some health boards are developing their approaches to pre-habilitation, although the starting point can vary, with some advocating for pre-habilitation to begin in primary care, while others at the decision to treat. Pre-habilitation is included in the national optimal pathways, where appropriate. There were some calls to our inquiry for a standardised approach to support health boards in implementing pre-habilitation across diagnostic pathways. This should be backed up by robust evaluation to help develop the evidence base for pre-habilitation across the NHS.

RECOMMENDATION 17: *The Wales Cancer Network should establish a standardised approach to pre-habilitation to support local health boards in developing this across their pathways.*

PATIENT EXPERIENCE

106. It is vital to remember the importance of patient experience alongside the improvement sought for cancer survival. Being diagnosed and treated for cancer can be incredibly difficult physically, mentally and emotionally. Patients need to be provided with the right support to help them through this time. The most recent Wales Cancer Patient Experience Survey (CPES) by the Welsh Government and Macmillan Cancer Support showed that 93% of patients rated their care as seven out of ten or more.⁸⁶ However, the Single Cancer Pathway offers an opportunity to improve this further, through a focus on patient information and communication, alongside the decreased waiting times. Given that increased speed of diagnosis could leave some patients “traumatised”, as one clinical respondent told us, it is critical that patient experience receives as much attention as improvements to pathways, so that patients have the right information and are properly supported throughout.
107. The results of the CPES also showed that 86% of patients were given the name and contact details of their key worker,⁸⁷ while every health board who responded to our consultation told us that the standard practice is for a patient to be made aware, and possibly meet, their key worker immediately following their diagnosis. However, third sector organisations responded to us that they regularly hear from people who are unaware of their key worker or have little contact with them. The Cancer Delivery Plan 2016 outlined the ambition that all cancer patients have a key worker,⁸⁸ so it is important that the true picture is understood. The Single Cancer Pathway provides an opportunity to identify how to ensure all patients have meaningful contact with a key worker to support them through their diagnosis and treatment.
108. One role of the key worker is to conduct a holistic needs assessment. This helps to ensure that a patient’s wider needs beyond their immediate treatment are considered and appropriate support is given. This can lead to signposting to services, including in the third sector, that provide emotional support, advice on topics such as welfare benefits, and other information. Health boards told us that their patients receive a holistic needs assessment following a diagnosis. However, again third sector organisations said that this provision can be patchy.
109. We understand that a new CPES for Wales is due to be conducted and published soon. This presents the chance to assess how person centred care is progressing, including access to a key worker and a holistic needs assessment.

RECOMMENDATION 18: Following the next Cancer Patient Experience Survey, the Wales Cancer Network, supported by the third sector, should develop a plan to ensure every cancer patient has a key worker and receives a holistic needs assessment.

DATA AND INFORMATICS

110. The opportunities from the Single Cancer Pathway to improve data on cancer diagnosis, and therefore our understanding of both patient experience and how to improve pathways, is significant. As mentioned previously, shifting waiting time reporting to be broken down by cancer site and age, in the case of children, teenagers and young adults, would help pinpoint which cancers are closer to meeting the standards laid out in the national optimal pathways. However, this could go even further. For example, if all patients are tracked through their diagnostic pathway, then it should be possible to routinely report on the routes to diagnosis. This would enable an understanding of how many patients are diagnosed through routine GP referral or at an emergency presentation, when diagnosis tends to be at a later stage and therefore with lower survival rates. Understanding this will show where there are opportunities for improvements in early diagnosis, patient experience and patient outcomes.
111. However, to achieve this requires a robust, fit for purpose and future-proofed informatics system, through which data can be securely captured and reported, including comparisons between health boards and cancer sites, to support understanding and improvements, and to reduce unwarranted variation. Health boards told us that they tend to have different informatic systems that can be difficult to integrate with other systems and across health board boundaries. This can make entering and accessing data labour intensive, as waiting times require some manual input, which also increases the risk of human error and reduction in data quality.
112. The Cancer Network Information System Cymru (CaNISC) is the national cancer informatics system used across health boards. However, as the Public Accounts Committee concluded in November 2018, CaNISC is not fit for purpose and constitutes a ‘red risk’, as the software has not been supported for a number of years and represents a cyber-security threat.⁸⁹ As recently as July 2020, it was reported that health boards and Velindre Cancer Centre had experienced an outage in CaNISC, preventing clinicians from being able to access patient records for a period.⁹⁰ A replacement for CaNISC was a key action for the Cancer Delivery Plan⁹¹ and in February 2020, the Welsh Government committed £6.5m towards a replacement system.⁹² We understand work is underway to develop this replacement, however it is disappointing that it has yet to be delivered, given the critical importance of a robust informatics system for cancer services.

RECOMMENDATION 19: The Welsh Government should outline its plan for the future of cancer data and informatics, including:

- a statement on progress in the development of a replacement for the CaNISC informatics system. This should include the timeframes for when a new system will be operational; and*
- how the Single Cancer Pathway can maximise opportunities to exploit data to build understanding of patient experience and where improvements can be made across pathways, for example, exploring the feasibility of routine reporting of routes to diagnosis. This should include both health boards and the national cancer registry having sufficient staff to process and analyse data in a timely way.*

CONCLUSION

113. The Single Cancer Pathway is a bold and ambitious programme, for which the Welsh Government and NHS Wales should be congratulated for implementing. It is UK-leading, particularly in monitoring and tracking the waiting times for cancer patients diagnosed through a non-urgent referral route. However, the true potential of the Single Cancer Pathway lies in the opportunity to shine a spotlight on diagnostic pathways to optimise and improve for better outcomes, but this will require some changes, such as reporting against a 28-day diagnosis target.
114. The strongest theme we heard throughout our inquiry was that without the right capacity and workforce within diagnostic services, any effort to improve earlier diagnosis of cancer would be held back.
115. That the COVID-19 pandemic has effectively halted progress in the development of the Single Cancer Pathway in its first year of operation is a source of disappointment for everyone. Equally, it presents the chance to reset and consider the next steps to achieve this potential. Our recommendations in this report are intended to support those conversations that are already happening in the restarting of Single Cancer Pathway reporting. As has been demonstrated by everyone who has contributed to this inquiry, we all want to see cancer survival in Wales improve to save more lives, and we are committed to working together to achieve that goal.

APPENDIX A – LIST OF CONSULTATION RESPONDENTS

Health Boards and clinicians:

- Aneurin Bevan University Health Board
- Betsi Cadwaladr University Health Board
- Cardiff and Vale University Health Board
- Cwm Taf Morgannwg University Health Board
- Hywel Dda University Health Board
- A clinician from Cwm Taf Morgannwg University Health Board
- A clinician from Velindre Cancer Centre NHS Trust

Other stakeholders:

- ABPI Cymru
- Bowel Cancer UK
- Cancer Research UK
- Cancer Research Wales
- Macmillan Cancer Support
- MSD
- North Wales Centre for Primary Care Research
- Old Mill Foundation
- Prostate Cancer UK
- Teenage Cancer Trust
- Tenovus Cancer Care

APPENDIX B – CONSULTATION QUESTIONS

Responses should make clear when referring to the Single Cancer Pathway pre-COVID or in relation to the impact of the pandemic.

Waiting times so far- So far waiting times under the Single Cancer Pathway have been static – with no statistically significant changes. The most recent results from January 2020 showed that 73.7% of patients were diagnosed and treated within the 62-day target.

1. What is your assessment of the waiting times results under the Single Cancer Pathway so far?

Impact of COVID-19 pandemic. It is important to recognise the impact the pandemic has had on the implementation of the Single Cancer Pathway and its ability to improve early diagnosis. We are also keen to understand any potential opportunities that could arise during the recovery of diagnostic and cancer services.

2. What impact on cancer diagnosis and treatment have you observed as a result of the COVID-19 pandemic?
3. What do you think is required to support the recovery and restoration of diagnostic and cancer services in Wales?
4. If there should be further peaks of COVID-19 infections in Wales later in 2020 or 2021, how can diagnostic and cancer services be protected to minimise disruption?
5. Are there any opportunities for the Single Cancer Pathway as diagnostic and cancer services recover from the pandemic?

Public awareness (patient interval)

6. What is the single most important action that should be taken to improve population awareness of cancer symptoms across all socio-economic groups to reduce health inequalities?

Primary care- NICE's NG12 guidelines for suspected cancer outline that a GP should refer their patient for further diagnostic tests if there is a 3% chance that the patient has cancer and set out the actions GPs should take depending on the presenting patient.

NICE's DG30 guidance outlines the procedure for referral for colorectal cancer.

7. Do you think that NG12 referral guidelines are applied uniformly across Wales?
8. What do you think is the biggest challenge to the uniform implementation of NG12?
9. How could GPs be supported to implement NG12?
10. What would be the impact of the uniform implementation of NG12?
11. How well do you think DG30 guidance is being applied across Wales?

Screening

12. What is the role of cancer screening in delivering the aims of the Single Cancer Pathway?
13. How can cancer screening be optimised to detect more early cancers?

Diagnostic capacity. Diagnostic capacity includes the diagnostic workforce as well as any equipment needed for diagnosis patients, and is vital for timely and early diagnosis of cancer.

14. What challenges currently exist in diagnostic capacity?
15. What are the future challenges to diagnosing cancers early?
16. What opportunities exist for improving early and timely cancer diagnosis?
17. Considering the pilots currently operating in Swansea Bay and Cwm Taf, what role do you envisage for RDCs in the future of cancer diagnosis in Wales?

Treatment

18. What are Local Health Boards currently doing, and what do they need to do in future, following a diagnosis and decision to treat to ensure that patients can start treatment as soon as possible?

National Optimal Pathways. National Optimal Pathways are pathways for different cancer sites which outline the best practice for each cancer site. These are currently being developed and rolled out to support Local Health Boards in implementing the Single Cancer Pathway.

19. What impact do you think the national optimal pathways will have?

Patient experience.

20. What impact has the Single Cancer Pathway had on patient experience?
21. What impact should the Single Cancer Pathway have on experience and how do you foresee this being achieved?
22. Are patients being routinely made aware of their key worker following their diagnosis?
23. What does patient experience look like following diagnosis? How could the Single Cancer Pathway offer opportunities on this?

Data & informatics

24. What are the limits of the data currently collected under the Single Cancer Pathway?
25. What are the opportunities and challenges are presented by the Single Cancer Pathway in data collection?

Other

26. Do you have any final comments on the Single Cancer Pathway?

APPENDIX C – LIST OF INQUIRY MEETINGS

Meeting 1 – 26 February 2020 – Ty Hywel

- Andy Glyde, Public Affairs Manager (Wales), Cancer Research UK – Overview of the Single Cancer Pathway
- Group discussion on the inquiry terms of reference and general reflections of the Single Cancer Pathway

Meeting 2 – 14 July 2020 – Online

- Bethan Hawkes, Interim Manager, Wales Cancer Network – Impact of COVID-19 on cancer services in Wales
- Richard Pugh, Chair of the Wales Cancer Alliance and Head of Partnerships, Macmillan Cymru – Impact of COVID-19 on cancer patients in Wales
- Re-opening of inquiry consultation

Meeting 3 – 24 September 2020 – Online

- Prof. Kate Brain, Professor of Health Psychology – Screening, Prevention & Early Diagnosis Lead, Cardiff University – Public awareness of cancer and help-seeking behaviour in the COVID era
- Prof. Clare Wilkinson, Professor of General Practice, North Wales Centre for Primary Care Research, Bangor University - The development and evaluation of primary care interventions to expedite the diagnosis of symptomatic cancer in Wales
- Dr. Jodie Moffat, Head of Early Diagnosis, Cancer Research UK – Next steps for early diagnosis of cancer

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