MOONDANCE
CANCER INITIATIVE

TOWARDS ZERO DEATHS FROM BOWEL CANCER IN WALES

Case for Change

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2023

GIG CYMRU NHS WALES | Rhwydwaith Canser Cymru Wales Cancer Network

The Association of Coloproctology of Great Britain & Ireland

Bowel Cancer UK

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Evidence Review

Robust and thorough literature review to identify opportunities to reduce bowel cancer deaths

Evidence Consultation

Validated evidence review and gained insight in Wales from >60 bowel cancer professionals

Patient Consultation

Collaborated with Cedar Research Group and Bowel Cancer UK for experiences and priorities of >70 bowel cancer patients and carers in Wales

Workshops

UK-leading experts, professionals and patients, discussing how to take opportunities

A Case for Change

Cocreated summary of actions to reduce bowel cancer deaths in Wales

Outputs

Projects/Initiatives to improve bowel cancer outcomes in Wales

Over 150 patients and professionals consulted over 14 months, designing impactful actions for Moondance Cancer Initiative and others to support.

Endorsed by:

GIG CYMRU NHS WALES
Rhwydwaith Canser Cymru
Wales Cancer Network

The Association of Coloproctology of Great Britain & Ireland

Bowel Cancer UK
Beating bowel cancer together
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Foreword by **Rachel Reed**

Bowel Cancer Survivor, Patient Advocate
Board Member, Towards Zero Deaths from Bowel Cancer in Wales

Receiving a stage 4 bowel cancer diagnosis at the age of 33 is the most challenging and traumatic experience I will ever go through.

In December 2018, I had an operation to remove a tumour in my bowel. I was wheeled down to theatre thinking I would back on the ward by lunchtime, but instead I woke up 9 hours later feeling like I had been eaten by a lion. The complexity of my case and the delay in my diagnosis meant I had a hysterectomy, a colostomy bag, a stent in my bladder and 2 sections of my bowel removed.

This is what happens when your cancer is discovered late. My life changed overnight, I lost my 'normal' and who I used to be. Four years on, navigating life post cancer is tough. The mental and physical challenges never stop. This is why I choose to share my story, to highlight the need to make things better and help create positive change.

This focus on moving towards a Wales with zero deaths from bowel cancer is a huge step forward and will bring hope to many touched by cancer. I hope this work will reduce the chances of anyone else receiving a late diagnosis at a young age and potentially losing their life. Cedar's patient consultation showed that half of the patients that were under 50 were diagnosed at Stage 4, with multiple delays to referral and diagnosis. I was one of those younger patients. It doesn't need to happen to others.

If we can work together quickly to seize the opportunities highlighted, we can make life saving changes which are desperately needed.

On behalf of all bowel cancer patients in Wales, I'd like to thank Moondance Cancer Initiative for their time and hard work compiling this Case for Change. Fewer lives will be lost if this powerful and comprehensive piece of work is acted on.

Contents

Abbreviations

ACPGBI	Association of Coloproctology of Great Britain and Ireland
AHP	Allied Health Professional
AWMGS	All-Wales Medical Genomics Service
BSG	British Society of Gastroenterology
BSW	Bowel Screening Wales
CCE	Colon Capsule Endoscopy
CNS	Clinical Nurse Specialist
ED&D	Early Detection and Diagnosis
EP	Emergency Presentation
FIT	Faecal Immunochemical Test
GP	General Practitioner
HEIW	Health Education and Improvement Wales
LSQIP	Lynch Syndrome Quality Improvement Project
MDT	Multi-Disciplinary Team
MSI	Microsatellite Instability
NGS	Next Generation Sequencing
NOP	National Optimal Pathway
PHW	Public Health Wales
RCT	Randomised Controlled Trial
RDC	Rapid Diagnostic Clinic
RDH	Regional Diagnostic Hub
SACT	Systemic Anti-Cancer Therapies
TNT	Total Neoadjuvant Therapy
USC	Urgent Suspected Cancer

Background

Bowel cancer is among the most common cancers in Wales, with approximately 2300 new diagnoses a year. It is the second biggest source of cancer mortality, causing over 900 deaths annually.[1, 2] From prevention to early detection and diagnosis , through to treatment, bowel cancer is near-unique among cancers in the number and effectiveness of opportunities we have available to prevent people dying.

Moondance Cancer Initiative has previously funded several improvement projects for bowel cancer. Examples include supporting the establishment of a bowel cancer specific pathway within an established Rapid Diagnosis Clinic (RDC), investment to make multi-disciplinary teams (MDTs) more research active, and funding the development of training for non-medical endoscopists, to bolster our colonoscopy workforce.

We believe that the number of bowel cancer deaths in Wales could be greatly reduced if all the recognised opportunities are taken. "Zero Deaths" will not be achieved in the immediate future, but we believe Wales should aspire to move Towards Zero Deaths from Bowel Cancer.

Throughout this programme, we have been ambitious in co-creating a plan with healthcare, policy, and patient communities, that can and will reduce the number of people dying from bowel cancer. Moondance Cancer Initiative find, fund and fuel brave ideas for improving cancer care, and we aim to support improvement projects emerging from this plan.

We have conducted an evidence review, analysing opportunities with the potential to reduce bowel cancer deaths in Wales and considered how each might fit within the reality of services in Wales today. Never before have so many patients and clinicians taken part in finding solutions. We consulted with over 60 bowel cancer care professionals to ensure it accurately represented where we stand, and what we could achieve. Most importantly, with the assistance of Bowel Cancer UK in recruitment, we commissioned the NHS research group Cedar to consult with patients and carers, understanding their experiences and priorities for change.

Patients are the only ones who truly see what happens at every stage of bowel cancer. Their experiences and insights are invaluable and have never before been gathered at this scale and depth in Wales. To save lives, we must look at what we do through their eyes, making improvements at every stage and joining up.

Patient and professional-backed opinion was discussed in three workshops held in November and December 2022, with the aim of arriving at tangible actions and strategies for taking opportunities for reducing deaths forward. The opportunities presented to these workshops can be found in Appendix A.

Current Outcomes in Wales

Data available on bowel cancer outcomes and performance clearly demonstrate the need for change and improvement in Wales. As shown in the figure below:

- Bowel cancer cases and deaths have been increasing since 2002.[1, 2]
- There has been no significant increase in early-stage diagnosis since 2011.[1]
- Inequalities in bowel cancer deaths are increasing at a staggering rate, with our most deprived population quintile experiencing an 83% higher risk of bowel cancer death than our least in 2021.[2]
- Performance against the Single Cancer Pathway (SCP) 62 day target has been declining since 2021.[3]

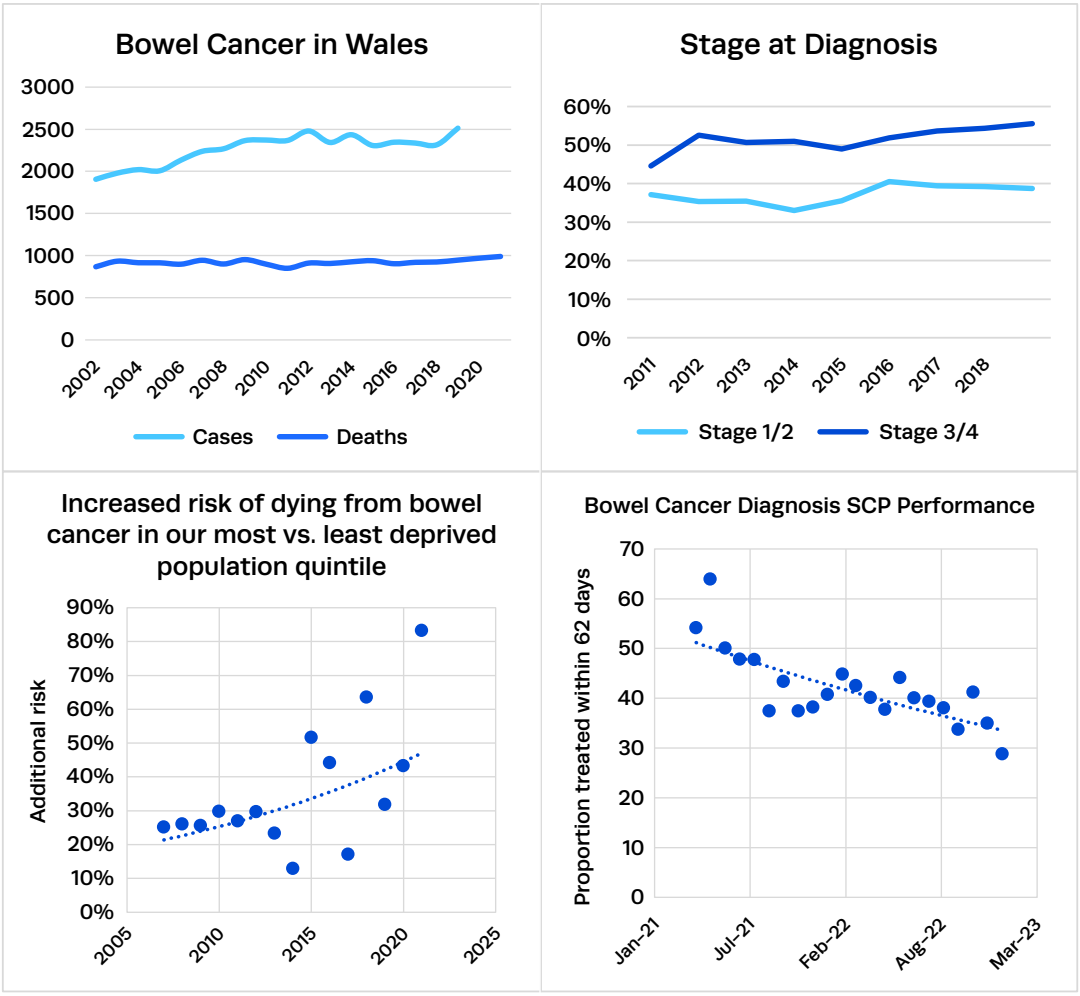

Figure 1. Bowel cancer outcomes and performance in Wales.

Case for Change

Prevention

Deploy and sustain targeted initiatives to reduce inequity in bowel cancer outcomes

Rollout a patient decision aid on aspirin, for recipients of bowel screening

Detection

Create a service user panel for bowel cancer screening & invest in adopt/discard capacity

Increase target participation for bowel screening

Collaboratively quality-improve FIT test processes in GPs for patients with symptoms

Develop support programme for trainee screening endoscopists to ambitiously optimize screening sensitivity

Diagnosis

Coordinate the pathway to diagnose more people with Lynch syndrome, more rapidly

Adopt rapid diagnostic pathways and technology for bowel cancer, at scale

Pilot multigene panels in diagnostic pathways, future proofing for personalized treatments

Streamline pathways to make genetic results available for first treatment decisions

Treatment

Regularly monitor care continuity in Wales and trial innovative approaches for improvement

Provide tools for rationally planned and value-driven prehabilitation services

Raise awareness of cutting-edge therapies and trial options

Establish dedicated early rectal cancer management and consider introducing contact radiotherapy

Expand successful research coordinator and champion roles

MOONDANCE CANCER INITIATIVE

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This is the time for ambition and focus. The evidence in this report is overwhelming. The statistics on inequality and death should galvanize us all into coordinated and comprehensive action. Thanks to the brilliant clinicians and patients in Wales who worked with us, we know what needs to be done and we know there is an appetite to do it.

Moondance Cancer Initiative find, fund, and fuel brave people and brilliant ideas. We aim to support some of the changes and interventions described in this report, as well as others which emerge as the programme continues to progress. We describe many evidenced and stakeholder-backed opportunities for NHS Wales and others arising from our consultations and workshops, as well as patient and professional perspectives on the current state of care. The strong message is that these opportunities need to be taken together rather than 'cherry picked'. Patients need their diagnosis and care to be coherent if it is also to be to effective.

This report is endorsed by Bowel Cancer UK, The Association of Coloproctology of Great Britain and Ireland, the Welsh Association for Gastroenterology and Endoscopy, Wales Cancer Network, Wales Bowel Cancer Initiative, and the Royal College of Surgeons of England.

We present this report with thanks to Prof. Nicola Fearnhead, and Rachel Reed for their support through our programme board, and to all those who have contributed to the programme:

Sian Morgan *All Wales Medical Genomics Service*
Mary Craig *Aneurin Bevan UHB*
Alison Davies *Betsi Cadwaladr UHB*
Jackie Pottle *Betsi Cadwaladr UHB*
Claire Coughlan *Bowel Cancer UK*
Gerard McMahon *Bowel Cancer UK*
Sarah Weston *Bowel Cancer UK*
Sian Salkeld *Bowel Cancer UK*
Lindsay Richards *Bowel Screening Wales*
Benji Williams *Cardiff and Vale UHB*
James Ansell *Cardiff and Vale UHB*
Mark Rogers *Cardiff and Vale UHB*
Mike Davies *Cardiff and Vale UHB*
Sunil Dolwani *Cardiff and Vale UHB*
Grace McCutchan *Cardiff University*
Harriet Quinn-Scoggins *Cardiff University*
Kate Brain *Cardiff University*
Peter Elwood *Cardiff University*

Stephanie Smitts *Cardiff University*
Michael Beddard *Cedar NHS Research Group*
Nia Jones *Cedar NHS Research Group*
Helen Wilson *Cwm Taf Morgannwg UHB*
Gary Howell *Cwm Taf Morgannwg UHB*
Hayley Benjamin *Cwm Taf Morgannwg UHB*
Pawan Kumar *Cwm Taf Morgannwg UHB*
Rhian Collins *Cwm Taf Morgannwg UHB*
Rhidian Jones *Cwm Taf Morgannwg UHB*
Gareth Morgan *Hywel Dda UHB*
Rachel Lewis *Hywel Dda UHB*
Nicola Fearnhead *National Bowel Cancer Audit*
Hayley Heard *National Endoscopy Programme*
Laura Monjes-Garcia *NHS England*
Kevin Monahan *NHS England*
Maggie Vance *NHS England*
Angus Watson *NHS Scotland*
Debbie Provan *NHS Scotland*
Julie Hepburn *Patient Participant*
Natasha de Teran *Patient Participant*
Rhian Martens *Patient Participant*
Rachel Reed *Patient Participant*
Diana Bright *Public Health Wales*
Fliss Bennee *Public Health Wales*
Giles Greene *Public Health Wales*
Katie Palmer *Public Health Wales*
Saddaf Shaheen *Public Health Wales*
Dean Harris *Swansea Bay UHB*
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Helen Gray *Swansea Bay UHB*
Martyn Evans *Swansea Bay UHB*
Louise Condon *Swansea University*
Hannah O'Mahoney *Tenovus Cancer Care*
Lowri Griffiths *Tenovus Cancer Care*
Maddy Young *Tenovus Cancer Care*
Richard Adams *Velindre Cancer Centre*
Seema Arif *Velindre Cancer Centre*
Sonali Dasgupta *Velindre Cancer Centre*
Rachel Evans *Wales Cancer Network*
Tom Crosby *Wales Cancer Network*

Participation, Awareness, Presentation

Screening Participation

Having bowel cancer detected by screening, with a stool test known as a FIT test sent by post, is often life-saving.[4] One study of 1,580 bowel cancer patients in Spain found that people diagnosed by screening had a 65.9% reduction in deaths 10 years after diagnosis, compared to those diagnosed via other routes.[5] Currently, Wales diagnoses just 12% of bowel cancers via screening.[6]

> *It was a stage one cancer, so they removed the cancer in November and I've been recovering since and absolutely feel fine now and I feel I've been quite lucky in that sense. But if it wasn't for that cancer check the ones they send you, I wouldn't have known anything and it would have gone on and on, so I'm very grateful for that.*
>
> – ***Patient Participant***

Currently, just over 60% of those eligible for screening in Wales return their FIT tests.[6] There are several evidence-backed interventions shown to increase participation, such as telephone outreach (by 23%), GPs endorsing letters (17%), and advance notification of receipt (9%).[7-9] Local patient navigators, sitting within a screening programme, serving areas of high deprivation and low participation, have been shown to increase a communities' participation rate by 23%, and decrease their time to participation by 26%.[10] Digital tools, to identify non-participants for phone calls, mass-media campaigns, and community outreach are also all supported by evidence as increasing screening participation.[11, 12]

> *The other thing is, is that a doctor has never asked me... 'you're now 62, have you had your bowel screening form? It's important that you do it and you take it and you get it back.' The first I knew of it when I was 60, it came through the post and I gotta be honest, I didn't know much about it.*
>
> – ***Patient Participant***

With these tools, many world-leading services are aiming to achieve at least 80% screening participation.[13] Bowel screening in Wales currently operates under a minimum participation standard of 60%, which has been consistently exceeded since the introduction of FIT tests.

> *I cannot understand why we've not re-looked at the 60% target [for participation] ...what's the point in a target that doesn't drive action?*
> – ***Quality Improvement Lead***

During interviews and focus groups with Cedar, participants described how being sent a package in the post with no recommendation by their GP or campaign alongside it, made them unlikely to engage with screening if they were not symptomatic. Many felt uninformed and anxious about what might come next and so most were open to other methods of communication to increase uptake of screening:

> *I think I might have been more inclined to do it had I had an appointment and talked to somebody... I just don't think sending things in the post, they're certainly not going to engage people like me.*
> – ***Patient Participant***

Workshop attendees expressed frustration that these evidence-backed opportunities are not being rapidly tested, adopted, and discarded where appropriate. A lack of capacity, service user input, and dedicated quality improvement expertise in the relevant services was cited as a barrier to change. Whilst Public Health Wales (PHW) does work with a public information group on screening overall, we are unaware of any dedicated service user panel that Bowel Screening Wales (BSW) are able to consult as a basis for improvement.

Following on from a project funded by Moondance Cancer Initiative, patients registered with 313/408 GP practices in Wales will begin receiving bowel screening invitation letters co-signed by their GP from March 2023. This could be capitalized on with continual adaptation and improvement of the invitation offer, shaped by service users.

Moondance Cancer Initiative has also funded BSW to develop near real-time digital monitoring of programme performance, which could be leveraged to rapidly monitor and report on quality improvement initiatives.

ACTION 1: Bringing ambition to bowel screening participation.

Increase target participation in bowel screening to drive aspiration for improvement. In addition, create a service user panel within BSW for regular user testing and feedback, asking recipients what could be better for them. Invest in capacity and expertise within the bowel screening programme for rapid adopt/discard-style testing of evidence-backed solutions to increase screening participation.

Symptom Awareness and Presentation

Early presentation of people experiencing bowel cancer symptoms is extremely important for survival. Stage 1 disease has over 90% 5-year survival, and high rates of curative treatment, compared to stage 2 disease (80%), stage 3 (70%), and stage 4 (10%).[14, 15] Emergency presentation (EP) is increasing in Wales, with one hospital reporting an increase from 28.6% to 36% of all bowel cancer diagnoses. 10% increases in EP could lead to 7% fewer people surviving 1-year post-diagnosis.[16, 17]

Whilst it is difficult to measure the full benefit of such interventions through to earlier diagnosis, programmes such as the Be Clear On Cancer mass-media campaign have proven effective in increasing symptom awareness and GP presentations, during the campaign.[18, 19]

> *The reason I went to the doctor was because I was feeling very giddy and lightheaded... my diagnosis was a total shock because I had very few symptoms*
> **– *Patient Participant***

Other innovative opportunities include the Bowel Cancer UK 'Get on a roll' campaign – printing information on loo roll in supermarkets,[20] or in taking advantage of the huge swell in public interest when well-known figures are diagnosed with cancer.[21] The patients that Cedar spoke to were generally open and interested in such innovative methods. There is clearly an opportunity in continued investment and exploration of potential new channels for raising awareness.

One such initiative with a strong foundation in Wales is Community Champions. Our bowel cancer evidence review and previous work on barriers to presentation,[22] showed that training champions in the community to raise awareness of cancer symptoms is a potentially effective opportunity.[22] We understand that several community champion projects are underway in Wales. New managers are being hired to run champion programmes, for example with funding from Macmillan.[23] Trials are also ongoing of community champion approaches, such as with in

TIC–TOC, with the aim of raising awareness in more deprived communities. Supported by Moondance Cancer Initiative, Bowel Cancer UK are rolling out awareness kits to community pharmacies in Wales.[24]

Patients may not seek help early in primary care due to not understanding symptoms or to other barriers, such as not wanting to waste a doctor's time, regarding cancer as taboo or a death sentence, or being unable to travel/make time for a GP appointment.[22] As such, 'pushes' from public campaigns need to be matched to a 'pull' from GP surgeries, making their services accessible. Some participants spoken to by Cedar expressed a lack of accessibility in this area:

> *Nowadays, getting to see a GP for a face-to-face appointment is almost a luxury.*
> – ***Patient Participant***

Existing activity in Wales: Community Champions

Community champion initiatives are being rolled out and trialled across Wales, and may represent an effective route to increasing cancer awareness. We are unaware of any centralized strategy or support pertaining to these initiatives, potentially leaving them vulnerable to drop-off and inconsistency across Wales. There may therefore be an opportunity to coordinate and expand these initiatives.

Screening Optimization

FIT Threshold

When a bowel cancer is detected by screening, this increases the chances of survival. In bowel cancer screening, a threshold is set for how much blood there is in faeces, which triggers onward referral for direct endoscopic assessment. In Wales, this threshold is currently at 150µg/g. As reported in our evidence review, at this threshold, approximately half of cancers, and the vast majority of precancers (polyps) are likely to be missed. Lower thresholds, detecting a greater proportion of cancers, are used in several countries with similar healthcare systems to Wales (Figure 2).

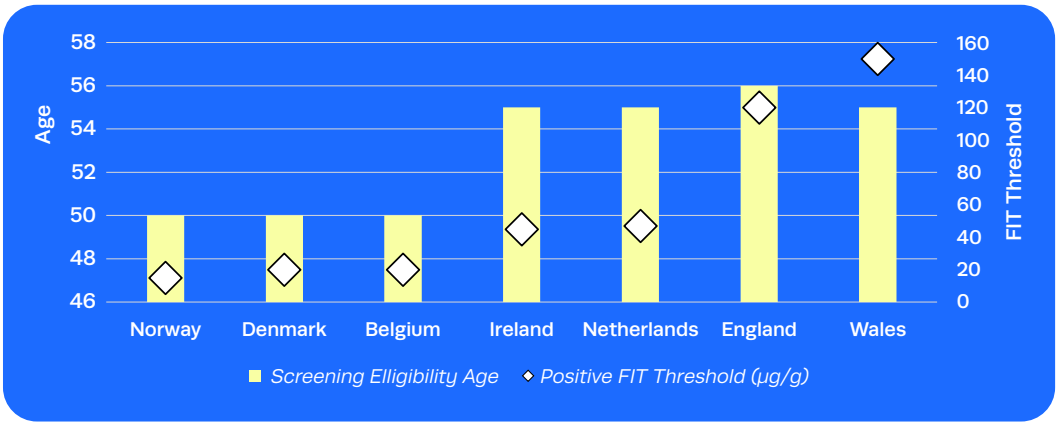

Figure 2. Bowel screening eligibility and threshold for onward referral in Wales and comparable European countries

> *I had taken all bowel screening tests and none of them had come back positive even though the consultant said the tumour had been there for a while.*
> – ***Patient Participant***

Multiple participants Cedar consulted **had their cancers missed** by the screening programme, even when diagnosed soon afterwards at late stage, and expressed a distrust in the screening test, alongside a feeling that they had been falsely reassured. This will harm the reputation of the bowel screening programme amongst patient peer groups and potentially reduce uptake.

> *I assumed it was a bit like a smear. I assumed that it meant he was clear, and that there was no risk of cancer*
> – ***Carer Participant***

Age

In addition, the benefits of screening could be extended by lowering the age threshold for bowel screening from 58 to 50, in line with both guidelines,[25] and comparator countries in Europe, as shown in Figure 2. This would extend the benefits of screening to the 12% of patients diagnosed with bowel cancer who are aged 50–59,[1] as well as preventing cases and late stage diagnoses in people aged 60+. As of October 2022, the invitation age has been lowered to 55 in Wales.

Opportunities

We are aware of plans in Wales to reduce the Faecal immunochemical testing (FIT) threshold to 80µg/g, and age of eligibility to 50 through to 2024, roughly doubling demand for screening colonoscopies. Optimization of threshold and age have been constrained since the inception of the programme nearly 15 years ago by Wales' capacity to perform more screening colonoscopies.[26]

Therefore an absolutely crucial opportunity is to increase screening colonoscopy capacity, through ambitious and new interventions in training, recruitment, returning, and retention of endoscopists, and capital investment/reorganization of our functional capacity. One key opportunity in this space is training clinical nurse screening colonoscopists. Wales gained its first nurse screener in October 2022.

> *We don't have the luxury to wait for people to come to us and become a screener*
> – ***Consultant Colorectal Surgeon***

Workshop attendees described a notably onerous process to qualify as a screening colonoscopist (medical or clinical). In clinical terms, this may be justified by the strict quality assurance applied to screening colonoscopy in Wales, however this is not unform across the UK, with the perception that the process of becoming a screening endoscopist is more accessible in for example Scotland. Furthermore, there is an additional significant administrative burden for applicants, as well as uncertainty around functions and protections for the role.

Though evidence is currently immature, technologies such as Colon Capsule Endoscopy (CCE),[27] and blood-based tests (e.g. Cansense Raman Spectroscopy) could represent useful tools or adjuncts to manage screening colonoscopy demand in the near future, if adopted rapidly and at scale. These technologies could relieve worry for patients who might otherwise be on a waiting list for a colonoscopy and enable those who warrant further investigation to be prioritized for further testing.

ACTION 2: Opening access to screening colonoscopist training.

Aligned with the planned Academy of Clinical Endoscopists, accelerate and bring ambition to the development a programme to encourage medical and clinical staff to train as screening colonoscopists, for example by raising awareness, addressing the concerns of interested staff, or investing in project/administrative management capacity to remove the onerous administrative barrier for new applicants.

Aspirin

Over recent years, evidence has been accumulating that certain at-risk populations may be able to decrease their chance of developing bowel cancer with long-term Aspirin use, and that when taken by people diagnosed with bowel cancer, it may lead to a better prognosis.

There are questions over how long aspirin should be taken to reduce risk, and who would benefit sufficiently from its use to overcome the small associated risk of hypertension and bleeding (see our evidence review for more information). Nonetheless, reductions in bowel cancer risk of 23–44% have been reported with long-term aspirin use, and an up to 28% reduced risk of bowel cancer death having developed the disease.[28–32]

Despite evidence arguably not yet being mature enough for formal recommendation, given the ease-of-access of aspirin, there is a drive toward informing at-risk people of the potential risks and benefits, and making aspirin available to those who choose it.[33] In 2017, Cancer Council Australia issued guidance recommending that GPs actively consider prescribing aspirin for people in the bowel screening programme (aged 50–70).[34]

Many participants consulted by Cedar had little or no knowledge of the link between Aspirin and bowel cancer prevention, with many in need of professional guidance.

> *I have read about aspirin, but not once have I been told to take it by a health professional.*
> – ***Patient Participant***

A patient decision aid on aspirin, to be provided for screening for participants, has been designed and tested in Wales.[35] Rather than recommending aspirin, it uses accessible language to advise readers on the benefits and risk of low-dose aspirin. Despite completion of the project, and peer-reviewed publication in 2021, we were advised by the lead academic involved that it had not progressed into clinical use, due to research grant funding running out. Aspirin is in widespread use for the mitigation of cardiovascular disease, and the opportunity in cancer prevention should not be missed.

> *I took aspirin for 10 years for a genetic heart condition before I developed cancer and I remain convinced that it helped prevent the spread.*
> – ***Patient Participant***

ACTION 3: Raising awareness of aspirin

Support the implementation of the already designed patient decision aid on aspirin into practice, delivering to recipients of bowel screening.

Referral & Diagnostic Pathways

> *6 months of seeing my GP with what I now know to be blatant symptoms, and being dismissed. 3 trips to A&E with an obstructed bowel and was sent home each time. By the time I was seen by a surgeon on the 4th visit, I had to have emergency surgery and he has since told me I was 24-48 hours from death*
>
> – ***Patient Participant***

Primary Care

In countries like Wales, as many as 85% of cancer diagnoses come through GP referral.[36] One of the strongest themes coming through from Cedar's patient consultation was of difficulty being referred by a GP for suspected bowel cancer, and then a delay getting diagnosis, often spent waiting for a colonoscopy.

> *It's been really hard for me to get diagnosed. Took me over two years to get a diagnosis, and I got referred for a colonoscopy, which found my cancer, through a dermatology referral.*
>
> – ***Patient Participant***

Rapid diagnosis for patients with symptoms is critical in bowel cancer. A 3-month delay to diagnosis has been associated with a 10–16% reduction in 10-year survival. A 12-week delay in referral from a GP is associated with 104–165% increase in risk of mortality. Just 4 weeks delay to surgery or adjuvant chemotherapy post-operation can increase risk of mortality by 6% and 13% respectively.[37-42]

> *It took 18 – 24 months to get a diagnosis. I was told repeatedly I had IBS and once that I was upset because I was menopausal. I was told the pain I had was from a fall – I hadn't had a fall. I was told the blood in my stools was due to anal fissures.*
>
> – ***Patient Participant***

Recognition, and cross-referencing of numerous less obvious cancer symptoms can be a difficult exercise for GPs, who only encounter approximately 7 patients with any cancer type each year.[43] There may therefore be some opportunities in supporting their ability to recognise and refer patients with suspected cancer.

Never Too Young

Historically, younger people (aged under 50) have struggled to be referred for suspected bowel cancer. Bowel Cancer UK's 'Never Too Young' report found that 40% of younger people had to visit their GP 3 or more times to get a referral.[44]

This pattern came through very strongly in Cedar's patient consultation. 54% of participants aged under 50 were diagnosed at stage 4, compared to 11% in those aged over 50. Multiple participants spoke of difficulties getting referred, and a feeling that their symptoms had not been taken seriously or investigated thoroughly enough, leading to a delay in diagnosis.

> *My consultant kept telling me I was too young (31) and it was stress related IBS until I challenged him to a colonoscopy to prove me wrong. Put through as non-urgent and found the tumour in my ICV. Overall took 2 years to diagnose..*
>
> – ***Patient Participant***

Secondary Care Delays

After referral, delays to diagnosis are increasing. In January 2020, 380 patients in Wales had been waiting for a colonoscopy for over 14 weeks. In 2021, this was 2,683, and in 2022, 3,872. In January 2023, 50% of people diagnosed with bowel cancer waited more than 92 days from referral to starting treatment. 25% of people waited more than 130 days.[45]

> *I had to wait for various appointments along the way which added to this timescale, such as the colonoscopy, CT scan and MRI scan and the surgery itself had a 6 week wait.*
>
> – ***Patient Participant***

Solutions must come from both primary and secondary care

Stakeholders stressed to us that these two problems are essentially linked. Backlogs and pressure in diagnostics are understood by GPs, who are reticent to increase referrals, as they fear the harm that will come from patients (most of whom will not have cancer) sitting on waiting lists for extended periods. They also feel discouraged from overburdening secondary care which they know is under pressure.

This is especially the case with younger patients, where more referrals will have to be made per cancer detected. Interventions to increase referrals from GPs, or to

streamline and improve diagnostic pathways, should therefore be applied together, to maximise their impact on improving rapid diagnosis.

> *There's still an unconscious mindset that there's nothing you can really do to pick up more cancers in young people – given the low return rate*
> **– *General Practitioner***

Existing activity in Wales: Regional Diagnostic Hubs

Work is underway in Wales to develop several all-elective Regional Diagnostic Hubs (RDHs), which are expected to add endoscopy (as well as radiology and pathology) capacity. As with other diagnostic services, workforce remains a critical component for delivery of an effective service. Nonetheless, with RDHs due to come online within 12–18 months, they may play a vital role in supplementing diagnostic capacity.

GP Solutions

A number of evidence-backed opportunities are available to help GPs identify and refer patients with suspected cancer. Commercially available automated decision aids and training, such as C-the-signs and Gateway-C can help to remind GPs when risk-symptoms are present, and have been piloted successfully in England.[46–48] Gateway-C has recently become available for use by GPs and pharmacies across Wales, and there may be an opportunity to increase engagement across primary care to fully utilise the platform.

The ThinkCancer! platform, developed and tested in Wales, helps the whole primary care team increase their skills, and is being tested in a Randomised Controlled Trial (RCT) in 30 Welsh GP practices. Importantly, this intervention both encourages GPs to identify cancers, and upskills their practice in identifying and safety-netting individuals at risk – for example those that have visited multiple times.[49–50]

Existing activity in Wales: GP solutions for early detection

Provided by Health Education and Improvement Wales (HEIW), the Gateway-C learning platform is becoming available to all GPs and pharmacies in Wales; we were advised that a primary care engagement programme might help to drive uptake and use. In addition, the ThinkCancer! intervention is being trialled in Wales: if positive results are reported, engagement to increase uptake may be useful.

Diagnostic Pathways Solutions

As described above in screening, with a huge backlog of cases, and capacity not currently matching demand, increasing our colonoscopy (and other diagnostic services e.g. pathology) capacity is essential to improving this service. However, there remain other opportunities to streamline and improve our diagnostic pathways.

> *Increasing endoscopy capacity is a must*
> – ***National Endoscopy Programme Representative***

Symptomatic FIT

Performing a FIT test in symptomatic patients to guide cancer referrals, and rule out those at low risk of cancer could theoretically safely reduce colonoscopy demand by about 70%[51], and reports from Spain and Scotland indicate its use increases survival and decreases EP. This approach is now backed by the Association of Coloproctology of Great Britain and Ireland (ACPGBI) and British Society of Gastroenterology (BSG) for all cancer referrals, with appropriate safety netting for certain symptoms (e.g. rectal bleeding).[52, 53]

Symptomatic FIT was rapidly adopted in Wales during the COVID pandemic. FIT test use is now widespread, but uptake and referral practice are thought to be inconsistent, with clear benefits to be gained through standardising an optimal pathway.[54] After being piloted in Aneurin Bevan Health Board, and in combination with a risk-stratification score in Cardiff and Vale, symptomatic FIT is available to GPs in Wales, with a FIT framework available from the National Endoscopy Programme.

Though the rapid rollout of symptomatic FIT in Wales has been a success story, our workshops revealed that there are still opportunities in standardising pathways, ensuring completion for all bowel cancer referrals, and appropriate systems to safety net the pathway.

> *Rule out tests can work – but you have to convince GPs they are reliable*
> – ***General Practitioner***

ACTION 4: Safety netting the symptomatic FIT pathway.

Design and implement a symptomatic FIT quality improvement project, identifying and incentivising GP practices across Wales to engage with a toolkit of options for improving their symptomatic FIT offer rate, return rate, and safety netting practices

Colon Capsule Endoscopy

Colon Capsule Endoscopy (CCE), involving swallowing a pill camera, is another evidence-backed solution to find bowel cancer cases and triage access to colonoscopy. With superior sensitivity to other non-invasive tests,[55–57] unpublished data from the Scottish implementation shows that it can spare 39.8% of patients suspected to have bowel cancer from unnecessary colonoscopy.

In Scotland, CCE has been partnered with Symptomatic FIT in a new diagnostic pathway:

- Patients with undetectable results (<10µg/g) are reassured and discharged with safety netting.

- Patients with intermediate results (10–150µg/g) undergo CCE and are only sent for colonoscopy upon positive findings.

- Patients with high-risk results (150µg/g+, or red flag presentation) are offered urgent colonoscopy.

Stakeholders in Scotland indicated this had effectively reduced demand for colonoscopies for suspected cancer by 50%, once well established. CCE can be used in different ways depending on local adoption needs. For example, in the Western Isles Model, GPs act as the gatekeepers for the test and ongoing cancer referrals, whereas in Argyll and Bute, health and social workers deliver CCE into people's homes.

Existing activity in Wales: CCE

CCE is currently being piloted in Wales in four health boards, with the pilot due to conclude and report results in March 2023. There is a clear opportunity in rapidly scaling its' use, should it prove cost-effective.

Liquid Biopsy for Detection and Diagnosis of Bowel Cancer

Bowel-specific liquid biopsies, such as Epi Procolon have been used in screening in the USA, displaying sensitivity comparable to (optimized) FIT testing.[58, 59] In addition, the Galleri blood test for over 50 cancer sites is currently being evaluated as a screening test in asymptomatic people aged over 50.[60, 61] If clinically beneficial results are reported from this trial, it would present a huge opportunity to detect more people with bowel cancer early.

Liquid biopsies may also potentially be used to reassure symptomatic patients that they do not have bowel cancer without colonoscopy, and may present an opportunity in streamlining diagnostic pathways. The Cansense Raman Spectroscopy test developed to detect bowel cancer,[62] has been proposed as a rule-out test for bowel cancer, potentially reducing colonoscopy demand by nearly half, whilst missing very few bowel cancer cases.[63]

These opportunities, and more generally the arrival of liquid biopsies for detection and diagnosis of cancer, would come with numerous associated challenges. For example, do we have the phlebotomy capacity to deliver liquid biopsy testing across a population? If a person has a negative liquid biopsy test, are they less likely to participate in bowel screening? If a person tests positive in liquid biopsy screening for more than one cancer, what pathway do we refer them to? If liquid biopsy screening is adopted, patients with detected bowel cancer will still need colonoscopy – do we have the capacity for this?

Moondance Cancer Initiative Activity: Preparing for Liquid Biopsies

We have stimulated the creation of a Welsh Government led Task and Finish Group with all relevant stakeholders, to produce a position statement for Wales on the conditions necessary, and consequences of, the adoption of liquid biopsies for detection and diagnosis of cancer in Wales.

Rapid Diagnostic Pathways

Another approach is to **streamline diagnostic pathways**, for example via Welsh RDCs or diagnostic hubs, which aim to safely resolve tensions between primary care demand and secondary care capacity. Guided by principles of patient centred triage, they move away from a model where GPs are unable to refer all the patients they are concerned about, as these patients will overwhelm secondary care, or bounce between siloed care settings with no definitive answers. This is especially relevant in young people, who experience a high symptom burden, but relatively low incidence of bowel cancer, meaning GPs can be reluctant to refer them onwards.[44]

> *Tell me what it is, not what it isn't*
> **– *General Practitioner***

One bowel-specific RDC in England, incorporating symptomatic FIT, achieved a median time from point of suspicion to tissue diagnosis of 23 and 27 days (urgent and normal diagnostic referral); 57.3% of patients were diagnosed with stage 1 or 2 disease (60.3% in urgent referral patients).[64–67]

One opportunity for younger "low-but-not-no" risk patients is the Danish no-yes clinic (NYC). These are similar to RDCs, but operate with an emphasis on quick, low resource intensity tests – an example might be a liquid biopsy blood test. With these clinics available, GPs can identify and appropriately refer those at risk of cancer, whilst safely discharging those who are not.[68]

Moondance Cancer Initiative is currently funding an expansion of the Swansea Bay vague symptom RDC, with a pathway for those aged 30–60 with suspected bowel cancer, who would not usually be given an urgent suspected cancer (USC) referral. The pathway has been established in care, and a full cost-effectiveness analysis will be published in 2024. We are also aware of several aligned initiatives across Wales, seeking to improve the coordination and timelines of the bowel cancer diagnostic journey, such as the Radiology Navigator function in Cwm Taf Morgannwg, and Endoscopy-Straight to CT project in Aneurin Bevan.

ACTION 5: Expanding bowel rapid diagnostic pathways across Wales.

Capitalise upon the success of the vague symptom RDC programme in Wales, as well as the groundswell in bowel cancer diagnostic improvement projects, to lay the groundwork for adoption of bowel cancer rapid diagnostic pathways at scale.

Diagnosing Lynch Syndrome

Lynch syndrome is a hereditary condition, with affected people at over 60% risk of bowel cancer (as well as other cancers), often developing at a young age.[69] Recommended by national guidance,[70, 71] colonoscopic surveillance is absolutely essential, and can eliminate the difference in risk of bowel cancer death between Lynch and non-Lynch patients. Aspirin may reduce the bowel cancer incidence by 40% in this population of patients.[72–74]

The affected population suffer an extremely high disease burden. Cedar interviewed a carer whose husband had developed bowel cancer aged 25 in 1994 and was still

living with various effects of highly invasive treatments, his father having died from bowel cancer aged 43. Five members of his family have been diagnosed with Lynch syndrome and his sister and daughter have also developed bowel cancer.

Lynch syndrome is hugely under-diagnosed, leaving people without the care they need.[75, 76] In 2019, Wales committed to the recommended practice[71, 77] of testing all bowel tumours for Lynch syndrome and testing first-degree relatives (FDRs) where appropriate.[78]

Workshop attendees from the Lynch Syndrome Quality Improvement Project (LSQIP) in England described to us how the complex testing pathway for Lynch syndrome was vulnerable to cases falling between services, and lengthy delays – in 2019, they report that the average time to a Lynch syndrome diagnosis was 477 days.

Although KPIs from Welsh genomics services suggest that, once samples arrive, testing is being done quickly and efficiently, our patient consultation was consistent with a picture of service disconnect. Participants told us of a lack of understanding of the result and coordination in receiving this testing, with some receiving results 6 months after treatment. Those who had received a result had little information or follow-up and were often left wondering what the purpose of the test was.

With the support of a project management team, the English LSQIP has delivered a number of simple interventions, such as appointing a Lynch champion within MDTs, implementing 'reflex testing' with pre-filled referral forms and introducing online training modules. After initial success locally, the project is in the process of being scaled across England, for both bowel and endometrial cancer (the other most common cancer caused by Lynch syndrome).[76, 79]

> *"People think about three things: patients, the service, and time. It's about covering those three things. It's a benefit to your patients, your service, and you. It just happens automatically after a while. No extra work for anybody!*
> **– *Project Manager, LSQIP***

ACTION 6: A Lynch Syndrome Quality Improvement Project for Wales.

Work with the All-Wales Medical Genomics Service (AWMGS), Wales Bowel Cancer Initiative, and original LSQIP delivery team to design an LSQIP for Wales. Implement a project that ensures rapid and well-communicated journeys to Lynch Syndrome diagnosis, genetic counselling, and surveillance.

Ensure that this work is aligned with efforts (detailed below) to deliver rapid turnaround of MSI results – which are both important for treatment decisions, and one option for the first step in Lynch syndrome diagnosis.

Treatment

> *There has been so much progress in colorectal cancer treatments in the last decade – it's an international success story, really.*
> – ***Consultant Colorectal Surgeon***

Surgery, Systemic Anti-Cancer Therapies (SACT), and Radiotherapy treatment options for bowel cancer are all fast-developing, and patients have a great deal to be gained through access to cutting-edge treatment and trials.

Genomic Medicine

One particular area of development has been in personalised genomic medicine, where treatments are selected to target the molecular profile of the cancer being treated. Currently, Microsatellite Instability (MSI) and proto-oncogene B-Raf (BRAF) genomic markers can be used to select bowel cancer treatment; and these are increasingly used for both early and late-stage cancers.[80-82]

At present, the National Optimal Pathway (NOP) only recommends genomic testing for Lynch syndrome, not for personalised medicine. In this pathway, only one of MSI or BRAF are generally required, and timelines are not aligned with treatment decision-making. Oncologists advised us that personalised treatments were often delayed by ordering and waiting for BRAF or MSI results.

ACTION 7: Streamline genomic testing for bowel cancer treatment.

Work with the Wales Cancer Network and AWMGS to establish a streamlined NOP, which mandates BRAF and MSI testing, and makes results rapidly available to MDTs for treatment decision-making.

Workshop attendees advised us that, in the longer-term, dozens more target genes and more personalised treatment options for bowel cancer are likely to emerge, which will require an efficient testing pathway. This is already the situation with lung cancer.[83, 84] Moondance Cancer Initiative have part-funded the QuicDNA project, introducing a 500-gene liquid biopsy test, to rapidly deliver genomic results during lung cancer diagnosis, enabling MDTs to rapidly decide personalised treatment.

ACTION 8: Enabling the future of personalised bowel cancer treatment.

Following on from QuicDNA (using a liquid biopsy to test each tumour for 500 targetable markers), establish a pilot integrating a liquid biopsy multi-gene panel into the bowel cancer diagnostic pathway, future proofing the pathway for the next generation of targeted therapies.

Cutting edge treatment and trials

Even outside genomic medicine, several cutting-edge treatments, some still in trials, are presenting an opportunity for a step change in bowel cancer care. Some examples are summarised below, with a more comprehensive picture in our evidence review:

• With greater knowledge of which patients can undergo **endoscopic resection for stage 1 tumours** safely by transanal surgery or endoscopic submucosal dissection, more patents might be eligible for so called organ-sparing treatment.85

• **Laparoscopic surgery** could increase 5-year survival by over 10%,[86] but is currently used for just over 50% of bowel cancer surgeries in Wales. 4 **Robotic surgery** may maximise the number of patients eligible for such minimal access surgery and allow improvements in the quality assurance of surgery and decrease complications in some high-risk patients.[87-92] Robotic surgery has only recently become available to patients in some parts of Wales.

• **Adjuvant therapy** in colon cancer and **neoadjuvant therapy** in rectal cancer are recommended, but sometimes underutilized interventions, with high-quality evidence showing they can reduce cancer mortality.[4, 93] Evidence has also recently emerged of the disease control benefit of neoadjuvant chemotherapy in locally advanced colon cancer.[94]

• **Total Neoadjuvant Therapy (TNT)** for rectal cancer is a promising recent approach, showing high rates of response, and potentially sparing patients unnecessary surgery, which stakeholders told us needs to be promoted in Wales.[95, 96]

• Wales has chosen not to fund **Hyperthermic Intraperitoneal Chemotherapy (HIPEC)**[97] for colorectal peritoneal metastases due to cost-effectiveness concerns. This has led Wales to be out of step with other European countries where the service is available. A study is underway in Cardiff and Vale UHB funded by Moondance Cancer Initiative and will report in late 2023 to evidence whether a service is sustainable in Wales.

• Cutting edge research is being led in Wales to assess treatments for peritoneal metastases by the use of **Pressurised intraperitoneal Aerosol Chemotherapy (PIPAC)**[98].

• **Welsh researchers are assessing** treatments for the management of one of the potential functional consequences of rectal cancer surgery – **Low Anterior Resection Syndrome (LARS).**[99]

> *I asked about clinical trials and was told there aren't many places in Wales that take part in them*
> **– *Patient Participant***

Patients consulted by Cedar spoke of a lack of informed choice in treatment and felt there was a 'postcode lottery' in terms of access to trials. Our clinical consultation suggested difficulties in spreading access and awareness of new treatments.

ACTION 9: Increasing awareness of cutting-edge therapies.

Deliver a quality improvement project in bowel cancer MDTs across Wales, promoting awareness of cutting edge therapies and ongoing trials which might benefit patients. Interventions suggested by workshop attendees included restructuring MDT meetings, digital MDT support software and networks (of which several commercial solutions are available), dedicated research nurse attendees, or experts 'touring' several MDTs to raise awareness.

> *The first thing I asked was regarding clinical trials and he said, we don't have any in this area and went, you might not have any in this area, but if it's my life, I'm prepared to travel, I will go elsewhere to have a clinical trial. But I was just dismissed straight away*
> **– *Patient Participant***

There are also enormous opportunities for patient benefit in increasing participation in clinical research. Moondance Cancer Initiative is funding a project in that is putting organisational capacity and processes in place to help increase the number and spread of bowel cancer patients offered the chance to participate in clinical trials in less research active health boards. So far, over 800 patients have been recruited to trials and we have seen clinical teams re-energized and engaged.

ACTION 10: Expand research champion and coordinator roles.

If positive results are reported from the Moondance Cancer Initiative Enabling Research project, expand the project to health boards across Wales, with a pathway to long-term funding of the research champion and coordinator roles.

The management of rectal cancer is another area where Wales could improve our service provision. Oncologists told us of care options for rectal cancer, such as contact radiotherapy (recommended for certain early and advanced rectal cancers in 2015 and 2019, respectively[100, 101]) which is not currently available in Wales, or TNT approaches with potentially improved outcomes, which are not widely practiced in Wales.[95, 86, 102]

ACTION 11: Specialist rectal cancer management.

Establish dedicated MDTs for the specialized management of patients with rectal cancers, and consider introducing a contact radiotherapy service to Wales, as an option to spare patients life-altering surgeries.

Person–Centered Care Continuity

> *I had to follow everything up myself. I work for the NHS so know how the system works and who to contact. I worry about those people who don't.*
> – ***Patient Participant***

Continuity and coordination of information, management, and communication, across different care settings, is essential for delivering effective, patient–centred cancer care. It strongly influences outcomes, with continuity associated with risk of cancer metastases, hospitalization, mortality, and length of survival with poor prognosis cancers.[103–105]

With growing recognition of the value of cancer care continuity, several predominantly nurse–led interventions have been developed, which might represent an opportunity to improve this aspect of care in Wales. In most, an overarching named nurse coordinator monitors a patient's navigation and information across several care sites.[106, 107] However, non–clinical key workers have also proven successful for coordinating cancer care, particularly in assisting with financial, social, and emotional needs of underserved patients.[108]

> *This disconnection I found was stressful for me.... I spent an awful lot of my time getting one bit in the NHS to talk to another bit of the NHS, which should have been happening but wasn't.*
> – ***Patient Participant***

The bowel cancer NOP for Wales mandates allocation of a key worker from the point of diagnosis, before handover to primary care when the patient is no longer under direct care from the MDT. In the 2016 Wales cancer patient experience survey, 1 in 7 respondents indicated they had never been allocated a named key worker.[109] Although this has fallen to 1 in 10 in the 2021 survey, 3 in 10 patients reported difficulties contacting their key worker.[110]

Participants consulted by Cedar had experienced a consistent lack of continuity, through primary care, diagnosis, treatment, and afterwards:

> *I've never had a CNS. Is that what they're called? Never had one person that I could go to again, I've been passed from colorectal to liver to gynae, it's all been quite displaced*
> – ***Patient Participant***

Evidence from workshop attendees suggested that care coordination has struggled in recent years, with some consultants being the only point of contact for patients entering their clinic:

> *So many times, I have had to be everything to a patient*
> **– *Consultant Oncologist***

Clinical nurse specialists (CNSs) attending workshops also told us that the current way of conducting key worker handovers, as patients move between departments and care settings, means patients are at risk of falling between the cracks with not all relevant information being transferred. Besides patient experience surveys, we are not aware of any initiatives to monitor continuity in cancer care – both in terms of key worker allocation, and informational and management continuity between healthcare settings.

ACTION 12: Innovative approaches to continuity and key workers.

Invest in an audit or monitoring platform to regularly assess the extent of cancer care continuity in Wales, as a key quality improvement tool for patient-centred care.

Work with clinical and patient stakeholders to design and trial the implementation of innovative key worker approaches, such as a CNS responsible for overarching care through multiple settings, or nonclinical key workers dedicated to supporting vulnerable or underserved patients.

Prehabilitation

Prehabilitation is the process of optimising a patient's functional capacity before surgery to improve recovery and the outcomes of treatment.

When delivered effectively, prehabilitation can result in up to a 20% increase in recurrence-free survival.[111] Reducing frailty and increasing physical activity is vital, with more active patients associated with 8% increases in 10-year survival.[112] Prehabilitation can also help to relieve pressure on secondary care by reducing hospital length of stay.[113, 114]

Whilst the evidence base of prehabilitation is still immature, consensus on best practice is emerging. There is broad agreement that multimodal offerings should be provided, with involvement of allied health professionals (AHPs) (for example, physiotherapists), with interventions tailored to need. Information (or a digital platform) can be offered to those with less need of support, and a more intensive, in-person intervention provided for others with greater needs.[115]

> *Well it worked for me and I went to effectively cardio classes before my operation, and anything that raises your level of fitness and gives your immune system a bit of a kick has got to help*
>
> – ***Patient Participant***

Existing activity in Wales: Coordinating Prehabilitation

The Prehabilitation working group, seated within the Wales Cancer Network, are undertaking work to baseline, coordinate, and set minimal standards for prehabilitation services across Wales.

However, many patients consulted by Cedar painted a complex picture of prehabilitation, with many regarding it as not a priority for their care at that time. When patients received prehabilitation, care coordination was often lacking and specialist support and information (e.g. dietary advice for patients with stoma bags) insufficient. The offer of prehabilitation was also felt to be a post-code lottery with those living in cities more likely to be offered it.

> *You've got so much to take on board and lots of hospital appointments to go to, so to be given guidance at that point about diet and exercise. I think maybe it's not the right time. I think certainly post operatively.*
>
> – ***Patient Participant***

Whilst prehabilitation may present an opportunity to improve outcomes, Cedar's study into patient and caregiver priorities makes it clear that it must be done in a patient-centred way. Standard prehabilitation might not be right for every patient: information and support must be provided on their terms, and patients should have a say in the design of services.

> *I'm trying to get back to like endurance sport and things like that. I'm not trying to get up and down stairs or whatever... It's great that Velindre do have diet and exercise programs afterwards. But if I just said it's not for me... I struggled a bit with kind of imposter syndrome when it comes to cancer because I feel like I shouldn't be there... so I think it's great initiative, but more personalized might be better.*
>
> – ***Patient Participant***

Several locally adapted prehabilitation services have been established across Wales, but stakeholders have told us that little is known about how to model demand, delivery, and workforce, and subsequently demonstrate value and make the case for continued funding.

ACTION 13: Facilitating Value-Driven Prehabilitation.

Optimize and expand the reach of prehabilitation services for bowel cancer care, working across disciplines to build a set of tools for modelling service requirements and demonstrating value, and thereby enabling prehabilitation services to be sustainably funded into the future.

Prehabilitation in Scotland

One example of a successful national approach to prehabilitation is in Scotland. Written into the Scottish Government's Cancer Plan, and overseen by national Cancer Prehabilitation Steering Group, a set of key principles for prehabilitation across the country has been published, making recommendations for both the service (timing, multimodal offering), and for ensuring continuity with the rest of the patient's cancer journey.[116]

The Scottish website, 'Prehab and Me', is a resource for patients, with suggestions for how to prepare for cancer treatment and signposting for further support.[117] Lastly, the Scottish Government have funded a two-year pilot for multimodal prehabilitation to be provided in all 8 Maggie's cancer support centres across the country.[118]

In Cedar's patient/carer consultation, Maggie's charity stood out as receiving 'an incredible amount of praise' for their support service.

> *Going to Maggie's and getting to know other people with who are going through the same thing as me honestly, I can't imagine having done this without having Maggie's. To me they've saved my sanity*
> **– *Patient Participant***

Addressing Inequalities

It is vitally important to acknowledge the influence that inequalities have over bowel cancer outcomes. The most socially and economically disadvantaged people in Wales are more likely to develop bowel cancer and to have it diagnosed late:

• Young people from more deprived families and schools are more likely to adopt behaviours which increase their risk of developing bowel cancer.[119]

• Participation in bowel screening is lower in more deprived Welsh communities, with a 15% difference between the most and least deprived quintiles in 2019–20.[6]

• In the UK, people from more deprived backgrounds report more barriers to timely help-seeking with bowel cancer symptoms, in a pattern which has worsened as a result of the COVID pandemic.[120]

• People with comorbidities experience longer times from symptoms to tests and are less likely to receive a timely colonoscopy/sigmoidoscopy.[121]

> *You can't ignore the social justice component of this, and recognize that people exhibiting risk behaviours, not engaging with screening, and not presenting to healthcare are likely the same.*
> – **Third Sector Research Manager**

As a collective result of all these factors, people in the most deprived quintile in Wales suffered an 83% higher risk of death from bowel cancer than the least.[2] There are huge gains to be made from addressing these inequalities in a long-term, sustained and collaborative way.

Solutions cannot be imposed but must come from building mutually respectful and engaging relationships, working out together what will make a difference and acting on that. An example is ongoing research to engage Traveller/Roma communities in bowel screening,[122] another, the TIC-TOC study, aiming to increase awareness and help-seeking behaviours for cancer amongst more deprived Welsh populations.[123]

However, these predominantly research-led efforts are rendered precarious by the short-term and insecure nature of research grants and lack mechanisms to directly translate and scale solutions to wider cancer care practice. A positive example of change in this space is Te Aho O Te Kahu, and the New Zealand cancer control agency's efforts to weave equity into core cancer services.[124]

ACTION 14: Addressing Inequalities as core service

Mandate healthcare providers, with academic support, to deploy initiatives engaging with populations underserved by cancer care, both in terms of protected characteristics (e.g. ethnicity), and vulnerable groups (e.g. more deprived communities, homeless people, people in prison). Dedicated health equality teams may be well positioned to deliver this.

> *When our funding ends or a new project comes up, we have to change tack again... A few projects fall off the edge of a cliff. We create something and then it gets left.*
>
> – **Cancer Inequalities Researcher**

Next Steps

Moondance Cancer Initiative **find, fund, and fuel** brave ideas and brilliant people, aiming to improve cancer care, reducing deaths and inequalities in Wales.

We will be supporting projects in 2023 and onwards which deliver on some of the strategies described above, as well as considering any others which arise as we progress and share our programme. We'll also keep bringing energy to working Towards Zero Deaths, including more detailed analysis of solutions at critical pathway stages.

While we know that we won't get to 'zero deaths' from bowel cancer quickly, we strongly believe that setting a hopeful and achievable direction is much needed. We are heartened by the support and energy unleashed by this case for change. There is already a growing understanding that by addressing every element set out in this report we can begin to turn the tide. We have noted a motivation to work differently and collaborate across boundaries, with ambition and purpose.

Partnership and collaboration across government, patient groups, NHS, third sector, and industry will be essential to deliver the most impactful possible programme for Wales. We will continue to build widespread understanding and support for this case for change. Also to work alongside partners to develop, fund and support new and better ways of doing things, evaluating and gathering the evidence needed to sustain change.

The publication of this Case for Change Towards Zero Deaths from Bowel Cancer in Wales in June 2023, emphasises commitment to supporting improvements in care, with some projects already under development. With widespread collaboration and support, it could mark the start of an impactful and long-term movement towards better bowel cancer care in Wales.

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Appendix A – Opportunities for Change in Wales Discussed in Workshops

Opportunity	What could we achieve in Wales?
Preventing Bowel Cancer Cases	
Invest in public health measures to inform and empower patients to adopt behaviours which reduce risk: smoking cessation, dietary/alcohol changes, exercise	• Reduce the incidence of bowel cancer by 25%+ for each additional behaviour adopted by members of the public.
Utilize primary care and screening programmes to advise and empower people at risk of bowel cancer on potential benefits of aspirin.	• Potentially reduce the incidence of bowel cancer in some at-risk populations by ~20%, by providing training and guidance through a low-cost and readily accessible pharmaceutical.
Preventing Bowel Cancer Cases	
Increase the target for screening participation, and drive this aspiration with low-cost interventions such as text reminders, GP endorsed letters, and advanced notification of receipt.	• Increase by 20%+ the number of cancers prevented and detected by screening (240 detected in 2019/20) – enabling a 65%+ mortality reduction in screening detected patients.
Encourage early presentation through media campaigns, community campaigns (e.g. TIC-TOC) and other innovative methods (e.g. 'Get on a Roll'), matched to a 'pull' from GP surgeries.	• Reduce emergency presentation (EP), from over 35% of diagnoses, reducing deaths by ~7% for every 10% reduction in EP. • Stage shift in presentation would significantly reduce mortality: the 29% of patients diagnosed at stage 4 in Wales could have their mortality rates reduced from ~90% to ~45% if diagnosed at stage 3.
Screening Optimzation	
As rapidly as possible, decrease the Faecal Immunochemical Test (FIT) threshold for onward referral to a level comparable with other developed countries, and lower the age of eligibility for bowel screening to 50. To facilitate this, expand and streamline our colonoscopy capacity, considering how services could be organized and improved to meet this need.	• More than double the number of cancers prevented, and detected by screening, and extend the benefits of bowel screening to the 12% of bowel cancer patients diagnosed at ages 50-59 (plus those later diagnosed via symptoms aged 60+). Patients diagnosed via screening could experience 65%+ less cancer mortality.

Referral and Diagnostic Pathways	
Implement and scale interventions (decision aids, algorithms, ThinkCancer!) to aid GPs in promptly identifying and referring patients with suspected cancer.	• Reduce delays to treatment, with studies suggesting delays of just 4 weeks can increase a person's risk of dying from bowel cancer by between 6–13%.
Safely streamline and safety net our diagnostic pathways, through models such as bowel-specific rapid diagnostic pathways, empowered by diagnostic tools such as Colon Capsule Endoscopy (CCE) and FIT.	• Avoiding treatment delays of 3 months could reduce short-term (3 year) mortality by 50%+, and long-term (10 year) mortality by 15%+. In December 2022, 50% of people diagnosed with bowel cancer waited more than 84 days from referral to starting treatment in Wales.
Inform and empower young people with symptoms to present and GPs to refer those with suspected cancer, using the above opportunities.	• In Cedar's patient consultation, >50% of younger patients were diagnosed at Stage 4, with multiple delays to referral and diagnosis. Stage 4 patients could have their mortality reduced from ~90% to ~45% if diagnosed at Stage 3.
Diagnosing Lynch Syndrome	
Invest in a Lynch Syndrome Quality Improvement Project, to ensure that all eligible patients and family members are promptly given testing opportunities, are kept informed, and offered appropriate interventions.	• ~8,000 people with Lynch syndrome in Wales have an 80% lifetime risk of bowel cancer, predominantly whilst they are young, of whom <5% know about their condition. • Being prescribed aspirin can reduce their risk of bowel cancer by 40%, and surveillance can eliminate their excess risk of bowel cancer death compared to the non Lynch population
Cutting Edge Treatment and Trials	
Open up eligibility and accessibility of bowel cancer treatments known to improve outcomes, eliminating the 'postcode' lottery.	• Increase the ~50% of surgeries in Wales which are laparoscopic, possible decreasing mortality by 10%. • Increase availability of robotic surgery for specific cases, possibly improving post-surgery function. • Increase the proportion (currently 61%) of eligible patients with stage 3 colon cancer receiving adjuvant therapy (and immunotherapy where appropriate). Increase access to neoadjuvant therapy in eligible patients with rectal cancer. Both actions could decrease mortality rates in the currently untreated proportion of patients by 20%+.

Increase and improve access for clinical research activity, opening eligibility for: · Neo/adjuvant therapies in earlier stage colon cancer. · Total Neoadjuvant Therapy (TNT) approaches in rectal cancer · Novel immunotherapies and immunotherapy combinations · Novel surgical modalities	• Strong potential to decrease mortality in patients receiving innovative therapies, though extent remains to be proven.
Person-Centred Care Continuity	
Invest in service design and resource which prioritises patient centred continuity and communication, for example nurse-led services or cross-setting care coordination meetings.	• Improve the most universal reason that patients consulted by Cedar cited for poor experience of care, with evidence suggesting this will also reduce risk of hospitalisation, metastases, and even risk of death from cancer.
Consolidate, improve, and mainstream multimodal prehabilitation services in Wales – in a manner that is led by, and is designed according to the needs of, patients, giving them choice in their treatments and support.	• If an effective prehabilitation service is delivered, 10-year survival in participating patients could be increased by up to 8%, and recurrence free survival by 20%, as well as decreasing pressure on secondary care through reduced length of stay after treatment.
Addressing Inequalities	
Take advantage of expertise and innovative programme design in Wales to engage with underserved communities, looking to close inequality gaps in high risk behaviours, screening participation, presentation, rapid diagnosis, and treatment options.	• Close the gap in risk of deaths from bowel cancer. Each inequality gap contributes towards a total 83% higher rate of deaths in Wales most deprived compared to least deprived quintile.

Moondance Cancer Initiative find, fund, and fuel brilliant people and brave ideas, to transform and improve cancer outcomes in Wales. We actively support people and projects with potential to transform outcomes across the country, and we undertake research and insight to inform our work.

Published by:

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