



Towards zero deaths from bowel cancer in Wales

Final report

Authors: Michael Beddard, Senior Researcher

Dr Nia Jones, Senior Researcher

Kathleen Withers, Deputy Director

Dr Rhys Morris, Director

Date: 12/09/22



Contents

1	Introduction	6
2	Background	6
2.1	Evidence review	7
2.2	Aims and Objectives.....	8
2.3	Purpose of data gathering	9
3	Methods.....	9
3.1	Overview	9
3.2	Survey.....	12
3.2.1	Survey design	12
3.3	Recruitment	13
3.4	Data protection	13
4	Survey Results	14
4.1	About you.....	14
4.2	Your bowel cancer history	19
4.3	Your experience of bowel cancer care.....	22
4.4	Bowel cancer prevention, awareness & diagnosis	28
4.5	Improving bowel cancer care.....	30
4.6	Summary of survey responses	32
5	Interviews	32
6	Focus Groups.....	35
7	Themes	36
7.1	Everyday impact.....	38
7.2	Suspicion to diagnosis	40
7.2.1	Accessing a GP.....	40
7.2.2	Recognising less obvious symptoms	41
7.2.3	‘My GP won’t listen to me’	42
7.2.4	A trigger for further action.....	43
7.2.5	‘You are too young’	44
7.3	‘You are too young’ – A story for change.....	46
7.4	Awareness.....	47
7.4.1	Increased GP awareness	47
7.4.2	Social media	48



7.4.3	Public figures.....	49
7.5	Bowel Cancer Screening.....	50
7.5.1	A ‘false sense of security’	50
7.5.2	Increasing screening engagement	52
7.5.3	Increase the screening eligibility.....	53
7.6	‘It gave me false hope’ - A story for change	55
7.7	Communication.....	55
7.7.1	‘How I was told’	55
7.7.2	Uncoordinated care	56
7.7.3	‘Scanxiety’	57
7.7.4	Continuity of care.....	58
7.7.5	Communicating treatment options	59
7.8	‘They sent me home to die’ - A story for change.....	62
7.9	Genetic testing	64
7.9.1	The value of genetic testing.....	64
7.9.2	Miscommunication and service disconnect.....	65
7.10	Living with Lynch syndrome – One family’s story.....	67
7.11	My cancer, my choice	69
7.11.1	‘Postcode lottery’	69
7.11.2	Having a choice in my treatment	71
7.12	Diet and lifestyle	73
7.12.1	Exercise and prehabilitation	73
7.12.2	Diet.....	75
7.12.3	Stoma bag dietary advice.....	77
7.12.4	Prophylactic Aspirin	78
7.13	Support.....	78
7.13.1	Aftercare	79
7.13.2	Types of support	81
7.13.3	Support from care team.....	82
7.13.4	Charity support	83
7.13.5	Maggie’s charity.....	84
7.13.6	Mental health and counselling.....	85
7.13.7	Monitoring post-treatment.....	87
8	Discussion	89



8.1	Diagnosis of Bowel Cancer	92
6.3	Genetic testing for bowel cancer	95
6.4	The impact on quality of life	95
9	Conclusion.....	97
10	Acknowledgements	98
11	References	99
12	Appendices.....	101
12.1	Appendix A - Bowel Cancer Survey	101
12.2	Appendix B - Survey participant demographics.....	112
12.3	Appendix C - Interview Topic Guide.....	114
12.4	Appendix D - Interview participant demographics	116
12.5	Appendix E - Focus group topic guide 1.....	118
12.6	Appendix F - Focus group topic guide 2.....	120
12.7	Appendix G - Focus group participant demographics.....	122



Abbreviations list

Abbreviation	Definition
BCUK	Bowel Cancer UK
CNS	Clinical Nurse Specialist
CRC	Colorectal Cancer
CT	Computed Tomography
CTMHB	Cwm Taf Morgannwg University Health Board
FIT	Faecal Immunochemical Testing
FOB	Faecal Occult Blood
GI	Gastrointestinal
GP	General Practitioner
GT (Lite)	Grounded Theory Lite
IBD	Inflammatory Bowel Disease
IBS	Irritable Bowel Syndrome
ICV	Ileocaecal Valve
ITU	Intensive Trauma Unit
KRAS	Kirsten Rat Sarcoma Viral oncogene
MCI	Moondance Cancer Initiative
MDT	Multidisciplinary Team
NBOCA	National Bowel Cancer Audit
NICE	The National Institute for Health and Care Excellence



1 Introduction

Moondance Cancer Initiative (MCI) is a not-for-profit company dedicated to finding solutions to help more people in Wales survive cancer. Their priority is to accelerate adoption of innovations and improvements to cancer services in Wales which lead to fewer deaths from cancer, with a particular focus on closing inequalities in outcomes. MCI has recruited Cedar, an NHS Health Technology Research Centre (<https://cedar.nhs.wales/>) independent of MCI, to lead a project which aims to identify areas for potential improvement in bowel cancer care across Wales.

2 Background

Bowel, or colorectal cancer (CRC) is among the most commonly diagnosed cancers in Wales, with approximately 2,300 diagnoses per year. It is the second biggest source of cancer mortality causing approximately 900 deaths annually in Wales.¹ Yet it is also near-unique among cancers in the *number* and *effectiveness* of opportunities available to prevent people dying from it. These include:

- An ability to screen for highly predictive genetic risk factors of bowel cancer²
- A thorough understanding of the causes of approximately 50% of bowel cancers which are theoretically preventable^{3–5}
- Bowel cancer has an extremely long pre-cancer phase of 10-20 years, when treatable lesions, polyps, and adenomas can be detected³
- Sensitive screening methods for bowel cancer and pre-cancer in asymptomatic people⁶
- Curative treatment for pre-cancer and early-stage bowel cancer has extremely good outcomes, with the vast majority of patients surviving beyond their cancers^{7,8}
- An understanding of numerous lifestyle factors which can improve prognosis and response to treatment in patients with advanced bowel cancer⁵
- A new generation of systemic immunotherapies for advanced-stage bowel cancer may possess the ability to enable resection of their cancers, or even to ‘cure’ a subset of patients^{9,10}



Opinion is growing in the bowel cancer community worldwide that, if each of these opportunities were fully taken, in combination with impending innovations for diagnosis and treatment, the number of people who die from bowel cancer could be greatly reduced. Put simply, the objective of the MCI project is that Wales should aim to move *towards zero deaths* from bowel cancer.

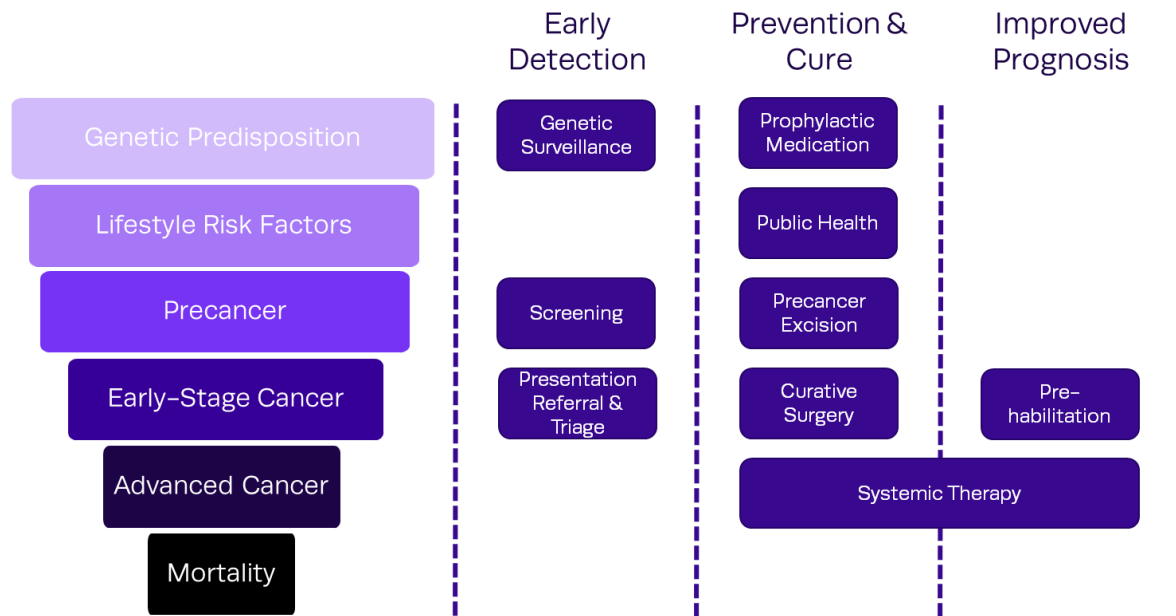
2.1 Evidence review

An evidence review of interventions which aimed to reduce bowel cancer mortality was conducted by MCI. This examined every stage of the development, diagnosis and treatment of bowel cancer, from genetic risk factors through to advanced disease. From this, MCI has identified nine key areas of opportunity to reduce bowel cancer deaths:

1. Genetic testing to identify people at risk of bowel cancer, and surveillance programmes to diagnose their cancers early.
2. Use of prophylactic aspirin to reduce the risk of developing bowel cancer in those with genetic (or other) risk factors.
3. Public health measures to reduce the prevalence of behavioural risks, such as smoking, alcohol consumption, and diet.
4. Screening to detect and diagnose bowel cancers as early as possible.
5. Improving early presentation and rapid diagnosis of symptomatic cancers, ensuring they are diagnosed at as early a stage as possible.
6. Utilising prehabilitation programmes to maximise functional status, and the number of patients eligible for more effective, but more demanding, curative treatments.
7. Maximising the outcomes of curative treatments through adjuvant/neoadjuvant therapies and innovative surgery approaches.
8. Maximising the benefits of systemic therapies for advanced cancers, using new innovative modalities, such as immunotherapy.
9. Effectively monitoring for recurrence in patients who have finished treatment, identifying their recurrent disease at as early a stage as possible.

This information was used to develop a proposed framework of patient progression through bowel cancer as detailed in Figure 1.

Figure 1. Framework for the prevention of bowel cancer mortality



2.2 Aims and Objectives

The aim of this stage of the project was to assess the current status of bowel cancer care in Wales. Cedar's role was to explore the opinions of patients who have (or have had) bowel cancer and carers of patients, on the quality of bowel cancer care in Wales, and identify opportunities and priorities for potential future change.

In order to gather feedback on patient and carer perspectives on each of the nine key areas identified by MCI, Cedar was tasked with several objectives including:

- Design a survey with oversight from MCI to collect data on the experiences and priorities of patients who have (or have had) bowel cancer and their relatives/carers.
- Use survey data to identify participants for interviews and focus groups.
- Design a semi-structured interview topic guide using survey responses, and to use these during a series of interviews to explore perspectives and experiences of bowel cancer care in Wales.
- Use emerging and important themes identified in the interviews to design and conduct small focus groups with patients and families to assess their attitudes



toward, and the acceptability of potential improvements to drive bowel cancer care forward.

- Qualitatively analyse and report the findings.

This report outlines the results of the ‘Towards zero deaths from bowel cancer in Wales a year without bowel cancer mortality’ study, funded by MCI.

The findings of this report will be used to add patient input into a larger project for change. The larger project by MCI is to produce a roadmap, setting out a series of realistic goals for innovation and change, to push Wales towards a year without bowel cancer mortality.

2.3 Purpose of data gathering

Using the framework of patient progression in Figure 1, discussions during interviews and focus groups with participants aimed to focus on three broad areas:

- Early detection: innovations to catch the disease early, when it is most treatable
- Prevention and cure: interventions to stop people developing bowel cancer, and cure it at early stage
- Improved prognosis: interventions to improve patients’ prognosis, extending their life, and improving the possibility of future curative intervention.

Researchers aimed to explore participant experiences in each area and help identify their priorities for future improvement. Throughout the project, Researchers also sought to highlight where participants identified examples of good care. These examples will provide opportunities to share good practice throughout Wales.

3 Methods

3.1 Overview

In order to gather views from a wide range of people with experience of bowel cancer services in Wales, it was agreed that several qualitative methods would be used to give depth and breadth of feedback including surveys, interviews and focus groups (figure 2). Initially people with bowel cancer or those who have had bowel cancer and/or were family members/carers were invited to complete a survey. Survey questions were a mix of open and closed answers and results were used to identify priorities of survey participants. Cedar



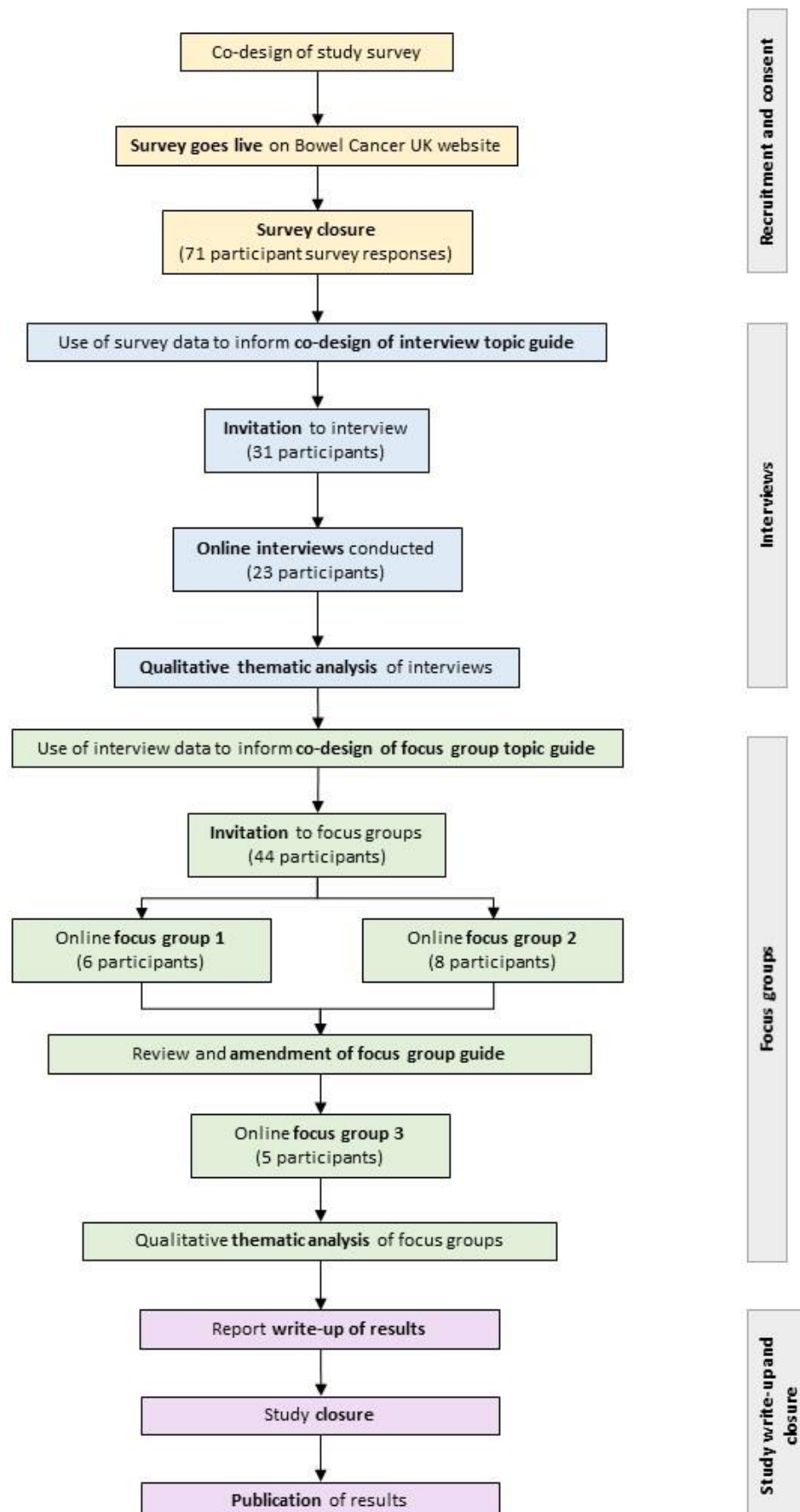
sought to explore them further by completing a series of semi-structured interviews with a subset of the survey respondents. These interviews also allowed Cedar to explore areas of interest as identified by the survey and to ensure all aspects of care had been explored.

The interviews helped inform topics for several open group discussions in the form of online focus groups with patients identified from the survey and interviews.

All surveys and topic guides for both the interview and focus groups were designed by Cedar researchers with input and approval from representatives of MCI.



Figure 2: Study flowchart



3.2 Survey

3.2.1 Survey design

Bowel Cancer UK (BCUK) developed promotional materials including background information of this project and a signup link to a publicly accessible form. This form led participants to an online survey created by Cedar with support from the MCI team.

Using the three themes identified by MCI as being of interest, an 18-question survey was developed in both English and Welsh languages ([Appendix A](#)). The purpose was to collect demographic data and identify key themes and priorities to be explored further in the interview stage of the project. Questions were split into five sections:

- About you (6 questions)
- Your bowel cancer history (6 questions)
- Your experience of bowel cancer care (4 questions)
- Bowel cancer prevention, awareness & diagnosis (2 questions)
- Improving bowel cancer care (2 questions)

Survey participants were also asked if they would be interested in participating in interviews and / or focus groups with an option to leave contact details if they wanted to take part. They were also able to opt to allow Cedar to pass on their details to BCUK if they wanted to be contacted with information on available support and advice. Cedar transferred all consenting participants' contact information to BCUK.

Questions comprised a mix of closed text and open ended free-text questions. Free-text questions allowed participants to report their personal experiences of being diagnosed with bowel cancer and the care they received in their own words, whether positive and/or negative.

Participants were also asked to identify a single priority for potential improvement by asking 'At what point in the bowel cancer journey could the most improvement have been made and why?'. The responses to this question in particular helped establish the key topics for discussion in the interviews.



Question 17 related to bowel cancer prevention, awareness and diagnosis, and question 18 related to how to improve bowel cancer care. Participants were asked to number the options in order of what was important to them with 1 being the most important. For both questions 17 and 18, participants were asked why they had chosen that option as the most important for them. The highest and lowest priorities for both questions helped guide question design for the interviews.

A total of 71 surveys were completed, however not all questions were answered by all participants. Survey participant demographics can be found in Table 2. Additionally, demographics for those participants who completed the survey but did not participate in any other stage of the study be found in table 6 ([Appendix B](#)).

3.3 Recruitment

To facilitate recruitment of people with an experience of bowel cancer, a number of English and Welsh language promotional materials were developed by Bowel Cancer UK, with support from both MCI and Cedar.

Recruitment was approached via three routes:

- Bowel Cancer UK shared promotional materials and signup forms amongst charity stakeholder groups. This was primarily conducted through the Bowel Cancer UK (BCUK) voices for Wales group. Other groups included patient representative groups (Carmarthenshire Association of Voluntary Services, 2022; Bridgend Association of Voluntary Organisations, 2022) and Macmillan and Tenovus stakeholder groups (Tenovus Cancer Care, 2022)
- MCI coordinated with several Welsh health boards to help share promotional materials and signup forms via social media including Twitter and Facebook
- MCI contacted several clinical nurse specialists in cancer, asking them to invite their patients to participate, and shared details for completing the survey.

3.4 Data protection

All documentation containing identifiable data corresponding to the project was password protected for restricted access to the two researchers and primary study authors. All



feedback and any quotes used throughout the report have been anonymised and no participant names or identifiable details have been included.

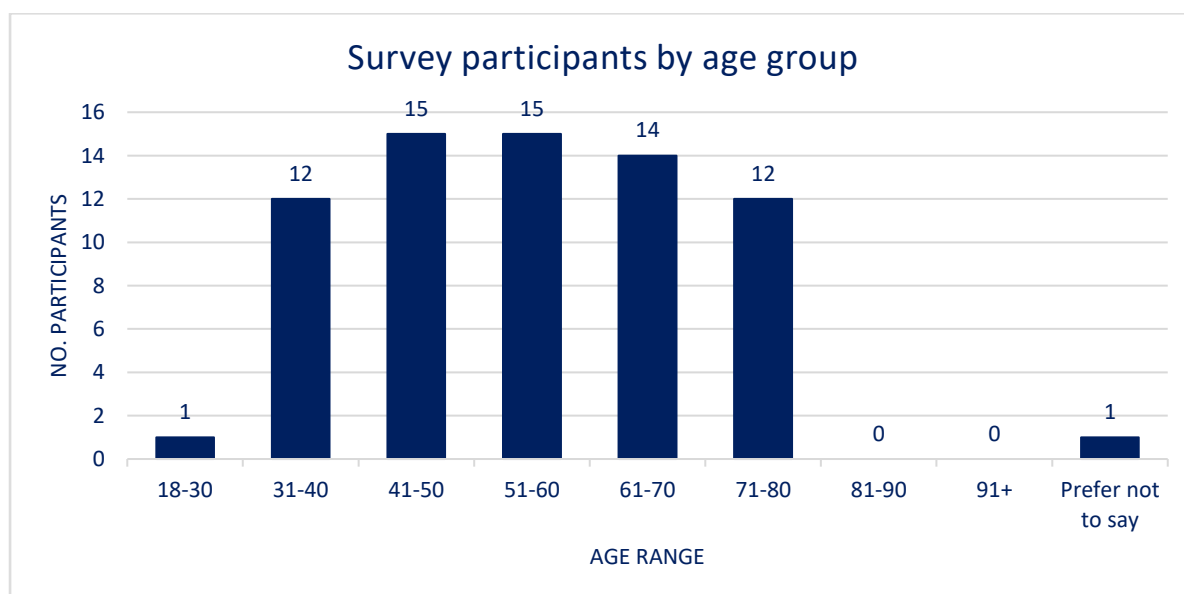
4 Survey Results

4.1 About you

There were 71 total responses to the survey although not all questions were answered by each participant. Some questions also gave the option of selecting multiple answers, so in some instances there may be more than 71 answers to any single question.

Of the 70 participants who completed question 2, 55 (79%) were female and 15 (21%) were male. Age of participants ranged from 31 years to 80 years. Age was categorised into eight groups and the proportion of participants in each age group was fairly evenly distributed between ages 31-80; with 12 (17%) aged 31-40, 15 (21%) participants in both the 41-50 and 51-60 age groups, and 12 (17%) aged 71-80 (Figure 3). There were however no participants recruited aged over 81 or under the age of 18. One participant chose not to disclose their age.

Figure 3: Survey participants by age group





Regarding ethnicity, 68 (97%) of survey participants were of a white ethnicity (including Welsh, English, Scottish, Northern Irish, British, Irish). There was 1 (1%) person of Indian ethnicity and 1 (1%) of 'other / mixed background'.

Of the 71 survey participants, 70 responded to question 5 which asked their employment status at the time of their bowel cancer diagnosis. Forty two (61%) of survey participants were in employment, either part-time, full-time or self-employed. Nineteen (27%) of participants were retired, another 4 (6%) were looking after home or family, 2 (3%) were unemployed/seeking work, 1 (%) was disabled, 1 (1%) was on long-term sick leave, and 1 (1%) answered 'other'.

Question 6 asked if the participants employment status had changed as a result of their cancer journey. Of the 68 people who answered this question, 19 (28%) answered that their employment status had changed as a result of their cancer journey and 48 (71%) had not. There was also 1 participant who answered 'I don't know/not sure'. The five reasons for change in employment are detailed in table 1 below.

Table 1: Free-text responses to question 6

<p><i>"Was self-employed part time but no longer working due to chemo" (Participant 20)</i></p> <p><i>"I was sacked due to taking sick leave" (Participant 29)</i></p> <p><i>"I have decided to retire from teaching and will soon be working as a telephone receptionist/pa" (Participant 11)</i></p> <p><i>"They decided to finish me due to ill health" (Participant 35)</i></p> <p><i>"I am currently on full sick pay as unable to work with my treatment" (Participant 18)</i></p>
--

All 70 participants who answered question 1 lived in Wales (Figure 4) with most survey participants living in the South of Wales in areas including the Vale of Glamorgan, Rhondda Cynon Taf, and Carmarthenshire – areas which are among the most populated in Wales (Welsh Government, 2020). There were no survey participants from Ceredigion, Denbighshire, and Merthyr Tydfil, however this may be in part due to the smaller population in these areas.

In the initial plan for sampling, there was an objective to interview participants from deprived postcodes or regions, however, to preserve anonymity, address details were not



taken in the survey. It was therefore not possible to ascertain whether participants who completed the survey were from a deprived region.

Figure 4: Survey responses to question 1

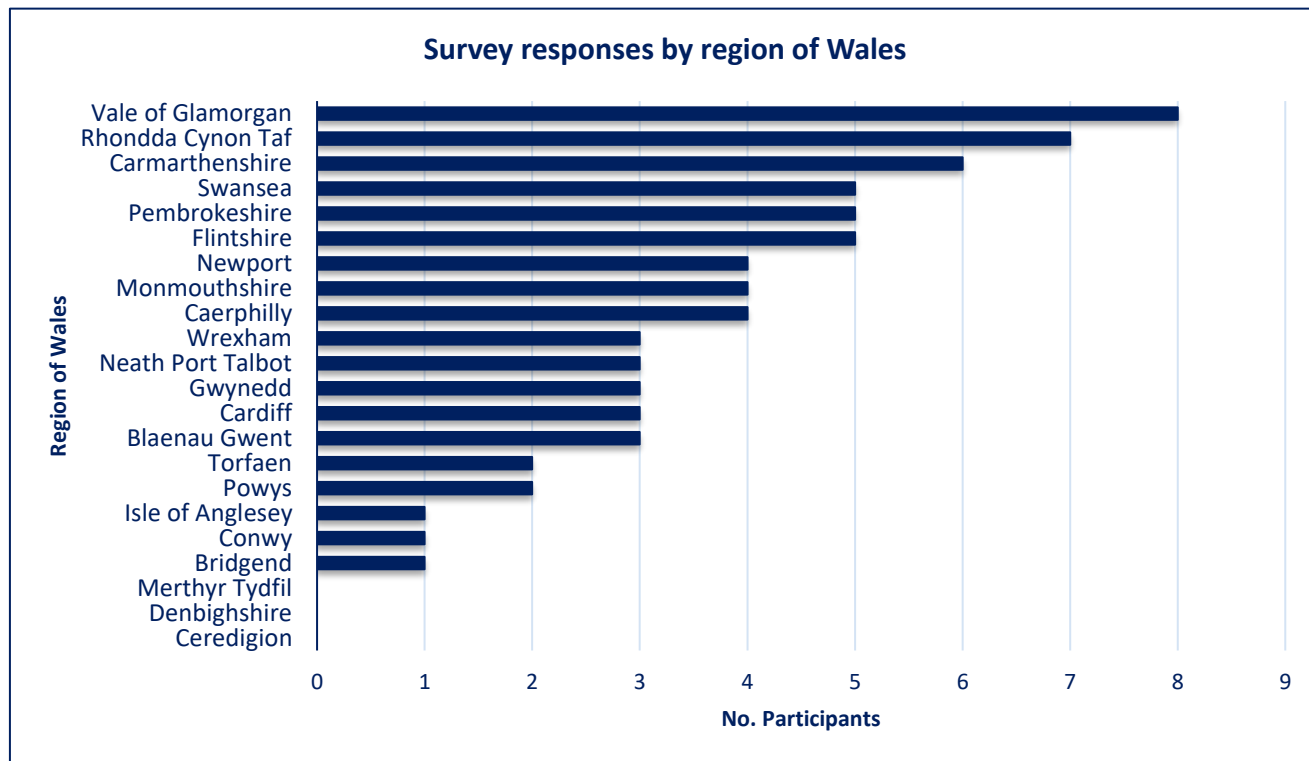




Table 2: Overall Participant Demographics

Demographic	Category	No. participants N(%)
Gender	Male	15 (21%)
	Female	55 (79%)
	Non-Binary	0 (0%)
	Prefer not to say	0 (0%)
Age Group	18-30	1 (1.4%)
	31-40	12 (17%)
	41-50	15 (21%)
	51-60	15 (21%)
	61-70	14 (20%)
	71-80	12 (17%)
	81-90	0 (0%)
	91+	0 (0%)
	Prefer not to say	1 (1%)
Ethnicity	Any White background*	68 (97%)
	Indian	1 (1%)
	Gypsy or Irish Traveller	0 (0%)
	White and Black Caribbean	0 (0%)
	White and Black African	0 (0%)
	White and Asian	0 (0%)
	Pakistani	0 (0%)
	Bangladeshi	0 (0%)
	Chinese	0 (0%)
	Any other Asian background	0 (0%)
	Caribbean	0 (0%)
	African	0 (0%)
	Any other Black background	0 (0%)
	Arab	0 (0%)
	Any other ethnic group	0 (0%)
	Any other mixed background	1 (1%)
	Prefer not to say	0 (0%)
Location by region	Blaenau Gwent	3 (4%)
	Bridgend	1 (1%)
	Caerphilly	4 (6%)
	Cardiff	3 (4%)
	Carmarthenshire	6 (9%)
	Ceredigion	0 (0%)
	Conwy	1 (1%)
	Denbighshire	0 (0%)
	Flintshire	5 (7%)
	Gwynedd	3 (4%)
	Isle of Anglesey	1 (1%)
	Merthyr Tydfil	0 (0%)
	Monmouthshire	4 (6%)
	Neath Port Talbot	3 (4%)
	Newport	4 (6%)
	Pembrokeshire	5 (7%)
	Powys	2 (3%)
	Rhondda Cynon Taf	7 (10%)
	Swansea	5 (7%)



Demographic	Category	No. participants N(%)
	Torfaen	2 (3%)
	Vale of Glamorgan	8 (11%)
	Wrexham	3 (4%)
	I live outside of Wales	0 (0%)
Employment status at the time of diagnosis	Full-time employed or self-employed	30 (44%)
	Retired	19 (28%)
	Part-time employed or self-employed	12 (17%)
	Looking after home or family	4 (6%)
	Unemployed/Seeking work	2 (3%)
	Long-term sick	1 (1%)
	Disabled	1 (1%)
	Student	0 (0%)
	Other	1 (1%)
Family history of bowel cancer	Yes, two or more family members	9 (13%)
	Yes, one family member	17 (24%)
	No	39 (56%)
	I don't know	5 (7%)

*Including Welsh, English, Scottish, Northern Irish, British, Irish



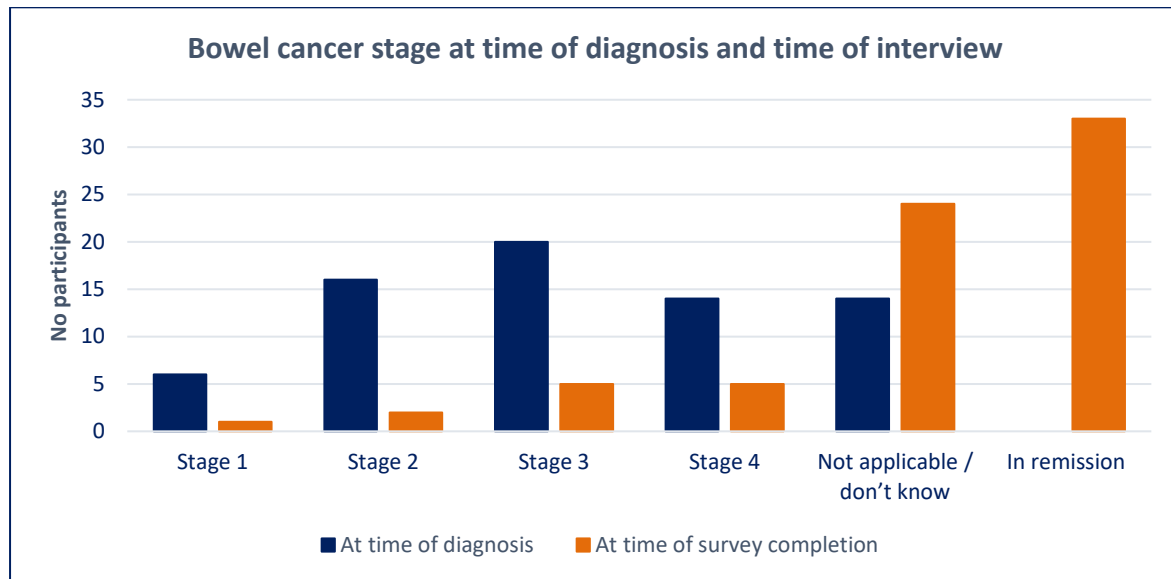
4.2 Your bowel cancer history

All participants answered question 7 which asked who had been diagnosed with bowel cancer. Fifty (73%) had been diagnosed with bowel cancer themselves, with 20 (29%) participants being the partner, friend or family member of someone that has/had bowel cancer. One (1%) answered 'Other'.

Question 12 asked whether participants had a family history of bowel cancer. A total of 26 (37%) participants had a known family history of bowel cancer with either 1 (17/26) or 2 or more (9/26) family members diagnosed. Those who answered 'yes' to Q12 were asked if the participants immediate family members had ever been tested for genetic risk factors. Seven (18%) responded 'yes' and 30 (75%) answered 'no'. Three (7.5%) participants did not know if they had been genetically tested. These responses were influential in the design of question 10 of the interview topic guide which aimed to explore the participants experience of genetic testing, and their perspective on whether they would have liked to have been genetically tested.

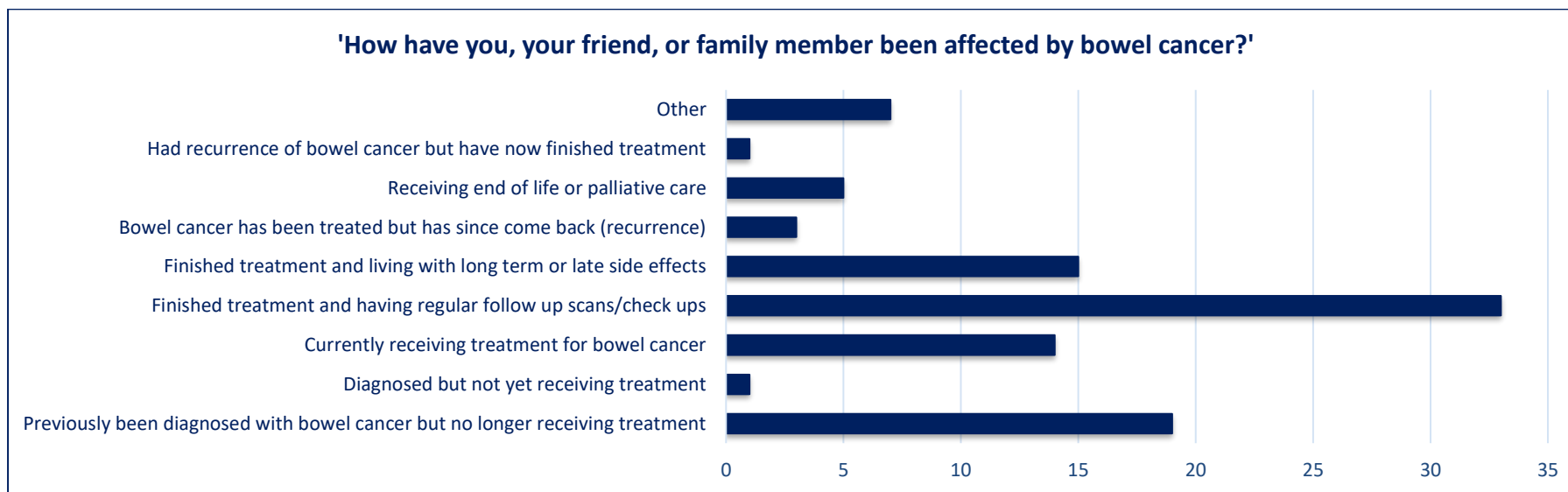
At the time of their cancer diagnosis, 29% of participants were at stage 3, and 20% at stage 4. However, at the time of survey completion in February-March 2022, 7% were stage 3 and 7% stage 4, with the majority (47%) having been treated and in remission (Figure 5). This cohort of participants in remission captured data on the whole care pathway experience, with people able to share their experiences from diagnosis through to aftercare.

Figure 5: Stage of survey participants at the time of diagnosis and time of interview
(questions 10 & 11)



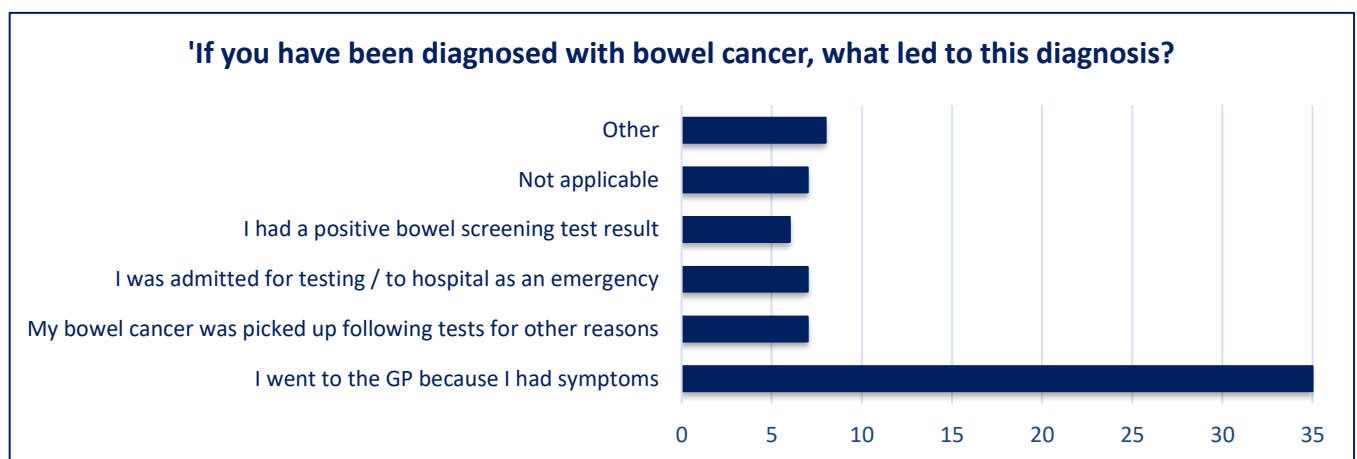
Question 8 asked how the participant had been affected by bowel cancer; whether they had been diagnosed themselves or were the friend or family member of someone who had been. The question allowed participants to give multiple answers and there were 98 responses in total (Figure 6). The most frequent response was from patients or carers of those who had finished treatment and were having regular follow up scans/check-ups (33/98), or those previously diagnosed but no longer receiving treatment (19/98).

Figure 6: Survey responses to Question 8.



Researchers were also keen to explore the participants journey from the ‘point of suspicion’ to being diagnosed and so question 9 asks what led to their diagnosis. Seventy participants answered this question, with 35/70 (50%) being diagnosed through their GP due to symptoms and 7 (10%) diagnosed due to investigations for other reasons (Figure 7). A further 7/70 (10%) were diagnosed due to being admitted to hospital as an emergency including profuse rectal bleeding. For those who answered ‘other’, they were asked to specify. One participant was diagnosed through a dermatology referral and another was diagnosed using a bowel screening test while in hospital receiving blood transfusion treatment for severe anaemia.

Figure 7: Survey responses to question 9



4.3 Your experience of bowel cancer care

Questions 13 and 14 of the survey aimed to recognise what went well in relation to participants diagnosis and subsequent care and there were consistent themes identified. There were mixed positive and negative responses in respect to what went well in the diagnosis. Several participants commented that everything went well from the point of diagnosis until the end of treatment. As many of the participants were diagnosed by their GP, many participants commented that they felt listened to by their GP and thought that the referral process for further investigations was quick.

In contrast to these experiences, some participants felt that nothing went well:

“Nothing, it was all shockingly unacceptable” (Participant 6)



Others had delays in receiving diagnostic test results:

“delays in all areas of tests and treatment due to total incompetence” (Participant 39)

On the topic of diagnostics, one participant with a family history of Lynch syndrome commented:

*“The poo sampling in my opinion doesn’t work for those with Lynch syndrome (clear poo test in Dec 21, cancer diagnoses in March 22)”
(Participant 19)*

For treatment and surgery, most responses were positive with many noting that once diagnosed, treatment happened quickly. One participant noted:

“Once the tumour was detected, treatment has been quick, efficient and well managed” (Participant 58)

Some commented on the value of feeling supported and being told to call any time they needed anything was very reassuring. Many felt that NHS staff were kind and caring:

*“They were so gentle in their delivery of the news and so reassuring”
(Participant 43)*

Participants were also very complimentary about the support received from specialist nurses and felt that being well-informed about their care was very important to them. One commented:

“Being kept in the loop was very important to me. My husband’s treatment by all concerned was fantastic. Any problems we had we could call the specialist nurses” (Participant 48)

The survey responses concerning support received from specialist nurses was very complimentary, and similarly several participants expressed praise for the care received by their consultant. The responses to survey questions 13 and 14 around having a choice in your treatment and feeling supported helped inform the addition of question incorporation of questions 12 and 13 into the [interview topic guide](#) in order to gather more detail.

Conversely, survey question 15 asked participants what did not go well in relation to their bowel cancer diagnosis. There were some positive experiences, with two participants commenting that there were no negatives at any point in the bowel cancer journey:



"I can honestly say there were no negatives. I understood the symptoms and contacted my GP immediately, therefore catching the cancer at an early stage." (Participant 51)

However most responses to Q15 were negative in respect to diagnosis. The most commonly recurring feedback was that participants felt that their relatively young age made diagnosis difficult and they often were not taken seriously by their GP. A strong theme across many responses was the delay to diagnosis due to being mis-diagnosed with other conditions such as irritable bowel syndrome (IBS), colitis, haemorrhoids, and food intolerances:

"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." (Participant 29)

"It would have been nice for my GP to take my symptoms seriously and not write off cancer based on my age and gender. I've been having symptoms since my mid 30s which were written off as food intolerance/IBS. It was only when I was sent for a scan on my gall bladder the cancer was spotted." (Participant 58)

"Misdiagnosed for 8 months as Doctors wouldn't listen to me telling me I was "too young" to have Rectal/bowel cancer." (Participant 55)

Several participants also commented on the inaccuracy of the faecal occult blood (FOB) test and faecal immunochemical testing (FIT):

"After contacting GP with symptoms, a FOB test was done (too young for regular FOB screening). This came back negative and therefore no further investigations were undertaken. When went back to GP a few weeks later a referral was made. It is not generally known that FOB tests can be unreliable." (Participant 7)

"The FIT test was negative, only because of the team in my local GP listening to my bowels was I admitted to hospital" (Participant 47)

One participant noted that they had taken part in screening tests, which were negative despite the presence of a tumour:

"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." (Participant 46)



The responses to this question around age prompted researchers to add a follow-up to question 7 of the interview topic guide which asks if they have ever participated in the bowel screening programme. For those who had not participated, they were asked 'if you were eligible, would you have been interested in taking part?'.

One participant commented that they struggled to come to a decision on a treatment option and opted for surgery but felt overwhelmed and uninformed, but were very happy with the outcome. On the topic of support from staff, there were several comments on the miscommunication between teams dealing with participant care:

"Communication from the oncology team was not always clear and between hospital and GP was not always clear." (Participant 11)

"Since he has been out of hospital we are getting mixed messages regarding his continuing treatment as nobody is talking to each other." (Participant 42)

One participant living in a rural area had to pay privately to see a consultant and felt their care was uncoordinated:

"Ended up having to pay privately to see the Consultant, as there were no clinics running and they couldn't tell me when I would have been seen. Luckily I did, I had Stage 3. I was told directly after my colonoscopy that I had cancer then didn't hear anything for three weeks. Had to follow everything up myself." (Participant 26)

The issue of miscommunication during diagnosis or treatment and not feeling very well informed was evident in these survey responses and was noted by researchers as an area of interest to be explored further during interviews. Therefore question 9 of the interview topic guide was added to ask if anything could have improved the journey from diagnosis to treatment.

There were a few comments around the kind of support participants sought during their diagnosis and treatment.

"Delay in diagnosis resulted in my stage 4 diagnosis, extensive surgery and traumatic experience. Due to my age I was seen as a rare case. Lack of young patient support in CTMHB, sought [sic] mental health support from cancer charities and online." (Participant 26)



It was obvious from these responses that support both during and after cancer was very important and was therefore incorporated into the interview topic guide in question 13.

The final question in the 'Your experience of bowel cancer care' section asked participants to comment on where in the bowel cancer journey they thought the most improvement could have been made, and why.

Responses around diagnosis primarily concerned the eligibility of screening and lack of GP awareness around the development of bowel cancer in younger participants. One participant commented:

"The doctors need to stop looking at statistics and listen to patients"
(Participant 29)

Others noted:

"Early diagnosis could have prevented this. A colonoscopy should have been done via GP when I initially presented with ongoing symptoms, due to being young it was seen as nothing serious." (Participant 26)

"Diagnosis, GP awareness needs to be improved. I was the wrong gender and age for bowel cancer... apparently." (Participant 64)

One participant responded that diagnosis was the one important change that needs to be made in Wales as by the time they were treated their tumour was too large and had attached itself to other abdominal organs which made surgery life-threatening. Another participant felt that their GP did not believe that they had rectal bleeding and was asked to take photographs of the blood in the toilet.

On the topic of treatment there were a couple of recommendations for the waiting times for scan, colonoscopy and surgery dates to be shortened. The issue of a lack of effective communication was once again highlighted with one participant waiting four months between emergency surgery and treatment:

"Speed of diagnosis and post diagnosis. It was 4 months between the emergency operation and starting treatment." (Participant 4)

Another wrote:



“During chemoradiotherapy better communication could have prevented serious complications that resulted in hospitalisation - including time spent in Intensive Care.” (Participant 7)

One participant was seen by two different consultants, each with different opinions, only to be transferred over to another health board for another consultants input. This common theme of uncoordinated care was felt to be important and explored further in subsequent interviews as part of the iterative changes to the interview topic guide.

From the outset of the study, two of the overarching themes for discussion were genetic testing for bowel cancer, and shared decision making in choosing a treatment. In the survey responses there were several comments on participants wanting additional information on their test results and having a choice in their treatment.

“Would like to have had more information on the treatment and results of tests.” (Participant 56)

From these responses, researchers were interested in exploring views on having a choice in your treatment and how test results were communicated.

Aftercare was a very important theme identified in response to question 15 which asked what did not go well, and in question 16, many of the suggested improvements were around the lack of aftercare. One participant commented on the absence of support out-of-hours:

“Aftercare after and during treatment especially with dealing with side effects after 5 o’clock and weekends.” (Participant 18)

Others commented on how much they needed aftercare and the difference it could have made to them:

“Aftercare in terms of advice for building up strength would have made a difference. Also advice on avoiding the parastomal hernia which occurred within 6 months of surgery.” (Participant 7)

“There is a lack of post cancer care available. I needed help to recover physically and mentally from the trauma of a sudden cancer diagnosis” (Participant 26)

Throughout the survey responses there was a recurring theme of inadequate support with many commenting that it would have been useful to have been signposted to a support group during diagnosis and after treatment. One participant felt that the care they received



was non-existent and was 'disgusted' by the way cancer patients are treated in Wales as they had to fight for six months to receive any counselling during their treatment. This issue of aftercare and support after treatment was an emotive area and a real priority of participants and so was incorporated into the interview topic guide in question 13.

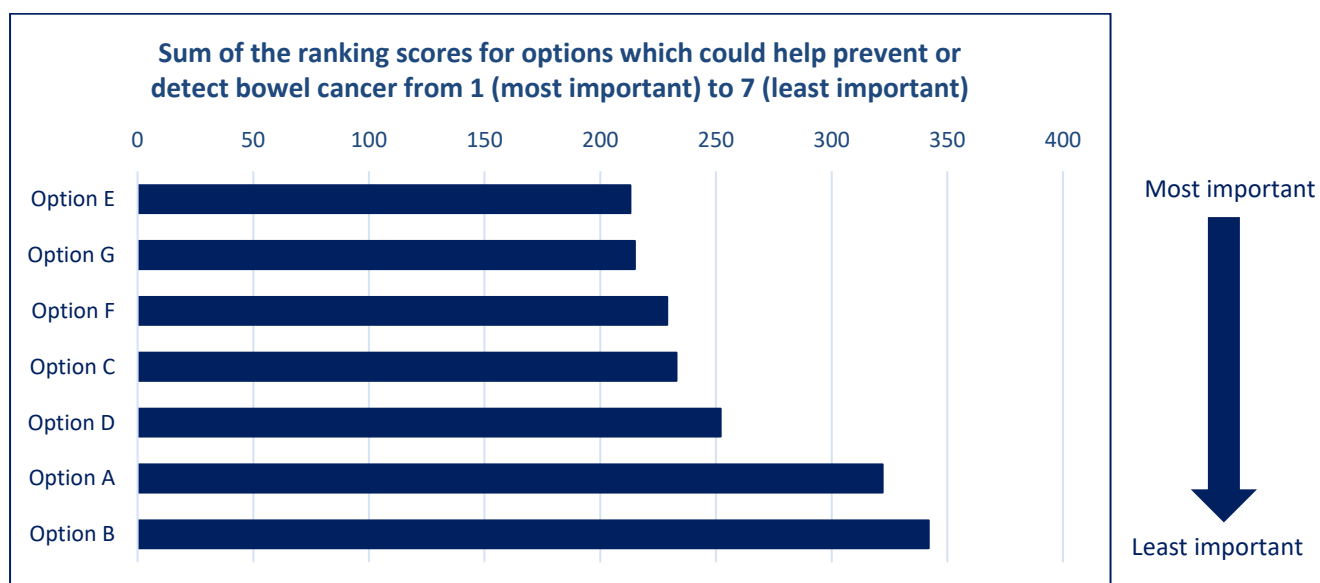
4.4 Bowel cancer prevention, awareness & diagnosis

Question 17 of the survey was related to options that could help prevent or detect bowel cancer and asked participants to rank seven options (A-G) in order of their importance which could help prevent or detect bowel cancer from 1 (most important) to 7 (least important):

- A. Improve people's understanding of how diet, exercise and smoking can increase the risk of bowel cancer (e.g. by awareness campaigns)
- B. Provide more advice on the benefit and risk of taking aspirin to reduce your risk of bowel cancer
- C. Improved testing for people who are at risk of bowel cancer (e.g. genetic testing or colonoscopies for people with an increased genetic risk of bowel cancer)
- D. Encourage more people to take part in bowel cancer screening (e.g. by sending out reminder letters or texts)
- E. Increase the number of people eligible for screening (e.g. by reducing the screening age)
- F. Improve knowledge on what symptoms to look out for and when to visit the GP (e.g. by awareness campaigns)
- G. Provide better access to GP support and early detection centres

The ranking given for each option was totalled for all participants and are shown in Figure 8 below.

Figure 8: Sum of the ranking scores for each option in response to question 17.



As shown in figure 8, the option with the lowest score and therefore the most important to participants was E: 'Increase the number of people eligible for screening (e.g. by reducing the screening age)', followed by G 'Provide better access to GP support and early detection centres'.

Question 17a asked participants to tell us why they had chosen the option they thought was most important. Some of the responses concerning the most important priorities are in table 3 below:

Table 3: Free-text responses concerning highest priorities - question 17a

"I feel that if genetic testing will reduce the risk of bowel cancer it should be prioritised." (Participant 37)

"Several family members have died of bowel cancer in their 50's. It's essential to screen regularly when strong family history." (Participant 19)

"Without the screening we would not have found out about my husband cancer because he had no symptoms." (Participant 48)

"As a 29 year old man, screening age needs to reduce particularly for IBS and IBD sufferers." (Participant 60)

"If my husband had been screened he might still be with me" (Participant 57)

The highest scoring and least important to participants was B: 'Provide more advice on the benefit and risk of taking aspirin to reduce your risk of bowel cancer'. This was closely



followed by A: ‘Improve people’s understanding of how diet, exercise and smoking can increase the risk of bowel cancer (e.g. by awareness campaigns)’. When asked why participants chose this option, several comments in relation to the two lowest priorities can be found in table 4 below.

Table 4: Free-text responses concerning lowest priorities – question 17a

“I have never heard of aspirin in connection with bowel cancer.” (Participant 22)

“I have read about aspirin but not once have I been told to take it by a health professional.” (Participant 20)

“I wasn’t aware that poor diet and exercise could contribute towards cancer.” (Participant 10)

Researchers felt it was important to explore why diet, lifestyle and aspirin were of lowest priority to participants and so developed question 11 of the interview topic guide: ‘After the diagnosis, were you or your family offered any diet or lifestyle advice to help improve your treatment and recovery?’.

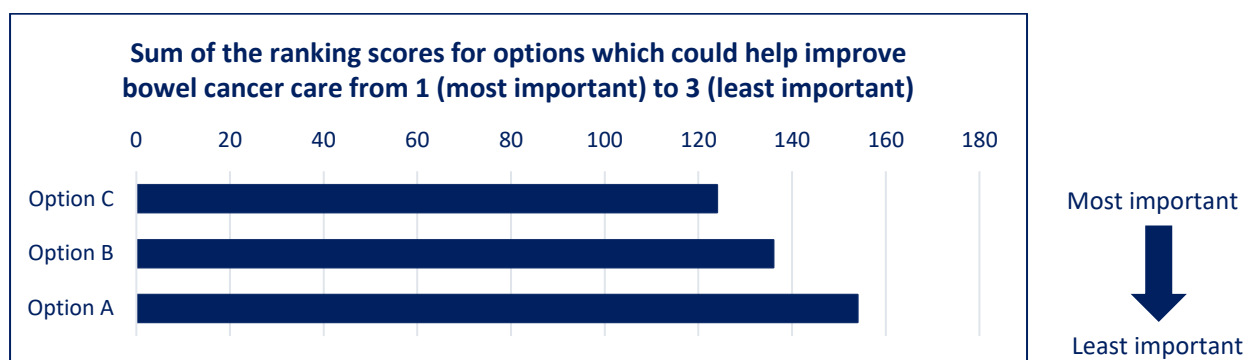
4.5 Improving bowel cancer care

Similar to question 17, question 18 of the survey was related to bowel cancer care and once again asked participants to place the options below (A-C) in order of what was most important to them from 1 (most important) to 3 (least important):

- A. Helping people improve their general health and wellbeing before and during bowel cancer treatment (e.g. by providing more advice on diet and exercise)
- B. Improving access to new treatments (e.g. by including people in trials)
- C. Improve post treatment monitoring (e.g. carrying out more regular colonoscopies and blood tests)

The ranking given for each option was totalled for all participants and are shown in figure 9 below.

Figure 9: Sum of the ranking scores for each option in response to question 18.



As shown in figure 9, the option with the lowest score and therefore the most important to participants was C: ‘Improve post-treatment monitoring (e.g. carrying out more regular colonoscopies and blood tests)’. As this was a priority for survey participants, it reinforced the need for question 13 which asks about aftercare and support.

Option A ‘Helping people improve their general health and wellbeing before and during bowel cancer treatment (e.g. by providing more advice on diet and exercise)’ was the highest scoring and therefore the least important. This was an interesting finding and so researchers used this to inform the design of question 11 of the interview topic guide ‘After the diagnosis, were you or your family offered any diet or lifestyle advice to help improve your treatment and recovery’. Participants were also asked to provide an answer as to why they chose the option they thought was the most/least important, with some responses quoted in Table 5.

Table 5: Free-text responses to question 18a

“Diet and exercise can help cope with the effects of treatment but often in the midst of treatment it’s too hard to keep motivation going.” (Participant 47)

“The Welsh population deserve up to date treatment and facilities.” (Participant 67)

“I haven’t had a lot of diet advice despite asking for some, I’ve had to do it by trial and error.” (Participant 60)

“Access to trials and new treatments are imperative to stage 4 patients I feel!” (Participant 66)

“I was only aware of the benefits of diet following diagnosis.” (Participant 63)

“Access to new treatments. I found it very difficult to get any information in relation to current trials.” (Participant 65)



4.6 Summary of survey responses

The majority of survey participants were female aged 41-60, of white ethnicity and lived in the South of Wales. Most participants were diagnosed through their GP due to symptoms and a large number had bowel cancer themselves, with half diagnosed with stage 3 or 4 bowel cancer. However at the time of survey completion, a large proportion of participants were in remission having finished treatment and were able to share their experience of bowel cancer care from the beginning through to aftercare.

Participants were mostly employed at the time of their diagnosis but many had a change in employment due to their diagnosis. More than half of the participants did not have a known family history of bowel cancer, and only a small proportion had been genetically screened for bowel cancer during their diagnosis.

Many reported problems in getting a diagnosis from their GP after being misdiagnosed or not being listened to. There was strong commentary on the inaccuracy of the bowel cancer screening programme and the need for early detection through a decrease in age eligibility, which was a key priority of many. However preventative measures such as diet, exercise and aspirin were not a priority to this cohort which was interesting to researchers.

Once treatment had finished, survey participants felt unsupported by healthcare professionals and monitoring post-treatment was identified as a top priority.

Each of these survey priorities were explored further in interviews and focus groups.

5 Interviews

In selecting participants to take part in an interview, one of the targets was to try and include as widely representative a group as possible by including the following:

- A range of ethnicities
- A mix of genders
- A representative age range
- Participants from each of the 7 health boards in Wales
- Participants from both urban and rural settings
- Participants from more deprived postcodes/regions
- A number of friends or family of patients who have (or have had) bowel cancer



However as only 31 participants were willing to take part in an interview, researchers decided to invite all 31 willing participants to interview.

Interviews were scheduled between 1st June – 17th June 2022 with all participants interested contacted by e-mail to select a date and time most appropriate for them. Interviews were held via video call with the option of a telephone interview if requested and ran for an hour with the capacity to allow them to run shorter or longer as required.

Using the responses provided in the survey, a topic guide was designed around the most relevant and important themes to those who completed the survey and potential areas for future improvement ([Appendix C](#)). Broadly speaking, the themes for discussion were:

- Awareness of bowel cancer symptoms and how to raise awareness further
- Journey from suspicion to diagnosis
- Bowel Cancer Screening programme eligibility
- Genetic testing for bowel cancer
- Dietary and lifestyle advice post-diagnosis
- Shared decision making in choosing a treatment
- Support and post-operative monitoring

Interviews were semi-structured with a topic guide ([Appendix C](#)) to help guide themes of interest throughout and ensure consistency in addressing each theme while ensuring an open approach. Researchers also incorporated 'prompts' for several questions if participants gave certain answers to allow researchers to explore the answers in more depth (Flick, 2018).

A total of 23 interviews, including participant 17 were conducted virtually using the NHS-approved Microsoft Teams software via video call or audio dial-in. One participant was interviewed using Zoom as they were more familiar with it. Interviews were recorded with the permission of the participant and researchers took notes to support the recording. Interviews were also listened back to by a member of the Cedar team and interview transcripts checked for accuracy. Demographics of each participant can be found in table 7 in [Appendix D](#). Many interviews lasted longer than the hour time allocation with the average interview length being 69 minutes (range 45-124) and yielded rich data on experiences that mattered most to each participant. Data saturation was reached during the interviews as



key themes were identified on a recurring basis, with no new issues or concerns identified in the final stages.

Interviews were conducted by two Cedar researchers – one primary interviewer to lead the interview questions, and another to take detailed notes. Participants were offered the option of turning their camera off to remain anonymous if this made them feel more comfortable, however, 21 of the 23 participants chose to keep their video turned on. While researchers were able to use non-verbal communication and cues to some extent, it is recognised that using virtual interviews as a methodological approach limited their ability to directly observe emotion or other visual cues.

Interviews followed a grounded theory lite (GT-lite) process with iterative changes throughout to allow flexibility for recurrent and important issues to inform and guide subsequent interviews in addition to the topic guide (Braun & Clarke, 2013). Recurrent and new themes emerging in each of the interviews were noted using a ‘memo writing’ approach as part of the grounded theory process. In qualitative research, memos are the ideas generated and documented through interacting with the data which allow for reflective interpretation by researchers. An example of an iterative change during the interviews was the early realisation when asking question 7: ‘If eligible, have you ever participated in the bowel screening programme?’, that many participants were too young to have participated in the bowel cancer screening programme. If this was the case, the question was asked differently and sought their views on the eligibility criteria of the current bowel cancer screening programme and what changes they would suggest, if any.

Throughout the interview process, several themes incorporated additional subthemes, for example in the theme of ‘Suspicion to diagnosis’, five subthemes were identified; ‘Accessing a GP’, ‘Recognising less well-known symptoms’, ‘My GP won’t listen to me’, ‘You are too young to have cancer’, and ‘A trigger for action’.

Following a grounded theory approach, interviewing as a method of data collection requires researchers carrying out the study to not have engaged with the relevant literature prior to beginning the analysis. This avoids the interviews being shaped by preconceptions from existing research, rather than being truly grounded in the data (Braun & Clarke, 2013). Neither researcher conducting interviews are experts in Bowel Cancer Care although one



researcher did have some knowledge of the genetic diagnosis pathways for Bowel Cancer and Lynch syndrome. As the interviews and focus groups progressed and researchers gained more knowledge, they took care not to ask leading questions or influence the direction of subsequent interviews.

6 Focus Groups

Following thematic content analysis of the interview transcripts and notes, key topic areas and participant priorities for further discussion were identified. These key topic areas were used to inform the development of a topic guide ([Appendix E](#)) to help direct each focus group. This was developed by two Cedar researchers with input from colleagues in the MCI team.

All survey participants who had opted to be contacted about taking part in a focus group were contacted via email. Participants were asked in the survey if they would be willing to take part in a focus group, and 36/71 (49%) of survey participants agreed to be contacted. All of those interviewed were again asked if they would like to take part and 22 of 23 participants interviewed agreed to be contacted – many of which had previously agreed in the survey. In total, 44 participants were invited to take part in one of the three focus groups. Each were conducted online via Microsoft Teams scheduled over three days (28th June, 29th June, and 19th July 2022). There was however one participant who chose to dial into one of the focus groups and was not visible on camera, and so there was a risk of disconnect between these participants and those visible by video call which researchers tried to overcome by prompting the participant who dialled in.

Focus groups were planned to last 90-120 minutes in duration, and lasted an average of 122 minutes (range 118-130 mins) after the introduction and group consent was gained to record the discussion. Notes were taken during each of the focus groups, alongside live transcriptions using Microsoft teams which were subsequently listened back to by researchers and checked for accuracy.

Following two focus groups (n=14 participants total), it was agreed that data saturation had been reached with respect to several of the responses. For the third focus group the topic guide was amended to allow exploration of opinions and perspective on questions that still

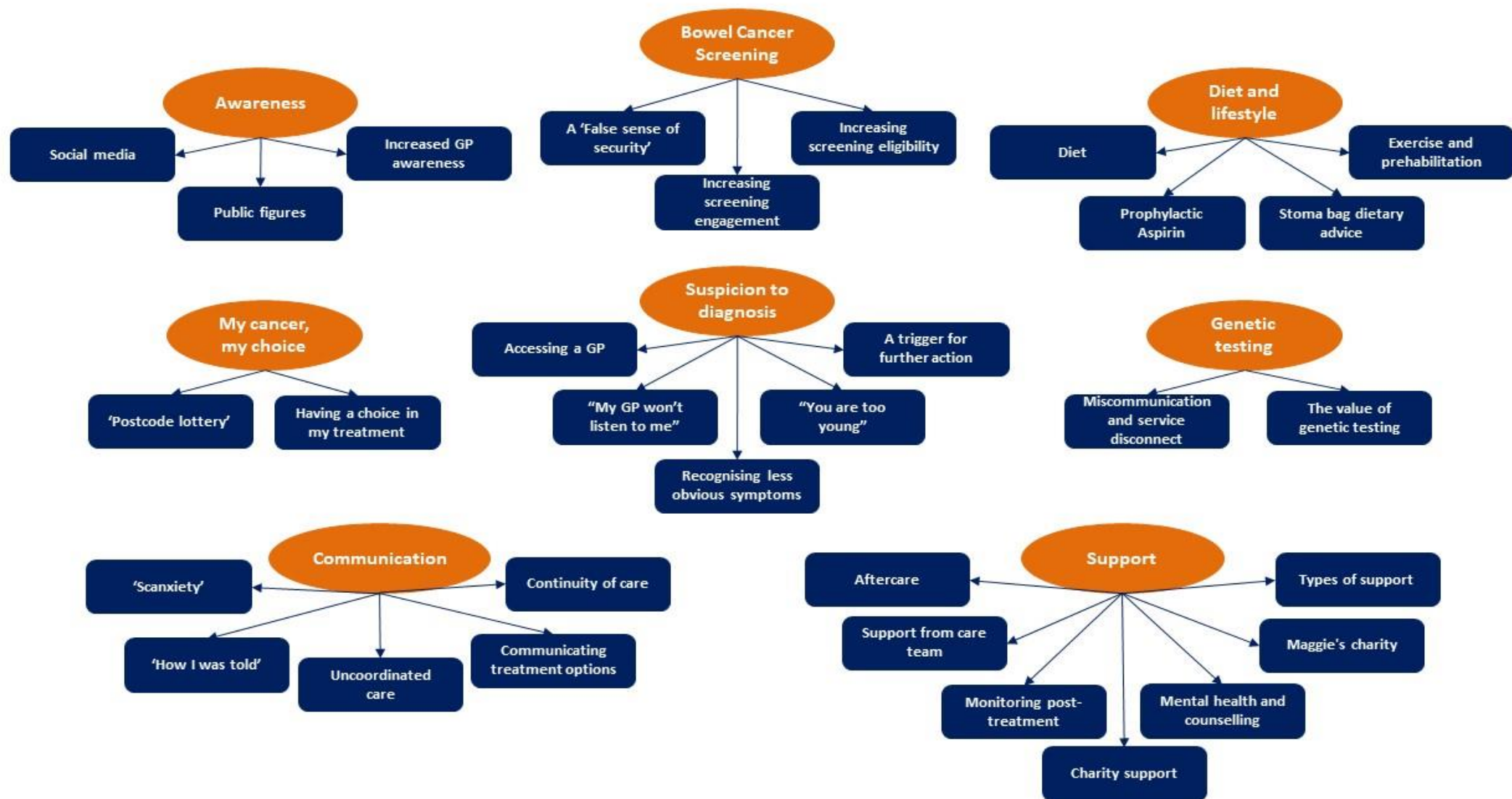


had variability in their responses. The final focus group consisting of 5 participants used this amended topic guide ([Appendix F](#)). The demographics of all focus group participants and attendance for each focus group can be found in table 7 in [Appendix G](#).

7 Themes

Throughout the interviews and focus groups, it was identified that there were eight overarching themes with several subthemes within each of them. These are illustrated in figure 10 below and summarised in the follow section with excerpts taken from conversations to put each theme into context.

Figure 10: Theme map of all 8 themes and subthemes



Throughout the reports thematic findings there are several 'stories for change' which summarise a few participants experience.

For each of the stories for change, participants were contacted for permission to include the story and given the opportunity to make any changes or clarify points further to ensure it was an accurate reflection of the participants experience.

7.1 Everyday impact

Participants experiences of how bowel cancer impacted their life are collated in this section to show how life changing the diagnosis can be on both patients who have (or have had) bowel cancer, or their carers/family members.

Participants spoke emotionally of the impact that bowel cancer had on their life, whether diagnosed themselves or being the carer/family member of someone that has/had been. It was important for researchers to gather the experience from both a carer and patient perspective as these were very different. Many spoke of the psychological stress of the diagnosis but how they remained positive, optimistic for treatment success and focused on getting through the treatment/surgery. However many needed emotional support in the form of a partner, family or friends throughout treatment, and even more so once the treatment had finished.

In speaking with carers and family members of people diagnosed, they told of the impact of a partner/family member being diagnosed. Many had to remain strong for the sake of their family member/partner, and having to change their lifestyle to support them by modifying work patterns or leaving their job completely. Some had become carers for their partner overnight which in some instances had changed the dynamics of their relationship with their partner from one of a sexual relationship to one of friendship and support.

All participants with children were very emotive in describing the impact the diagnosis had on their child's life. One participant spoke of how her whole world fell apart on hearing the news and started to write her will to leave something for her children.



For the children themselves, one parent spoke of how their child struggled with the diagnosis and sought mental health support at an early age in school, and how they found it incredibly difficult not being able to support the child themselves due to treatment.

Many participants spoke about the drastic change in their quality of life as a result of a bowel cancer diagnosis – many had to change careers, take prolonged periods away from work, or quit their job completely. One participant was a dentist before their diagnosis and after being fitted with a stoma, spoke of the challenge in doing their job with the unpredictability and smell of having a stoma bag. Another was a teaching assistant and was passionate about her job, but having had so long away from work for treatment, she was not sure whether she could ever go back.

Several participants spoke of fears of being fitted with a stoma bag and concerns related to how they would manage to live with it, and the impact that having a stoma bag fitted had on their life. Some commented on how it limited their ability to socialise or go out of the house through fear of having an accident. One participant avoided socialising altogether and would sit away from people in restaurants and cinemas, and would book a seat by the toilet when travelling on an aeroplane. However, many felt that compared to their symptoms before their stoma, having a stoma had improved their quality of life and they grew to ‘love’ their stoma bag and would feel proud in chatting to other members of the public with stoma bags, and even helping alleviate the anxieties of others going through the process. Of those who had a stoma bag, generally, one of the biggest impacts on their life was the change in diet; often having to avoid foods they had always loved and having to ‘trial and error’ what they could safely eat which took many years for some.

As many of the participants interviewed were diagnosed or treated during the coronavirus pandemic, there were several discussions around the impact that the pandemic had on an already physically and psychologically stressful time in their lives. One participant spoke of their heightened anxiety about leaving the house through fear of being put at increased risk after their diagnosis. This person lived alone and did not leave their house for more than six months, reporting that this was an incredibly lonely time with very little support for them.

One positive implication on the lives of those interviewed who had recovered from cancer and were in remission was the realisation afterwards that ‘life is too short’ and felt that



going through cancer helped them appreciate things in their life so much more, not take things for granted and to value the little things. Many felt lucky to be alive and wanted to give back in the form of volunteering or setting up their own support groups.

7.2 Suspicion to diagnosis

In survey responses researchers identified the difficulty many had in having their symptoms recognised and subsequently being diagnosed. The theme of ‘suspicion to diagnosis’ emerged with five subthemes within it.

7.2.1 Accessing a GP

Some participants spoke of how difficult it was to get through to a GP and their difficulty in accessing a GP in person as many were diagnosed during the coronavirus pandemic and therefore had telephone consultations.

“Nowadays, getting to see a GP for a face to face appointment is almost a luxury.” (Participant 21)

Younger participants felt that their symptoms were not urgent enough or taken seriously to be seen in person by their GP and felt ‘fobbed off’ by diagnosed with constipation, Irritable Bowel Syndrome (IBS), Crohn’s Disease and Colitis.

“It just it got to the point where I just felt like I was just being fobbed off and I was sick of the sound of my own voice. I was sick of, you know, waiting at 8:00 o'clock in the morning on the phone to ask for an appointment and then having to go through it all again, and if that particular doctor wasn't in, I'd have to go back to the beginning [of my diagnosis] with another doctor” (Participant 6)

There were several comments on the importance of having an allocated/named GP when going through a significant diagnosis such as cancer, although most recognised the staffing difficulties of the NHS and knew this was not always possible. However, they noted how frustrating it can be when visiting their GP surgery and not being able to see a doctor they were familiar with as it would mean they had to explain their medical history at length and re-live it all again.

“You never see the same doctor twice and there was no continuity of understanding the patient. You are in there 10 minutes and it would be



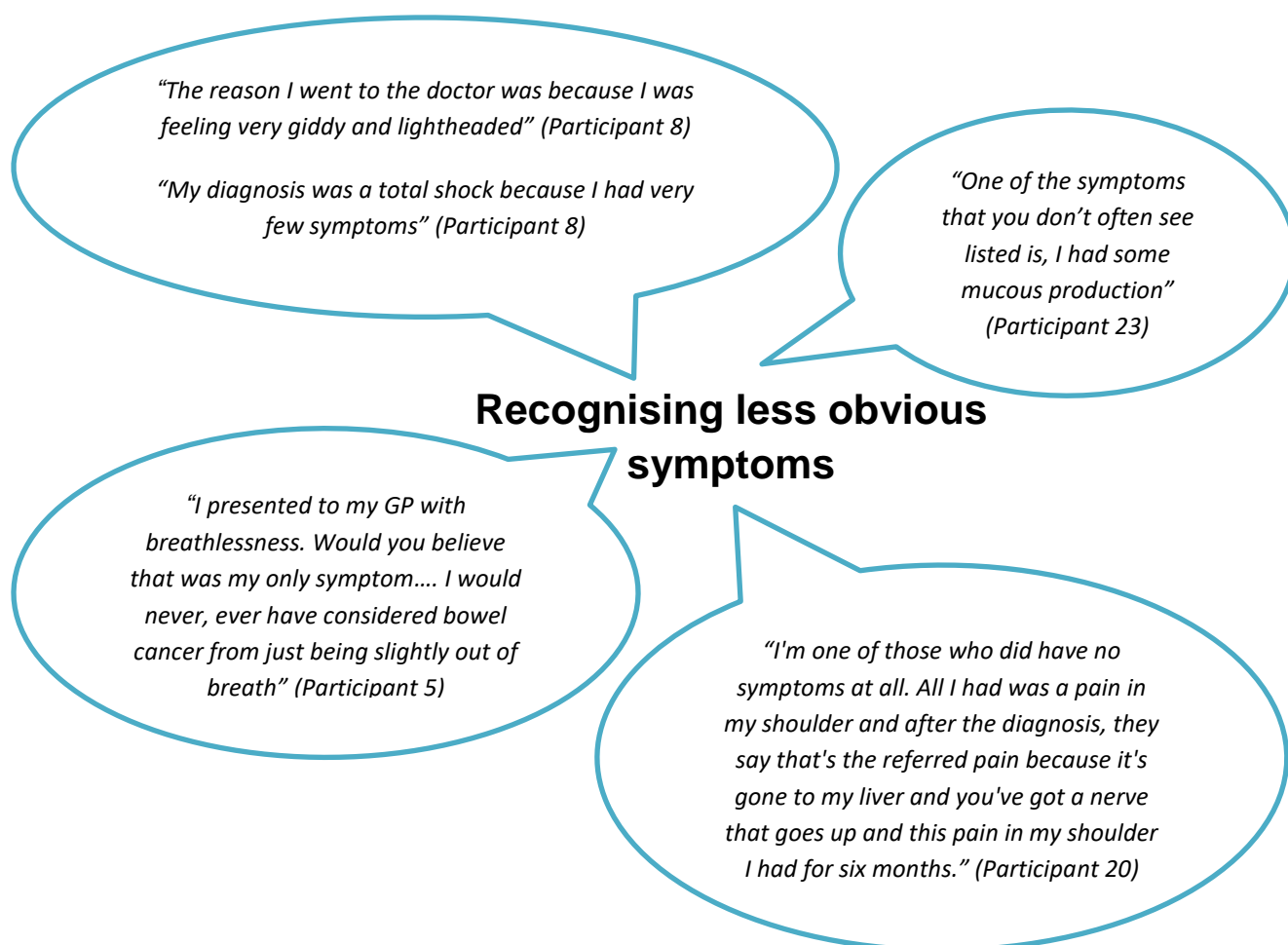
somebody completely different....and I very rarely saw a doctor, I would see the nurse practitioner.” (Participant 24)

One participant who had great difficulty having her GP listen to her initially, felt as though she got ‘priority treatment’ after her diagnosis and treatment, and is now taken more seriously by her GP. However, this patient reported feeling angry that it should not take a bowel cancer diagnosis to be taken seriously.

7.2.2 Recognising less obvious symptoms

During interviews and focus groups, many participants spoke of how they did not have either any symptoms, or any of the known symptoms for bowel cancer. Many of these had very few symptoms or atypical symptoms that they felt they themselves and especially their GPs were not aware of. Some spoke of how they had read on social media and cancer forums about a number of people being diagnosed after having very few or less well-known symptoms (Figure 11).

Figure 11: Excerpts from discussions on recognising less obvious symptoms





7.2.3 'My GP won't listen to me'

Many of those interviewed were of a younger demographic than the typical bowel cancer patient, and one of the strongest themes that emerged during interview was not being listened to by their GP. Many spoke of how they had repeatedly been back and forth to their GP insistent that something was wrong, but did not feel listened to and were often either misdiagnosed or falsely reassured by their GP.

"When I was diagnosed, I couldn't get my GP to take me seriously either....I had to actually take photos of the blood that I was passing and go to the GP and show the photos on my phone and say because she said no, no, it's definitely just Crohns or Colitis" (Participant 27)

Some were subsequently diagnosed following referral via other routes:

"It's been really hard for me to get a diagnosis took me over two years to get a diagnosis and I got referred for a colonoscopy, which found my cancer through a dermatology referral." (Participant 2)

One participant created a social media account to share her experiences of bowel cancer and after speaking with many people online, was able to highlight the wider issue of younger participants not being listened to:

"I do a lot of raising awareness on social media to try and get younger people to push and be your own health advocate and I get a lot of inbox messages saying my GP won't listen to me and they've had to try and get some money to get a colonoscopy privately." (Participant 26)

In contrast to these experiences, participants above the age of ~60 years often spoke positively of their experience and felt listened to and supported by their GP. Many felt that the period of 'suspicion to diagnosis' for them was rapid and often coordinated. For example, one participant (aged 72) who was joined on the call by his Wife, an ex-nurse, presented to his GP with shortness of breath and colour changes in his eyelids. He saw his GP quickly; a blood test was done and he was diagnosed with anaemia. His GP then quickly referred him for an endoscopy and colonoscopy where a stage 1 tumour in his large intestine was discovered. However they did describe their shock in being diagnosed as he had participated in the bowel cancer screening programme 2-yearly, half a dozen times – all of which were negative. Despite this, he and his wife spoke very positively of their



experience and couldn't fault the process at all, but recognised the importance of advocating for yourself:

"When you attend the doctor, you must be almost forceful in saying no, I feel I've got a problem here. It needs to be followed through and very often you'll find that you're the one that was right to go along because you know your body better than your GP and those signals are important so we shouldn't ignore them.....You need to keep pushing until you've had a colonoscopy until you've had the full works basically and you know, don't just give up at the first hurdle if your GP doesn't put you in for a colonoscopy" (Participant 8)

7.2.4 A trigger for further action

During interviews, researchers identified early on that there were vast differences in the 'trigger' for which a referral by a GP for a colonoscopy was made. In keeping with the other subthemes within 'suspicion to diagnosis', younger participants felt that they had to repeatedly present to their GP with the same symptoms and often did not feel as though they were being taken seriously.

"The thing that is gonna change around prevention is getting that colonoscopy, regardless of your age. And if you're back and forth the GP within a three month period or six month period with the same bowel symptoms, that should warrant an automatic referral for a colonoscopy." (Participant 2)

Several younger participants were prescribed medication such as laxatives, enemas, and creams instead of having further investigations. During interview, participant 6 spoke very openly about their experience of feeling 'fobbed off' and ignored, leading to their emergency admission.

"There needs to be a line in the sand that says right, we've tried this and this, now we need to do some more investigation because you know, six months is a hell of a long time to ignore it basically and throw laxatives at it from in my experience." (Participant 6)

Her story is highlighted in a ['Story for change'](#).

Interview responses suggested that some patients experience an inequality in the bowel cancer care and referral thresholds for different ages, and so in several of the interview's researchers used a probe to gather opinions on the prospect of a pathway or a 'trigger



point' for referral to colonoscopy. The idea of a trigger point for further action was received very positively by all participants as many felt that after several attendances at the GP with the same problem, with no treatment success, there should be a point at which the GP has to escalate the problem.

"The thing that is gonna change around prevention is getting that colonoscopy, regardless of your age. And if you're back and forth the GP within a three month period or six month period with the same bowel symptoms, that should warrant an automatic referral for a colonoscopy."
(Participant 2)

Participants spoke of how this trigger for further action does not necessarily have to be for a colonoscopy as they appreciated it was costly. Instead, they suggested perhaps allowing those outside of the usual eligibility criteria for bowel cancer screening kits such as those less than 58 years of age, to be screened.

7.2.5 'You are too young'

As discussed, many of the participants researchers spoke to were of a younger demographic than the typical bowel cancer patient. When presenting to their GP with symptoms indicative of possible bowel cancer, they were often told they were too young.

"When I was in hospital about to have the surgery, they kept telling me it was likely to be Crohn's because I'm too young. I'm too fit. I'm too healthy. It's not a case that I wasn't aware of the symptoms. It was that I was continually told it's nothing sinister....I still get told now that I'm really rare and there's a lot of us on social media that are diagnosed at stage four because of our age." (Participant 2)

Being told 'you are too young' was not only frustrating, but falsely reassuring for many of them who would then go for months or years with symptoms and attribute it to IBS/Crohns/Colitis. Many of these participants felt that if they had been taken seriously by their GP in the beginning, or if there was a pathway of investigations to be done, their cancer would have been picked up sooner and they may not have been diagnosed at such a late stage.

When comparing the stages at diagnosis of the younger and older participants, younger participants had a higher stage of cancer diagnosis than those of an older age.



Almost all participants spoke of a lack of understanding by GPs that bowel cancer can affect people below the age of 50, which leads to misdiagnosis, late diagnosis and poorer outcomes for younger people:

“I think they need to forget this, or if you're under 50 then the chances of you having bowel cancer are extremely low as it's just not true.” (Participant 27)

Participant 20 is part of a social media group for patients who have (or have had) bowel cancer and commented:

“There are more and more patients every week being diagnosed. There's somebody new popping up and it's inevitably a young person in their 30s, you know, and their lives are just being torn apart” (Participant 20)

7.3 'You are too young' – A story for change

Participant 6 is a 34 year old mother to a 5 year old boy from North Wales. During the UK lockdown in Summer of 2020 she started to notice changes in her bowel habits. In August 2020 she discussed her symptoms with her GP over a phone consultation and was prescribed laxatives. Over the next 5 months she was back and forth to her GP with recurrent symptoms and each time was given a combination of laxatives, suppositories and enemas – None of which worked.

"There needs to be a line in the sand that says right, we've tried this and this, now we need to do some more investigation because you know, six months is a hell of a long time to ignore it basically and throw laxatives at it from in my experience."

During October 2020 she became pregnant and started to have prolonged periods of constipation and fatigue which her GP attributed to her pregnancy. Her GP repeatedly told her that she was too young for it to be anything serious. At no point did she have blood in her stool:

"Never had any pain or any blood until right at the end. I had pain, but no, nothing but I think if I had have had pain or blood, it might have made things all a bit more urgent and something might have been done a bit sooner"

One weekend in January 2021 she was admitted to A&E twice with severe stomach pains after not passing stool but was triaged to the gynaecology team due to her being pregnant, but then discharged. She was told by doctors in A&E that she should eat more fibre and more vegetables.

In February 2021 she was again admitted to A&E with a distended stomach, constipation for 7 days and persistent black vomiting and refused to go home until further investigations were performed. She was then seen by a colorectal surgeon who felt a tumour in her rectum and she required emergency surgery.

"Another 48 hours maximum and my bowel would have ruptured and it would have killed me"

The participant was 18 weeks pregnant during her surgery and sadly lost her baby the following day. After the surgery she was diagnosed with cancer that had spread to her liver. She was treated with chemotherapy and radiotherapy but treatment had little impact and the cancer had spread. The treating oncologist then retired and she was never given a clinical nurse specialist or any consistent healthcare professional to go to for support. While being treated in Wales she was never offered any mental health support for herself or her husband which was really needed. As she was so unhappy with everything that had happened at her hospital, she decided to move to England where she was successfully treated using immunotherapy in a specialist hospital.

"I've lost all faith in the GP, all trust, everything"

At the time of the interview in June 2022 she was having tumours removed from both her rectum and liver. She was also repeatedly told that cysts on her ovaries were benign, but has recently been told that it might be cancer and needs a full hysterectomy.

7.4 Awareness

Participants agreed that there was a need for increased awareness about many aspects of bowel cancer. During focus group discussions there were many suggestions from participants on how to increase public awareness of bowel cancer symptoms, and specifically bowel cancer affecting younger people. Some of the ideas on how to target different people and get the message across were:

- Social media videos of different people of different ages highlighting the usual red flag symptoms and also less typical symptoms
- Putting key messages on toilet roll. Marks and Spencer were mentioned as being the first supermarket to participate in the #GetOnARoll campaign which many other supermarkets have subsequently followed (Bowel Cancer UK, 2022).
- Having posters on the back of toilet doors in restaurants, airports, service stations etc
- Leaflets and advice in pharmacies
- Making messages more hard hitting, similar to the smoking campaigns and images on the back of cigarette packets.
- Pamphlets for charities that can help including MacMillan, Marie Curie, and Tenovus.
- Having volunteers and 'community champions' embedded in the community as a point of contact.

Many participants spoke of their fear of the unknown when starting out on their bowel cancer journey such as not knowing what a colonoscopy or stoma bag is. They felt that to have increased awareness of all aspects of bowel cancer through campaigns would be useful.

7.4.1 Increased GP awareness

As previously discussed, many commented on the increasingly younger patient population being diagnosed with bowel cancer and also that they felt GPs were unaware of this or did not recognise it as a concern. Participants felt that GPs too often focused on statistics such as the likelihood of bowel cancer in young ages, rather than addressing the patient as an



individual. Many described the need to educate GPs on how it can be a disease of the young.

"I think the young people's issue is more having that message filtered down from the oncologists and the surgeons to the GPs....my oncologist has said herself that the message is not getting down to the front line." (Participant 2)

Building on the 'Recognising less obvious symptoms' theme, participants also spoke of the need for GPs themselves to recognise less obvious symptoms in all ages such as anaemia, referred pain and tiredness. Participants felt that GPs often focused too heavily on the more well-known and obvious symptoms and their knowledge of the less typical symptoms needed to be addressed. Many recognised that if their GP had been more aware of what to look out for, they would have been diagnosed sooner. One elderly patient commented:

"The point of diagnosis has got to be the GP and they do just try anything to sort of, as you say, laxatives, fissures, creams, anything. It sounds as if there needs to be a lot more awareness with the first point of contact, which has got to be GP." (Participant 5)

They appreciated that many of these symptoms can occur with other conditions but felt they were unappreciated by GPs during investigations for bowel cancer, who too often focused on the main known symptoms such as blood in the stool, change in bowel habit and abdominal pain or bloating from eating (NHS, 2021).

"It does get associated with IBS or colitis or some sort of inflammatory stuff, and I think depending on your age as well, that can sort of influence the GP's reaction. So I think the GP is key. I think if someone's going with problems in the GP, they need to flag it" (Participant 14)

7.4.2 Social media

A couple of participants who took part had recognised the need for increased younger bowel cancer patient awareness and had created a social media account dedicated to their journey. These participants were able to give a wider voice from their interactions with other patients who have (or have had) bowel cancer.

Many spoke of the importance of social media in spreading the message across young people and learning from one another. Participant 27 spoke of how they were made aware of clinical trials outside of her area from social media:



“I think social media is the way to go because you just pick up so many different things from different people on social media.” (Participant 27)

Several followed the #NeverTooYoung campaign by Bowel Cancer UK which was set up in 2013 to raise awareness amongst the public and clinical community about bowel cancer in young people (Bowel Cancer UK, 2020). However some acknowledged that if something on their social media feed is not relevant to them such as bowel cancer symptoms, they would likely scroll past:

“I think that it would be really difficult on social media to actually grab a young person's attention about something which has got such a stigma. Nobody wants to talk about poo.....I have started following #NeverTooYoung since developing myself, but I would never have looked at that, it would have never crossed my news feed, it's all puppies and kittens and things” (Participant 2)

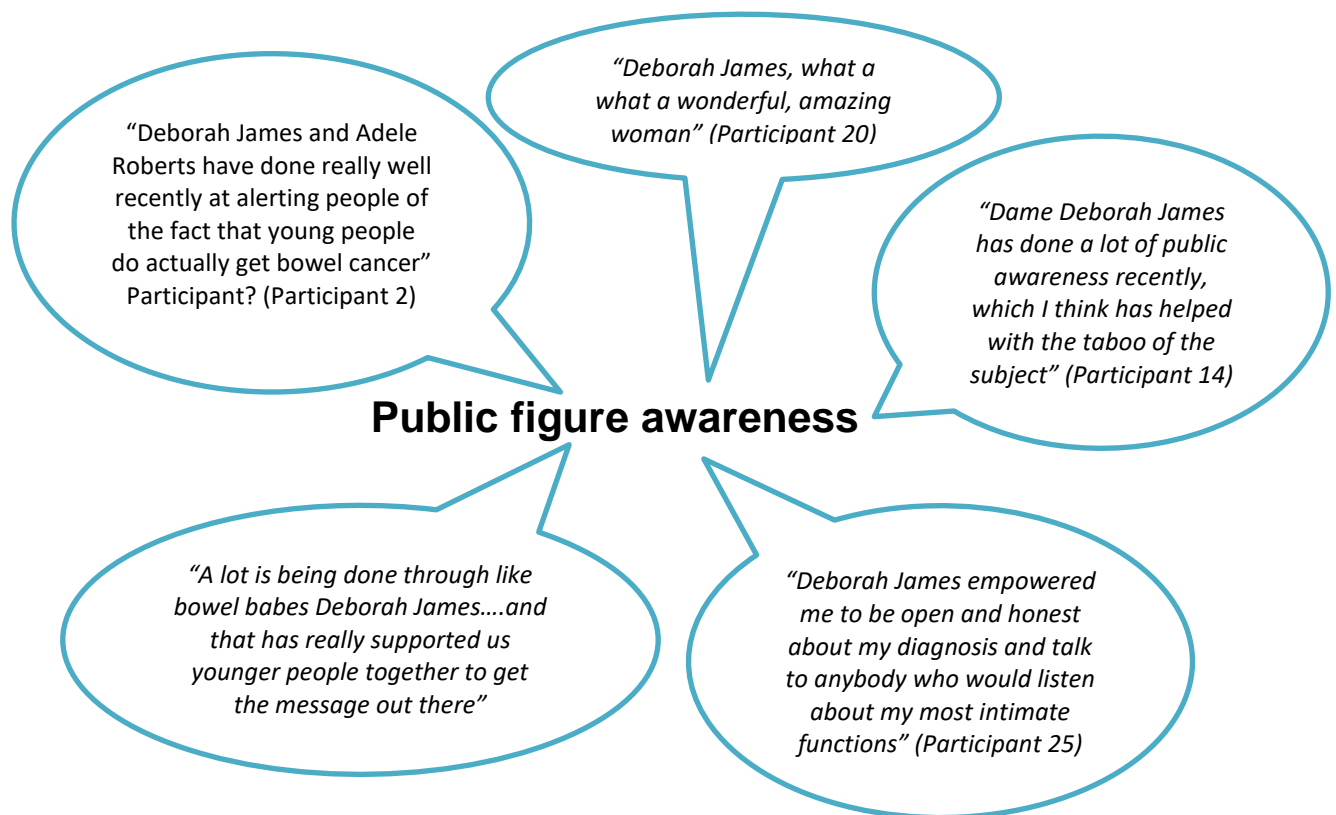
There were also discussions around the dangers of social media posts causing fear and worry to those newly diagnosed when they read of people's stories online and wondered if they would go through the same. Older participants in particular felt that social media was not likely to reach them, as many used it infrequently or not at all, but were constructive in suggesting alternative means of raising awareness:

“Social media tends to be for the young. The only reason I used to use social media is cause my children, my grandchildren are on there, and otherwise I wouldn't do.” (Participant 21)

7.4.3 Public figures

During both interviews and focus group discussions, when discussing how best to raise awareness to the public, one of the most frequent suggestions was how impactful a public figure in the media can be. Many spoke overwhelmingly with praise for people such as Dame Deborah James and Adele Roberts, and how they have empowered people to speak up and be more honest about their experience, which many felt can often be a taboo subject (Figure 12).

Figure 12: Quotes from discussions on public figure awareness



7.5 Bowel Cancer Screening

Bowel Cancer Screening was a key area of discussion throughout interviews and focus groups as many of the participants had either participated in screening, or were too young to participate. Several participants were positive about the value of the bowel cancer screening programme, despite many having a negative result not long before being diagnosed. Participants who were most positive about the screening were those that had a positive result which instigated a colonoscopy referral and early diagnosis:

"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." (Participant 3)

7.5.1 A 'false sense of security'

Researchers spoke to several participants who had a negative bowel screening test result but had later been diagnosed with bowel cancer. These participants were less positive about the programme as they felt it can people a false sense of security that they do not have



bowel cancer. This led to several of them seeing their symptoms as less urgent and as a result, delayed seeing their GP or escalating the problem:

"I did it religiously every year and that picked up nothing at all..... Of course yeah, you said when they wrote back and said we couldn't find anything. I thought. Ohh, great, good, there was no reason for me to query those cause because I was asymptomatic, I just thought great ticking the box, done it this year, will do it next year." (Participant 5)

On the theme of a 'false sense of security', before her diagnosis, participant 4 had an annual 'well women' check at her GP surgery. She was not of eligible age to participate in the bowel cancer screening programme but explained how this well women check reassured her that everything was fine. Because of this, she felt as though she would have ignored the screening test if it had been posted to her. However after 17 months of fainting and being referred to many specialists, she was diagnosed with bowel cancer and required emergency surgery.

During both interviews and focus groups, many felt that while screening is important, it is equally as important for the inaccuracy of the tests to be communicated with patients during the screening. Some female participants mentioned that they thought of the bowel cancer screening test in a similar way to other diagnostic or screening tests such as cervical smear tests and mammograms, and were not made aware of the chance of a false negative:

"When he first went to the GP and they gave him the FOB test, and that actually came back negative. So luckily he did go back and the GP was very good and referred him for a colonoscopy. But someone else might not have done that....and because that test came back negative, I assumed it was a bit like a smear. I assumed that it meant he was clear that there was no risk of cancer and when we went for the colonoscopy, it just didn't occur to me." (Participant 7)

One participant with a family history of Lynch syndrome and bowel cancer answered:

"If I received it, and I completed it, I wouldn't have much faith in the outcome of it" (Participant 19)

Overall all participants agreed that the letter sent with the screening kit should strongly specify that the test is not 100% accurate and does not completely rule out the chance of bowel cancer.



7.5.2 Increasing screening engagement

Most participants seemed aware of the problems with engaging the eligible public with bowel cancer screening. Many felt that when their own testing kit arrived, they did not have any significant symptoms at that time, and so the test was not relevant to them.

“it's no good just sending it out in the post to people because the quite a lot of people will ignore it unless they get the relevant information. So I think it's important to publicize it in the right places and how important it is to do these tests.” (Participant 3)

It was suggested by a few that having testing samples sent out without prior knowledge or a recommendation to complete it was not the best way to engage participation in the screening. People felt that they would have been more likely to engage with the bowel cancer screening programme if it was better communicated to them by either a campaign, GP, or another patient:

“Even for older people as well, I think there's a lot that don't do the test. They don't return the samples. So it's, you know, it's getting GP's to reinforce that with them as well that think it was important that they do.” (Participant 14)

“I think I might have been more inclined to do it had I had an appointment and talked to somebody. Perhaps if I talked to somebody who had had bowel cancer who had said this is actually really very important, that you should do this. So I just don't think sending things in the post they're certainly not going to engage people like me.” (Participant 24)

Many expressed their fears initially with the concept of stool testing or colonoscopies and suggested that this fear of what comes next may be why people avoid testing.

“I think just a bit more awareness of what it involves.....But also what it leads to because the thought of having a colonoscopy to people is terrifying, and so a bit more education around what it involves....if you have the screening and something comes up of concern, a more clear road map of why you do it and what it could potentially prevent or flag up I suppose would be helpful because you know that these tests exist and you know what you have to do, but they might not necessarily know why or how potentially lifesaving it could be.” (Participant 6)

A couple of people spoke about how more people would be engaged if there were campaigns showing people what the testing entails and what might come next:



“there has to be the campaign to encourage people to go and have those diagnostic procedures and not to be frightened” (Participant 7)

7.5.3 Increase the screening eligibility

The highest priority in the survey was to increase the number of people eligible for screening (e.g. by reducing the screening age). At the time of interview in June 2022, people aged 58-74 years living in Wales were eligible, and were invited by post to take part in the bowel cancer screening programme.

As this was a priority of the survey participants, researchers explored this eligibility theme further during interview and focus groups. Opinions were sought on the current eligibility, even where individuals had not participated before or were not eligible.

Previously, the eligibility for screening in Wales was 60 years of age, but has recently been expanded to those aged 58-59, although many of the participants were not aware of this (Public Health Wales, 2022). However all participants also felt that age 58 was still much too high and should be lowered significantly.

“I think maybe 40 needs to be the new 50 with the screening as well because I'm 47 and was diagnosed at 45 and they said I was young” (Participant 20)

Researchers prompted focus group discussions on the topic by noting that the age for screening to start in England was 50, and Scotland was 52. Participants questioned the justification for Wales' eligibility being several years later and felt that screening should not be a '[Postcode lottery](#)'. All focus group participants felt that the bowel cancer screening test should be routine in patients who have bowel cancer symptoms presenting to the GP such as rectal bleeding or persistent gastrointestinal problems. They linked this back into previous thematic discussions on the need for '[A trigger for further action](#)' or a pathway for further investigation.

As the current age eligibility for the bowel cancer screening programme in Wales is age 58-74, a few focus group participants who were above the upper age of eligibility expressed disappointment in the programme no longer considering them eligible which they felt was discriminatory:

“Older people become invisible after certain point, and the NHS gives up on you..... I would say from my experience of over 70s, most are reasonably fit



and active and we deserve to be treated to the same tests and procedures as the rest of the population. I think it's really, really discriminatory. Terribly wrong." (Participant 5)

"It is wrong given that they keep going on about it's usually in older people, but then they stop screening in the older people and a lot of them don't perhaps get it till in their seventies." (Participant 14)

Participant 21 is over the age of 74, and was of the opinion that the age bracket should be extended to test in the elderly. This participant was in remission from cancer but felt that having a regular bowel cancer screening test would be reassuring in alleviating worries about recurrence:

"I wasn't too bothered about the upper age limit whilst I was still under the impression that I would have my 5 yearly surveillance, but now that the protocol has changed and that they don't do colonoscopies at regular intervals after you've had your first one year follow up, I'm a bit more concerned and I would like to see the upper age limit extended just to double check." (Participant 21)

Also during the focus group, researchers made the groups aware that in England there is the option to 'opt in' after exceeding the upper age eligibility of 74. The idea of being able to 'opt in' was received well by participants despite some losing faith in the accuracy of the tests, and were disappointed that this was not offered in Wales:

"Personally, I did lose faith in the test, but you know, it will pick up cases. So it is definitely worth doing, and as someone who is not only a couple of years off being 70, I would very much like to have a situation where we can opt in after 74 because I would still want to have the test. (Participant 7)"

There were also suggestions that irrespective of age, patients who have previously had bowel cancer should have the option of opting in to the bowel cancer screening programme as a safety net against recurrence.



7.6 'It gave me false hope' - A story for change

Participant 9 is a 66 year old male who was initially reluctant to complete the bowel cancer screening test through fear of what came next. But feeling like something might not be right, he participated twice over four years. The results of both were negative:

"I then took the screening test and it came back clear and then of course, that throws you, doesn't it? My symptoms then are irritable bowel. My problems are everything and anything else but cancer because it gave me effectively a false negative. It gave me false hope. It sent me off in a totally wrong direction. I even had another bowel screening test, which came back clear again as well"

Because of the negative test result, he was falsely reassured and did not go to see his GP:

"My biggest regret in my life is I should have gone in there at least two years before."

However despite negative tests and subsequently being diagnosed with stage 2 bowel cancer, he spoke passionately about the importance of the screening programme while being cautious of a negative result, but also the increased need for colonoscopies:

"I firmly believe that everybody should be dragged along with colonoscopy every five years when they hit 50. I don't think it's an expensive procedure, and I think that alone would pick it up sufficiently early. I think it is important, it's just that it needs to be emphasized on the paperwork when it comes back in big, bold letters if it comes back negative but if you have any of these symptoms, please return to your doctor."

After tumour removal he had 2 days of discomfort and received 6 months of tablet chemotherapy, but hoped in the future for the development of an alternative screening method such as a blood test.

7.7 Communication

7.7.1 'How I was told'

A few participants spoke of the way they were told their diagnosis and how they felt it could have been communicated better and in a more sensitive way. Some were told by their GP or consultant over the phone, although felt this was perhaps due to the coronavirus pandemic:

"he said sorry but I've got some very bad news. The consultant from the hospital has just rang me to ask me to get hold of you and tell you that your sigmoid colon is completely blocked. If you have any symptoms of sweating, if you're in pain, if you have any problems at all, then get yourself straight into A&E because you got a very small window of opportunity....that was very nice of him and he was extremely sensitive about the way that he said"



it, but isn't it a shame that it had to be done over the phone like that because of the COVID situation.” (Participant 9)

A couple of participants were not told about their diagnosis at all until they contacted their GP or hospital, and when speaking to them, it was almost as though the healthcare professional had forgotten to inform the participant and they were told their diagnosis in a rushed manner with little consideration towards how to break the news.

Participant 4 during interview described how she was told by her consultant she would hear from the GP about her pathology results. After not being contacted in some time, she eventually called the GP and questioned the results. She was then informed in an inconsiderate way that she had cancer which she described as huge shock and was a ‘breakdown in communication’. This uncoordinated care continued as she was diagnosed in February 2021 and did not start treatment until June 2021 as the colon specialist in her area only worked 2 days a week and so did the secretary. She has now had her treatment and had a stoma bag but is still on a possible 2-year waiting list for a reversal, but again is not being kept up to date with when this might happen.

7.7.2 Uncoordinated care

Uncoordinated care from diagnosis through to aftercare was a very common theme amongst those interviewed. Many commented on how they would often have to constantly chase up appointments and results which made an already very stressful time in their lives, even more difficult:

*“Fighting for what you need, it's hard work and exhausting - making those phone calls day after day after day and from my end of the age scale, I do feel for the older generation who still think that the doctor is God”
(Participant 5)*

“it is a constant battle with phone calls and waiting lists” (Participant 14)

Participant 9 spoke in detail about his experiences of uncoordinated care throughout, and how he never felt fully aware of what was going on. Even after treatment he had mixed messages regarding his monitoring:

“I went in for what I thought was a six month body scan at nine months and it was just an X-ray on my chest. Then the next opportunity which again



would have been about three or four months later, I said well, that last X-ray was just my chest and she said, oh, we'll put you in for a full body scan, as if it had been missed and whether it was I don't know, or whether or not it was some sort of miscalculation.” (Participant 9)

One participant had moved health boards between having her treatment and her monitoring/surveillance post-operatively, but has kept her monitoring under her previous health board due to fears of uncoordinated care:

“My surveillance is with Aneurin Bevan because at the time I was diagnosed I was living in Newport. And I'm leaving my GP and I'm leaving everything in Aneurin Bevan, and I'm not moving to Cardiff and the Vale for my Health Board, because I am not gonna get lost in the cracks between moving health boards....I'm staying with Aneurin Bevan, and yeah, I'm not risking it, I'm not moving. I'll actually physically move back to Newport if I need to. I will sell my house and move, I'm staying with them.” (Participant 2)

One participant had not yet started their monitoring post-treatment due to administrative problem:

“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.” (Participant 24)

Participant 15 was a midwife in the NHS and described how she experienced the delays and disconnect between services in the NHS in her work, but to be on the receiving end of it personally was very difficult:

“They sat me down then and there and said you have cancer, and then you hear nothing, you hear nothing for three weeks. Nothing at all. So again, because I knew the system I was calling and saying, you know, when's the MDT happening? Can you give me some more information? Who is my consultant gonna be? You know, all that kind of stuff? I am concerned about people who don't know the system and who don't have a voice. How much further has their cancer progressed because they've been waiting?....I think that was the big thing is that the waiting and the constantly having to kind of chase people up.”

7.7.3 ‘Scanxiety’

On the theme of uncoordinated care, many spoke of the anxiety they felt while waiting for test results after having a scan or blood test. Many added that although the time to wait for results may not be very long, they described any waiting as ‘scanxiety’.



"I get really bad scanxiety. The time of waiting for the scan to come, and then the two weeks after the scan until you get the results. I am unbearable to live with, I'm terrible, so moody...." (Participant 27)

This was a frequent term used on bowel cancer groups and forums which was particularly heightened once their treatment was over and they were awaiting surveillance results for recurrence:

"even though six months does go quick....I haven't had my scan dates through yet, but I'll go through scanxiety now. So when I get a scan through, I'll go through the anxiety of going for that scan again and....there's absolutely nothing you can do but wait until you get the results, and that's a scary time." (Participant 10)

7.7.4 Continuity of care

Continuity of care was an important priority raised by most of the participants during interview. As previously discussed, it was important for them to have a named GP or consultant who they could easily contact and who knew about their condition, but this was often not the case:

"I've had three colorectal consultants, and two oncologists, and I was only in the system for like six months" (Participant 15)

Nurses and clinical nurse specialists (CNS) were a topic spoke of positively by many participants and had praise for how much the CNS's had helped them:

"When I went to my initial consultation with my consultant, my Cancer Support Nurse was there from the minute that everything started and I was able to speak to her, she gave me a direct number that I could speak to her mostly on, you know, practical, clinical procedural stuff but she was there from the get go." (Participant 5)

Those who did have CNS contact did speak of the difficulty in getting hold of them sometimes and were never guaranteed to speak to the same person. Also there was often a wait to hear back from them and they were not accessible out of working hours:

"even when I ring the CNS nurses, there's like three of them. So any one of the three could call back and stuff. And obviously you've built up a relationship with your allocated one, but then you're speaking to someone else." (Participant 14)



Those who had not been allocated a CNS felt it would have been very beneficial as they often had questions that they could not ask their consultant:

*“I would have liked to have a designated person that was there throughout that you knew you could phone or you know, e-mail if there's a problem.”
(Participant 18)*

7.7.5 Communicating treatment options

In relation to how best to communicate treatment option, some participants preferred an in-person discussion with their healthcare professional:

“For me personally, it's going to be a verbal so and either with the consultant, which would be a rarity or probably through one of the team members of the multidisciplinary team” (Participant 21)

Many participants spoke of how they often started treatment with very little information on why they were having that specific treatment, and whether it was the best option for them. The concept of ‘mop up’ chemo was also discussed, with many not having it properly explained to them as they were not aware that it could be given in tablet form, and was not associated with as many side effects such as hair loss. These participants commented that they would have liked to have these options and their side effects explained more clearly, earlier on in the process, so that they could try plan a roadmap of their care. Many of those had questions throughout the treatment process and found it useful to have a dedicated healthcare professional to contact, but those that did not have anyone to contact felt left in the dark and resorted to social media and forums to gain an understanding:

“I've never been able to find out whether or not the chemotherapy was an essential part of the recovery of the repair or not. It was more precautionary. It was more just in case there's a couple of cells we think we've got it all out but let's give you this chemotherapy just in case, and I've never been able to get an answer from that to know what they actually found. You know. The biopsy on the tumour. Is it a fast growing one? Slow growing?” (Participant 9)

Participant 11 is the only participant of Indian ethnicity who took part in the study. She commented on how people from different ethnicities will have different religious beliefs and may not consider some kinds of treatment. However this can sometimes be due to a lack of understanding and so perhaps healthcare professionals should consider a more



thorough explanation of treatment options to these patients to help them make an informed choice:

“For some people they might not even look at having the treatments because they're concerned about those kinds of issues, and they could be reassured if someone would have a good chat to them and maybe work through why even on a religious sense actually you get the treatment because that will help you....You know, because some people don't understand the complexities, they just have the rules that they grew up with, and they haven't really explored that in more detail. So that sort of spiritual/practical level of where that comes in for different people, you know.” (Participant 11)

Others who did have treatment options discussed in their consultant appointment and spoke of feeling very overwhelmed and felt as though they did not take in much of what was discussed and would forget most by the time they got back home:

“I found that my appointments with either the nurses or the oncologist, I found them very overwhelming. There was so much information to take in. I took a friend to make notes and I still didn't necessarily remember everything, so I think definitely a face to face as close as you can get a verbal appointment and then followed up with either booklet or online.” (Participant 2)

These participants suggested that leaflets or a link to a video to watch in the comfort of their own home afterwards would be the most effective way for them to consider their options and decide on how to proceed:

“You could spend an awful lot of time forcing information onto people that they don't want the information....but if the patient does ask a question, a relevant and an intelligent question, then I think you should be able to respond then to that and think will hang on this, this one is a little bit different than Mrs. Jones that was in last, this one wants a little bit more” (Participant 9)

“I think it's so important then to have information to take away to reflect....access to a video about the whole process would be again a good method of passing on the relevant information” (Participant 3)

They thought that giving patients time to consult these resources at home would give them time to digest the news and make a plan. They suggested it would then be helpful to have a follow up phone call or appointment with their consultant to discuss their options.



Participants appreciated that every patient is different and it is up to the care team to establish early on how activated the patient is in choosing their own care, and how best to communicate this:

“I think it would be very useful to give people either a link that they can look at that you can watch online as well as written information. Because I think it's different for different people, and people respond to different things. So just giving them written or just giving them something electronic I don't think works” (Participant 11)

Many participants spoke of the discussions they had with their consultants in relation to being fitted with a stoma bag, and noted that being clearly told what this would entail early on was important to them. One participant recalled a conversation with their consultant where they had been told in detail what changes they would have to make such as eating a low fibre diet and regularly replacing the stoma bag and cleaning the stoma. They were then able to consider the impact that a stoma may have on their life and eventually decided to be fitted with one. Some participants who had been fitted with a stoma were given the potential option of a stoma reversal in the future. Discussing the potential of a stoma reversal early on in the treatment discussions was important to people to help them feel that they could ‘return to normal’ eventually.

7.8 'They sent me home to die' - A story for change

Participant 27 was 43 at the time of her diagnosis in 2019 and spoke openly during a focus group about her negative experience from suspicion to diagnosis. With recurrent symptoms, she struggled to get her GP to take her seriously and was repeatedly told '[you are too young](#)' to have cancer, and was diagnosed with either having Crohns or Colitis. After having to take photos of blood in her stool for her GP as proof of her symptoms, she was eventually referred for a colonoscopy and diagnosed with stage 4 bowel cancer. She initially experienced poor communication from her care team:

"So I went through all of the treatment, had sepsis, lost my hair and went to see the consultant that I was originally under who then just sat me down and said sorry we can't operate because although the radiotherapy had targeted the tumour, it hadn't targeted the lymph nodes. So basically, they sent me home to die. So I wasn't happy with his opinion, so I asked for a second opinion and was seen under a consultant in Morriston two weeks later who was excellent."

She spoke of how her tumour had a KRAS mutation, but was not aware of any genetic testing that had ever been done. Being given a poor prognosis, she enquired about clinical trials but was told that as she lived in Carmarthenshire – a rural area of Wales, this wasn't an option for her:

"he said, we don't have any in this area. And I 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."

She spoke of the uncoordinated care she received throughout her journey and suffered '[scanxiety](#)' when waiting for results, but had a lack of support as she never had a dedicated healthcare professional to seek advice from and so resorted to social media:

"I didn't have a dedicated cancer nurse. All along I haven't had anybody because when I was diagnosed with bowel cancer they said oh, but you've got it in your lungs as well, so you're gonna be treated by the lung team. So it was just being passed from pillar to post. So there was never any direct person that I could speak to. So I didn't have anything at all. Nothing. It was just friends, family and people that I could speak to on online chat rooms, and that was it."

At the time, her family were struggling and needed support and so she reached out to Macmillan who were unable to provide her family with support:

"They responded saying due to my diagnosis that it was very unlikely I was going to recover anyway and they didn't offer that kind of service, and I was like 'oh my god', you have just told me that I'm gonna die anyway, and you're not providing me with any help."

She then attended a Maggie's centre during radiotherapy treatment who were able to help her. Although Maggie's was not in her local area and so she had to make a three hour round trip to see them. Having begged her GP for help, they arranged for the local mental health team to get her someone to talk to which she found so helpful.



GIG
CYMRU
NHS
WALES

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



"I went to my GP and I said it's broken me. It's absolutely broken me because I fought so hard and then I just hit that black tunnel and I thought I don't know where to go."

She has since written to Maggie's and plans on setting up a similar support group in her local area.

7.9 Genetic testing

As of 2017 it was recommended by The National Institute for Health and Care Excellence (NICE) that all patients diagnosed with bowel cancer in England should be offered genetic testing (NICE, 2017). However this was not adopted in Wales until 2019 (Bowel Cancer UK, 2019). Genetic testing can help to identify people with Lynch syndrome. Lynch syndrome is an inherited cancer syndrome associated with a genetic predisposition to different cancer types, bowel cancer being the most prevalent.

Most of the participants who took part in interviews and focus groups were diagnosed after 2017 (see tables [7](#) and [8](#) in Appendices C and F), but the majority had never been offered genetic testing. However one patient had a strong family history of Lynch syndrome with six members of their family diagnosed. They felt very strongly about the value of genetic testing and as a result, they and their family members have regular colonoscopic screening which they felt was reassuring. Their family's story is described in the Living with [Lynch Syndrome story for change](#) below.

7.9.1 The value of genetic testing

Researchers asked those who had not had genetic testing if they would have liked the opportunity to be tested and most were willing to be tested if it was offered to them. Participants diagnosed before either the NICE guidance or genetic testing was available had not been contacted by genetic services, but would accept genetic testing if given the choice. Several commented that if there was the opportunity to identify family members at risk then this would be worth participating in and could be lifesaving for their family.

One participant in particular was very grateful for the genetic testing being done as it enabled her to be treated with targeted immunotherapy:

"The genetic testing also meant that I was able to have panitumumab, which is an immunotherapy drug which worked really, really well for me and helps shrink the tumour before I had surgery." (Participant 20)

However, the theme of a '[false sense of security](#)' arose from genetic testing discussions as some felt that if their family member had genetic testing and was found to be negative, this may prevent them from getting tested sooner if they had symptoms:



*"If my son goes along and is genetically tested and they comes back is no, it's not in the genes, dad was unlucky and it's something he ate when he was a teenager, is that gonna give you a false sense of security again?"
(Participant 9)*

Also there was some uncertainty around the value of genetic testing and recommendations that healthcare professionals should respect the wishes of people that prefer not to know:

"Genetic testing smacks a little bit of Big Brothers watching you, and I'm not sure how my children would take that up" (Participant 21)

"I think if I went along and they said, well, you got something that's gonna kill you in five years' time, I don't think I'd like that. I think I'd like to live in ignorance, to be honest." (Participant 9)

A few that had been genetically tested spoke of how it left them wondering what had caused the cancer:

"They found out that it's not genetic at all, it's sporadic, so unless you know what causes sporadic cancer, how can you actually do anything about it?....That's what really keeps me awake at night just to where it came from. Nobody's giving me any idea where suddenly these cells went OK, let's grow." (Participant 5)

7.9.2 Miscommunication and service disconnect

Researchers noted that there was a commonly reported issue related to the miscommunication of genetic testing. Many participants had not ever had genetic testing, or were not sure if they had been tested which was a cause of added frustration. Those who had been tested felt uninformed about the process and what tests were performed.

"Pathology tested the sample after my operation that was removed for lynch syndrome, but they don't often tell people that they are doing it. So I think some people perhaps are unaware that they have been tested or not..... if it's positive, I think they'll tell you. But if it's not, I don't think they perhaps feel that there's any need to." (Participant 14)

Many spoke of the significant delays they had experienced from diagnosis through to genetic testing results, many up to 6 months post-diagnosis. During interview, participant 10 spoke of her 5-6 month delay in getting her genetic test results after the genetics department losing her results:



“I did have to chase them up because I hadn't heard from them and my sisters they've got kids as well and obviously I was worried about my boys....So they were pushing asking if I'd heard anything, and in the end, I had to chase them up....they lost my first family history. (Participant 10)”

Another participant was adopted and no longer in contact with her biological parents and so asked her consultant to have genetic testing but getting the results back took a few months and nobody talked her through the results.

Across all participants there was a lack of understanding where the genetic tests were done and what the results might mean or them or their families. Researchers prompted a discussion in a focus group around using genetic testing for targeted immunotherapy, but many participants were not aware of what this was.

People spoke of how when they sought advice from their GP or consultant about the genetic screening, their healthcare professionals often were not aware of the results. Throughout the genetic screening process, participants felt there was a disconnect in communication between services such as cancer teams, GPs and the genetic services. They felt as though their oncology and surgical teams had very little input or awareness of the genetics and in trying to obtain genetic results, it was difficult to know who to contact and became frustrating.

There were a few comments during the focus groups about participants feeling as though their GP did not understand genetic testing and it would not be a priority for them:

“Patients need better access for face to face with their GP for all different kinds of services, but especially this one.” (Participant 12)

“There's no way you'd get into your GP for something like that.” (Participant 6)

7.10 Living with Lynch syndrome – One family's story

Participant 19 lives in Wales close to the English border, meaning they could opt for treatment in either in England or Wales. Both her husband and daughter were treated in England, attending hospitals at the Countess of Chester, Arrow Park, Clatterbridge, Liverpool Women's, and on one occasion in London.

At the age of 25, her husband developed symptoms including weight loss, stomach pains, swelling. He was advised by his GP that he had piles, despite his father dying of bowel cancer at the age of 43. Her husband continued to experience problems and was finally diagnosed with bowel cancer 5 years later at age 30 in 1994. However during the 3 week wait from the time of diagnosis to surgery, the tumour burst through the wall of the bowel and his wife described how he was incredibly lucky to survive the procedure.

At no point during the diagnosis and wait for surgery did anyone discuss fertility risks with the couple or advise them to deposit sperm. At the time the couple had a two-year-old daughter and had plans to have more children. After the surgery had taken place, in discussions with chemotherapy specialists the couple indicated that they wanted more children and were worried about the consequences of chemotherapy. They were told:

"Your husband had a surgical procedure that was around the pelvis, which means that if any damage was to happen it already had"

This was a huge shock to them, but when discussed with the surgeon at a later date the wife was told:

"you are lucky to have a husband alive! now go on and live your life!"

Some years later the NHS agreed to pay for the first round of fertility treatment which proved unsuccessful. The couple then decided to pay privately for the second fertility treatment and his wife conceived, but at 18 weeks sadly lost the baby.

Genetic screening was not available at the time of his diagnosis in 1994, but colonoscopy checks were routinely performed. Ten years later at age 40 while her husband was having a routine check, polyps in the bowel were found and he was advised by his consultant to have a total colectomy, which he agreed to. His wife spoke openly about the tremendous impact this has had on his life as he needs to pass urine 12 times a day (3 times in the night), and as such he has been suffering from sleep deprivation for the past 17 years.

Years later, once genetic testing became available, the family were offered testing and her husband was diagnosed with Lynch syndrome. Since his diagnosis, five members of their family have undergone cascade testing and all have been identified as having Lynch syndrome.

When asked about bowel cancer screening eligibility, she noted:

"If you've got somebody that's got Lynch syndrome in the family, I think all the families should be routinely screened....in my opinion that that should start at"



21 and you know I don't think that it should be like let's reduce it to 40 because my daughter would be dead by now"

In November 2020 her husband's sister was diagnosed with bowel cancer and recently in March 2022, their daughter had symptoms and within a short period of time she had a colonoscopy and was also diagnosed with bowel cancer.

When asked about diet and lifestyle advice for her daughter with cancer, she commented:

"If you've got Lynch Syndrome, you've got Lynch syndrome, so it doesn't really matter what your life style choices are.... I don't know whether diet would have made any difference to her prognosis now"

In 2021 her husband was also diagnosed with prostate cancer which she noted could have also been linked to Lynch syndrome. However they learnt that as he had been treated with radiotherapy previously for bowel cancer, he was not able to have it again and required cryotherapy - freezing of the prostate. She described how her husband has both a bowel and a prostate care team, but the care between both can be frustrating as sometimes they are the carrier of the messages from one hospital to another. She advised that cancer care would benefit from a coordinated approach when complicated cancer histories are managed by a number of specialist teams and different hospitals.

7.11 My cancer, my choice

7.11.1 'Postcode lottery'

Early on in the project, researchers identified in interviews the stark disparity in access to facilities between those in rural and urban areas of Wales. Many participants spoke of how they had received an inadequate service in comparison to others they knew living in cities or more built up areas of Wales. A couple of participants even opted for treatment in England over Wales as services were not available in their local area. This often involved travelling long distances for treatment which added to their stress. One participant was offered chemotherapy in Wales, or the option of targeted immunotherapy if they were treated in Liverpool, and chose to be treated in England.

The theme of a postcode lottery was not limited to secondary care as one participant who is an ex-nurse, described during interview the contrast in care from their GP surgery in London to rural Wales. They felt that the care received in NHS Wales was inferior to that received in London and there was a serious lack of communication across all areas. He spoke of how he now warns people against moving to Wales while undergoing treatment for cancer:

"I think that that the key issue in all of it is communication between health professionals and patients or services....to me it contrasts starkly between my experience in London. My experience having moved from London to the South Coast and, not having a closer relationship with the GP surgery there but a good one, to coming up here to almost having a really hands off very distant relationship with GP surgery. Just the lack of consultation, the lack of understanding, and the fact that I had to write everything to them rather than being able to discuss face to face" (Participant 21)

Others found that their consultant or specialist did not work in their local hospital very frequently and so this limited appointment availability. One participant lived in a region of Wales that did not have a consultant oncologist or oncology team nearby. They added that they were confident that if they lived in a city such as Cardiff or Swansea, they would have had a better chance of a positive outcome due to the availability of resources and facilities.

A nurse interviewed about her father's experience of bowel cancer spoke of how when her father was receiving palliative care, while living in a rural area of Wales, was treated in a mobile unit:



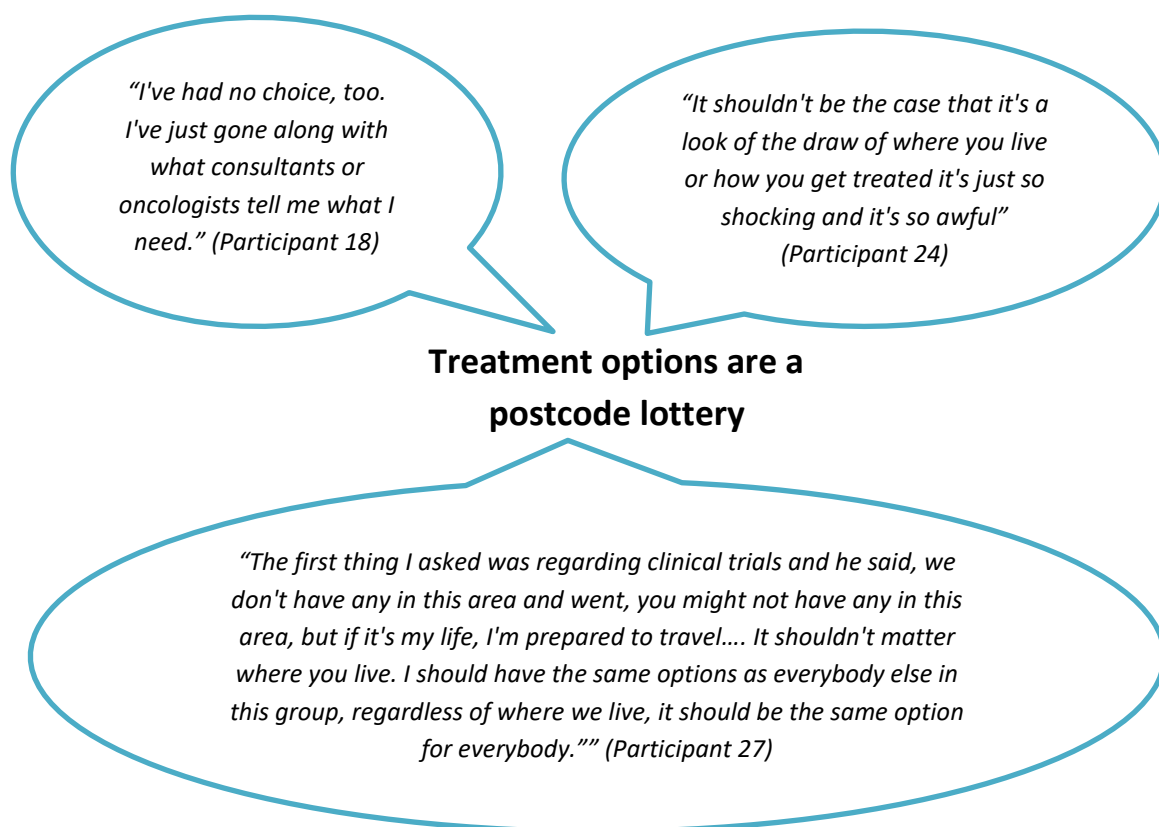
“All of his treatment actually took place in one of the Tenovus mobile units which was quite close to our house, so that was great because as the disease progressed he was getting more tired and fed up....the trips to Velindre which was miles and miles from our house were not as frequent was a good thing.” (Participant 16)

Participant 20 spoke in detail about how useful she found Bowel Cancer UK’s website as they have a forum on Facebook for stage 4 patients who have (or have had) bowel cancer with information on new technologies and treatments. However she spoke about the inequalities across the UK and health boards in accessing these treatments:

“it is a postcode lottery out there and what I’d hate is for somebody to read about an amazing new....cyber knife or nanobots and all this sort of thing and think, yeah, that would be brilliant for me, but then find that they can’t get it on the NHS.... So I think there needs to be a fine balance with making sure that our hopes aren’t dashed by the fact that you won’t get it in your trust.” (Participant 20)

One of the questions around choice of treatment was related to whether participants thought it was important to be offered the option of being included in a clinical trial. A few patients were enrolled into clinical trials and spoke of how it helped them as it made them feel as though they were helping to prevent others from going through the same experience. However many patients living in rural areas had never had clinical trials offered to them and they thought that there was not this option in their area, with it being something offered more routinely to patients that live in cities. They commented on how the opportunity to be enrolled in a clinical trial was a ‘[postcode lottery](#)’. Excerpts from a focus group discussion on the theme of a postcode lottery are shown in figure 13.

Figure 13: Quotes from discussions on treatment being a 'postcode lottery'



7.11.2 Having a choice in my treatment

Most participants felt very strongly that having a choice in their treatment was important to them. Many spoke of the options discussed with their care teams, although most were happy to take their consultant's recommendation. However, to be given the option and be involved in the decision making, and to have side-effects and lifestyle impacts discussed with them beforehand was extremely important.

On the theme of having a choice in treatment decisions, one participant's personal story of how the impact of surgery on fertility was not discussed is described in the '[living with Lynch syndrome](#)' story for change.

A couple of participants noted that although they were not medically trained and did not fully understand the treatment options, they thought it was important to have a say in their own treatment, but ultimately would take the consultant's recommendation.



"I wasn't given a choice, really. My oncologist just told me I was having chemo. I was like, right, OK. When do I start? And off you go" (Participant 14)

Participant 15 spoke of how she would have liked to have a discussion with her consultant about alternative treatments as she was suffering from nausea. She eventually resorted to looking online for anti-sickness therapies and purchased cannabis oil online after reading about it on the Macmillan website.

"I was never offered and like she said, if your oncologist has got a plan and because you're in that desperate situation you just listen don't you, and no I wasn't ever offered anything or told about anything." (Participant 6)

Participant 2 described in detail how important having a choice in her treatment was, as she was recommended eight rounds of the chemotherapy drug Oxaliplatin by her consultant. However after doing her own research she found out that four rounds was as effective as eight, and the chance of nerve damage between four and eight rounds increases exponentially. However her consultant was dismissive of what was best for her when discussing this with her oncologist:

"I did a lot of research and I do a lot of research about my chemotherapy to have a discussion with my oncologist because they were very tunnel vision. This is what I want for you when actually I don't think it was necessarily the right thing for me personally, and I had to have a very assertive conversation with her about it." (Participant 2)

At the time of his treatment, participant 9 was living with his wife in his fathers-in-law's house so that his wife could look after her father. He described how it was very important for him to have a choice in his own treatment because if any treatment option required him to be supported by his wife, he would not have wanted to put added pressure on her and it would have therefore been unsuitable.

"If a doctor was stood in front of me and he said, well, these are your options, we can do this and that will happen. We can do that and this might happen. You know, whatever there's three or four options. I would like to know the options and I would like to know the outcome. I would like to know the odds you know. I would like to know. But at the end of the day I would then throw it back at him and say, what do you recommend?" (Participant 9)



A small number of participants did not see much benefit in being given a choice and would prefer to just trust the opinions of the people looking after. However, all participants felt that it was very important to feel well informed about the treatment/surgery they were going to undertake, but many felt this was not the case for them:

“I felt really unsupported in trying to find out more information so that I could make that decision from the informed point of view.” (Participant 25)

7.12 Diet and lifestyle

7.12.1 Exercise and prehabilitation

The importance of exercise during treatment was raised with most participants. All felt that they were able to do minimal exercise during treatment or surgery, but even a slow walk was beneficial physically and mentally for them. Some spoke of physiotherapy appointments being beneficial to provide them with information on suitable exercises catered specifically for patients with bowel cancer, including those with stoma bags fitted.

One participant is the wife of an avid tennis player. She spoke of how, despite him being given a prognosis of just a few years, he made it his focus to get out and play tennis as much as he could as it shifted his focus away from cancer and enabled him to socialise with other players which was hugely beneficial for his mental health.

Many participants spoke of them leading a healthy lifestyle with a good diet prior to diagnosis, and having done everything they could to stay healthy, and therefore found it a shock to be diagnosed with bowel cancer:

“For me, for lifestyle, I hit none of the triggers for the bowel cancer like I was very fit and healthy. I used to do triathlons, keen cyclist, climber, I ate really well, I'm not overweight, I'm young, I don't smoke, I don't overdrink. The whole list of them on the NHS website I hit none of the triggers so lifestyle for me is a bit irrelevant and I think I'm just super unlucky.” (Participant 2)

“because I was quite healthy, I am a healthy person, I eat well, cycle a lot and my mindset was this can't be cancer, it must be haemorrhoids. And I had blood in my poo and I wasn't worried about it....I had self-diagnosed completely wrong, but because of my mindset, I'm a healthy person it won't happen to me. I was young. I was only just over 50.” (Participant 25)



Some participants commented on how after their diagnosis they did not find diet and lifestyle advice relevant to them and received mixed messages about its usefulness, but thought it may be useful in helping their recovery.

“I was desperate to eat healthily, I was desperate to exercise, but everything was just contradictory to everything” (Participant 23)

However there was a general lack of support about dietary/lifestyle aftercare advice and felt woefully unsupported in making the best dietary decisions.

Prehabilitation was not a prominent theme during interviews, with many commenting on how it was not useful to them:

“I don't think my husband had he been offered any pre surgical pre-habilitation advice he would of taken it.” (Participant 7)

When researchers explored this further during focus groups, many participants felt that being physically fitter before their surgery was beneficial for them in helping them respond to, and recover from surgery/treatment.

“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” (Participant 5)

One participant was diagnosed during the coronavirus pandemic, and was given prehabilitation advice over the phone:

“Because it was lockdown, I had everything over the phone, so nutrition advice, exercise advice, everything which is actually quite useful and it might help” (Participant 11)

However, many noted that exercise classes or ‘prehabilitation’ was not something offered to them after their diagnosis and many exercised alone or had to search for programmes themselves. These participants commented on how it would have been useful to be signposted to the services available to them:

“if I'm going to have an operation, the idea of perhaps having a period of time where you can maybe improve your health is obviously going to help you when you have the operation. So that's something that we need to push more really” (Participant 8)



Participants often commented on how after their diagnosis they were not in the right frame of mind to be exercising, and instead were dealing with the diagnosis and would be unlikely to have taken part.

“So when I was diagnosed, it was only two weeks and then I was in for surgery. So you've got to sort of wrap your head around the diagnosis first. If somebody said to me go and exercise, I don't think I could, I would be constantly crying all the time and it's the emotional side of things.”

(Participant 26)

Also, some of those that did take part in prehabilitation exercises did not find them suitable. As we spoke with a younger cohort of patients who have (or have had) bowel cancer, they described how their aim was to get back to running or cycling etc., whereas the exercise classes they attended catered towards an elderly population with limited exercise capacity who wanted to get up a flight of stairs:

“I did get referred to the exercise referral scheme because I asked my stoma nurse to do that, but when they attended again, I was the youngest there and I could walk around and I had a good level of fitness. So it again, I didn't suit me so as well as looking at prehab, we need to look at rehab as well.”

(Participant 26)

However many commented that during treatment and particularly after treatment, rehabilitation and exercise was useful or it is something they would have liked to have been offered:

“I thought the experience of the hospital was very good because the physios came onto the scene very early on after the operation and they give a lot of good advice about fitness and getting out after an operation like that. So I think you're right, it's a very important feature of the post operation is to have that sort of advice” (Participant 3)

“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.” (Participant 23)

7.12.2 Diet

As discussed, diet for prevention was not of interest to many participants, but dietary advice after surgery/treatment and to assist in their recovery was important.



Several people spoke of the contradiction of being told to stay healthy, but when admitted for to hospital, there was a lack of nutritionally rich foods offered:

“The quality of food in hospitals and the nutrition of the food in hospitals is not going to help anyone to recover from anything.” (Participant 11)

Participant 11 spoke passionately about how there needs to be more consideration towards giving dietary advice for people with bowel cancer from different ethnicities both while in hospital and as part of their rehabilitation afterwards:

“I’m from an Indian background, and it doesn’t play a huge part in my life in terms of I don’t have any body images issues or anything, none of that bothers me and I’m sure there are people who would have, or people with diet issues....and I don’t know how much or little support or advice there is. I know you get the ‘do you have any dietary requirements’ but people can be quite shy about that, and I don’t know if more input in those kinds of things.” (Participant 11)

A few participants spoken to had seen a dietitian during their treatment but found the advice to be outdated, non-specific and not relevant to patients who have (or have had) bowel cancer. Many participants were not complimentary about the dietary advice throughout their journey and it was therefore not a priority of theirs:

“they come around in the morning give me my protein drink. Give me the list of the foods I should eat and off they go again.” (Participant 14)

Participants advised that if a dietitian were to be on hand to give advice during or after treatment, they should be trained in dietetics relevant to oncology specifically. They described how dietary advice is a minefield to sift through and there are certain food groups which are beneficial for cancer prevention or recovery and this needs to be considered by care teams. Some had found out what was best to eat through internet forums, friends and books rather than being given advice by a healthcare professional.

Many participants had never spoken to a dietitian at any point in their bowel cancer journey, but thought that it would be very beneficial as they felt it was left to them to manage using ‘trial and error’. Others were given no, or very little advice during their treatment and were left wondering what changes they should be making, if any:

“she said don’t worry about eating healthily and eat lots of vegetables and all the rest of it, she said eat as much rubbish as you like.... Was it my fault?”



Did I do anything wrong? Was it the stuff that I ate in the past? Is it the stuff that I drank in the past? Should I now be stopping drinking alcohol? Should I now be stopping eating red meat.” (Participant 9)

Similarly, after the above participant had finished treatment, he felt that dietary advice to minimise recurrence would have been useful:

“I haven't had any dietary advice. I'm still drinking rum and Coke, I still eat sausage rolls, and I don't know whether they're going to kill me tomorrow or not.” (Participant 9)

7.12.3 Stoma bag dietary advice

The lack of dietary advice was especially the case for participants with a stoma bag as although stoma nurses sometimes gave very minimal dietary advice, having a stoma requires a significant change in diet and participants felt that there was not the support available to help with this. Some sought advice from online forums, social media groups and charities such as Maggie's, but it was not specific to those living with a stoma bag:

“I did get some recipe books and stuff from them, but then again because I had a stoma bag, it was all like healthy green vegetables and I said I can't have all those so I'll just stick to my chips and bread” (Participant 14)

Therefore many participants spoke of having a year or so of 'trial and error' to see what worked for them and what did not, and so to have more advice or support would have been beneficial for them immediately after surgery/treatment.

“I do remember being really shocked at the stoma diet guidance because it was all the stuff I loved eating but I couldn't - it had risks. So that was a real surprise to me because fruit and lots of vegetables or all what I thought was a really good diet, I was cautioned against to you know, just white bread and rice. That was just not a great diet. So I think that was a bit difficult for a whole year and then I ended up just eating what I wanted to and risked a blockage or whatever and that was a shock for me, the dietary advice for the stoma.” (Participant 25)

“I was absolutely mortified when I was given advice by a dietitian about my stoma because it completely did my head in because I thought this all the healthy things I'd always been eating, I couldn't eat and it took a very long time for me to see a dietitian..... So for me, having that dietary and exercise advice straight away afterwards to make me feel better.” (Participant 23)



7.12.4 Prophylactic Aspirin

Taking prophylactic aspirin and improving understanding of the impact of diet, exercise and smoking on the risk of bowel cancer was the lowest priority of those scored in the survey.

The question of whether aspirin had been recommended was explored a little in the interviews and further in the focus groups for this reason. However this theme did not come through strongly as most participants were unaware of the benefits of taking aspirin and how it was relevant to bowel cancer:

“I queried it with my GP and I was told that is was only for people with Lynch syndrome.”

Some did quote that if it would potentially reduce their chances of recurrence then they would happily take it prophylactically. Participant 2 was currently enrolled on the Add-Aspirin trial which is a phase 3 randomised controlled trial assessing the effects of Aspirin on disease recurrence and survival after primary cancer therapy (National Library of Medicine, 2021). She spoke of how she thought it was worth enrolling on if there was a chance of reduced recurrence, but hoped that she was not taking a placebo.

During the same focus group others were more cautious of taking aspirin without further evidence proving its benefit for them:

“I am sceptical because there's so many trials for aspirin for other diseases as well that the results from those say take it it's good, take it it's bad for you, so until we get more positive research findings, I would be wary.”
(Participant 21)

“Salicylic acid just seems to be this amazing drug, but also you know it can damage your stomach too. So it's that balance.....I mean my great hope is that advances in genetics and the genome will allow much more individual drugs. So instead of having this great sort of carpet bombing that we have now. It's something that's very much more personalized.....I think it's very dangerous, just blankly saying, oh, it's good for this, let's do this.”
(Participant 24)

7.13 Support

Researchers identified early during interviews that social media groups and online forums were particularly helpful for some patients, not just the younger participants but those of all



ages. This help was not exclusive to any particular part of their journey as most seemed to engage in one form or another after their diagnosis and throughout their journey. Two younger participants were strong advocates for the benefits of online support and had each created an online Instagram account during their bowel cancer journey. Both spoke of how they posted content throughout their treatment to try and help others and found this personally rewarding. However some participants were reluctant to join such groups through fear of being scared by other people's stories.

"I did join like a cancer forum on Facebook and that quite scared me actually, because people are telling you know how you are feeling and they quite scared me at the time thinking, oh my god, I'm going to be feeling like that." (Participant 18)

Several participants spoke of help usually on offer to help with patient's wellbeing such as Reiki, group therapies, art sessions etc., but as they were treated during the coronavirus pandemic, these were not an option and were not offered virtually. However, several did have access to online support in the form of cancer forums and online mindfulness courses which they found very helpful. Another person regularly engaged in a virtual group session with other cancer patients during the pandemic and had found speaking to others very helpful during a lonely and scary time in their life.

Question 13 of the interview topic guide asked about specifically about the aftercare support provided. However, early on during interviews it was highlighted that support post-diagnosis was lacking for many participants and so this question was adapted slightly for the focus groups to question the support given from both healthcare professionals and other forums (social media, charities, family etc.). Many participants commented that they had to search for sources of support themselves and were not signposted to them by healthcare professionals and so were unsure what advice to follow.

7.13.1 Aftercare

Most participants spoke of feeling deserted once their treatment was complete. They felt that after a long period of having appointments, treatment etc., once treatment was over, any support they had seemed to cease. Many would have very intermittent contact with their specialist nurse or stoma nurse following treatment and so good aftercare was one of the very consistent themes of importance to all participants.



People spoke of focusing so much on getting through treatment/surgery and once it was over this was the time they started to process everything they had been through. This was often the hardest time psychologically, and several participants needed mental health and counselling support as a result. However mental health support and aftercare was often reported as not being forthcoming from their care team, again leading them to search for it themselves or take recommendations from other patients:

“There's no support on exercise postop and you see perhaps a physio when you're in hospital, but like the longer term benefits you said of, you know, reducing recurrence and stuff, that's not really stressed or any guidance on that after.” (Participant 14)

Similar to the dietary recommendations before surgery, findings suggested that when it came to emotional support before treatment or an operation, it was not a priority but rather the support was needed afterwards. One participant commented:

“If someone offered me a support group before an operation I wouldn't have accepted it, I would have had too much on my mind. I'd be thinking about other things rather than having it brought up again and talked about.” (Participant 9)

Another commented on where support was most needed throughout their journey:

“Support before I'd say more preparation for the operations and the treatment, and then support after I think there's a longer period where perhaps you do need that support afterwards.” (Participant 14)

One participant spoke of his surprise in being discharged from Velindre hospital as he was never formally told he had been discharged. He described being pleased but it being a double edged sword and feeling as though his safety net had been removed and felt a bit let down by his care team. He found it difficult having to look out for symptoms and wished for more aftercare support:

“she said if you have any symptoms dear, now make sure you come back to us. The trouble is when you're a cancer patient, you have a headache - it's in your brain, you have pain in your leg - it's in your bones, and it's difficult for me to identify what is a symptom of cancer and what is a symptom of getting off my bike at the wrong time of the day!” (Participant 9)



7.13.2 Types of support

Through speaking with so many different participants, researchers learnt of the wide range of support available for patients who have (or have had) bowel cancer but support was often reported as not being very personal to the individual. For example many younger participants felt strongly about the lack of support available for them and that materials such as leaflets and group sessions were targeted more at an older demographic. When asked about support groups for younger participants, all added that they would have benefitted from this:

“I suppose that the more support for me has been after. So before, I think it would have been good to maybe have someone in a similar situation or having been in that situation to know what to expect, but whenever you go anywhere, there's a lot of breast cancer groups. There's not much on bowel....they've set-up a young person's group at Maggie's specifically for younger people....but again, in that there is a lot of breast cancers, blood cancers, there's no one else with bowel cancer there to have some relatable experience”. (Participant 14)

Participant 1 had small bowel cancer which is less common than other types of GI cancers. They attended reiki sessions which were helpful, but described how she felt guilty attending as none of the patients attending had small bowel cancer. She explained how it would have been useful to have resources and support specific for patients with small bowel cancer, and how this could be something the hospital or CNS could help support.

A couple of participants spoke of their lack of contact with their GP throughout their treatment period and thought it would have been nice to have had a short phone call from their GP during their treatment to let them know they were being thought of. However many GPs were far removed from the process once diagnosed and many thought they could be better utilised in signposting for support.

One elderly couple (Participant(s) 8) interviewed together both recommended that having people to speak to who had been through the experience would have been beneficial. Others who had attended Maggie's and other support groups had found meeting people going through something similar was helpful as they felt more understood. There was some suggestions that going into the hospital for an introduction to what they were about to undergo to give people peace of mind would be of benefit. Even just speaking to ex- and



current patients rather than taking up healthcare professionals time as the prospect of attending hospital for major surgery or treatment was scary for them.

Participant 12 spoke of how she sought support during the COVID-19 national lockdown from her church group, as some of her friends there had also developed cancer during this time. The group set up a creative writing and literature group and she found interacting with others very helpful to take her mind off of cancer. Another (Participant 13) joined a reiki class, a craft class and choir with her hospital after her treatment and found speaking to others with different cancers very supportive.

7.13.3 Support from care team

Many participants were complimentary about their consultant, and spoke of their gratitude for saving their life. However in discussions around support from care teams, consultants were not the focus as many did not wholly expect wraparound support from consultants as they were there to diagnose and treat. Nurses on the other hand were felt to be the most supportive to patients who have (or have had) bowel cancer and more specifically clinical nurse specialists (CNS). CNS support was most beneficial the earlier in the journey as they were able to form a trusting relationship with them and appreciated how they were there sometimes to just answer some of their more trivial questions.

“I think one for me, the most important source of support was the Macmillan nurse that I was allocated before I'd even been formally told my diagnosis.” (Participant 21)

However those who had CNS support spoke of how it was not always easy to contact them for immediate help, being described as a 9am-5pm service by a few, and was less common for those in more rural areas:

“I can honestly say that in the past two years, I've had very, very little contact with clinicians you know whether it be, you know, the Macmillan nurses who do ring up regularly are really, really nice but I struggled to understand the disease. I've struggled to get information on the disease.... She, she said. If you have any symptoms now, if you have any symptoms dear. Now make sure you come back to us. The trouble is when you're a cancer patient. You have a headache - It's in your brain. You're have pain in your leg - it's in your bones, and it's difficult for me to identify what is a symptom of cancer and what is a symptom of getting off my bike at the wrong time of the day.” (Participant 9)



7.13.4 Charity support

As previously mentioned, support from charities was very well received by many as these were often a 'one stop shop' for signposting people to support available for mental health, families, financial advice, and group activities.

"I found the cancer charities were very good in sign posting what was there - Macmillan, Marie Curie, Tenovus, those people. If you wanted to talk to them about what the possibilities were, obviously their pamphlets and social media are quite generically blank but there are people there who know what's ongoing in your area. They're very good. They're very helpful."
(Participant 5)

During many discussions, feedback was received on the wide range of support available to patients at different times in their journey, from helping people get back to work....

"I've also had a lot of help from Macmillan and I found them very useful....thankfully they've been there, you know, if I have a problem. I ring up and somebody will call me back eventually. You know, even if it's not straight away.... I'm worried about not being able to get back to work. So Macmillan have been very helpful in, you know, discussing, you know, going back to work and also retirement and things like that they've been very helpful like that" (Participant 18)

....to post-operative exercise advice:

"Macmillan are really good and their post-operative exercise advice is really good as well online and, in their booklets, but that didn't, you know, come directly" (Participant 11)

One participant did an online mindfulness course with Tenovus cancer charity which they found useful:

"When I was just finishing treatment I did mindfulness with them....but again because of COVID and fear of getting the virus, I couldn't really access anything on a face to face. But I did do the mindfulness, which was good. Very supportive as well." (Participant 12)

One of the younger participants who was interviewed and later took part in a focus group was an endurance athlete, and after surgery was recommended an exercise programme by their care team. However her personal circumstances were not understood as the group was attended mainly by people aged 50+ looking at rehabilitating themselves to do light exercise such as walking around their house. She spoke of how attending these groups at a



relatively young age gave her 'imposter syndrome'. Attending body image and hair loss groups she would 'feel like a fraud' as she was fortunate enough to not lose her hair and felt that she does not look like the 'typical cancer patient', so was often mistaken for a member of staff. She eventually found a young person's cancer charity who have helped her get onto an exercise program more specific to her and her endurance training needs.

Several participants spoke of the need for support for family members throughout the journey as their partners were often the ones taking on a lot of the emotional burden while having to still provide for their family. However family support was often lacking and only very few charities offered this kind of support.

After one participant's diagnosis, she felt 'lost' and as though she had 'nowhere to go' with little support for her children. Due to her concerns, she started to write her will and contacted the Samaritans for help, but was disappointed with the wait for a reply and instead found support from the online community she had in a Facebook group she had joined.

7.13.5 Maggie's charity

Of all the kinds of support discussed throughout the study, Maggie's charity stood out as one that had an incredible amount of praise. However this was a service only available for those close to one of two centres in Wales; Velindre Cancer Centre in Cardiff, and Singleton Hospital in Swansea (Maggies, 2022).

Many spoke of how the charity felt like a home to them at such a difficult time and were offered counselling through the charity, however, some found that just being able to speak to someone was helpful:

*"I've used Maggie's a lot and they've been great. I did turn up there sort of maybe before my operation and didn't really know what to say, but had a one-on-one with a councillor there....I just felt like I needed to speak to someone. Maggie's have been great and you can go in and even though they're not the same cancer, I suppose if they're in the similar situation like you said about talking openly just to get it off your chest type of thing
(Participant 14)*

The same participant discussed how Maggie's were useful in supporting not only them but their family members:



"That's where Maggie's has been useful, so they do have family open days and places. So I did take my husband there quite early at the start, just to show him where it was if he needs it. I mean he hasn't, but I suppose there's knowing that he could if he wanted." (Participant 14)

Participant 2 was a young participant and a real advocate for Maggie's charity, attending an art therapy group every week which helped give her some routine while not in work:

"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" (Participant 2)

Not long before her own diagnosis she had lost her mum to cancer, Maggie's offered her a place on their bereavement group which she plans on attending once she has finished her own treatment.

"I took my best friend with me who was accompanying me that day and we went in and she actually started crying when we were there because she said the reason why is that she felt that she could hand my care over to them and that she knew I'd be looked after and that there were people there to help, and it's just such a wonderful place." (Participant 2)

Another participant had such a positive experience of Maggie's that they hoped to set up a similar group in their own rural area of Wales:

"I would happily raise money for Maggie's centre, and that's what I said when I went back to work last year. My intention is that I want to bring something the equivalent of the Maggie's Centre to our remote area down here because there's nothing." (Participant 27)

7.13.6 Mental health and counselling

There was an overwhelming number of participants who spoke of the psychological after effect of cancer once they had finished their treatment, as they had overcome a life threatening disease and were now left to process all that had happened to them:

"Apart from killing you, the worst thing that cancer does is it messes with your head something terrible....Initially I would go to sleep at night thinking about it and I wake up and the first thing I think about it in the morning was the cancer." (Participant 9)

"you can get through the cancer, get through your recovery, get through treatment and that's kind of you're in those phases and that's all you're kind



of thinking about really....but then you're left with all the emotional stuff after, and that's when you start thinking about the longer term or recurrence, and what if it comes back." (Participant 14)

"Everybody expects that, yeah, you're going to be depressed because you've got cancer, but the stages of the diagnosis, having the treatment, fighting for the treatment, your head is just in overdrive, but like we said, it's when you get to the end and you think maybe I do need some help now" (Participant 27)

Some were signposted to where they could seek help, mainly by charities, but again many felt helpless and 'left in the dark'. They felt that they should have been pointed in the direction of mental health and counselling support by their healthcare team who knew them best but this very often was not the case:

"I have had some counselling sessions through Velindre, but I did have to ask for that and I have then been referred." (Participant 14)

"Most of these most hospitals will offer a counselling service at some point. Whether it's an effective one or not is a different matter. But when do you need it? How do you know you need it? And how are you gonna take it up? Because most of the times you want things, they're not available because you've either finished your treatment plan or it's not available because you're too early in in your cycle of the cancer journey" (Participant 21)

However those who had received counselling or mental health support after treatment were very complimentary about the difference it had made. One participant spoke positively about her experiences of Tenovus Cancer Charities counselling services, which she was referred to by her care team:

"I had my first session last week and it was all about the trauma of ITU for me personally, but I was absolutely amazed at how quickly that referral went through....I've got now another five weeks of support if I want it which was absolutely amazing that it happened so quickly and it's done through teams or zoom." (Participant 20)

However there were some discussions about how sometimes the number of sessions are limited, but one participant described how it was difficult to process something so traumatic in a short period of time:



“I got seen so quickly and there's no time limit on it, which I find with a lot of counselling that you get. My work would provide counselling for some things, but you're limited to six or eight sessions and you can't deal with a life changing event in six to 8 sessions.” (Participant 2)

As some participants were diagnosed during the coronavirus pandemic, mental health support was offered virtually:

“I had a course of six counselling sessions over the phone because of COVID everything with all the restrictions and they did help because she said to me, what do you want to gain at the end of all of these sessions, I said all I want is to be able to tell my story and she went OK....And then I went straight back to work afterwards and I'm much stronger now than what I was” (Participant 27)

Overall there was a strong consensus from the whole cohort of a need of increased healthcare professional recognition of when a patient needs help and better signposting to mental health and counselling services.

7.13.7 Monitoring post-treatment

Improving post-treatment monitoring was identified in the survey as the highest priority to participants and so this topic was discussed in depth. All of those who were undergoing monitoring reported that it helps to alleviate the anxiety of recurrence following treatment as it feels as though someone is keeping an eye on you. The time from treatment ending to being screened again was often up to a year, which patients reported as being an unnerving time waiting to know if the treatment had been successful so they could be reassured that the cancer had not come back.

“when you've got cancer you have cancer for the rest of your life. Whether or not it's been treated and you know never mind how many people tell you it's gone and you're in remission all these words. You will always worry that it's gonna come back” (Participant 9)

Some had experienced long delays in their monitoring post-treatment and considered alternatives:

“I won't be waiting past September. I am going to have to pay privately to get a colonoscopy when I'm supposed to have a routine follow up.” (Participant 14)



All participants recognised the importance of monitoring post-treatment, however very few were aware of their monitoring plan. As a result, during the focus groups it was proposed that, upon discharge patients could be given a pamphlet or letter with an approximate timescale for monitoring over the next few years. For example at 1 year they would have a colonoscopy, 2 years a blood test, and 3 years a scan. The idea of a monitoring plan upon discharge was received very well as most had a rough idea of when they might have monitoring but were generally waiting on a letter to arrive in the post. Those who were given a monitoring plan found it helpful to forward plan:

“I've been very pleased with my health board since I've had this operation, they put me on a 3 year monitoring scheme and so far, it seems to be going well. I've had contact with one of the specialist nurses after about two months and next thing, now she's arranging my first full check-up in 12 months, but I believe I'm getting a second one as well after two years.”
(Participant 3)

During a focus group, one participant living in the urban area of Cardiff and Vale spoke highly of their monitoring plan which was a contrast to others in the group who lived in more rural areas:

“I was diagnosed in 2020 and after my treatment finished, I went back to the University Hospital and I got a plan for the next five years really. Everything is in place. Every scan, colonoscopy where it's going to be, when my bloods are, I see the nurse face to face every six months now, but excellent, I can't fault them, really, really, very good. And I know I can ring them about anything at all, and I have open Access to any worries I have and it's been really positive and I feel very well supported.” (Participant 12)

However a couple of participants who had experienced care in both England and rural Wales felt that bowel cancer care was better in England and spoke passionately about the difference:

“One word of advice I would say is don't change from one area to another when you have bowel cancer, because the follow up when I lived in London was brilliant, and when we retired and we moved down to Sussex, yeah, that was pretty good. But coming back to Wales, it is abysmal. Appalling. There isn't any and you know, that's it. So to me, don't come back to Wales until you're well into your pathway recovery.” (Participant 21)

One participant had breast cancer before bowel cancer and spoke of the contrast in monitoring post-treatment:



"I've got the experience of breast cancer screening post-operative and bowel cancer, and they're very, very different. I felt that the breast was more about screening. I've had regular mammograms; breast care team were on call if I needed them. The bowel cancer seems to be more about the surgical recovery and is the stoma reversed successfully rather than actually more screening, I have had one colonoscopy since but that might be it, but I'm not very clear about where I go for support or screening sort of thing for the bowel cancer and so they're two very different from experiences and both in the same health boards." (Participant 25)

The frequency of colonoscopy monitoring post-treatment has recently been amended, meaning patients are not monitored for as long after their treatment which was frightening for some:

"It terrifies me that they just drop you off the face of the earth at year four and it's like crack on" (Participant 2)

One participant spoke of the difficulty in taking part in the bowel cancer screening programme after their recovery due to having a stoma bag which is not considered by healthcare professionals:

"I definitely don't think they should stop screening anybody who's had bowel cancer as I think it should be ongoing because I've got a Stoma and one of the problems with having a stoma is the stoma itself has got a lot of blood around it, you know, and any poo I have is contaminated. You know, it's always got blood in it. So I can't look at my poo in the same way, you know I can't get the same signs that I would have done if I didn't have a stoma. So I think from that point of view, having maybe once every five years would be good." (Participant 23)

8 Discussion

Bowel cancer is the fourth most common cancer in the UK and the second biggest cancer killer with nearly 43,000 people being diagnosed with every year in the UK. Around 268,000 people living in the UK today have been diagnosed with bowel cancer (Cancer Research UK, 2022).

On average 1 in 15 men and 1 in 18 women will be diagnosed with bowel cancer during their lifetime, with men making up 56% of the bowel cancer patient population (Cancer Research UK, 2022). However, it is important to acknowledge that the demographic of our cohort in this study was not representative of these published estimates; with the male proportion of



participants accounting for only 21% (15/70) of survey respondents and 18% (5/27) of pooled interview and focus groups participants. This may be partly due to the relatively small number of participants who took part in the interviews (n=23) and focus groups (n=14), and it is important to acknowledge that as with any qualitative data collection, the cohort was a self-selecting group that agreed to voluntarily participate in the study.

According to Cancer Research UK (2018), nine out of ten (94%) new cases of bowel cancer are diagnosed in people over the age of 50; and nearly six out of ten (59%) of these cases are diagnosed in people aged 70 years old or over. However, bowel cancer can affect anyone of any age and gender. It is estimated that more than 2,600 new cases are diagnosed each year in people under the age of 50 years old (Cancer Research UK, 2022) and this demographic was reflected in the self-selecting group that voluntarily agreed to participate in our study. In respect of the survey respondents, only 42/70 (60%) were over the age of 50 years when compared with the Cancer Research UK reported figure of 94%. Of those who were interviewed and also participated in the focus groups, 9/27 (33%) were under the age of 50 years old.

It is possible that this demographic disproportion is related to the fact that the younger population living in the UK may be more likely to engage with online surveys and platforms than their older counterparts (Age UK, 2021). It must also be considered that in order to complete an online survey or take part in a virtual interview or focus groups a networked computer or mobile device is required. Survey participants also require a certain level of competence in reading and writing in the English or Welsh language to enable them to complete the survey.

It is generally regarded that individuals with high levels of digital literacy tend to be from a more affluent background. Although detail on the social deprivation of participants was not known, it has to be acknowledged that this online methodological approach may have potentially contributed towards a cohort or sampling bias which was unrepresentative of the typical bowel cancer patient population.

According to Welsh Government the percentage of people living in Wales that are either black, asian, or from a minority ethnic group is in the region of 5.2% (Welsh Government,



2021). In respect of ethnic diversity, only 2/70 (3%) of respondents to the survey recorded their ethnic status as either black, asian, minority ethnic or mixed race.

It is estimated that black people are almost twice as likely as other races to die from cancer of the colon and rectum and tend to develop bowel cancer at a younger age (Askari, et al., 2017). A previous study shown that ethnicity, deprivation and age were all positive predictors of advanced tumour staging at time of diagnosis (Ashktorab, et al., 2016). Black patients were more likely to present with Stage 4 tumours than white patients (OR 1.37, 95% CI 1.18-1.59, $p < 0.001$). Social deprivation was also a predictor of Stage 4 bowel cancer presentation, with the most deprived group 1.26 times more likely to be diagnosed with Stage 4 bowel cancer when compared with the most affluent group (CI 1.13-1.40, $p < 0.001$). Sub-group analyses shown that black and affluent patients were still at greater risk of Stage 4 bowel cancer than their white and affluent counterparts (OR 1.24, 95% CI 1.11-1.45, $p = 0.023$) (National Bowel Cancer Audit, 2020).

This significant health inequality could be attributed to the fact that uptake for bowel cancer screening is substantially lower in black, asian, and minority ethnic communities when compared to the most deprived White British communities (National Bowel Cancer Audit, 2020). However it is not possible to draw any conclusions related to the influence of ethnicity and social deprivation on bowel cancer risk due to the lack of meaningful representation from most ethnic groups. However, during an interview with the only Indian participant in the study, it was suggested that a concerted effort is required to raise greater awareness of bowel cancer risk and early detection to eliminate the current health inequality in bowel cancer care that exists for those patients from Black, Asian, and Minority Ethnic backgrounds.

Despite the fact that the group of participants involved were not fully representative of the bowel cancer patient cohort as a whole, a number of important key themes (Bowel cancer screening, Communication, Diet & Lifestyle, Genetic testing, Increased awareness, My cancer My choice, Support, and Suspicion to diagnosis) emerged from the data. These highlight issues that are important to patients and may be used to help inform the case for change and highlight the need for continuity of care across Wales.



8.1 Diagnosis of Bowel Cancer

Bowel cancer is treatable and often curable especially if diagnosed early. The literature suggests that almost everyone has an increased chance of survival from bowel cancer if diagnosed at an early stage (Cancer Research UK, 2022). The majority of those that participated in this study felt that increasing awareness of bowel cancer risk in the younger population was instrumental in improving survival outcomes. Furthermore, participants felt very strongly about increasing the knowledge of general practitioners and other healthcare staff in recognising fewer common symptoms, and more specifically, symptoms in the younger population. The majority of the younger demographic (< 50 years) that participated in this study highlighted the lack of GP awareness related to bowel cancer risk in the young. Many felt that despite a number of visits to the doctors regarding symptoms that they were dismissed and not listened to by the GP. Another cause for concern was the lacking continuity of care and the experiences of these participants highlighted the importance of having a designated named GP. This continuity in the diagnostic stage of bowel cancer may help to trigger further investigations within a timely manner as the GP would likely be more familiar with the recurrent presentation of symptoms. Because of this, many felt that their bowel cancer care had been delayed due to a lack of continuity within primary care and this had contributed towards the symptoms not being investigated at the point of suspicion.

It is a well-established fact that the chances of survival significantly reduce as the disease progresses in the absence of prompt medical intervention (National Bowel Cancer Audit, 2020). The findings from this study suggest that age (< 50 years) and late diagnosis may have been predictive of advanced bowel cancer staging (Stage 3 =22%, and Stage 4 =54%) when compared with their older counterparts that were diagnosed earlier (Stage 3 = 38%, and Stage 4 =11%). However, the context of these findings must be interpreted in view of the limitations of the study. The cohort was self-selecting and the younger participants may have had a stronger motivation to share their experiences in the hope of raising awareness of bowel cancer in the young. Researchers recognised that those patients who have (or have had) bowel cancer of a more typical demographic for the disease may have had a more positive experience and may have been less inclined to engage with an online survey designed to guide future improvement in bowel cancer care.



The National Bowel Cancer Audit (2020) reported that the bowel screening programme detected patients who had less advanced disease and were generally fitter (National Bowel Cancer Audit, 2020). However, this observation was not reflected in a significant proportion (96%) of the cohort that participated in both the interviews and focus groups. Only 1/27 (4%) participant reported a bowel cancer diagnosis following a positive screening result. Three (11%) participants were diagnosed following an emergency admission to hospital and a further 15 (56%) participants were diagnosed after raising concerns with their General Practitioner. The remaining participants were diagnosed following incidental findings for other health conditions.

In England and Wales it is reported that 10% of patients diagnosed with bowel cancer were detected following participation in the bowel screening programme (National Bowel Cancer Audit, 2020). However, the findings from this study shown that only 33% of the cohort that participated in the interviews and focus groups were eligible for the bowel screening programme in Wales. The majority of participants were currently regarded as either too young (≤ 58 years) or too old (≥ 74 years) to meet the Public Health Wales eligibility criteria (Public Health Wales, 2022). One participant stated during his interview that despite having survived bowel cancer that he was now no longer eligible for screening given that he had exceeded the upper age limit. This caused him significant distress and he felt there was a real lack of aftercare support for bowel cancer survivors in Wales. Another participant expressed concerns that despite having participated in the bowel screening programme he still developed bowel cancer. He wanted to raise awareness that a negative bowel cancer screening result can lead people into a false sense of security and that more needs to be done to highlight the fact that the test is not 100% accurate.

In March 2020, the decision was taken to pause the National Bowel Screening Programme in Wales as a response to the COVID-19 pandemic. Invitations ceased on March 20th and but this only affected a very small proportion of invites for the financial year 2019-20. However, any screening kits received in the laboratory after Friday 3rd April were not tested as they had stopped performing colonoscopy procedures across Wales (National Bowel Cancer Audit, 2020). Many participants 15/27 (56%) felt that the impact of the pandemic on healthcare delivery in Wales had compromised their continuity of care as a large proportion were diagnosed or treated during the pandemic. They reported a lack of coordinated care



and having to constantly chase up appointments and test results. Over half (60%) of these participants diagnosed during the COVID-19 pandemic had progressed to either Stage 3 or Stage 4 advanced bowel cancer.

It is important to recognise that these observations must be interpreted in light of the limitations of the study. The majority of participants at the time of their engagement with the study were currently in remission and had completed their bowel cancer treatment. Therefore, gathering opinions on particular aspects such as lifestyle modification behaviours and the wider benefits of population screening, while acknowledging that the test is not 100% accurate, was somewhat biased by their individual experiences. However, despite these limitations there were consistent themes which kept emerging throughout all stages of this study. Participants expressed their dissatisfaction with the current eligibility for screening and lack of continuity within primary care and felt that these presented a strong case for change. There was strong support for the age for eligibility to be lowered significantly and also for those with bowel cancer symptoms to be eligible for further investigation at the point of suspicion regardless of age and gender. Further to this, a case made by several elderly participants was that, similar to England, they should be able to opt in to bowel cancer screening once they exceeded the age for screening eligibility. Participants felt that addressing these key priorities were instrumental in ensuring a prompt earlier diagnosis and imperative in preventing the progression of disease.

In light of recent events, Public Health Wales recently published online the following statement which corroborates the overarching views of our study participants (Public Health Wales, 2022):

‘Evidence supports population screening in the 50 - 74 age group. In Wales, there is an improvement plan to offer screening to that aged 50- 59 by 2024 and we have developed a plan to achieve this in stages.’

Participants also stated that they wanted to see increased awareness of symptoms and promotion of bowel cancer screening programme within primary care, and through advertisements, social media (e.g. the #NeverTooYoung campaign), and public figures that they could relate to in the media.



6.3 Genetic testing for bowel cancer

The 2017 NICE guidelines recommend that all patients diagnosed with bowel cancer should be tested for Lynch syndrome (NICE, 2017). This has since been extended to include all patients diagnosed with endometrial cancer (NICE, 2020). However, a national survey carried out by the National Bowel Cancer Audit in 2020, shown that only around half of bowel cancer care providers were able to offer the appropriate test for Lynch Syndrome to all patients (National Bowel Cancer Audit, 2020). This disparity in accessing genetic screening services for Lynch Syndrome was deemed by the cohort in this study as a 'postcode lottery' and highlighted further the health inequality across Wales.

Only 9/27 (33%) participants from the interviews and focus groups were referred for genetic testing, despite 12% having a strong family history of bowel cancer. The majority of participants expressed a desire to undergo genetic testing along with their blood relatives if genetic screening was readily available. However, participants spoke negatively of the miscommunication and disconnect between genetic services and other care teams. Many also experienced lengthy delays in processing genetic test results, often taking months. Furthermore, some were only given results when the tests were positive, and even then, felt they were given very little advice or guidance on the implications of testing positive for Lynch Syndrome.

6.4 The impact on quality of life

In England, the incidence rates for bowel cancer in patients aged 20 – 39 have tripled between 1990 and 2014 (National Bowel Cancer Audit, 2020). Possible explanations for this dramatic increase have been attributed to the rising levels of obesity within the younger generation, dietary factors, lack of exercise, tobacco smoking, and excess alcohol consumption. During both the interviews and focus groups we explored participants views on lifestyle modification factors, such as diet and exercise. We also discussed the perceived benefits of aspirin as a prophylactic preventative measure. The majority of participants believed that maintaining a healthy lifestyle most definitely contributes towards improving patient related outcome measures and a better quality of life but many felt that living a healthy lifestyle did not ultimately prevent them from developing bowel cancer. Most of the participants in this study felt that dietary advice for patients with bowel cancer was either



absent or inadequate and there was not enough specific advice for those patients with stoma bags. Some participants felt that engaging in exercise prior to surgery was beneficial in accelerating the rate of their recovery. However, others felt that there was a lack of specific exercise advice tailored to patients who have (or have had) bowel cancer, in particular those with post-operative stoma bags. Most were unaware of the benefits of taking prophylactic aspirin daily and were unsure about its mode of action. A large proportion of the total cohort in this study agreed that more research is required into the mechanisms which contribute towards bowel cancer and that its aetiology remains poorly understood within the medical community.

Another key theme that kept emerging was the psycho-social impact of bowel cancer on both the respective patients and their families. Many reporting the lack of aftercare support following treatment and having to create their own support community through social media networks, the charities, such as Maggie's, and family members. Other participants disclosed the ongoing fear of recurrence and the importance of surveillance monitoring once discharged. The term "scanxiety" was frequently used during both the interviews and focus groups to describe the trepidation involved in awaiting a scan and then having the additional wait for the scan results. The majority of participants felt consumed by the fear of recurrence and this had a devastating impact on their quality of life. All of the participants felt that signposting for counselling during treatment and afterwards was lacking within Wales and support in the form of aftercare was again deemed as a postcode lottery.

Postcode lottery was a prominent recurring theme throughout the study. The majority of participants, especially those living in more rural areas of Wales, felt that there was an overall lack of knowledge pertaining to their treatment options and this left them feeling overwhelmed. Many expressed interests in accessing novel therapies that they had researched online and would have been keen to participate in clinical trials. However, further stating that these opportunities were only offered to patients living in the big cities. Despite the demographic challenges of delivering bowel cancer care across Wales, the majority of patients in this study felt that it was important to have a choice in your treatment options, and that adopting this shared-care approach would help optimise the quality of life for themselves and their respective families.



9 Conclusion

The aim of this qualitative study commissioned by Moondance Cancer Initiative was to assess the current status of bowel cancer care in Wales from the perspective of patients and caregivers, and to recognise potential opportunities for future change.

Through the use of surveys, interviews and focus groups, participants' first-hand experience of living with bowel cancer was explored, which provided useful insight into factors that are most important in the patient experience and how changes may improve the quality of health care.

Through thematic analysis, eight key themes were identified related to bowel cancer care from diagnosis through to aftercare; Suspicion to diagnosis; Awareness; Bowel Cancer Screening; Communication; Genetic testing, My cancer, my choice; Diet and lifestyle; and support. The theme of communication was ubiquitous across all stages of the cancer (and treatment) trajectory and had implications for the way healthcare professionals respond to both patients and caregivers in the care setting. This included ensuring continuity with a compassionate and supportive healthcare professional throughout, improving the way treatment options are offered, effectively communicating scan and genetic test results, and personalising dietary advice. Patients and their families also highlighted the need for better support from healthcare professionals, specifically in relation to aftercare such as mental health and counselling.

From a patient and caregivers' perspective, Moondance's aim to move towards zero deaths from bowel cancer would require improved GP recognition of bowel cancer in the young; a standardised and rapid approach to colonoscopy referrals; increased eligibility to bowel cancer screening; longer-term monitoring post-treatment; and equal access to treatment and clinical trials, making bowel cancer care in Wales less of a 'postcode lottery'.



10 Acknowledgements

The study and report would not have been possible without the cooperation of all participants and their willingness to take part. The authors would like to thank all those who took the time to complete the survey, participate in interviews and/or focus groups.

We would also like to thank Dr Susan O'Connell at Cedar for her advice and support throughout and for quality checking the report. Thanks also goes to other staff at Cedar; Ruth Poole and Ayesha Rahim for help in taking notes, and finally Ann James for her help with transcribing interviews.

Finally we would like to thank Bowel Cancer UK for sharing the survey on their website and social media, and also the team at Moondance Cancer Initiative for their continued support with the project throughout.



11 References

- Age UK. (2021, March). *Digital inclusion and older people - how have things changed in a Covid-19 world?* Retrieved from Age UK: <https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/active-communities/digital-inclusion-in-the-pandemic-final-march-2021.pdf>
- Ashktorab, H., Vilmenay, K., Brim, H., Laiyemo, O. A., Kibreab, A., & Nouraie, M. (2016). Colorectal Cancer in Young African Americans: Is It Time to Revisit Guidelines and Prevention? *Digestive diseases and sciences*, 61(10), 3026-3030. Retrieved from <https://doi.org/10.1007/s10620-016-4207-1>
- Askari, A., Nachiappan, S., Currie, A., Latchford, A., Stebbing, J., Bottle, A., . . . Faiz, O. (2017). The relationship between ethnicity, social deprivation and late presentation of colorectal cancer. *Cancer epidemiology*, 47, 88-93. Retrieved from <https://doi.org/10.1016/j.canep.2017.01.007>
- Bowel Cancer UK. (2020). *Never Too Young*. Retrieved from Bowel Cancer UK: https://bowelcancerorguk.s3.amazonaws.com/N2Y%202020/NeverTooYoung2020_BowelCancerUK.pdf
- Bowel Cancer UK. (2022). *#GetOnARoll*. Retrieved from Bowel Cancer UK: <https://www.bowelcanceruk.org.uk/campaigning/getonaroll/>
- Braun, V., & Clarke, V. (2013). *Successful Qualitative Research - A practical guide for beginners*. Sage Publications Ltd.
- Bridgend Association of Voluntary Organisations. (2022). *Bowel Cancer Improvement Project*. Retrieved from Bridgend Association of Voluntary Organisations: <https://www.bavo.org.uk/bowel-cancer-improvement-project/>
- Cancer Research UK. (2022). *Bowel cancer incidence statistics*. Retrieved from Cancer Research UK: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer/incidence#heading-One>
- Carmarthenshire Association of Voluntary Services. (2022, February). *How can we improve bowel cancer survival in Wales*. Retrieved from <https://cavs.org.uk/2022/02/how-can-we-improve-bowel-cancer-survival-in-wales/>
- Flick, U. (2018). *An Introduction to Qualitative Research* (6th ed.). Sage Publications Ltd.
- Maggies. (2022). *Find a Centre*. Retrieved from Maggies: <https://www.maggies.org/our-centres/search-results/?location=uk>
- National Bowel Cancer Audit. (2020). *National Bowel Cancer Audit Annual Report 2020*. Retrieved from National Bowel Cancer Audit: <https://www.nboca.org.uk/content/uploads/2020/12/NBOCA-2020-Annual-Report.pdf>



- National Library of Medicine. (2021, February). *Add-Aspirin: A Trial Assessing the Effects of Aspirin on Disease Recurrence and Survival After Primary Therapy in Common Non Metastatic Solid Tumours*. Retrieved from ClinicalTrials.Gov: <https://clinicaltrials.gov/ct2/show/NCT02804815>
- NHS. (2021). *Bowel Cancer Symptoms*. Retrieved from NHS: <https://www.nhs.uk/conditions/bowel-cancer/symptoms/#:~:text=Bowel%20obstruction&text=intermittent%2C%20and%20occasionally%20severe%2C%20abdominal,sick%20%E2%80%93%20with%20constant%20abdominal%20swelling>
- NICE. (2017, February). *Molecular testing strategies for Lynch syndrome in people with colorectal cancer*. Retrieved from National Institute for Health and Care Excellence: <https://www.nice.org.uk/guidance/dg27>
- NICE. (2020, October). *Testing strategies for Lynch syndrome in people with endometrial cancer*. Retrieved from National Institute for Health and Care Excellence: <https://www.nice.org.uk/guidance/dg42/resources>
- Public Health Wales. (2022). *About Bowel Screening*. Retrieved from Public Health Wales: <https://phw.nhs.wales/services-and-teams/screening/bowel-screening/about-bowel-screening/>
- Public Health Wales. (2022). *Bowel Screening Wales*. Retrieved from Public Health Wales: <https://phw.nhs.wales/services-and-teams/screening/bowel-screening/>
- Tenovus Cancer Care. (2022). *How can we improve bowel cancer survival in Wales? Share your views*. Retrieved from Tenovus Cancer Care: <https://www.tenovuscancercare.org.uk/research-listings/research-opportunities/how-can-we-improve-bowel-cancer-survival-in-wales/share-your-views>
- Welsh Government. (2020). *Summary statistics for Wales, by region: 2020*. Retrieved from Statistics for Wales: <https://gov.wales/sites/default/files/statistics-and-research/2020-05/summary-statistics-regions-wales-2020-629.pdf>
- Welsh Government. (2021). *Wellbeing of Wales: 2021*. Retrieved from Gov.Wales: <https://gov.wales/sites/default/files/pdf-versions/2022/8/1/1661170070/wellbeing-wales-2021.pdf>



12 Appendices

12.1 Appendix A - Bowel Cancer Survey

You are being invited to provide feedback on work that is taking place across Wales to understand how bowel cancer services can be improved and how acceptable new approaches to care might be to those patients with bowel cancer.

About us

This project is led by Professor Jared Torkington, a clinician based in Cardiff who wants to learn how we can improve bowel cancer care in Wales. The work will be carried out by Cedar, an NHS Research Group, and is funded by [Moondance Cancer Initiative](#) which is a Welsh non-profit organisation. They fund projects which aim to make Wales a world-leader in cancer survival. Bowel Cancer UK are the UK's leading bowel cancer charity and they are supporting the project by sharing the survey on their website.

What is the purpose of this?

Speaking to people who have experience of bowel cancer care in Wales can help us understand what works well and what we can do to make it better.

Why have I been asked?

We want to talk a range of patients and families of patients who have received care from bowel cancer treatment teams across Wales. By talking to you we can try to understand how bowel cancer services can be improved from your point of view. It is important that we talk to a range of different people, and we would like to know about your experience and whether it was good or bad.

What will I have to do?

We are asking you to complete this survey about the care you have received and how we can improve the services we provide. We would also like some people to take part in interviews or focus groups so we can learn more about your thoughts on bowel cancer care. The survey and interviews are available in English and in Welsh. The focus groups may be run in English or Welsh depending on participation. If you are interested in taking part in these interviews or focus groups, when you fill in the survey you can leave your name and



contact details for us to get in touch, this means that we will know what your answers to the questions have been. Your survey response will be anonymous unless you provide your name and contact details in the survey itself.

What will happen to the information I give?

The information from your survey will be used with the feedback from others to help us understand more about peoples experience of bowel cancer care in Wales. This will help us to improve future services.

Can I access support without taking part?

If you would like some support at any point in your bowel cancer journey, you can access this from Bowel Cancer UK by visiting their website at www.bowelcanceruk.org.uk/how-we-can-help/support-for-you/. If you decide to complete the survey, you can also choose to have your contact details passed on to Bowel Cancer UK and they will contact you to offer support and advice.

Will my taking part be confidential and will my personal details be secure?

All information which you provide will be confidential. The handling and storage of personal information will be covered by strict NHS data protection standards. We will aim to use the information we get from the surveys to write a report which will be publicly available for anyone can read. Because the surveys are anonymous, no one reading the report will be able to identify you.

What will happen if I change my mind?

We would like to emphasise that it is completely voluntary to take part. If you provide your contact details and agree to take part in an interview or focus group, but later change your mind, you are able to withdraw at any time. If you do not wish to participate, it will not affect the standard of care you receive or your legal rights as a patient.

If you wish to contact us to ask any question, please contact:

Kathleen Withers at Cedar on 02920 744771 or via Kathleen.withers@wales.nhs.uk

Your help would be greatly appreciated by us, but it is not compulsory.



Thank you for taking the time to read this information

Thank you for your interest in this survey. The responses that you provide will be anonymous unless you would like to provide more detailed feedback on your experience and opinions at a later date and choose to tell us your name at the end of the survey.

The feedback we gather will tell us more about people's experience of bowel cancer care and will help us understand how we could improve the services provided in Wales. Results from this project will be made publicly available on Moondance Cancer Initiative website throughout 2022, however all responses will be reported anonymously even if you choose to tell us your name, and no-one will be able to identify you in the report.

Please tell us about the experience you, your friend, or loved one has had.

About you

Please answer the following questions so we know a little bit more about you. This will help us make sure we have had feedback from a range of different people and will help us understand more about the information that we get.

1. What area of Wales do you live in?

<input type="checkbox"/> Blaenau Gwent	<input type="checkbox"/> Monmouthshire
<input type="checkbox"/> Bridgend	<input type="checkbox"/> Neath Port Talbot
<input type="checkbox"/> Caerphilly	<input type="checkbox"/> Newport
<input type="checkbox"/> Cardiff	<input type="checkbox"/> Pembrokeshire
<input type="checkbox"/> Carmarthenshire	<input type="checkbox"/> Powys
<input type="checkbox"/> Ceredigion	<input type="checkbox"/> Rhondda Cynon Taf
<input type="checkbox"/> Conwy	<input type="checkbox"/> Swansea
<input type="checkbox"/> Denbighshire	<input type="checkbox"/> Torfaen
<input type="checkbox"/> Flintshire	<input type="checkbox"/> Vale of Glamorgan
<input type="checkbox"/> Gwynedd	<input type="checkbox"/> Wrexham
<input type="checkbox"/> Isle of Anglesey	<input type="checkbox"/> I live outside of Wales
<input type="checkbox"/> Merthyr Tydfil	



2. Please tell us your **gender**

☐ Male

☐ Female

☐ Non-Binary

☐ Prefer not to say

☐ Prefer to self-describe

If you prefer to self-describe, please tell us here _____

3. Please tell us your **age range**

☐ 17 and under

☐ 18 - 30

☐ 31 - 40

☐ 41 - 50

☐ 51 - 60

☐ 61 - 70

☐ 71 - 80

☐ 81 - 90

☐ 91 and over

☐ Prefer not to say

4. Please tell us your **ethnic group** (Please select one)

☐ Any White background including Welsh, English, Scottish, Northern Irish, British, Irish

☐ Gypsy or Irish Traveller

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other mixed background / multiple ethnic background



- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background
- ☐ Caribbean
- ☐ African
- ☐ Any other Black background
- ☐ Arab
- ☐ Any other ethnic group
- ☐ Prefer not to say

5. Which of these describe your **employment status** at time of your bowel cancer diagnosis? (Please select all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Full-time employed or self-employed | <input type="checkbox"/> Student |
| <input type="checkbox"/> Part-time employed or self-employed | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Unemployed / seeking work | <input type="checkbox"/> Long-term sick |
| <input type="checkbox"/> Looking after home or family | <input type="checkbox"/> Disabled |
| | <input type="checkbox"/> Other |

If other, please specify _____

6. Has your employment status changed as a result of your cancer journey?

- ☐ Yes
- ☐ I don't know / not sure
- ☐ No

If your employment status has changed as a result of your cancer journey, please tell us how: _____

Your bowel cancer history



7. Please tell us who has been diagnosed with bowel cancer? Please tick all that apply

- ☐ I have / had bowel cancer
- ☐ My partner, friend or family member has / had bowel cancer
- ☐ Other

If other, please specify _____

8. How have you, your friend, or family member been affected by bowel cancer? Please tick all that apply

- ☐ Previously been diagnosed with bowel cancer but no longer receiving treatment
- ☐ Diagnosed but not yet receiving treatment
- ☐ Currently receiving treatment for bowel cancer
- ☐ Finished treatment and having regular follow up scans / check ups
- ☐ Finished treatment and living with long term or late side effects
- ☐ Bowel cancer has been treated but has since come back (recurrence)
- ☐ Receiving end of life or palliative care
- ☐ Had recurrence of bowel cancer but have now finished treatment
- ☐ Other

If other, please specify _____

9. If you have been diagnosed with bowel cancer, what led to this diagnosis?

- ☐ I went to the GP because I had symptoms
- ☐ My bowel cancer was picked up following tests for other reasons
- ☐ I was admitted for testing / to hospital as an emergency
- ☐ I had a positive bowel screening test result
- ☐ Other
- ☐ Not applicable



If other, please specify _____

10. What stage were you when you were diagnosed?

- ☐ Stage 1
- ☐ Stage 2
- ☐ Stage 3
- ☐ Stage 4
- ☐ Not applicable / don't know

11. What stage are you in currently?

- ☐ Stage 1
- ☐ Stage 2
- ☐ Stage 3
- ☐ Stage 4
- ☐ I am in remission
- ☐ Not applicable / don't know

12. Do you have a family history of bowel cancer?

- ☐ Yes, two or more family members
- ☐ Yes, one family member
- ☐ No
- ☐ I don't know

12 a) If you answered yes to Q12, have your immediate family members been tested for genetic risk factors?

- ☐ Yes, all of them
- ☐ Yes, some of them
- ☐ No



☐ I don't know

Your experience of bowel cancer care

This section asks about your experience of bowel cancer care. If you have had bowel cancer please tell us about your own experience. If you have not had bowel cancer but have been affected by a friend or family member with bowel cancer, please feel free to tell us about their experience.

13. Please tell us what went well in relation to your bowel cancer diagnosis? _____

14. Please tell us what went well in relation to your bowel cancer care? _____

15. Please tell us what didn't go well in relation to your bowel cancer diagnosis?

16. At what point in your bowel cancer journey do you think the most improvement could have been made, and why? (e.g. during diagnosis, treatment, aftercare)

Bowel cancer prevention, awareness & diagnosis

17. The following table relates to options which could help prevent or detect bowel cancer. Please place these options in order of what is important to you, from 1 (most important), to 7 (least important). Please do not select more than one answer per row or column.

	1	2	3	4	5	6
Improve people's understanding of how diet, exercise and smoking can increase the risk of bowel cancer (e.g. by awareness campaigns)						



Provide more advice on the benefit and risk of taking aspirin to reduce your risk of bowel cancer						
Improved testing for people who are at risk of bowel cancer (e.g. genetic testing or colonoscopies for people with an increased genetic risk of bowel cancer)						
Encourage more people to take part in bowel cancer screening (e.g. by sending out reminder letters or texts)						
Increase the number of people eligible for screening (e.g. by reducing the screening age)						
Improve knowledge on what symptoms to look out for and when to visit the GP (e.g. by awareness campaigns)						
Provide better access to GP support and early detection centres						

17 a) Please tell us why you have chosen the one you think is the most important? _____

Improving bowel cancer care

18. The following table relates to options that might help improve bowel cancer care.

Please place these options in order of what is important to you, from 1 (most important), to 3 (least important). Please do not select more than one answer per row or column.

	1	2	3
Helping people improve their general health and wellbeing before and during bowel cancer treatment (e.g. by providing more advice on diet and exercise)			



Improving access to new treatments (e.g. by including people in trials)			
Improve post treatment monitoring (e.g. carrying out more regular colonoscopies and blood tests)			

18 a) Please tell us why you have chosen the one you think is the most important? _____

Further involvement and accessing support

Thank you for completing this survey, we appreciate your help and support.

So that we can get more detailed information, we would like to ask some people to take part in one-to-one interviews, or focus groups. These would all be done remotely (i.e. by telephone or video) and would allow us to learn more about the experiences of people like you.

We are also working with Bowel Cancer UK who can offer wrap around support and advice on bowel cancer. If you would like them to contact you and tell you what support is available please provide your details below. **None of your survey responses will be shared with Bowel Cancer UK. Your name and contact details will only be sent to them if you tick the box below.**

Please tick one or more box if you would like us to contact you about taking part in an interview or focus group:

- ☐ I am interested in taking part in an interview
- ☐ I am interested in taking part in a focus group
- ☐ I am interested in taking part in a focus group AND an interview

Please tick the box below if you would like us to pass your details on to Bowel Cancer UK for them to contact you with information on available support and advice:



☐ I would like to be contacted by Bowel Cancer UK to receive information about available support and advice. **(If you tick this box, you are agreeing to us sharing your name and contact details with Bowel Cancer UK)**

☐ I do not want to be contacted by Bowel Cancer UK

If you would like to learn more about taking part in an interview or focus group **OR** if you would like to be contacted by Bowel Cancer UK to receive information on available support, please provide your name and contact details below:

Name: _____

Email: _____

Mobile/Home Telephone Number: _____

Preferred method of contact: ☐ Email ☐ Telephone

Thank you again for your time.

12.2 Appendix B - Survey participant demographics

Table 6: Participant demographics of those who only participated in the survey

Participant number	Region	Gender	Age Range	Ethnicity	Employment Status	Stage at diagnosis	Family History	Offered Genetic Testing
28	Pembrokeshire	Female	51-60	White	Looking after home or family	Stage 3	Yes	No
29	Caerphilly	Female	31-40	White	Disabled	Stage 2	Yes	Yes, all of them
30	Gwynedd	Female	31-40	White	Part-time employed or self-employed	Stage 3	No	
31	Swansea	Female	31-40	White	Full-time employed or self-employed	Stage 2	No	
32	Neath Port Talbot	Female	41-50	White	Full-time employed or self-employed	Stage 2	No	
33	Rhondda Cynon Taf	Female	51-60	White	Retired	N/A	Yes	No
34	Swansea	Male	41-50	White	Full-time employed or self-employed	Stage 2	No	
35	Carmarthenshire	Female	41-50	White	Full-time employed or self-employed	Stage 4	No	No
36	Caerphilly	Female	71-80	White	Retired	Stage 4	Yes	No
37	Conwy	Female	Prefer not to say	White	Full-time employed or self-employed	N/A	Yes	Yes, some of them
38	Pembrokeshire	Female	61-70	White	Part-time employed or self-employed	N/A	No	No
39	Carmarthenshire	Female	71-80	White	Retired	Stage 3	No	
40	Vale of Glamorgan	Female	41-50	White	Looking after home or family	N/A	Yes	No
41	Carmarthenshire	Female	41-50	White	Full-time employed or self-employed	N/A	No	
42	Blaenau Gwent	Female	51-60	White	Retired	Stage 1	No	
43	Vale of Glamorgan	Female	51-60	White	Full-time employed or self-employed	Stage 1	No	
44	Rhondda Cynon Taf	Female	71-80	White	Retired	Stage 2	No	No
45	Newport	Female	31-40	White	Full-time employed or self-employed	N/A	No	
46	Newport	Female	71-80	White	Retired	N/A	No	



47	Caerphilly	Male	51-60	White	Full-time employed or self-employed	Stage 4	No	No
48	Blaenau Gwent	Female	61-70	White	Part-time employed or self-employed	Stage 3	No	
49	Vale of Glamorgan	Male	71-80	White	Retired	Stage 2	No	
50	Monmouthshire	Female	31-40	White	Full-time employed or self-employed	N/A	Yes	I don't know
51	Carmarthenshire	Male	61-70	White	Full-time employed or self-employed	Stage 2	No	
52	Caerphilly	Male	71-80	White	Retired	Stage 2	Yes	No
53	Flintshire	Male	71-80	White	Full-time employed or self-employed	Stage 1	No	
54	Pembrokeshire	Female	61-70	White	Retired	Stage 2	No	
55	Bridgend	Female	31-40	White	Full-time employed or self-employed	Stage 3	Yes	No
56	Carmarthenshire	Male	51-60	White	Looking after home or family	Stage 2	No	
57	Flintshire	Male	51-60	White	Part-time employed or self-employed	Stage 4	No	
58	Rhondda Cynon Taf	Female	41-50	White	Full-time employed or self-employed	Stage 3	No	
59	Wrexham	Female	41-50	White	Part-time employed or self-employed	Stage 2	Yes	No
60	Torfaen	Male	18-30	White	Full-time employed or self-employed	Stage 3	I don't know	No
61	Swansea	Female	31-40	White	Full-time employed or self-employed	Stage 4	No	No
62	Rhondda Cynon Taf	Female	71-80	White	Retired	Stage 4	Yes	No
63	Neath Port Talbot	Male	61-70	White	Retired	Stage 1	Yes	I don't know
64	Rhondda Cynon Taf	Female	41-50	White	Full-time employed or self-employed	Stage 3	No	
65	Cardiff	Female	41-50	White	Part-time employed or self-employed	Stage 4	Yes	No
66	Vale of Glamorgan	Female	51-60	White	Part-time employed or self-employed	N/A	Yes	No
67	Swansea	Female	61-70	White	Looking after home or family	Stage 3	Yes	Yes, all of them
68	Neath Port Talbot	Female	41-50	White	Full-time employed or self-employed	Stage 3	No	No
69	Blaenau Gwent	Female	31-40	White	Full-time employed or self-employed	Stage 4	No	

N/A: Not Applicable/Don't know

12.3 Appendix C - Interview Topic Guide

1. First of all, please tell me a little bit about yourself? (Date of diagnosis)
2. Can you tell me about the impact bowel cancer has had on your life?
3. Before the diagnosis, what did you know about the symptoms of bowel cancer?
4. Was there anything in particular that encouraged you to seek help?
5. Did you feel that there was something holding you back from seeing a doctor earlier?
6. Was the GP appointment carried out in person or was it over the phone/video call?
(Virtual appointments with GP/consultant etc)
7. If eligible, have you ever participated in the bowel screening programme?

YES: what was your experience of the service?

NO: was there anything in particular that prevented you from accessing this service?

a. If you were eligible, would you have been interested in taking part?

8. Do you mind telling me how the bowel cancer was first recognised? (suspicion by a healthcare professional – e.g. screening, GP, emergency appointment, incidental findings etc)
9. Can you think of anything that would have improved the journey from your cancer being recognized to starting treatment? (From suspicion to diagnosis, for example waiting for a colonoscopy)
10. Have you or your family ever been offered any genetic testing to detect bowel cancer risk?
 - a) YES: what was your experience of genetic testing?



- b) NO: do you think it would have been helpful to have had genetic testing offered to you and your family at that early stage in the treatment journey?
11. After the diagnosis, were you or your family offered any diet or lifestyle advice to help improve your treatment and recovery?
12. How important was it for you to have a choice about the treatment? (Participation in clinical trials)
13. After finishing treatment, can you think of any monitoring or support that would have benefited you in an ideal world?
14. What do you think is the one important change that we could make to improve bowel cancer services in Wales?
15. Do you have any further comments on how bowel cancer care could be improved in Wales?

12.4 Appendix D - Interview participant demographics

Table 7: Demographics of Interview participants

Participant number	Region	Gender	Age Range	Ethnicity	Employment Status	Year of Diagnosis	Age at diagnosis	Stage at diagnosis	Family History	Offered Genetic Testing
1	Powys	Female	41-50	White	Unemployed / seeking work, Other	2013		N/A	No	No
2	Newport	Female	31-40	White	Full-time employed or self-employed	2021		Stage 3	No	
3	Monmouthshire	Male	61-70	White	Part-time employed or self-employed	2021		Stage 2	No	
4	Powys	Female	51-60	†	Unemployed / seeking work			Stage 3	No	No
5	Vale of Glamorgan	Female	71-80	White	Retired	2021		N/A	No	
6	Flintshire	Female	31-40	White	Long-term sick	2021		Stage 4	Yes	No
7	Monmouthshire	Female	61-70	White	Retired	2009		Stage 3	No	No
8	Gwynedd	Male	71-80	White	Retired			Stage 1	I don't know	No
9	Vale of Glamorgan	Male	61-70	White	Retired	2020		Stage 2	No	
10	Rhondda Cynon Taf	Female	41-50	White	Part-time employed or self-employed			Stage 4	Yes	No
11	Wrexham	Female	51-60	Indian	Part-time employed or self-employed	2018		Stage 2	No	
12	Vale of Glamorgan	Female	61-70	White	Retired			Stage 3	Yes	No
13	Newport	Female	61-70	White	Retired			Stage 3	I don't know	No
14	Cardiff	Female	41-50	White	Full-time employed or self-employed	2021		Stage 3	Yes	No
15	Swansea	Female	51-60	White	Full-time employed or self-employed			Stage 3	I don't know	
16	Torfaen	Female	31-40	White	Full-time employed or self-employed			Stage 4	Yes	No



17*	Carmarthenshire	Female	71-80	White	Retired	2021		Stage 4	No	Yes
18	Gwynedd	Female	51-60	White	Full-time employed or self-employed	2021		N/A	Yes	Yes
19	Monmouthshire	Female	51-60	White	Part-time employed or self-employed			N/A	Yes	Yes
20	Isle of Anglesey	Female	41-50	White	Was self-employed	2020		Stage 4	No	
21	Flintshire	Male	71-80	White	Retired	2003		Stage 2	Yes	I don't know
22	Pembrokeshire	Female	71-80	White	Retired			Stage 3	No	Yes
23	Cardiff	Female	61-70	White	Full-time employed or self-employed			Stage 3	Yes	No

N/A: Not Applicable/Don't know;

*Survey not completed and demographics completed from interview data

† Any other mixed background / multiple ethnic background

12.5 Appendix E - Focus group topic guide 1

1. Speaking with many of you about bowel cancer symptoms and how you first recognised something was wrong, many of you weren't aware of the less obvious symptoms to look out for. How could awareness of bowel cancer symptoms be improved? (PROMPT: TV ad, radio, newspaper, leaflet in GP, social media, community champions).

2. How could your experience of gaining access to a doctor, and having your symptoms recognised, have been improved?

3. Evidence shows that there are a few things people can do which might reduce their risk of bowel cancer, including changes in diet, lifestyle, exercise and taking simple medications such as aspirin. How important are these to you in reducing your future risk?

Follow up - How do you think we can better support future generations in trying to prevent bowel cancer?

4. Before and during your treatment, were you willing to receive advice/help on diet, exercise, and psychological support if it helped you recover both physically and mentally faster from your treatment?

If yes – how would you like it to be delivered?

If no – what support would you prefer?

5. Once someone is diagnosed with bowel cancer, genetic testing can be offered to test if your bowel cancer could be genetic, and if so, it can be offered to your family, to see if they are also at risk. How would you feel about your family being tested, and monitored if they are at risk?

6. The current eligibility for the bowel cancer screening programme in Wales is for people aged 58-74 and at this age you should receive a test automatically every 2 years. For most other European nations the screening starts at 50+.

Many of you in the surveys and interviews had some experience of the bowel cancer screening programme, but is there anything you would change about any the programme i.e. age, frequency? (PROMPT: The option to opt in for screening after 74 in England & Scotland)



7. If any of you were eligible for screening but have not participated, what might have encouraged you to take part? (PROMPT: telephone reminders from nurse, advance notification of receipt of test (letter), different test methods – e.g. blood tests, reassurance about colonoscopy).

8. During the interviews, many of you felt that being well informed about any potential treatment or surgery options was important to you, including clinical trials. What do you think would be the best way to explain the different treatments and innovations available? (PROMPT: Consultant discussion, video to watch at home, leaflets).

9. During treatment what kind of support did you find the most helpful? (PROMPT: Social media, forums, group discussions, mental health support).

Follow up – What type of support did you feel was missing and would like to have had? (PROMPT: Support for family members, counselling, dietary/exercise).

10. For those of you that have finished treatment, what type of monitoring have you received and would you change anything about the monitoring? (PROMPT: Frequency, type of monitoring such as colonoscopies, blood tests etc)

11. Do you have any further comments on how bowel cancer care could be improved in Wales?



12.6 Appendix F - Focus group topic guide 2

1. Speaking with many of you about bowel cancer symptoms and how you first recognised something was wrong, many of you weren't aware of the less obvious symptoms to look out for. How could awareness of bowel cancer symptoms be improved? (PROMPT: TV ad, radio, newspaper, leaflet in GP, social media, community champions).

2. Evidence shows that there are a few things people can do which might reduce their risk of bowel cancer, including changes in diet, lifestyle, exercise and taking simple medications such as aspirin. How important are these to you in reducing your future risk?

Follow up - How do you think we can better support future generations in trying to prevent bowel cancer?

3. Once someone is diagnosed with bowel cancer, genetic testing can be offered to test if your bowel cancer could be genetic, and if so, it can be offered to your family, to see if they are also at risk. How would you feel about your family being tested, and monitored if they are at risk?

If there is anyone who has had genetic testing, how was it communicated (direct to patient or through GP). Also was there any information on what results meant.

4. If any of you were eligible for the bowel cancer screening programme but have not participated, what might have encouraged you to take part? (PROMPT: telephone reminders from nurse, advance notification of receipt of test (letter), different test methods – e.g. blood tests, reassurance about colonoscopy).

5. During the interviews, many of you felt that being well informed about any potential treatment or surgery options was important to you, including clinical trials. What do you think would be the best way to explain the different treatments and innovations available? (PROMPT: Consultant discussion, video to watch at home, leaflets).

6. Support can come from healthcare professionals, social media, group discussions such as Maggie's etc, but where in the journey did you find support most helpful?

Follow up – What type of support did you feel was missing and would like to have had? (PROMPT: Support for family members, counselling, dietary/exercise).



7. For those of you that have finished treatment, what type of monitoring have you received and would you change anything about the monitoring? (PROMPT: Frequency, type of monitoring such as colonoscopies, blood tests etc)
8. Do you have any further comments on how bowel cancer care could be improved in Wales?

12.7 Appendix G - Focus group participant demographics

Table 8: Demographics of focus group participants

Participant number	Region of Wales	Gender	Age Range	Ethnicity	Employment Status	Year of Diagnosis	Age at diagnosis	Stage at diagnosis	Family History	Offered Genetic Testing	Focus group attended
2	Newport	Female	31-40	White	Full-time employed or self-employed	2021		Stage 3	No		1
3	Monmouthshire	Male	61-70	White	Part-time employed or self-employed	2021		Stage 2	No		1
5	Vale of Glamorgan	Female	71-80	White	Retired	2021		N/A	No		3
6	Flintshire	Female	31-40	White	Long-term sick	2021		Stage 4	Yes	No	3
7	Monmouthshire	Female	61-70	White	Retired	2009		Stage 3	No	No	2
8	Gwynedd	Male	71-80	White	Retired			Stage 1	I don't know	No	1
9	Vale of Glamorgan	Male	61-70	White	Retired	2020		Stage 2	No		2
11	Wrexham	Female	51-60	Indian	Part-time employed or self-employed	2018		Stage 2	No		2
12	Vale of Glamorgan	Female	61-70	White	Retired			Stage 3	Yes	No	2
14	Cardiff	Female	41-50	White	Full-time employed or self-employed	2021		Stage 3	Yes	No	3
18	Gwynedd	Female	51-60	White	Full-time employed or self-employed	2021		N/A	Yes	Yes	3
20	Isle of Anglesey	Female	41-50	White	Was self-employed	2020		Stage 4	No		2
21	Flintshire	Male	71-80	White	Retired	2003		Stage 2	Yes	I don't know	1
23	Cardiff	Female	61-70	White	Full-time employed or self-employed			Stage 3	Yes	No	2
24	Pembrokeshire	Male	61-70	White	Full-time employed or self-employed	2021		Stage 1	No	No	1
25	Wrexham	Female	51-60	White	Full-time employed or self-employed	2018		Stage 2	No	No	2
26	Rhondda Cynon Taf	Female	31-40	White	Full-time employed or self-employed	2018		Stage 4	No	No	2
27	Carmarthenshire	Female	41-50	White	Part-time employed or self-employed	2019		Stage 4	I don't know	No	3