

## Study Executive Summary

### 'Towards zero deaths from bowel cancer in Wales'

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**Mission:** Towards zero deaths from bowel cancer in Wales

**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. In this programme, their aim is to produce a shared vision for how Wales could begin moving ['towards zero deaths from bowel cancer'](#).

**Background:** Bowel, or colorectal cancer (CRC) is among the most commonly diagnosed cancers in Wales, and the second biggest cancer killer in the UK. However bowel cancer is unique among cancers in the number of opportunities there are to prevent people dying from the disease. Moondance Cancer Initiative have published an evidence review analysing key opportunities to reduce bowel cancer deaths.

**Aims and Objectives:** The aim of this project was to assess the current status of bowel cancer care in Wales from the viewpoint of people who have (or have had) bowel cancer, and their caregivers. MCI commissioned [Cedar](#) to conduct qualitative research to gather patient and caregiver feedback on bowel cancer care in Wales, and gain insight into the feasibility of the key opportunities identified in their evidence review. Cedar did this through a series of objectives:

- Design a survey to explore patient and caregiver experiences of bowel cancer care in Wales, and their priorities for change.
- Use survey responses to identify participants for interviews and focus groups.
- Design a semi-structured interview topic guide using survey responses.
- Use emerging and important themes identified in the interviews to design and conduct small focus groups with patients and families to further explore opinions on the acceptability of potential changes to drive bowel cancer care forward in Wales.
- Qualitatively analyse and report the findings.

**Methods:** Several qualitative research methods were used to give depth and breadth of feedback; including an online survey (available in English and Welsh), and online semi-

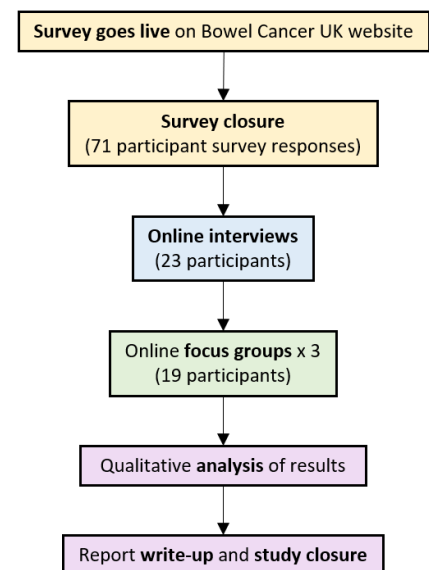


Figure 2: Simplified study flowchart

structured interviews and focus groups following a grounded theory approach. Descriptive statistics were used for survey data, and interview/focus group transcripts were thematically analysed.

**Survey Results:** There were 71 total responses to the survey. The majority of participants were female aged 41-60, of white ethnicity and lived in the south of Wales. Half of the survey participants were diagnosed at stage 3 or 4, but a large proportion were in remission at the time of survey completion. More than half of the participants did not have a known family history of bowel cancer, and a very small proportion had been genetically screened for bowel cancer.

There were mixed positive and negative free-text responses in the survey. Some commented that everything went well throughout their care, but many individuals, particularly younger participants, reported problems in getting a diagnosis from their GP. These participants spoke of problems being misdiagnosed or feeling as though they were not listened to, often for several years. There was also strong commentary on the inaccuracy of the bowel cancer screening programme and the increased need for early detection through changes in the screening eligibility. However with respect to treatment and survey, most responses were positive, with many noting that once diagnosed, treatment happened quickly.

Once treatment had finished, survey participants reported feeling unsupported by healthcare professionals, and improved monitoring post-treatment was identified as a priority. These survey responses were then used to inform the interview topic guide design to explore each in more depth.

**Interviews:** A total of 23 interviews were scheduled between 1<sup>st</sup> June – 17<sup>th</sup> June 2022. All were invited to participate by video call, with the option of a telephone interview if requested. Interviews were conducted by two researchers, lasting an average duration of 69 minutes (range 45-124). Each were recorded with a live transcript, and yielded rich data on experiences that mattered most to each participant and what they felt needed to change about bowel cancer care in Wales. At the end of each interview participants were invited to take part in a small focus group. Interview themes were then used to inform the topic guide for a series of focus groups.

**Focus Groups:** Three focus groups with a total of 19 participants were scheduled between 28<sup>th</sup> June – 19<sup>th</sup> July 2022. Data saturation was met after two focus groups with respect to several responses and so the topic guide was amended for the final group. The average duration was 122 minutes (range 118-130).



## Themes

After thematic analysis of the interview and focus group transcripts, eight overarching themes related to bowel cancer care from diagnosis through to aftercare were identified, with additional 'subthemes' within each of them. Each theme and subtheme can be found in the theme map in figure 2 below. For a detailed discussion on each theme, click [here](#) for the full report.

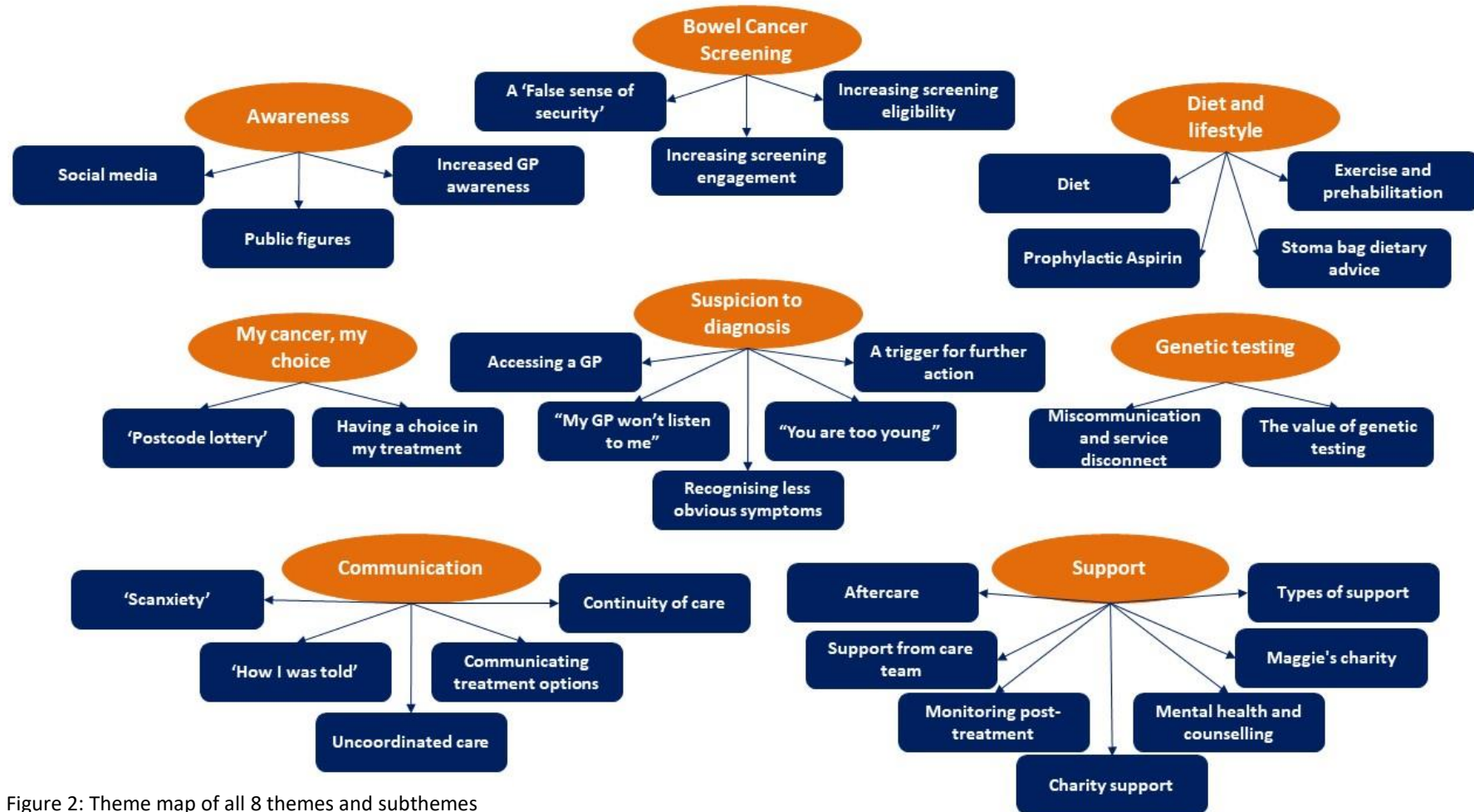


Figure 2: Theme map of all 8 themes and subthemes



Throughout the final report, quotes are used from interviews and focus groups to support each theme and highlight the key messages. Although all stories were powerful, some were particularly impactful in demonstrating the urgent need for improvement in specific areas of bowel cancer care in Wales. These are summarised in four detailed personal accounts of a participant's experience called 'stories for change' in the full report. An example quote from two of them is given below:

**'It gave me false hope'** – A 66 year old male

*"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"*

**'It's a postcode lottery'** – A 43 year old female

*"The first thing I asked was regarding clinical trials and 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.... It shouldn't matter where you live. I should have the same options as everybody else in this group, regardless of where we live"*

## Discussion:

Throughout the study we identified several areas for improvement across the bowel cancer care pathway in Wales. A detailed discussion of each theme is provided in the full report, but key improvements identified were; increased GP and public recognition of bowel cancer in the young; a standardised and rapid approach to referral for diagnosis; making more people eligible for bowel cancer screening; giving patients a choice in their treatment; improved aftercare support and longer-term monitoring post-treatment; and making treatments and clinical trials accessible to everyone, reducing the bowel cancer care 'postcode lottery' in Wales.

*"It's been really hard for me to get a diagnosed, it took me over two years to get a diagnosis and get referred for a colonoscopy, which found my cancer through a dermatology referral."*

*"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"*

The theme of communication was relevant to all aspects of care from suspicion of symptoms, through to aftercare. This included ensuring continuity with a compassionate and supportive healthcare professional throughout; improving the way treatment options are offered; ensuring care was coordinated across departments; effectively communicating scan and genetic test results; and personalising dietary advice.



*“The 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.”*

It is important to acknowledge that the study participants were a self-selecting, younger, female dominant group with a lack of representation from most ethnic groups. The study participants were therefore not fully representative of people with bowel cancer in Wales. However, this unique cohort with a wide range of participant ages enabled the study to highlight the stark contrast in the experiences of different age groups. In particular, participants below the age of 40 spoke of struggling to be taken seriously; being too young for screening; unsuitable or non-existent support, and having to navigate their way through a system which is catered towards the older patient.

**Conclusion:** Many participants who have undergone bowel cancer care in Wales feel failed by the system. These failings span the entire care pathway but are particularly evident in the younger bowel cancer population. This study highlighted that change is desperately needed in Wales in order to help Wales move *‘towards zero deaths from bowel cancer’*.

**Acknowledgements:** We would like to thank Bowel Cancer UK for sharing the survey on their website and social media. Thank you also to colleagues at Moondance Cancer Initiative for their continued support. Finally, this project would not have been possible without the cooperation and kindness of all the participants, and their willingness to share their experiences.