



# Cancer awareness and early presentation to healthcare: what works?

Executive Summary

## About Moondance Cancer Initiative

Moondance Cancer Initiative is a not-for-profit company established to find solutions so that more people in Wales survive cancer. We want to help achieve significant and sustained improvements in cancer survival outcomes over the next ten years:

- We identify and trial new pathways, practices, and technologies, so that more people in Wales survive cancer
- We work in partnership with the Welsh health community and beyond - connecting great people across different disciplines, sectors, and regions
- Our work is evidence-informed, rigorous, and adventurous: we see value in moving quickly, trying and learning
- We bring funding, research intelligence, and an ethos of collaboration to the table

We're a not-for-profit company (company number 12305964), privileged to be funded by the Moondance Foundation.

## About this paper

A key contributory factor to better survival outcomes is for people to present to healthcare as early as possible if they have potential cancer symptoms. In Wales, we are currently underperforming compared to similar countries in terms of diagnosing cancers early, with late presentation to healthcare widely considered a major issue (even prior to the Covid-19 pandemic).

In Summer 2021, Moondance Cancer Initiative commissioned [Mair Bell](#) to undertake a review of the available evidence on barriers to cancer help-seeking, and on 'what works' to encourage early presentation. We will use this evidence internally, to inform our projects and funding; and we're publishing it in this summary format and full length as part of our commitment to 'learning in the open'.

# Barriers to early presentation

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The most important barriers to early presentation include:

- **Symptom awareness.** People tend to recognise and refer early with cancer-specific symptoms (lumps, rectal bleeding), so long as the symptoms match their expectation of cancer. Nonspecific symptoms (back pain, chest pain), and symptoms normalised outside of cancer (e.g. respiratory problems in smokers) are less well recognized.
- **Emotional and attitudinal barriers relating to cancer.** People often hold fearful or fatalistic views about cancer (such as associating cancer with death), which prevent early presentation, and these fears tend to be especially held by more deprived and ethnic minority groups. Stoic attitudes (“not wanting to make a fuss”) are another consistent attitudinal barrier to presentation.
- **Practical issues.** Demands on time, social and financial constraints, and other external stressors, which are particularly felt by people with more deprived backgrounds, are all significant barriers to help-seeking behaviour. People from deprived backgrounds can also find it difficult to get a convenient GP appointment due to these constraints, further inhibiting early referral.
- **Emotional barriers relating to GPs and the NHS.** Worrying about wasting a doctor’s time is a common barrier to help-seeking, and prevalent in the UK. People can also be concerned that GPs will not take symptoms seriously, or judge them as responsible for their own health problems. Evidence suggests that both of these barriers – whether perceived or actual - are alleviated by continuity of care, and a perception of friendly GPs with good listening skills.
- The **COVID pandemic** has increased these barriers, with alarming drop-offs in the number of GP-referrals to cancer services, and patients reporting they are more likely to ignore severe ‘red-flag’ symptoms seen in the wake of public messaging about protecting the NHS. Delays in diagnosis caused by the COVID backlog are also likely to further entrench attitudes which delay referral, such as concerns over lack of access, and not wanting to stretch healthcare resources.
- **GP interpretation.** ‘Gut feeling’ is a generally effective tool for GPs to decide on cancer referrals, but can present barriers for patients who: frequently attend their GPs, do not fit the mould of a typical cancer patient (e.g. young patients), have a more difficult encounter, or exhibit more rare/vague cancer symptoms.
- **Comorbidities and suspecting cancer.** Comorbidities are very common in cancer patients, and can blur perception of disease in both patients and GPs, thwarting early recognition of cancer. This is a complex picture: certain comorbidities may encourage regular GP visits, which help to detect cancer earlier, whereas more severe conditions may delay recognition, in favour of more pressing, immediate, symptoms.

## Past campaigns – what can we learn?

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There is less evidence available on what works to encourage and enable earlier presentation with possible cancer symptoms. What is known is that well-designed, long-term campaigns, both nationwide and community focused, can have real impact on cancer outcomes - but have to consider the cancer diagnostic process holistically. For example:

- **Be Clear on Cancer** benefitted from a robust test-expand process, a focus on the approachability of GPs, a multi-pronged media approach and effective targeting to lower socioeconomic groups. However, an attempt to replicate the observed stage shift in Wales failed, due to barriers to diagnostic access between primary and secondary care.
- A series of initiatives to increase breast screening uptake in Pakistani and Bangladeshi communities in Central and East London saw success through not just targeted and effective community-level work (for example the family/friend level 'Bosom Buddy' scheme), but also through holistically improving breast screening provision, from GP incentives, to training for breast screening staff.

# Recommendations

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Researchers also extrapolate from their evidence-based insights into barriers to suggest measures they believe *should* help to encourage or enable earlier presentation. Key advice includes to:

Invest in crafting effective messages:

- Increase awareness about key symptoms and risks, particularly those that are age-related
- Encourage people to question their multiple or vague symptoms
- Emphasise the benefits of early diagnosis and improvements to the efficacy of treatments
- Dispel negative attitudes about cancer and outcomes
- Empower at-risk patients to get checked in primary care
- Make it personal

Use effective channels:

- Multiple channels should be used in order to be successful
- The most influential factor is to 'push' to attend healthcare from outside (local press, community centres), but should be accompanied by 'pull' from GPs to encourage and welcome people presenting
- Providing an avenue for active engagement (e.g. a conversation) is more effective than simply providing information
- Targeted change is difficult to achieve via mass media, though social media may provide a good opportunity for properly-targeted campaigns.

Choose the right targets:

- Campaigns can best be targeted to cancers with easily recognizable, but less well-known symptoms, and should be sensitive to the relationship between incidence and familiarity with specific cancers, which can change depending on the community.
- Campaigns should be targeted to communities most likely to delay referral, with a focus on referring to locations outside of traditional healthcare settings - and on building trust between socioeconomically deprived areas and healthcare providers, who are likely to be socially outside these communities.

Also enhancing patient-clinician interaction:

- As part of the 'pull' of a campaign, GPs should be encouraged/trained to listen and communicate effectively with incoming patients, reducing their gatekeeping function, and taking a more active 'case-finding' stance. We believe that novel diagnostic provision, such as rapid diagnostic centres, may help to minimise any resultant tension with secondary care from sending too many patients who bounce back and forth between community and specialist settings.

Harness effective messengers:

- Government, NHS, and charity literature is widely consumed, and a key facilitator in interpreting symptoms, and in legitimizing help-seeking, but may suffer from being less engaged and targeted.
- GPs and other healthcare professionals are well placed as vehicles for providing greater symptom awareness in those who visit regularly, but may struggle to reach less engaged members of the public.
- Community initiatives (innovative examples involve e.g., barbershops) can carry through broader health messages, whilst generally helping to motivate and directly encourage help-seeking behaviour, but are difficult to scale.
- Friends and family are highly effective at reaching otherwise difficult to engage populations, with word-of-mouth communication and personal recommendation helping to build trust and overcome emotional barriers to presentation.

Invest in high-quality evaluation:

- To measure changes in attitude or knowledge, studies should evaluate over a long period of time, conduct regular surveys, ensure local data are collected, and make comparisons with non-intervention areas, to afford confidence in any analysis of how much these interventions lead to real behavioural changes.
- If at all possible, studies should also measure real-world clinical outcomes. These might include: emergency presentations, incidence by age, stage at diagnosis, treatment outcomes, and quality of life.

## Our reflections

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This evidence review offers insights that can inform both service and policy change; however our focus is to inform **Moondance Cancer Initiative's** own funding and action. Reflecting 'out loud', some initial thoughts on implications of this evidence review for us includes (by no means exhaustively):

- Recognising that some of the most compelling evidence comes from the very large scale, longer-term and multi-pronged campaigns – which are potentially also quite costly
- There is a need to target those least likely to present, to help address Wales' unequal cancer outcomes; this may include socio-economically deprived communities as well as people facing cultural and language barriers
- Any action should be driven by local data analysis
- Efforts to increase presentation should ideally be mirrored by services ready to receive them
- There is as yet little detailed evidence publicly available on what works in social media campaigns, especially across age-ranges
- We should review our own language and framings, given evidence on the importance of removing the taboos around cancer, and about positive framings and associations.

The full evidence review is available on the Moondance Cancer Initiative website.



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Moondance Cancer Initiative helps find solutions so that more people in Wales survive cancer. We find and actively support projects with potential to transform survival outcomes across the country, and we undertake research and insight projects to inform our work.

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[www.moondance-cancer.wales](http://www.moondance-cancer.wales)

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