EVIDENCE
REVIEW

MOONDANCE
CANCER INITIATIVE

Cancer awareness and early presentation to healthcare: what works?

An evidence review

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About Moondance Cancer Initiative

Moondance Cancer Initiative is a new, 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. What we do:

- 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.

Purpose and context of this paper

One of the most important and controllable predictors of cancer survival, quality of life, and likelihood of curative intervention is the stage at which a cancer is diagnosed. If caught early, many cancers are treatable, and patients can go on to live well with and beyond their cancer.

Treating cancer successfully is easier and more likely when a cancer is diagnosed at as early a stage as possible. For patients with cancer diagnosed at an earlier stage, significant improvements are seen in morbidity and quality of life (Neal et al., 2015; Smith et al., 2010; Whitaker, 2020), and in short and long-term survival (although these measurements are subject to lead- and length-time bias) (CRUK, 2020a; Healthcare Quality Improvement Partnership, 2020; McPhail et al., 2015).

However currently in Wales, a large proportion of cancers are diagnosed at later stages – 55% at stages 3-4 in the latest available data (WCISU, 2021). Further, approximately 20% of newly diagnosed cancer patients present as emergencies (usually to A&E) (CRUK, 2020b), with acute symptoms and often when the cancer is at a late stage, making them much harder to treat successfully. Further, anecdotal evidence suggests that even more people are presenting with later-stage cancers in 2021 than previously, having not come forward during the first and second waves of the Covid-19 pandemic.

Alongside providing funding and support to innovative projects to improve early detection and diagnosis, Moondance Cancer Initiative is undertaking two insight projects that explore both the patient and health service sides of this problem:

- An evidence synthesis to understand what works to encourage people to attend cancer screening, or if they have potential cancer symptoms to access healthcare (this report);
- Imagining a routemap for cancer early diagnosis and detection services over the next 5 to 10 years (parallel project).

In this paper

This report takes stock of what is known about cancer help-seeking behaviour and its influences. This is a substantial subject, revealing a complex and multifaceted interplay of physical, contextual, behavioural and disease-related factors that can act as drivers or barriers to early presentation, and which can vary from person to person.

The report then considers what this evidence tells us about the features of interventions that may be worth pursuing to further encourage early presentation, and reflects on what can be learned from past and existing interventions.

As an independent third-party funder, we're keen to understand this, to know where we can best help. Understanding the available evidence on what works to enable more people to present to services earlier with cancer symptoms is a crucial first step for us, before considering what interventions Moondance might fund and support in future. Effective interventions should have the potential to catch a cancer quickly, shift the stage at which it is detected, and so reduce cancer's overall impact on the health and wellbeing of the Welsh population.

Research method

This evidence review takes into consideration a broad range of sources, from peer reviewed academic research to pieces by individuals and organisations.

A review of the Google Scholar database and NHS Wales E-Library for Health was performed for original (English medium) articles discussing research on barriers to early presentation of cancer symptoms and interventions to tackle the issue:

- Search terms included "early presentation", "help-seeking", "delay", "symptoms", "cancer", "intervention", "evaluation" and relevant combinations.
- References cited in the articles deemed relevant were searched for further related research, and a search of where else the relevant papers had been referenced revealed further pertinent articles.
- Other subject-specific collections of publications were reviewed, for example, the publication list of the International Cancer Benchmarking Partnership, which provided evidence from and comparison with key other developed countries.

Much of the evidence cited is reported at a UK level or specifically with reference to England. Where Welsh statistics and evidence exist, these have been presented; and while national health, public health and cancer services are a devolved matter, there are naturally commonalities across the health systems and populations of the UK.

We have sought to be sensitive to source quality; the research cited is overall of high (e.g., systematic reviews) and medium quality (randomised trials), with a smaller number of lower quality sources included (e.g. small sample qualitative interviews, focus group narratives, or comment pieces) where the findings are usefully illustrative. However, it is important to acknowledge this review does not reach the rigour of a full systematic review, as we have not conducted a full structured assessment of the quality of the research studies cited.

Chapter 1: Barriers to early presentation with cancer symptoms

The reasons why people delay or don't present to health services with cancer symptoms are manifold, or "multifactorial, individual and complex" (Jones et al. 2014) but can be broadly categorised as:

1) Patient factors: symptom awareness; behavioural or cultural norms; demographic, co-morbidities, practical access;
2) System factors: healthcare policy; service model or provider issues; diagnostic methods; resource availability; and
3) Disease factors: symptom vagueness; cancers that are difficult to detect and/or treat (Walter et al. 2012; Cassim et al. 2019).

This paper focusses on patient factors. This chapter will explore the evidence around the various patient factors and then examine the emergent research on the impact of the Covid-19 pandemic on exacerbating all three of the categories above.

Symptom awareness

Awareness of cancer symptoms varies across cancers, symptoms and populations. A survey asking people to identify, from a list, all the symptoms of six less survivable cancers in the UK which together account for half of all common cancer deaths in the UK (lung, liver, brain, oesophageal, pancreatic and stomach), found that symptom knowledge was poor, particularly for the gastrointestinal cancers (Less Survivable Cancers Taskforce, 2021).

Research consistently finds that while knowledge of specific or persistent symptoms such as lumps or bleeding can be good and encourages timely symptom presentation. In contrast, non-specific, vague or ambiguous symptoms are not well recognised (McCutchan et al. 2015). Analysis of cancer data in England identified 20 common presenting symptoms and found that neck lump, chest pain, and back pain, were more often associated with cancers diagnosed at a late stage (IV) as opposed to abnormal mole, breast lump, postmenopausal bleeding, and rectal bleeding which more often led to earlier stage diagnosis (Koo et al. 2020). While chest and back pain may be quite vague symptoms, often not associated with cancer, the latter set of symptoms are perhaps more specific and so prompt both early presentation and early diagnosis.

However, interpreting even specific symptoms is not straightforward. Taking breast cancer as example, research shows that women are uncertain about appraising non-lump symptoms and may not as a result interpret a dimple or dent in the breast as a symptom (Burgess et al. 2001; Jones et al. 2015). How seriously women perceive the symptoms is influenced by how far it matches their expectations of breast cancer as a painless breast lump (Burgess et al. 2001). For some, the presence of pain can falsely provide reassurance, as they understand that for a breast lump to be cancerous it should be painless, which can delay help-seeking. On the other hand, for some women a lack of pain can inhibit help-seeking (Burgess et al. 2001; Stapleton et al. 2011; Jones et al. 2015).

Surveys of cancer patients in England have found that 46% delayed seeing their doctor for 15 days or more from first noticing symptoms (Keeble et al. 2014), while 21% delayed for at least three months (Forbes et al. 2014). The Keeble et al survey found older or housebound patients were more likely to present promptly, and symptoms with abrupt and unexplained onset such as bleeding also prompted help-seeking. The Forbes et al survey found that 28% had not recognised their symptoms as serious, which was associated with a doubling in risk of delaying presentation.

Overall, the normalisation or low risk perception of potential cancer symptoms is a well-documented barrier. For example, many people who go on to develop lung cancer feel that respiratory symptoms and general ill-health are normal for smokers (Cassim et al. 2019).

Emotional and attitudinal barriers relating to cancer

Deciding to present to primary care is not simply a cognitive process once symptoms are established, but emotional and attitudinal dimensions are arguably just as influential over the decision.

While for most people, the fear that a symptom may be cancer will drive them to seek help, for others it can be a significant barrier (Whitaker et al. 2015a). The influence of social networks can also go either way, depending on the advice given, as can experience of cancer among family, friends or the media, depending on the perception of its survivability (Whitaker et al. 2015a; McCutchan et al. 2015 and 2016). One way to examine the nuances is to consider the differences between populations.

Data consistently shows in the UK and other developed countries that people from lower socioeconomic backgrounds have poorer cancer survival rates, in part owing to late-stage diagnosis. For example, one study reports about 20,000 extra cancer cases each year in more deprived areas of the UK, with rates of smoking-related cancers three times higher in the most deprived populations compared with the least deprived (Public Policy Projects, 2021).

When people across England were tested on their knowledge of cancer symptoms, the youngest and oldest, participants with the lowest socioeconomic status recognised the fewest cancer symptoms and reported most barriers to presentation (Niksic et al. 2015). Lower socioeconomic status, being male and being older, are all associated with lower health literacy and health expectations generally (Whitaker et al. 2015b). McCutchan and colleagues have studied the factors that influence delayed cancer symptom presentation in lower socioeconomic groups and their 2015 systematic review found that poorer symptom knowledge, fearful and fatalistic beliefs about cancer, and emotional barriers such as 'worry what the doctor might find' were most common in these groups and together contribute to delayed symptom presentation (McCutchan et al. 2015).

A subsequent qualitative study into symptom presentation behaviour explored these factors further (McCutchan et al. 2016). It highlighted the influence of social networks on knowledge and beliefs about cancer among lower socioeconomic groups. Social networks were found to have a formative and reinforcing influence on the knowledge, behavioural and normative beliefs of people. Often among these groups, the effect was to stoke fear and delay help seeking. Nonetheless, a review of all the relevant evidence found that disclosing symptoms to a family member or friend was in fact the most common factor that encourages people to seek medical help (McCutchan et al. 2015).

Evidence suggests that people from ethnic backgrounds in the UK are generally more likely to delay presenting to their GP with symptoms. Studies have found low cancer symptom awareness across all of the six largest ethnic groups in England (Indian, Pakistani, Bangladeshi, Caribbean, African and Chinese), but also many other barriers to help-seeking - with men identifying more practical barriers and women identifying more emotional barriers, although with considerable ethnic variation (Waller et al. 2009; Niksic et al. 2016).

In fact, women from ethnic minority backgrounds report around twice as many barriers to help-seeking than white women. They can be far more likely to feel too embarrassed to talk to a GP (75-91%) than white women (8%), more likely to put off seeing a doctor for fear the symptom is a sign of something serious, and be fatalistic about sickness and death (Williams et al. 2019; Jones et al. 2014). Qualitative research with Black African, Black Caribbean and White British women in the UK illustrates however how ethnic minorities should not be treated homogenously in research (in this case Black women in breast cancer research) as there were significant distinctions in help-seeking by country of birth, time spent in UK and age. First generation Black African women reported most barriers and were most likely to delay presenting to a doctor with potential breast cancer symptoms, while second generation Black Caribbean and White British women were similar and experienced fewest barriers (Jones et al. 2015).

While fear associated with a symptom most commonly drives people to seek help, fear of being diagnosed with cancer can for some be a major deterrent (Smith et al. 2005; Macdonald et al. 2006; Macleod et al. 2009), particularly if the person has a dread of screening, follow-up investigations, the impact on daily life of being a cancer patient (Whitaker et al. 2015a; Vrinten et al. 2016), treatment, or dying (McCutchan et al. 2015).

For example, in a survey of Irish citizens, 49% of respondents said that if they had a symptom which they thought might be serious they would be put off from going to a doctor because they would be worried about what the doctor might find. A third of women in the survey agreed that they would be so worried about what might be found at breast cancer screening that they would prefer not to have it and a quarter agreed with the statement 'I would not want to know if I have cancer' (Public Health Agency, 2014).

One study frames the response to fear as 'fight' - seeking help, or 'flight' - minimising the seriousness of symptoms, denial, avoidance or indecision (Dubayova et al. 2010; Cassim et al. 2019). Reasons for either reaction can depend on the way people cope with fear and the intensity of the negative feeling. Some people focus on bodily symptoms more than others and being in 'panic' is more likely to induce help seeking than being 'worried' or 'fearful' (Dubayova et al. 2010). A review of what people fear about cancer shows that fear is rooted in the view of cancer as an enemy, with associated military terminology (e.g., war analogies, 'fighting spirit'). Death is still often perceived as an inherent meaning of cancer across cultures, and is perhaps the most important component of cancer fear, together with fears about what it is like to be a cancer patient (Vrinten et al. 2016.; Stapleton et al. 2011).

Fearful and fatalistic beliefs about cancer are more likely to be expressed by individuals from lower socioeconomic groups (McCutchan et al. 2015), and patients' lack of awareness of cancer treatments can stoke fatalistic beliefs and fear of death from a cancer diagnosis, preventing help seeking (Cassim et al. 2019).

Stoicism is also reported as a barrier to early presentation, particularly amongst men, where patients put on a 'brave face' (Cassim et al. 2019). Similarly, feeling that they shouldn't 'make a fuss' was an active deterrent seen across both sexes and all socioeconomic backgrounds (Whitaker et al. 2015a).

A lack of fear or awareness of cancer can be due to a low perception of cancer risk to self, suggesting health-related defensive bias or optimism bias, further contributing to delayed presentation to health services. A lack of symptoms, no family history of cancer, and lower cancer risk perceptions among some ethnic minority groups have all been found to reduce fear of cancer to the point where screening is seen as unnecessary (Vrinten et al. 2016). Jones et al. (2015) found that the women they interviewed had tended to view themselves at low risk of developing breast cancer, with one in ten surveyed men also believing that they are healthy and therefore do not need to check their testicles (Movember, 2018).

A study seeking to understand late presentation among people in the UK at high risk of lung cancer e.g. current or former smokers, and living in highly deprived areas, found that managing 'treatable' short-term conditions, such as chest infections, provided a distraction from acting on perceived 'inevitable and incurable' long-term conditions e.g. lung cancer. It also found that these populations felt 'judged and unworthy of medical help because of their perceived social standing or lifestyle, particularly when difficult life circumstances and traumatic events led to tobacco and alcohol addiction' which also delayed help-seeking (McCutchan et al. 2019).

Practical access

Complex lives and a perceived lack of health service entitlement among lower socioeconomic groups can exacerbate barriers to accessing primary care to present with cancer symptoms. These can include being occupied by competing demands; trouble booking, reaching and attending an appointment; and perceptions of primary care practitioners and the broader health service.

Studies focussed on late cancer presentation among lower socioeconomic groups show that economic hardship can mean that fulfilling basic day-to-day needs, such as finding money for food, is prioritised over medical help seeking (McCutchan et al. 2016). Other external stressors can act as competing demands and result in depleted capacity to devote attention to symptoms and help seeking (Whitaker et al. 2015a). The same is found in less developed countries, with Egyptian breast cancer patients who reported having social, financial, or time constraints more likely to present at a late stage (Stapleton et al. 2011). More generally, women in one London hospital who delayed presenting with breast cancer symptoms listed domestic problems associated with other members of the family, work, and holidays as reasons why they felt too busy to arrange a medical appointment - in some cases reflecting a tendency to place the needs of others above their own (Burgess et al. 2001)

In a survey asking UK adults what might put them off visiting a doctor, the most common answer was difficulty getting an appointment with a particular doctor or at a particular time (42%). Women and people from lower socio-economic backgrounds were more likely to report barriers to making an appointment (National Health Executive, 2016). In a separate UK survey, a quarter of respondents admitted giving up trying to book a GP appointment because they failed to get an appointment that was convenient to them. Being able to book appointments for the same day, online, and being able to reach the practice by phone were considered important enablers (Co-op Health, 2019).

Emotional and attitudinal barriers relating to GPs and the NHS

Worry about wasting a doctor's time is another deterrent (National Health Executive, 2016; Whitaker et al. 2015a). This has been found to be most common when time constraints are visible or when the GP seems dismissive - to the extent that many people interviewed as part of one study felt that symptoms that were not persistent, worsening, or life-threatening did not warrant GP attention

(Cromme et al. 2016). Another UK study found back in 2008 that media reinforced an impression that people should not use primary care services unless a problem was extreme (Tod et al. 2008); worry about wasting a doctor's time has been cited as a barrier more often in the UK than in Australia, Canada, or Scandinavia (Forbes et al. 2013). Factors that alleviated worry about time-wasting included friendly GP relationships and continuity of care, economic reasoning recognising GP time as a public taxpayer-financed service, and a focus on the GP's responsibilities as a medical professional (Cromme et al. 2016). Notably, ethnic minority women who had moved to the UK as adults were around 40% less likely to report worrying about wasting a GP's time, than women from the same ethnic background born in the UK. One study speculates that this perhaps supports the notion that a 'stiff upper lip' is engrained in British society and exists for women born in the UK but is not usually adopted by women who arrive later in life (Williams et al. 2019).

While 20% of surveyed adults worried about wasting a doctor's time, 18% were worried the doctor wouldn't take their symptoms seriously and 16% said they had had a bad experience with a doctor in the past (National Health Executive, 2016). Negative attitudes towards interactions with GPs are widespread in the literature, including a lack of confidence in the doctor or the broader healthcare system (Whitaker et al. 2015a) and is also one of the most frequently reported barriers in the UK (Cassim et al. 2019). With regard to lung cancer, reported GP attitudes of 'nihilism' towards the disease and an inability to understand or relate to tobacco addiction contribute to this. The association between smoking and lung cancer and it therefore being 'the fault of the individual' increases stigma, and feelings of blame, guilt and shame. Rightly or wrongly, patients can be put off visiting healthcare professionals for fear of being lectured or reprimanded to cease smoking (Cassim et al. 2019).

A survey of UK adults over 50 found that although patients want shorter GP waiting times, most showed a willingness to wait an extra week for an appointment with a GP of their choice, and an extra 3.5 weeks for an appointment with a doctor with good/very good listening skills. This confirms that patient delay is influenced by GP relationships (Whitaker et al. 2017). Yet while many people have a preference for their 'own GP' and familiarity and continuity of care are considered key aspects of high-quality primary care, in some circumstances a 'fresh pair of eyes' may help diagnosis (Parsonage et al. 2017).

GP interpretation of cancer symptoms

GPs have to judge whether cancer is a possible explanation for patient symptoms, when those symptoms are often a signal of benign disease too – often in a very short appointment slot. In the process of interpreting symptoms, most GPs trust their clinical acumen, and are generally right to do so (Hamilton et al, 2010).

A Danish study suggested that when patients do voice concerns about cancer in primary care, GPs are more likely to suspect cancer or serious illness in their patients. However, when patients present with an ´intermediate´ or ´hard´ to diagnose cancer, such as brain cancer, GPs less often suspect cancer, even for their patients who express the most cancer worry (Virgilsen et al. 2011).

The Danish study team also found that GPs are less likely to suspect cancer in patients who frequently attend GP consultations, and for younger patients (under 55) GPs' cancer suspicion was lower in both rare and frequent attenders compared to average attenders (Jensen, et al. 2019). In another study, the same team found that GPs' use of gut feeling - considered important in suspecting cancer - is compromised when they have a difficult encounter with the patient, resulting in a low level of empathy (Fischer-Pedersen et al. 2018). These studies highlight the sensitivity of the patient-physician relationship and how it can influence both patient help-seeking, and GP cancer suspicion and early diagnosis.

The patient-GP relationship is particularly important in the UK setting because the GP is the first port of call and the key route for referral to diagnostics and specialist care. Data across European countries indicate that those with similar 'gatekeeping systems' have poorer one-year cancer survival rates, which can be used as a proxy for later diagnosis (Vedsted & Olesen 2011). Further research in Denmark, which also has a gatekeeping system, has highlighted that issues - such as when patients have not previously been referred, and the perceived need to 'legitimise' consultations - can be significant barriers to early presentation (Whitaker et al. 2015a).

Co-morbidities and suspecting cancer

The effects of co-morbidity are believed to be part of the reason why UK cancer survival lags behind other developed countries (Arnold et al. 2019), either because they can blur the picture for the clinician and delay diagnosis (Swann et al. 2018), or because patients initially attribute cancer symptoms to a known co-morbidity (Smith et al. 2005). Certain comorbidities seem to facilitate help-seeking for certain symptoms, while other comorbidities seem to act as a barrier to appraisal and help-seeking for other possible cancer symptoms – comorbidities therefore have complex effects on help-seeking and cancer diagnosis (Salika et al. 2018).

One study found that regular GP visits can facilitate help-seeking for possible cancer symptoms - in the case of patients who require routine visits to manage and monitor osteomuscular and hypertension/ hypercholesterolemia. It is thought this offers the opportunity to raise other health concerns with primary care staff. However, the same study found that patients attending healthcare settings with more serious or urgent morbidities such as cardiac problems tend to delay help-seeking for their less pressing possible cancer symptoms (Salika et al. 2018). Most people at risk of developing cancer have at least one pre-existing morbidity, and among older people, the vast majority who experience possible cancer symptoms also have chronic health problems.

Low risk of flooding the system with ‘the worried well’

There have been concerns, voiced by GPs and others, that increased symptom awareness among the public, particularly of general and vague symptoms (such as tiredness) could lead to overburdening of primary care by the “worried-well”. Some reassurance may come from a study that measured the UK public’s awareness of cancer symptoms and found that people with very good symptom awareness were not more likely to visit their doctor regularly (Simon et al. 2010). A study of the Danish public found that 91.5% of those surveyed had experienced at least one of 44 predefined possible cancer symptoms within the previous 4 weeks, however of only 21.7% of the symptoms experienced had led to the person contacting their GP as a result, and only half of the symptoms reported as extremely concerning or having extreme influence on daily activities resulted in contact with a GP. This confirms that GPs are only ever presented with an extract of the total symptom pool and are certainly not seeing everyone with a sign or symptom (Elnegaard et al. 2017).

Impact of Covid-19

The Covid-19 pandemic and associated lockdowns in 2020-2021 meant the NHS has been in a prolonged emergency status which has upended usual patient interactions with healthcare. Services and staff have been under intense pressure; and resource and capacity were moved away from many essential services, including cancer diagnostics and treatments, to cope with the demands of the virus.

Separately, the advice to ‘stay home, save lives and protect the NHS’, combined with strong advice not to present with Covid symptoms unless they were particularly severe, is viewed as undermining existing messaging encouraging help-seeking behaviour for cancer symptoms (for example, Jones et al 2020). Specifically, while a prolonged cough was a highly publicised Covid-19 symptom about which not to bother your doctor, lung cancer charities were busy trying to counter the message, highlighting that ‘not every cough is Covid’ and a cough of three weeks or more could be cancer and should be reported to a GP (Longworth, 2021).

The alarm was raised as early as April 2020 as GPs in Wales reported a worrying drop in the number of people coming to them with suspected cancer symptoms. Clinicians reported a 75% drop in urgent cancer referrals in Wales in the first months of the outbreak (Wales Cancer Alliance, 2020). In fact, Macmillan analysis shows that in April 2020 there were 61% fewer referrals to the Welsh Single Cancer Pathway than an average month and that there is estimated to be a backlog of 2,900 cancer diagnoses in Wales from the period between March and August 2020, which could take between 28 and 37 months to clear. Further, with so many cases anticipated to present late it is likely that these cancers will be more advanced and difficult to overcome (Macmillan Cancer Support, 2020).

By October 2020, a survey of UK GPs found that more than half (53%) were concerned that fewer older patients were presenting with cancer symptoms - indicating that more patients would be presenting late with more developed cancers leading to poorer outcomes (Bostock, 2020). GPs cited patients reporting symptoms 'since lockdown started', therefore presenting after a six-month delay. Almost half of GPs surveyed (45%) knew of a patient who had suffered because of delays to routine care caused by the pandemic. The most common reasons cited were delays in referrals for diagnostics and cancer treatment, surgery cancellation, and a struggle to access outpatient appointments (Bower, 2020).

A study published in early 2021 found that nearly half (44.8%) of surveyed adults who had experienced potential cancer symptoms between the beginning of the pandemic in March 2020 and August 2020 reported putting off contacting their GP, even for 'red flag' symptoms such as coughing up blood. Worries about wasting healthcare professionals' time, over-stretching limited healthcare resources, access to healthcare services and COVID-19 infection were frequently reported barriers to help-seeking. Fear around attending appointments and potentially catching or passing on the virus in healthcare settings was a significant concern, in part due to media reporting of COVID-19 in hospitals (Brain et al. 2021).

Chapter 2: Recommendations from studies assessing the barriers to earlier presentation

Studies assessing the barriers to early presentation of cancer symptoms highlight recommendations to promote symptom awareness and encourage help-seeking. Such recommendations typically draw on authors' informed views having analysed barriers, rather than validated evidence on what works. (See next chapter for a review of available evidence on what works). Here, these recommendations are synthesized into seven categories: messages; channels; targets; patient-clinician relationships; messengers; evaluation; and Covid-19.

Messages

Message 1: Increase awareness about key symptoms and risks, particularly age-related (Cassim et al., 2019)

This may spread awareness of the most clear and notable symptoms and should address the finding that the UK has low awareness of the age-related risk of cancer (Forbes et al. 2013). However, it is unlikely to support detection of clusters of vague symptoms associated with cancers such as myeloma, pancreatic, lung, liver and stomach cancer. Commonly those who delay help-seeking explain away slight changes or vague, infrequent and symptoms, such as loss of interest, less engagement or less ability to engage with daily living activities, owing to tiredness, stress, age or recent events; yet a combination of seemingly trivial changes *may* represent brain cancer (for example).

Message 2: Encourage people to question their multiple or vague symptoms

People who question their symptoms are more likely to seek help than those who have convinced themselves that there is nothing to worry about; therefore drawing attention to these cognitive biases may also have value – by prompting the latter group to think twice before explaining symptoms away (Scott et al. 2019).

Tackling the fear of a cancer diagnosis, treatment or death is also increasingly recognised as a cornerstone of any intervention:

Message 3: Emphasise the benefits of early diagnosis and improvements to the efficacy of treatments (Burgess et al. 2001; Waller et al. 2009; Dubayova et al. 2010; Stapleton et al. 2011; Forbes et al. 2014; McCutchan et al. 2016)

War terminology (e.g. "war on cancer" and "fighting cancer") may trigger a fight or flight response and distract from the importance of prevention and early presentation (Vrinten et al. 2016) and therefore should be avoided. Instead, embed and normalise positive routine messages which may slowly work to dispel negative (fatalistic and stigmatising) beliefs about cancer and outcomes. A meta-analysis of psychological factors related to time to help-seeking for cancer symptoms (all sites) found that alongside symptom knowledge and interpretation, beliefs about cancer are universal predictors of help-seeking. Positive beliefs that cancer is treatable encourage early presentation, while negative beliefs lead to delay (Petrova et al. 2020).

Interestingly, while people commonly endorse positive statements about improving cancer outcomes and the value of early detection, many, particularly those with lower levels of education, simultaneously hold negative beliefs, therefore, messages also need to focus on reducing negative attitudes, which is not necessarily achieved by promoting positive attitudes (Quaife et al. 2015).

Message 4: Dispel negative attitudes about cancer and outcomes

This could include using humour to lighten the topic or even mean avoiding use of the word 'cancer' (Eadie & MacAskill 2007). Those who present early are more likely to think of their appointment as a problem-solving measure which will give them reassurance or treatment, rather than something which is likely to have negative consequences (Burgess et al. 2001).

Reframing medical consultations may therefore also be important, helping to tackle anxieties that can be associated with presenting to primary care:

Message 5: Empowering at-risk patients to get checked in primary care

Among developed countries the UK has among the highest perceived barriers to symptomatic presentation (Forbes et al. 2013), from embarrassment around intimate symptoms such as breast changes and rectal bleeding, to worry about wasting the doctor's time for more vague symptoms (Smith et al. 2005; Donnelly et al. 2017), therefore increasing people's confidence to approach the GP is paramount. This may mean that (more) interventions need to tackle head-on the blame and stigma that patients (e.g., long-term smokers) can feel, and therefore work with both primary care staff and the public to reiterate the importance of non-judgemental professionals (Tod et al. 2008). Messages also need to work to counteract ongoing public rhetoric about an overstretched health service and struggling staff.

Message 6: Make it personal

Large-scale UK surveys show that most people have experienced cancer personally or in others close to them (80% in Quaife et al. 2015). It is therefore suggested that emphasising the personal relevance of cancer can be useful, particularly as those with personal experience have been found to perceive medicine or health professionals in a more positive way (Burgess et al. 2001).

Similarly, personal testimonies from cancer survivors and carers can help people help relate directly to the subject, and create a critical mass in the population (e.g. more survivor stories than death stories) (Stapleton et al. 2011). Celebrity experiences are less personal but can highlight human vulnerability and raise the public profile of cancer. Conversely, including statistics in messages can capture attention but in isolation they can depersonalise the individual risk (Eadie & MacAskill 2007).

Channels

The channels to carry these messages have been tested and evaluated through various public health campaigns and interventions (see next chapter), however, approaches generally need to be multi-pronged.

Disseminating cancer awareness materials, whether they be electronic via email and social media, or paper-based and displayed in relevant public spaces, are a form of public education and can extend to useful decision aids e.g. whether to present or not (Merriel and Hamilton, 2020).

Simply providing information doesn't equate to engagement however. One trial regarding oral cancer and mouth self-examination compared the effectiveness of reading a leaflet against having a one-to-one information session with a leaflet to follow up; it found both interventions were almost equally effective at increasing knowledge and awareness in the short term, however, trial participants read the leaflet in the presence of a researcher – there is no guarantee that in practice simply disseminating the leaflet would lead to engagement with the material (Scott et al. 2012).

Some researchers suggest that the potential for primary care to “pull” in people with symptoms earlier through messages and materials is likely to be limited. For example, focus groups in rural areas in Scotland found women were more familiar with primary care (for child healthcare or screening) than men (Eadie & MacAskil,l 2007).

For this reason, many interventions seek to broaden their reach by taking their messages out of clinical setting and into community spaces (e.g. faith centres, community centres, local clubs, pubs, bingo halls, barber shops) to facilitate, more informal, ad-hoc, open and even humorous discussions (Eadie & MacAskill, 2007). These are generally facilitated by local health care workers, or trained community advocates who engage with local networks and communities. The methods can be creative, including plays, games and comedy (Lyon et al. 2009; Whyte et al. 2012).

Working with community networks can reinforce broader campaign messages delivered through wider media channels and it is generally understood that multi-level and multi-faceted approaches combining media, interpersonal and community components act to reinforce and amplify their messages. One mixed-method community based social marketing intervention on lung cancer diagnosis in Doncaster used a "push – pull" approach:

- "Pushing" the public to present if they had a persistent cough were: messages in local press, radio, leaflets, beer mats, pharmacy bags, outdoor billboards and even bus stops with sound chips that "coughed".
- The "pulling" component was brief training to prepare healthcare professionals for the initiative and reassure them that there was sufficient capacity within secondary care to cope with increased referrals for chest x-rays.

Evaluation showed that 21% of the target audience recalled the campaign; and compared to a control area, more people said they would request a chest x-ray from their GP if they had a persistent cough, chest x-ray referral rates increased, as did lung cancer diagnoses (Athey et al. 2011).

TV messages (mass media / broadcast) are at present rarely used in isolation, and media audiences are far more fragmented than even a decade ago. Social media is instead often a key component of any campaign or intervention. Mobile technologies have enabled social media and health apps to have a broad reach, low or no cost, and high scalability. They can harness the power of photos, videos, social networks, communities and support, self-tracking, tailored feedback, data sharing and the potential for analytics, all of which can promote symptom awareness, early presentation and cancer management and support *(e.g. Alanzi et al. 2018)*. Also, for those in rural areas, unable to travel, or suffering from rare cancers, social media can give access to peers or role models (Prochaska et al. 2017).

A systematic review of the use of social media platforms for cancer prevention education, as part of a larger intervention, or the main component of interventions, concluded they have the potential to contribute to improvements in cancer prevention and management, although studies were not rigorous enough to test the effects of social media on clinical outcomes, or by age or gender (Han et al. 2018).

Similarly, the limited evidence that Plackett and colleagues found in their scoping review of evaluations of social media interventions targeting cancer screening and early diagnosis suggests that social media interventions <u>may</u> have a positive influence, but they found evaluations lacked robustness and needed a clear evaluation framework to measure behaviour change (Plackett et al. 2020). They also highlighted a need to better understand who engages with these interventions to know whether social media can be used to reduce health inequalities in cancer screening and early diagnosis - a point highlighted elsewhere, considering the higher risk by age for many cancers, the range of ages eligible for screening, and lower social media literacy and/or engagement among older age groups (Saab et al. 2021).

Targets

Targeting interventions at **help-seeking for specific cancers** or groups of cancers is a valid approach, albeit complicated by questions around the justification for prioritisation, e.g. the most/least common, the most/least treatable, the most/least clear symptoms.

Forbes et al. (2014) found that among their sample of UK cancer patients, those with prostate and rectal cancer were most likely to have delayed presenting from when they first noticed symptoms, and patients with breast cancer were least likely to delay. They recommend therefore that approaches to promote early presentation should aim to increase awareness that bleeding, and specifically rectal bleeding, is a possible symptom of cancer (as notably 35% of patients with rectal bleeding delayed presentation, but only 9% of patients with urinary bleeding did so).

A separate study found that prompt presentation was most frequent for bladder and renal cancer and least frequent for oro-pharyngeal and oesophageal cancer. The researchers believe that patient familiarity with symptoms in the context of previous illness (e.g. oral ulcerations) may be responsible for non-prompt presentation of patients with oro-pharyngeal cancer (Keeble et al. 2014). Cancer charities operate and arguably compete in the space of prompting awareness of site-specific cancers or groups of cancers, although alliances of charities perhaps help coordinate and align activities and therefore public messages.

The incidence of different cancers varies among ethnic groups in the UK and studies have found so too does awareness of different cancer symptoms. For example, the Bangladeshi people sampled in a 2009 study were less likely than their Caribbean counterparts to recognise a lump as a warning sign, however, the breast cancer incidence rate for Bangladeshi women is also lower than for Caribbean women. How cancer is conceptualised in different communities appears to be influenced by incidence; however rates of some cancers in ethnic minority groups are rising to equal or exceed general population prevalence, therefore so too should efforts to raise awareness and encourage help seeking (Waller et al. 2009). Notably, cancer symptom awareness among the ethnic minority groups sampled in this study was lower than even the lowest social class group in the population representative sample, a finding which still holds in more recent studies (Niksic et al. 2016).

To note: a report for the Race Equality Foundation (Fazil, 2018) underlines a series of problems associated with reporting ethnicity in cancer statistics; highlighting the complexities and nuances of cancer incidence by ethnicity in an effort to challenge generalised findings that people from black and minority ethnic groups in the UK are overall are less likely to get cancer than white populations. There is evidence that certain cancers can have a higher incidence in particular ethnic groups (National Cancer Intelligent Network, 2015) and that among South-Asians, for example, general cancer incidence is rising more rapidly and deprivation has less impact on cancer risk compared to non-South Asians (Maringe et al., 2013). The incidence of cancer is expected to rise as the UK black and minority ethnic population ages, therefore cancer awareness and early presentation strategies should focus efforts on these groups.

Targeting interventions at those **most likely to delay presentation** with cancer symptoms is a commonly researched approach. Among most-deprived populations, smoking-related cancers are three times higher compared with the least deprived (CRUK in Public Policy Projects, 2021), and overall the most deprived populations are more likely to be present later, be diagnosed with later stage cancers and have poorer survival rates. They also have lower expectations about their health (Whitaker et al. 2015b).

Key researchers recommend targeting the messages highlighted above at the most deprived communities and building their confidence in discussing and fully disclosing symptoms with GPs, who are generally socially *outside* their own community.

Some interventions engage groups of individuals in community-based programmes to seek to empower them through prompts and role play, learning settings and strategies that can appeal to at-risk groups. In focus groups of people at risk of developing lung cancer from socioeconomically deprived areas of England, Scotland and Wales participants were asked what they considered to be important features of a potential intervention. These included:

- Located outside of traditional healthcare setting – to reduce anxiety and preconceptions and add familiarity of a community space
- Participants invited to attend - to eliminate concerns about wasting a GP's time and legitimise attendance
- Led by non-judgemental and welcoming facilitators – to feel welcome and not judged or blamed for current of former lifestyle and to build trusting relationships
- Build confidence – to feel empowered to seek help and present early with symptoms
- (McCutchan et al. 2016; 2019)

Researchers believe that help-seeking can be encouraged through intensive approaches, to build trusting relationships and confidence. Potential providers should however be cognisant of the responsibilities of such relationships, be well trained, and able to signpost appropriately to wider services: over half of the sample used in this specific intervention described mental health problems and/or difficult current or former life circumstances (McCutchan et al. 2019).

Culturally sensitive and community-based interventions (Waller et al. 2009) are used also to encourage attendance at screening among other groups with low screening uptake (e.g. patients with learning difficulties, mental health problems, or from black and minority ethnic backgrounds) (Merriel and Hamilton, 2020).

There are however limits to community-based interventions, as they may still not reach the most socially excluded individuals, who do not participate in community groups and do not visit community settings (Mueller et al. 2021). Very direct personal approaches may help, but there is a fine line to navigate: a review of evaluation of interventions to improve participation in cancer screening services found that telephone calls from primary care were found to increase participation, particularly among populations of low socioeconomic status (above written reminders), however home visits had a negative effect (Duffy et al. 2017).

Co-morbidities are more prevalent among socio-economically deprived groups, some of whom will be accessing health services regularly. Researchers recommend a holistic form of clinical management for these patients with clear guidance encouraging them to report new symptoms when those occur (Salika et al. 2018).

Research that finds different barriers to early presentation among different ethnic groups and genders recommends focussing on tackling emotional barriers for South Asian and black women. For Bangladeshi women in particular, the key issue is embarrassment, alongside worry about wasting the doctor's time, and finding the doctor difficult to talk to (Waller et al. 2009; Forbes et al. 2011b; Williams et al. 2019). Ethnic minority groups surveyed are much more likely to believe that the doctor would be difficult to talk to (27% compared with 13% in the whole population sample) and to lack confidence in talking about their symptoms (30% compared with 12%). Recommendations centre on mediating a better patient-clinician relationship.

Patient-clinician relationships

The power imbalance between patient and clinician, especially given the GP's role as gate-keeper to diagnostic services and elective care, has led researchers from the ThinkCancer! Initiative to consider how the GP role can be reframed as a "case-finder" within a more participative relationship. Their approach includes enhancing communication – remembering that how long a patient delays approaching primary care for possible cancer symptoms seems to be particularly influenced by the anticipated listening skills of doctors. Therefore, improving GP communication skills is highly recommended, particularly as good listening skills can also contribute to more accurate detection and diagnosis (Whitaker et al. 2017).

The evaluation of a community-based symptom awareness intervention found engaging GPs to be a challenging and limiting factor, and therefore recommended researching the barriers to GP involvement to inform a dedicated and comprehensive GP engagement strategy for future interventions (Mueller et al. 2021). GPs have various pressures and tensions with secondary care, which can lead to a hesitancy to refer cases, however dedicated training programmes, such as those delivered by Cancer Research UK, tools and resources for GPs, such as those developed by Macmillan, and the development of Rapid Diagnostics Clinics (RDCs) for patients with vague symptoms may alleviate this. As half of UK cancer patients do not present with the necessary symptoms to be referred to an urgent suspected cancer pathway, RDCs have been welcomed as a promising alternative route (BBC News, 2020).

Practice-wide symptom awareness and early diagnosis training is a core feature of the ThinkCancer! trial in GP surgeries in Wales, which emphasises safety-netting, ensuring potential cancer patients are flagged and followed-up. When safety-netting is effectively implemented, it is possible that patients who would prefer not to see a GP with vague non-specific symptoms could perhaps see a nurse practitioner initially (Cromme et al. 2016).

Messengers

An important question that numerous studies seek to answer is 'who influences symptom awareness and early presentation with cancer symptoms?' There is no single answer and the truth may be that people's are influenced in their help-seeking behaviour by a combination of messengers.

Government (NHS and public health bodies) and charity campaign literature will be the most widely disseminated and indeed, research finds that public health campaigns are identified as a facilitator both in interpreting symptoms and legitimising help seeking, which supports the value of such public awareness campaigns (Whitaker et al. 2015a).

Nonetheless, the important role of friends and family in encouraging consultation (Smith et al. 2005) is highlighted throughout the literature, particularly with reference to higher-risk groups with lower propensity to present. Rather than seeking to encourage self-referral directly, Eadie & MacAskill (2007) suggest exploiting social networks through word-of-mouth communication and personal recommendations, as well as directing these messages towards key opinion formers who in turn influence those services find hard-to-reach. For example, their study identified older men living in rural communities as hard-to-reach but the women they are close to as key opinion formers and influences.

GPs will remain important messengers, but other healthcare professionals including nurses (Tod et al. 2008), dentists (Scott et al. 2012), pharmacists (Varela-Centelles et al. 2012) and radiographers (Omar et al., 2010) have all been the vehicles for interventions designed to encourage symptom awareness and early presentation. More broadly, people working across the health service, local government, community and voluntary sectors are considered to be well placed to have discussions about cancer prevention and early diagnosis with the public; Cancer Research UK has a training workshop that is designed for these groups. An evaluation of "Talk Cancer" found, among other outcomes that the majority of trainees (86%) indicated they had applied the training in their role (Roberts et al. 2019).

Community initiatives have also recruited unconventional messengers. For example, among US African-American men, prostate and colorectal cancer are two of the leading causes of cancer deaths, with screening rates trailing their white counterparts. In Birmingham, Alabama, barbers were trained as Community Health Advisors to educate their clients about prostate and colorectal cancer, encourage participation in screening, and motivate help-seeking behaviours (Holt et al. 2010). This followed similar interventions in barbershops to raise awareness of the risks of hypertension and prostate cancer. The results showed self-reported increases in cancer knowledge, more openness to examinations, screening and testing, and fewer reported barriers; however, these results come from a very small number of intervention group pre and post questionnaires (n=12, comparison group n=14) and should be interpreted with caution.

Evaluation: quality, challenges and models

Teams leading initiatives, campaigns and interventions promoting cancer symptom awareness and help-seeking do now regularly build in evaluation activities and report on their processes and outcomes. However, evaluations are not always published and their findings can be unreliable. More detailed and robust evaluations are a common recommendation from reviewers seeking evidence of findings to inform future interventions.

A systematic review of interventions internationally found limited rigorous evidence to inform policy on individual- or community-level interventions to promote cancer awareness and earlier presentation. There were insufficient good quality studies on interventions and while randomised control trials (RCTs) of some individual-level, intensive and tailored interventions found modest positive effects on cancer knowledge or attitudes, there was no evidence of sustained impact beyond six months and overall a lack of evidence-based approaches to promote early presentation for any cancer type (Austoker et al. 2009). Even a more recent systematic review finds that all studies are limited by a failure to assess sustainability of impacts over more than 6 months (which is hard to do), and that some fail to take a baseline measure (Saab et al. 2021).

It is variously recommended that future evaluations should attempt to:

1. Use study designs that generate high-quality evidence (e.g. RCTs)

2. Measure outcomes over a longer term (months/years)
3. Distil behavioural and cancer stage outcomes, as well as knowledge and attitudes (Austoker et al. 2009; O'Mahony et al. 2017)
4. Measure effect on incidence and effect by age
5. Measure impact on emergency presentations
6. Make comparisons with non-intervention regions (Whyte et al. 2012; Whyte & Harnan 2014)
7. Collect local data re. ethnicity and deprivation in presenting, accessing, diagnosis, treatment and outcomes (NHS England, 2020; Welsh Government, 2021)
8. Conduct regular surveys of patient interval in representative samples of cancer patients (Keeble et al, 2014)

It is common for reviewers to find little or no high-quality evidence relating to symptom awareness or early presentation:

- Cheewakriangkrai et al (2020) found no good quality trials to review to help them assess whether health education interventions promote early presentation and referral for women with symptoms of endometrial cancer
- A paucity of evidence was also reported relating to breast cancer awareness interventions specifically aimed at women with an intellectual disability (Walsh et al. 2019).
- A systematic review of evaluations of the effectiveness of media campaigns to improve cancer awareness and screening rates in Asia found small media campaigns did increase participation in screening, but there was insufficient evidence on the effects of mass media campaigns, or how either small or mass media campaigns improve knowledge and attitudes about cancer, or early detection (Schliemann et al. 2019).
- Another systematic review, this time on interventions to increase early detection of colorectal cancer through patient awareness campaigns to increase self-presentation or to increase screening attendance found that researchers failed to identify which components of interventions conferred the reported positive effects (Whyte et al. 2012). (This evidence review has noted the same issue in the wider literature, whereby little or no distinction is made to identify the specific contributions of different elements of an intervention to reported outcomes, resulting in a lack of evidence around which components make a difference).

Good data collection can also help assess the cost-effectiveness of campaigns and interventions to help policy makers and funders prioritise between cancer control strategies. For example, researchers used a mathematical model to extrapolate short-term outcomes from the "Signs and Symptoms" colorectal cancer awareness campaign to predict long-term impacts on cancer mortality, quality-adjusted life-years (QALYs), and costs. The findings however were compromised by data limitations and uncertainties (Whyte et al. 2012; Whyte & Harnan 2014).

The manipulation of big data is likely to present increasing opportunities. For example, Google Trends analytics could be a useful planning and evaluation tool, providing insights about the public's interest in certain cancers, and feedback about interventions aimed at increasing awareness (Schootman et al. 2015). It is already used on social media platforms to target messages to key groups.

It is very common for reviewers to find studies reporting positive results supporting early stages of the logic model of awareness raising and early presentation interventions, such as improved awareness and knowledge, but little, if any, evidence to inform the later and final stages of the logic model, e.g. increased early presentations, early detection of cancer and better survival outcomes (Whyte et al 2012). The following are similar examples:

- There was better awareness of colorectal cancer symptoms following a campaign in Malaysia but no immediate increase in presentations or health service use (Schliemann et al. 2020).
- There was better knowledge of breast cancer following a SnapChat campaign in Saudi Arabia but no evidence to suggest a change in decision-making and in future behaviour (Alanzi et al. 2018).
- There was improved knowledge of skin cancer risk and sun-protection behaviours in skin-of-colour populations in the US following educational interventions but less evidence of increased preventative action (Kailas et al. 2017).
- Breast cancer awareness interventions in the UK were found to increase the uptake of breast self-examination behaviours and increase the likelihood of breast cancer screening attendance, however the study authors note that predicting the impact on survivability outcomes remains a challenge due to a shortage of suitably evaluated campaigns (Anastasi & Lusher, 2017).
- School-based brief psycho-educational interventions were found to be easy to deliver, require very little resource, and have a modest effect on cancer awareness among UK teenagers; researchers concluded the intervention would need to be more intensive to tackle barriers to help-seeking (Hubbard et al. 2015).

Some researchers strongly recommend developing and using a detailed intervention mapping protocol or conceptual framework, such as a logic model, and exploring a theoretical framework, such as the theory of planned behaviour, behaviour change wheel or theory of change (Lamort-Bouché et al. 2017; Baumann et al. 2019; Saab et al. 2021). Where interventions have focussed on the use of social media and mHealth technologies, frameworks and evaluations seeking sustained behavioural change “are sorely needed” to build the evidence base and identify best practice (Prochaska et al. 2017).

Standardised tools and measurements can make the process of identifying impacts easier. CR UK’s Cancer Awareness Measure (CAM) is one validated and well-adopted tool.

Measuring patient delay (the time taken to consult a doctor) regarding possible cancer symptoms can be problematic as it relies on the patient to pinpoint when they first noticed a relevant symptom retrospectively (Andersen et al. 2009; Scott & Walter 2010). The General Model of Total Patient Delay (Andersen et al. 1995) suggests that from the point at which a patient detects possible cancer symptoms to when they make an appointment with their GP, there are three intervening stages (1. inferring illness; 2. deciding to seek medical attention; 3. acting on the decision by making an appointment) resulting in different delays (1. appraisal delay; 2. illness delay; 3. behavioural delay). A systematic review of this model’s application in cancer diagnosis however concludes that these initial opportunities for delay are difficult to distinguish from one another and that a more useful theoretical framework to address diagnostic delays in cancer patient pathways combines these stages and delays to “patient appraisal and self-management” and “help-seeking”. It also chooses to reframe “delays” as “time intervals” as not all patients experience delay and the term itself may be considered “value laden” (Walter et al. 2012). The stage of self-management, self-medication, or “watchful waiting” highlighted in this review is also commonly identified in qualitative research elsewhere (Smith et al. 2005; Elnegaard et al. 2016).

When evaluations find that interventions did not achieve their outcomes, they are of course still useful in informing future action. For example, an RCT of the ‘Improving Rural Cancer Outcomes’ trial that sought to reduce time to diagnosis in rural cancer patients in Western Australia via community and GP activities found no effect: no reduction in total diagnostic interval. The evaluation concluded that the dose of the intervention may have been insufficient, or perhaps better results would have emerged had they waited longer to follow up, or perhaps simply the intervention had no impact (Emery et al. 2017).

It is paramount that new interventions draw upon the evidence provided by good quality evaluations where it exists. A systematic review of studies exploring the determinants of, and interventions for, delayed presentation of women with breast cancer symptoms, found a whole range of multi-level influences on why people put off help-seeking. However, in response, intervention studies were almost exclusively focussed on raising awareness among postmenopausal women in high-income countries. This mismatch led the authors to call for the development of multi-level interventions to respond to the multi-level influences (Kailemia et al. 2020).

Covid-19

As we emerge from the global shock of the Covid-19 pandemic, the scale of the impact of national lockdowns on cancer diagnosis and treatment becomes clearer. Reduced presentations by people with cancer symptoms and a reduction in cancer services have led to "missing" diagnoses and increasing late-stage presentations.

Some researchers argue that "alternative strategies" need to be adopted during further waves of the current pandemic and any future pandemics to sustain levels of both presentation and treatment, and that "pandemic control measures and policy need to balance all health and welfare" (Purushotham et al. 2021).

One think tank report makes some succinct recommendations about how to re-engage patients with cancer pathways, reflecting messages found across cancer charities too:

1. The NHS needs help to restore public confidence in the safety of cancer services by publicising the steps being taken to ensure they are Covid-free. National and local messaging must constantly promote the safety of care facilities and explain the steps the health service is taking to protect cancer patients from Covid-19. (messaging)
2. The NHS and Government need to take targeted action to address inequalities in cancer service access, experiences and outcomes for people from deprived and ethnic minority backgrounds. This includes ensuring that the expansion of diagnostic and treatment services is focused on the communities that need them most. (targeting)
3. The pros and cons for cancer services of using remote consultations must be evaluated. (access)

- (Public Policy Projects, 2021)

Internationally, examples of initiatives that have sought to ameliorate the impacts of Covid-19 related delayed presentations include:

- **My Health Can't Wait** by Johnson & Johnson US: a public information campaign and online resource hub that seeks to encourage people to prioritise their health and reach out to their doctors about deferred care. A July 2020 Johnson & Johnson survey found that 68% of surveyed Americans said they or someone in their household had delayed or cancelled healthcare services due to COVID-19. https://www.jnjmedicaldevices.com/en-US/my-health-cant-wait
- **New Normal, Same Cancer** is an international awareness raising programme by Astra Zeneca in partnership with cancer patient coalitions (European and Global) and calls for patients to contact their doctor and return to cancer care services. https://www.astrazeneca.com/our-therapy-areas/oncology/new-normal-same-cancer.html

- **Get Checked** is a Cancer Research Wales campaign with the strapline "Cancer won't wait … and neither should you" which aims to encourage people to contact their GP if they experience possible cancer symptoms, highlighting that even during the Coronavirus pandemic, surgeries across Wales are open and safe to attend. https://www.getchecked.wales
- **Do it for yourself, not every cough is COVID** was a lung cancer awareness campaign by MSD which launched in December 2020 in the North-East of England urging people to visit their GP if they have a cough for more than three weeks. It was considered an important counter the earlier government messages around staying at home. It took a predominantly traditional media approach (television and radio) rather than social media, as the target audience was older, and used patient stories. The "DIY" message was informed by focus groups. https://pharmaphorum.com/views-analysis-oncology/world-cancer-day-msd-uk-lung-cancer-campaign/

Chapter 3: Existing campaigns: what can we learn?

Reviews of intervention studies over the years have highlighted some useful points to take forward into future interventions promoting early presentation with cancer symptoms: on messages, channels, targeting and evaluation.

All also recommend further research into what exactly an intervention or campaign needs to make it work, to be sustainable, to be replicable across different settings and to make it cost-effective (Austoker et al. 2009; Whitaker, 2019). Therefore, what can we learn from some of the most recently evaluated and current interventions in the UK about what works?

All cancers

'Be Clear on Cancer' was a long-running NHS England campaign that began in 2012. It was in fact a series of shorter, more focused campaigns that were typically active for around six weeks and were often tested locally and regionally before being rolled out nationally if shown to be effective. They aimed to increase earlier presentation with possible cancer symptoms by raising awareness of symptoms and their legitimacy for a GP consultation. The campaigns sought to emphasise the approachability of GPs and GPs were featured heavily in campaign advertising (designed by M&C Saatchi). The majority of campaigns targeted lower socioeconomic groups and people aged over 50, using multiple media channels – online, regional and national television and radio, posters - with simple messages to target both the at-risk groups and their key influencers, e.g. friends and family. (Moffat et al. 2015)

The 'Be Clear on Cancer' lung and bowel cancer campaigns increased public awareness of symptoms but failed to change perceptions of GP approachability (Power & Wardle, 2015). Nonetheless, GP attendances for symptoms directly linked to the campaigns still increased significantly (Moffat et al. 2015), and for lung cancer there were more urgent referrals and diagnoses and a shift to earlier stage diagnosis following the campaign (Ironmonger et al. 2015).

In an attempt to replicate this stage-shift, a Welsh version of the lung cancer mass media campaign ran in 2016 and saw better symptom awareness, more presentations and an increase in GP-ordered chest X-rays - but these didn't translate into increased urgent referrals, diagnoses or stage shift. This may have been down to a less intensive campaign, short follow-up or structural system and access barriers from primary to secondary care in Wales (McCutchan et al. 2020). The Welsh lung cancer campaign evaluation did find that those from lower socioeconomic backgrounds were less likely than before the campaign to state that they would be worried about wasting the GP's time. Similarly, results from the main English campaign found those from lower socioeconomic backgrounds were more likely than those from higher to consider the campaign relevant, nevertheless It was In less-deprived areas that the campaign prompted a greater increase in GP attendances (Moffat et al. 2015).

A survey of English GPs following the earliest phases of the campaign found that they were all aware of 'Be Clear on Cancer', were generally supportive, all reported increases in presentations from the campaign's target audiences (age 50+ and lower socioeconomic groups) and some GPs reported earlier diagnoses. The 'tidal wave of worried well' that some anticipated did not occur (Cancer Research UK, 2013). A retrospective review of the published evaluation results of 11 of the campaigns In England found significant evidence of impact on early parts of the patient pathway, notably, increased help-seeking by patients and urgent referrals by GPs. As for later parts of the pathway, there was some limited evidence of more and earlier stage diagnosis but no measurable Impact on survival. The study did not evaluate longer-term effects of campaigns (Lai et al. 2020).

In response to Covid-19 related reduced presentations, NHS England, NHS Improvement and Public Health England have since October 2020 been running the **'Help us, help you'** campaign. It seeks to tackle barriers to early presentation and encourage people to contact their GP if they are worried about a symptom that could be cancer. In this first phase, there have been posters and digital resources aiming to reassure patients that they can access services safely during Covid-19, with the tagline "The NHS is here to see you, safely." To what extent future phases, should there be any, will tackle the multitude of barriers to early presentation and the continuing inequalities in cancer outcomes, remains to be seen.

The **LUSH (LUng Symptom awareness and Health)** qualitative study involved interviews and focus groups with current or ex-smokers living in poorer areas of South Wales, Liverpool and North-east Scotland (Wales PRIME Centre 2017). It explored the barriers to presentation and concluded that a community-based intervention would be acceptable to this population (McCutchan et al. 2019). These findings have gone on to inform **TIC-TOC** (Targeted Intensive Community-based campaign To Optimise Cancer awareness) - a public awareness campaign and study funded by Cancer Research Wales designed to help people living in deprived communities recognise vague cancer symptoms and present to their GP. The campaign will run for 6-months in the second half of 2021 within the Cwm Taf Morgannwg Health Board area and will use cancer champions to distribute materials, engage communities and hold awareness raising events, complemented by positive messages on local media including buses, radio and Facebook. The study will seek to make best use of the RDC ("one-stop diagnostic shop") to accelerate referral of patients with vague but concerning symptoms and will aim to measure outcomes including a reduction in patient delay, increased referrals and campaign cost-effectiveness (Cardiff University, 2020).

A separate study protocol has been developed for the **ABACus** (Awareness and Beliefs About Cancer) trial, which will use a facilitated health check to seek to improve symptom awareness and help-seeking among adults living in socioeconomically deprived communities in the UK (Moriarty et al. 2019). This was Informed by a study to test a 30-question online health-check tool, originally developed by Tenovus Cancer Care. Based on the findings of a systematic review and focus groups, the study team applied information on barriers to help-seeking to Michie's behaviour change wheel to refine and update the tool and concluded that this online health-check facilitated by a trained community member may prove effective at engaging hard-to-reach groups and maximizing intervention usability, acceptability, reach, and feasibility (Smits et al. 2017).

A study examining **Health Awareness Days** found that, as an intervention to raise awareness and tackle health inequalities, they are misaligned with research on the social determinants of health and the principles of ecological models of health promotion, which recognise that health behaviours have many various influences. The study therefore calls into question the effectiveness of health awareness days (Purtle & Roman, 2015). The researchers note that there are nearly 200 health awareness days, weeks, and months on the US National Health Observances calendar, and more than 145 awareness day bills have been introduced in Congress since 2005.

Targeting specific cancers and populations

'Healthy Communities' ran from 2007 to 2010. Commissioned by the then Health Inequalities Unit of the Department for Health, it sought to promote earlier presentation of symptoms of bowel, breast and lung cancer in 19 of the most-deprived areas of England. The Healthy Communities approach supported community volunteers, in partnership with primary care staff and other specialist cancer service providers, to use improvement tools to drive change from within the community. The number of urgent 2-week referrals and diagnoses of these cancers increased, and an early evaluation found that the strengths of the programme lay in community involvement and the creativity and flexibility of the approach, which helped engage the hard-to-reach and link communities with clinical expertise (Lyon et al. 2009).

'Promoting Early Presentation' or PEP was an intervention designed to sustain increased breast cancer awareness in older women. It involved a scripted 10-minute individual presentation on breast symptom awareness and self-examination, delivered by a health professional, either the radiographer or nurses in general practice, at their last scheduled breast screening session, at age 67-70. A series of studies have shown positive outcomes, including increased breast cancer awareness at three years post-intervention (Linsell et al. 2009; Forbes et al. 2011a; Campbell et al. 2015; Kaushal et al. 2016; Dodd et al. 2017).

A **lung cancer** awareness initiative in North-East Scotland was designed and developed iteratively by researchers working in close consultation with patients and health professionals in the target area. Focus groups reflecting on first draft intervention components identified patient engagement, achieving behavioural change, and conflict at the patient–general practice interface as challenges, therefore measures were incorporated to tackle these and the final intervention delivery included:

- A detailed self-help manual using behaviour change techniques, including: a simple checklist of symptoms that need action and when; if–then action and coping plans based on identified barriers to consultation; specific advice on what to say and expect when making appointments; 1,2,3 action plan logo repeated throughout the manual
- An extended semi-scripted consultation with a trained research nurse at which specific action plans are devised, including prompts to self-monitoring - monthly postcards, texts, or stickers - to themselves and close others
- Celebrity endorsement by a Coronation Street actress with emphysema, and messages from local specialists, GPs and patients with chest disease encouraging consultation
- Messages referring to a range of lung disease, not only cancer; messages prompting 'special attention' rather than fear; frequent messages about the benefits of early consultation; stories and speech bubble messages from patients about early and late consultation.(Smith et al. 2012)

While the study found the intervention appealed to the patients and health professionals engaged in its development and had theoretical potential for benefit, it is unknown whether the intervention was rolled out further and evaluated.

A separate **early diagnosis campaign for lung cancer** in Leeds which ran from 2011 included public and primary care facing components:

1. Presentations to primary care teams about NICE guidelines for chest x-ray referral and the importance of early lung cancer diagnosis
2. A multi-faceted marketing communications campaign
3. Community health educators, or cancer champions, who engaged target populations
4. A self-request chest x-ray service for patients aged 50 years and over with respiratory symptoms lasting 3 weeks or longer

Following up in 2015, researchers found that chest x-ray rates had almost doubled and there had been a significant shift in lung cancers being diagnosed earlier. Inequalities recurred however: diagnoses among patients from the most deprived groups reduced over time, while diagnoses among patients from the least deprived groups increased (Kennedy, et al. 2018).

This paper has not explicitly reviewed the literature on cancer screening initiatives, as the behaviours around screening participation are different to those for symptom awareness and early presentation, and as a result so too are the Interventions. Nonetheless, cancer screening initiatives that focus on recruiting at-risk groups who are less likely to participate in universal or targeted screening initiatives can offer a useful Illustration of the particular components employed to engage participants.

With **oral cancer** rates on the rise and certain black and minority ethnic groups at elevated risk due to the prevalence of risk factor behaviours, an oral cancer screening initiative was developed targeting Bangladeshi residents of Tower Hamlets in East London who smoked or chewed tobacco, areca nut (betel nut) or paan. The researchers established a community advisory group and held focus groups with the target population to develop the screening activity. Together they identified appropriate sites for the mobile dental unit and developed the accompanying literature. Bi-lingual (English/Sylheti) advocates were recruited to ensure cultural acceptability and to provide support during and after the screening, including promoting the activity, collecting evaluation data, recruiting passers-by, following up referral letters with phone calls, offering to accompany patients to referral appointments. Of the 1320 people screened, 75 (5.7%) were referred to secondary care for further investigation, and of the 55 who attended their referral appointment, 17 (31%) were found to have potentially malignant disorders (these figures are in-line with other studies). Interestingly, in the second, more developed, phase of the initiative over 40% of tobacco users attending screening (202 of 485) were recruited to tobacco cessation (Nunn et al. 2009).

At around the same time significant differences in **breast screening uptake** between minority ethnic groups in Central and East London were discovered: 60% in white Indian populations, but 40% in Pakistani and 37% in Bangladeshi populations. A whole system approach to improve uptake was tested. For example, some women received a telephone call to invite them to screening, rather than a letter, specifically in response to some women who could not read or use a spoken-only dialect such as Sylheti. Community organisations called women who did not attend their appointments, rebooked their appointments for them and, in some cases, provided transport. A 'Bosom Buddy' pilot encouraged women who had been screened to recruit a friend or family member to screening and 'well-women' pilots provided 'prescriptions' for breast screening. GP practices received training and an incentive payment for additional eligible women screened, while the breast screening service staff received customer service training, developed a service charter and a dedicated call centre. Participation in breast cancer screening increased by 20% over four years (Eilbert et al. 2009).

Some reflections

Taking a long view reminds us that, broadly-speaking, cancer survival in Wales is better than 10 and 20 years ago; today, many more people survive beyond cancer each year.

However, “missing” diagnoses as a result of the Covid-19 pandemic are likely to set back recent progress in cancer survival (which had been slowing before a pandemic was declared). The infection control measures taken and public messaging to protect the NHS seem to have further discouraged many from accessing healthcare – potentially especially those previously less likely to present to healthcare with cancer symptoms. This alone seems likely to exacerbate inequality in cancer outcomes in Wales.

It therefore feels imperative that learning and evidence-informed innovation is accelerated to encourage, enable and empower people who potentially have cancer to access primary care and diagnosis services as early as possible.

There is a lot of nuanced, context-specific knowledge contained in the available literature referenced here, and this can appropriately inform Moondance Cancer Initiative’s thinking as we consider what role we might be able to play in improving rates of early presentation for cancer symptoms, especially for Wales’ more-deprived communities.

We will continue to digest this study, and ongoing developments. This evidence review offers insights that could inform both service and policy change but our immediate focus is to inform our own funding and action. Some initial thoughts on what this evidence could mean for us include (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 and the usual preserve of national public health agencies
- However, there is a space – and arguably 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 those facing cultural and language barriers – action should be driven by local data analysis
- A rigorous intervention design and evaluation is of course key, if our aim includes wider adoption of a trial intervention should it work
- Studies and interventions have been led by all sorts of organisations – indicating there is no firm ‘home’ for them
- Efforts to increase presentation should ideally be mirrored by services ready to receive them; conversely, the introduction of service changes –

such as RDCs – potentially provide a ‘hook’ for promoting awareness and attendance

- While most of the evidence afforded is UK based, while conducting this study we have identified a number of campaigns internationally that we can usefully evaluate further too
- 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.

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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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