

**P-05-936 Offer Bowel Cancer Screening After the Age of 74, Correspondence –
Bowel Cancer UK to Committee, 24.03.20**



Briefing Paper for Welsh Assembly Petitions Committee

Bowel Cancer Screening: self- referral from 75

March 2020

Bowel Cancer UK strongly believes that there should be parity across all four nations of the UK to ensure everyone has the same opportunity to have bowel cancer either prevented or detected early.

Currently in Wales, people who are aged 75 and over are not eligible to self-refer back into the screening programme as they are in England and Scotland. Welsh Government rationale for this is outlined below, but simply put, due to insufficient research studies being carried out, there is a lack of evidence that allowing those in this age cohort to self-refer would provide a benefit on a population base. The Welsh Government has therefore made a policy decision not to allow this group to continue to participate in ongoing bowel cancer screening.

As a result of this, we would expect the Welsh Government to take the necessary steps to explore developing modelling and a robust evidence base which enables them to review their position and allow those who are over the age of 75 to self-refer back into the Welsh Bowel Screening Programme.

If sufficient evidence is unavailable or, a definitive conclusion cannot be drawn, then we would expect a pragmatic approach to this and based on the representation made by older people themselves, we would expect Welsh Government and Public Health Wales to do the right thing and allow self-referral as they do in Scotland and England.

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1. Introduction

Bowel cancer screening is a way of testing people without symptoms of the disease to see if they show any signs of early cancer. Screening of the eligible population provides the greatest opportunity to detect bowel cancer early, when treatment has the best chance of working. The bowel screening Faecal Immunochemical Test (FIT) is designed to detect tiny amounts of blood in your poo which can indicate the presence of cancer or polyps (non-cancerous growths).

In England, Wales and Northern Ireland people aged 60-74 are invited to take part in bowel cancer screening. In Scotland, screening starts from age 50. People are invited to take part in screening every two years.

The Welsh Government has committed to lowering the screening age to 50 in line with Scotland and international best practice. Implementation of screening from 50 at a sensitivity threshold of FIT to 80 µgHb/g will be complete by 2023. England has not set out any clear timescales to date.

Whilst it is fantastic news that the screening age is to be lowered to 50, currently in Wales and Northern Ireland (unlike England and Scotland) participants are not permitted to self-refer back into to screening programme once they reach the age of 75.

2. Bowel Cancer in Wales

In Wales, 1 in 13 men and 1 in 18 women will be diagnosed with bowel cancer during their lifetime. It is the fourth most common cancer in Wales UK, and the second biggest cancer killer, with up to 16,000 people dying each year. In Wales, 2,300 people are diagnosed and 900 people die each year. Approximately 60% of those diagnosed with the disease will survive for five years or more.

The risk of developing bowel cancer increases with age. Nearly 6 in 10 cases are diagnosed in people age 70 or over¹. Regular bowel cancer screening has been shown to reduce the risk of dying from bowel cancer by over 16%, with new treatments increasing survival rates.

3. The UK National Screening Committee position on self-referral over the age of 75

The UK National Screening Committee (UK NSC) provides advice on screening to all four nations. It periodically reviews its position in light of new technologies and interventions. It currently does not make explicit recommendations around screening from the age of 75. The only reference to self-referral is made in the January 2016 guidance which states that:

“Eight out of 10 people with bowel cancer are over 60 years old. Screening is routinely offered every two years to men and women between the ages of 60-74. [People over the invitation age range can self - refer²](#).” (Click on the link to see the recommendation)

¹ UK National Screening Committee, August 2018

² UK NSC bowel cancer recommendation January 2018

This was raised at a recent meeting with the Welsh Government (see below). However, Bowel Cancer UK was informed that this was a presentation error and in fact the recommendation was only relevant to NHS England. As such, Welsh Government does not include recommendations for those who are aged 75 and over.

4. Seeking to change the Government's Position

In April 2019, Bowel Cancer UK in Wales was contacted by a north Wales constituent who had, in late 2018, made an approach to his GP when he turned 75 to ask about bowel screening. He was told that those over the age of 75 are no longer able to self-refer back into the programme. Following his GP visit, he wrote to his local Assembly Member to outline his concern as follows:

"My concern arises not only because of my age but also because my mother died of the disease. The latter is not a genetic risk factor but has served as a warning. Survival with bowel cancer is strongly dependent upon early diagnosis which is afforded by effective regular screening. For this reason both my wife and I have always participated in the NHS Wales biennial screening program available at present only for those aged 60-74. The GP in question confirmed that screening is not now available to me because of my age".

In response to this letter, his Assembly Member wrote to Vaughan Gething, the Welsh Government Health and Social Care Minister. The return correspondence was received on 3 January 2020. This was shared with Bowel Cancer UK. In it, he stated:

"Population screening is not without risk so there needs to be a balance between the benefits and harms of the screening test being offered. For asymptomatic bowel screening above the recommended age group, the additional risks from false positive results and any follow – up investigations outweigh the potential benefits in an older population"

He went on to say:

"I would like to reassure you that the decision not to offer screening to those outside the recommended age group is not based on economic factors".

In May 2019, further correspondence was sent to the Minister outlining an extensive literature review which had been conducted by the north Wales constituent involved and stated:

"Firstly the Minister states that Wales, like the rest of the UK, follows the expert advice of the recent UK NSC policy of 2018 which recommends that bowel cancer screening be offered to both men and women only up to 74 years of age. However, my concern derives from the difference in reaction to that recommendation by Scotland and England. Both of these nations allow faecal blood tests on patient request for those older than 74 years.

"The letter of the Minister suggests that this difference in reaction to the recommendation in Wales derives in the main from a perception that the risks of screening always outweigh the potential benefits in elderly patients. I have

examined the literature evidence for this view in order to satisfy myself that it is generally correct. Unfortunately I have failed to find conclusive evidence”.

In response to this letter, the Minister wrote back in June 2019 stating:

“That on the balance of available evidence, the UK National Screening committee does not recommend screening from the age of 74 years”.

The letter also stated that:

“Self-referral for men and women over the age of 74 is due to be considered in the autumn”

Bowel Cancer UK in Wales, working alongside the constituent involved, requested a meeting with the Minister to discuss the matter in person. A meeting was offered with civil servants. It was at this time, that we were informed that the Welsh Government had asked Public Health Wales to do some insight work into the issue of self-referral for those over the age of 75.

a) The view beyond Wales

It was also during this time, that Bowel Cancer UK in Wales wrote to experts and members of the UK National Screening Committee and also sought clarification from NHS England on their decision to allow self-referral for this cohort. We received the following from Public Health England:

“The UK NSC uses published evidence to justify recommendations on most aspects of programme: age, interval, tests, etc. The large research studies that underpin the cancer screening programmes were done a while ago and stop around 70/75 years. This means that there is an absence of evidence about whether screening does more harm than good at these ages. In that circumstance, recognising that cancer is commoner as you get older, the English programmes decided to allow self-referral over 70/75”.

b) Welsh Government Meeting

In October 2019 we met with the Welsh Government and patients. Below is an extract from the minutes:

“It was accepted that although the risks of screening are generally greater in an older population that the overall health of individuals is variable, and that individual risk assessments should be coproduced in every clinical contact. It was also agreed that it was not the initial screening test but the follow-up investigations that provide most risk. Welsh Government colleagues added that evidence from the whole pathway – from screening test to treatment - needed to be considered when assessing benefit and risk.

“Bowel Cancer UK made a comparison with risk from diagnostic pathway. Welsh Government colleagues commented that it was important to make the distinction between the risks from interventions for someone who is symptomatic (when clinical presentation should lead to appropriate

intervention) and someone who has no symptoms, perceiving themselves to be healthy (when there is a possibility for over diagnosis and unnecessary treatment as well as anxiety). Evaluation of a population screening programme has to take account of potential harms as well as benefits”.

In this meeting Bowel Cancer UK highlighted that there is a lack of research studies on which the decision not to provide screening to people over the age of 74 had been made. Welsh Government uses this lack of evidence base as a reason not to recommend self-referral. However Bowel Cancer UK argues that the UK Screening Committee and the Welsh Screening Committee should be seeking to develop new research studies to develop an evidence base. Until this is done, the Wales Screening Committee should be adopting the pragmatic approach to allow self-referral.

Welsh Government colleagues have suggested that Bowel Cancer UK make a request for modification to the bowel screening programme directly to the UK National Screening Committee for them to firm up their position. We are currently exploring all options, however it is unlikely that a modification would be made without rigorous data analysis to develop the evidence base as outlined above.

Based on representations that had been made to Bowel Cancer UK from members of the public who had been adversely affected by this policy position, we put forward the argument that this could be seen as ageism against those over 74 who were concerned about developing bowel cancer. The meeting notes state that “*Welsh Government Colleagues said it was emphatically not a policy affected by ageism, but by the evidence and UK NSC recommendation*”.

It was suggested that the constituent write to the UK Screening Committee to ask if he could join their public involvement group. This has been followed up and the request has been accepted, though to date he has not started in the role.

c) Older People’s Commissioner

Following the meeting and being dissatisfied with the rationale being offered regarding lack of evidence, Bowel Cancer UK wrote to the Older People’s Commissioner. A meeting took place on the 13 January 2020. Lack of data and evidence to make recommendations in the wider screening context were discussed. The Commissioner and Bowel Cancer UK wrote jointly to the UK NSC in February 2020, to state that both considered the development of an evidence base for the case for extending the screening programme beyond the age of 74, or for allowing older people to opt in, is a matter of urgency, and to ask the Committee, as a first step, to confirm how the evidence base could be strengthened, whether any steps are being taken to fill gaps in research, and if so, what they are. To date we have not received a response to this letter.

d) Wales Screening Committee

Bowel Cancer UK approached the Welsh Government to ask for the minutes of the Wales Screening Committee meeting that the Minister had referenced in his earlier letter was due to take place in the autumn of 2019. Due to changes that had been made to the website, the minutes had not been posted online, however civil servants sent an excerpt as follows:

“4.3 Bowel screening outside the recommended age range

The Public Health Wales representative presented a paper on self-referral into the bowel screening programme over the UKNSC recommended age range that had been commissioned by the Welsh Government. It was noted that there are no colorectal cancer screening trials that have specifically reported the effectiveness of screening in average to high risk individuals under 50 years of age or over 75 years of age, therefore, the benefits and risks are not fully known in this population.

It was noted that the only countries to allow self-referral over the age of 74 are England and Scotland with the USA allowing referral from a GP up to the age of 85. It was estimated that only 1.5% of the population who are over 74 would self-refer in Wales amounting to an estimated additional 85 colonoscopies per year.

It was agreed that although this is a relatively small number of referrals it should be seen in the wider context of the current demand on colonoscopy services and the optimisation of the bowel screening programme. The Committee agreed it was necessary to get clarification from the UKNSC on its position with regards to self-referral or await phase 2 of the SchARR report that should provide the analyses required to support a decision, but there was no evidence to warrant changing the recommendation at present.

Action 6: Chair to write to UKNSC”.

e) The SchARR Review

Following this communication, Bowel Cancer UK wrote to the School of Health and Related Research (SchARR) at Sheffield University to find ask whether their next phase of modelling around screening will indeed include self-referral modelling for those over the age of 75.

A response was received on 9 March 2020 outlining that their understanding was that the decision to allow persons over the age of 74 to opt back into the screening programme (in England and Scotland) is not based on a cost effectiveness analysis, rather this was a pragmatic decision as outlined in the NHS England response above.

They confirmed that phase two of the research has been completed and that it will be written up in the next few weeks.

Whilst the current scope of the phase two modelling did not set out to answer questions around self-referral from 75, they indicated that further analysis could be done. Bowel Cancer UK has made an offer to convene a meeting with Public Health Wales and Welsh Government colleagues to see if the report could indeed provide insight to help develop a sound evidence base with which to review the current position.

No response has been received to date.

5. What are older people themselves telling us?

Whilst Bowel Cancer UK continues to influence this policy area, regular representations are made to the charity by older people themselves who are frustrated by the current position.

Those who are contacting both Bowel Cancer UK and the office of the Older People's Commissioner are being told to contact Bowel Screening Wales helpline and lodge an official complaint.

Mrs Probert has given permission to share her experience:

My husband Clive wasn't screened after 73yrs because the next appointment fell after his 75th birthday. He was diagnosed at 76 stage 4 ascending bowel cancer. Until this time he had no illness except diet controlled diabetes. On diagnosis we were told if it was diagnosed earlier he may have lived. The doctors told us at time of diagnosis that they were able to treat him so he went through four major ops and two complete courses of chemo. The excellent consultant in Velindre stated to me if only they had found it early he would have survived as until his diagnosis he was very fit man. He was 76 when diagnosed and died aged 81. If only screening was open to over 75yrs after which age the bowel cancer becomes more prevalent. Some people may live longer and not cost the health services so much money to no avail. Yours Mrs A Probert"

Correspondence from the Older People's Council for Ynys Mon

I have been approached by people concerned that the bowel screening stops at the age of 74. It is my understanding from NHS Wales that that age is under review. It is also my understanding that the Older People's Commissioner for Wales has written to the Welsh Government regarding this issue too. I would be grateful if you could let me know the current position regarding this issue and how individuals or groups can make known their views too.

Whilst concluding this evidence briefing for the National Assembly's Petitions Committee, the UK is dealing with the national coronavirus emergency and all adult cancer screening programmes have been suspended for a period of eight weeks.

We fully appreciate that our severely overstretched NHS is facing unprecedented demand at the moment. We know that the Welsh Government, along with senior NHS colleagues will not have taken the decision to pause the Bowel Cancer Screening Programme lightly and there are a number of reasons why NHS health boards requested this pause, including the reallocation and availability of staff over the coming weeks and months.

This is not an ideal situation, but at times like these there is a need for pragmatism. The hope is that the service will resume as soon as it safe to do so and that the wider issues of self-referral for those over 75 be considered once our screening services return to normal and that the Welsh Government take the necessary steps to explore developing a robust evidence base which enables them to review their

position and allow those who are over the age of 75 to self-refer back into the Welsh Bowel Screening Programme.

For more information please contact Lowri Griffiths, Head of Wales, Bowel Cancer UK Lowri.griffiths@bowelcanceruk.org.uk