

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Gwasanaethau endosgopi](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Endoscopy Services](#)

EN 02

Ymateb gan: | Response from: Tenovus Cancer Care



Response to Endoscopy Services: Follow up Inquiry

Call for Evidence

December 2022

Tenovus Cancer Care is one of Wales's leading cancer charities, with a long and distinguished history of providing practical and emotional support to everyone affected by cancer in their community.

We are committed to working alongside people affected by cancer to champion their needs, raise awareness of the issues faced and ultimately improve cancer outcomes.

We welcome this follow up inquiry to the 2019 Health, Social Care and Sport Committee's inquiry and report [to which we contributed evidence](#). We wish to submit additional evidence to this follow up inquiry, only this time focus on the contributions we've received from people who have experienced endoscopy services in Wales.

Tenovus Cancer Care has set up the All-Wales Cancer Community (AWCC), a community of people affected by cancer from across Wales who want to improve cancer services. The people who join the AWCC are given opportunities to contribute to policy, services and cancer research in lots of different ways and they are able to pick and choose which ones suit them best. For example;

- Telling us about what they think needs to happen to improve early diagnosis, treatment, care and support for people affected by cancer,
- Helping us to understand the ever-changing issues affecting people with cancer across Wales to inform policy positions and campaigns

- Talking about the experience of having cancer at events and meetings with political decision-makers.
- Accessing consultations and other opportunities to have their voice heard by parties outside Tenovus Cancer Care.

Since the summer of 2022 104 people have signed up to the AWCC. Of those 8 have had a bowel cancer experience, 1 has had a HPV head and neck cancer experience and 1 has had laryngeal cancer. All of which would have an endoscopy experience in order to confirm their cancer diagnosis.

During the call for evidence period Tenovus Cancer Care, reached out to the members of the AWCC and through an online survey (appendix 1) sought to understand their recent experience of endoscopy services in Wales.

Cancer diagnosis

Three members of the AWCC responded to the survey, a response rate of 30% amongst people who may have had an endoscopy experience. All three respondents were diagnosed with their cancer following a referral from their GP, two were diagnosed with colorectal (respondent 1, female) / bowel (respondent 2, male) cancer, while the third was diagnosed with cancer at the base of the tongue (respondent 3, male).

Year of procedure

Of the two respondents with bowel cancer, one received her diagnosis in July 2021, while the other received his diagnosis in 2014. The latter, respondent 2, has received a colonoscopy every year since the initial 2014 diagnosis. Respondent 3 received his diagnosis in 2017.

Experience of procedure

Respondents were given the opportunity through an open-ended response to share their experience of undertaking the procedure. Respondents 2 and 3 had very different experiences. Respondent 2 :

“Very easy...but that has become easier over the years.”

Respondent 3:

“Very painful.”

Length of time waiting for procedure

Respondents also reported different lengths of time waiting for their endoscopy procedures. Respondent 1 waited 3 weeks in 2021 for a colonoscopy in North Wales, while respondent 2 had to wait 4 months around 2014 before getting his colonoscopy.

Respondent 3 waited 3 months for his procedure.

Additional comments concerning their procedure

Respondent 1:

“The Endocare team came to Ysbyty Gwynedd on a Saturday to do this procedure. They were a great team and putting me at ease and the consultant told me after the treatment that it was cancerous and that I would need treatment within 6 weeks.”

Respondent 2:

“I saw the tumour and questioned it during the initial sigmoidoscopy. I feel that seeing it helped me come to terms with having cancer.”

Respondent 3:

“Was explained in detail and was as told.”

While a limited number of responses, this evidence demonstrates lived experience of Wales' endoscopy services. The respondents contributed to the call for evidence over a short period of time and paint a mixed picture concerning their overall experience, from the very easy to very painful, and waiting times ranging from weeks to a number of months.

All of the respondents have given consent to be contacted again if there was an opportunity to contribute further to the ongoing follow-up inquiry. If the Committee wishes to follow up, please contact Greg Pycroft, Policy and Public Affairs Manager at Tenovus Cancer Care to discuss.



AWCC - Endoscopy Consultation

This survey is for people who have had a cancer diagnosed via an endoscopy.

An endoscopy is a test that looks inside the body. The endoscope is a long flexible tube which has a tiny camera and light on the end of it.

There are many types of endoscopes and the doctor uses these to look inside different parts of the body.

The name of the test you have will depend on which part of the body the doctor is looking at. An endoscopic procedure includes colonoscopy, flexible sigmoidoscopy, gastroscopy and bronchoscopy.

1. What cancer type(s) have you been diagnosed with?

2. How were you diagnosed?

- Endoscopy following GP referral
- Endoscopy following positive screening result
- Endoscopy following positive FIT test at the GP
- Endoscopy following emergency admission
- Incidental finding during other routine diagnostics or surgery
- Other (please specify)

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3. What is your experience of having an endoscopic procedure (e.g. colonoscopy, flexible sigmoidoscopy, gastroscopy, bronchoscopy)?


4. When did you have the procedure?

5. How long did you have to wait for the procedure, and did it feel appropriate?

6. Is there anything else you would like to say about your endoscopy experience?

7. We may wish to contact you for further discussion about your experiences, if you would like to participate further, please provide your email address here:

Done

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