

# Cross-Party Group Minutes

## **Cross Party Group Details**

### **Cross Party Group Title:**

Cross-Party Group on Cancer

### **Date and time of meeting:**

10:00am-11:00am, Thursday 12<sup>th</sup> December 2024

### **Location and state of holding (in-person/ remote/ hybrid):**

Remote – MS Teams

### **Name of Group Chair:**

David Rees MS

### **Name of Secretary and Organisation:**

Ella Davies - Cancer Research UK

### **Purpose of the Session:**

This meeting will mark one year since the 'Unheard: Women's Journey Through Gynaecological Cancer' report was published. This meeting will revisit this work, and will hear how the patient experience helped shape the report as well as what we can do, and what is planned, to improve these experiences.

### **Topic:**

This session focused on gynaecological cancer in Wales.

**In attendance:**

**Name/title/organisation:**

Dr Altaf Hussain MS, (AH)

Mark Major, Staff Cymorth yr Aelod | Member Support Staff for Dr Altaf Hussain MS

Ryland Doyle, Staff Cymorth yr Aelod | Member Support Staff for Mike Hedges MS

Rhys Hughes, Staff Cymorth yr Aelod | Member Support Staff for Rhun ap Iorwerth MS

Emily Hearne, Staff Cymorth yr Aelod | Member Support Staff for David Rees MS

Jamie Williams, Staff Cymorth yr Aelod | Member Support Staff for Dr Altaf Hussain MS

Mike Bryan, Staff Cymorth yr Aelod | Member Support Staff for Natasha Asghar MS

Rhys Thomas, Staff Cymorth yr Aelod | Member Support Staff for Sam Rowlands MS

Oliver Morgan, Staff Cymorth yr Aelod | Member Support Staff for Peter Fox MS

Claire O'Shea, Claire's Campaign (CO)

Dr James Baker, Cancer Research UK

Simon Scheeres, Cancer Research UK (SS)

Ella Davies, Cancer Research UK

Katrina Brown, Cancer Research UK

Ceri Wyborn, Cancer Research UK (CW)

Dr Peter Henley, Cancer Research Wales

Dr Lee Campbell, Cancer Research Wales (LC)

Claire Nelson, NHS Executive

Chloe Dobbin, NHS Executive

Andrew Jones, NHS Executive

Johanna Brown, NHS Executive

Lisa Wilks, NHS Executive

Dr Louise Hymers, NHS Executive

Bethan Williams, NHS Executive

Thomas Jones, NHS Executive

Roxanne Green, NHS Executive (RG)

James Davis, NHS Executive

Laura Keighan, NHS Executive

Phoebe Shanley, Tenovus Cancer Care

Maddy Young, Tenovus Cancer Care

Nirushan Sudarsan, Tenovus Cancer Care

Greg Pycroft, Tenovus Cancer Care

Lowri Griffiths, Tenovus Cancer Care

Tracey Burke, Cancer Aid Merthyr

Rebecca Elley, Fair Treatment for the Women of Wales

Krishna Patel, Deryn

Matthew Jones, Breast Cancer Now

Jessica Potter, Target Ovarian Cancer

Andrew Reynolds, Young Lives vs Cancer

Hilary Webb, Blood Cancer

Thomas Brayford, Brain Tumour Research

Juliet Jarvis, Teenage Cancer Trust

Dr Louise Hanna, Velindre University NHS Trust

Sian Jenkins, Betsi Cadwaladr UHB

Dr Geeta Kumar, Betsi Cadwaladr UHB (GK)

Elaine Hampton, Betsi Cadwaladr UHB

Joanne Hussein, Betsi Cadwaladr UHB

Lindsay Williams, Swansea Bay UHB

Holly Speare, Swansea Bay UHB

Amanda Howard, Health Education and Improvement Wales

Jonathan Clarke, Aneurin Bevan UHB

Rhiannon Griffiths, Aneurin Bevan UHB

Sally Spillane, Cardiff and Vale UHB

Dr Jeff Turner, Cardiff and Vale UHB (JT)

## Apologies

David Rees MS (Chair) was unable to attend. Dr Altaf Hussain MS chaired the meeting on his behalf.

## Minutes

### Opening:

- **Simon Scheeres (SS)** starts the meeting by welcoming attendees and giving notice that the group chair David Rees MS sends his apologies and **Dr Altaf Hussain MS (AH)** will be chairing this session on his behalf.
- **AH** introduces himself as a retired medical professional and Senedd Member and welcomes attendees.
- **SS** welcomes **Ceri Wyborn (CW)** from CRUK to begin her presentation on gynaecological cancer.

### Presentations:

- **CW** starts her presentation on behalf of Cancer Intelligence at CRUK by providing an overview of gynaecological cancers and points out that in the last three-year period, mortality rates for gynaecological cancers in Wales were significantly higher than the UK average.

- **CW** speaks of the risk factors for developing gynaecological cancers which include age, genetics, infections and preventable lifestyle factors such as smoking and obesity.
- **CW** talks of the survival outcomes by cancer stage, pointing out that at stage one for cervical, ovarian and uterine cancers, more than nine in ten women will survive their disease by five years or more, in comparison to one in ten women diagnosed with ovarian cancer at stage four, demonstrating the need for diagnosing cancers as soon as possible for better cancer survival outcomes.
- **CW** explains that patients diagnosed through emergency presentations are more likely to have later stage disease which impacts treatment options. In the case of cervical cancer, **CW** states that 38 per cent are diagnosed at the most advanced stage through emergency presentation compared to 10 per cent when diagnosed through GP referral.
- **CW** points out that currently there is no routinely published data on stage by routes to diagnosis in Wales.
- **CW** moves on to provide information about cancer waiting times, explaining that in July 2024, only 42 per cent of patients started their treatment on time.
- **CW** refers to data on individual health boards from July 2023/24, showing the proportion of patients receiving treatment on time has ranged from 22 to 60 per cent across health boards.
- **SS** thanks **CW** for her presentation and welcomes **Claire O'Shea (CO)** to share her experience and campaign.
- **CO** introduces herself and gives an overview of her cancer journey, speaking of the symptoms she began experiencing in 2021 such as the presentation of a lump, abdominal discomfort, bladder pressure and back pain which were misdiagnosed as irritable bowel syndrome.
- **CO** refers to the misdiagnosis as medical gaslighting as she doubted her own thoughts upon being dismissed by medical professionals in primary care services.
- **CO** talks about being diagnosed with fibroids and waiting eight months for a biopsy to be undertaken, to then receive a diagnosis of leiomyosarcoma six weeks later.
- **CO** describes being disappointed with the time taken to receive a diagnosis from first presenting with symptoms and how scans which had been recommended on her medical records had not been undertaken. Following her own request, a scan later revealed she had stage four sarcoma in her liver, lungs and hip bones.
- **CO** points out that leiomyosarcoma has a 5-year survival rate of 40 per cent, which crucially hinges on being diagnosed at an earlier stage.
- **CO** explains that following her diagnosis, she provided evidence to the Senedd Inquiry into gynaecological cancers and began working with Tenovus Cancer Care to raise awareness of her experience.

- **CO** points out that following her increased media presence, she has been contacted by many women with similar experiences of being misdiagnosed with irritable bowel conditions or having pain not being taken seriously, with many being diagnosed at a later stage through emergency presentations.
- **CO** shares information about 'Claire's Campaign', getting women together to share qualitative stories and experiences where they may have otherwise been scared to make complaints, challenge health boards through fear of impacting their care and to talk of the stigma of having gynaecological cancer.
- **CO** talks of the successes of the campaign, notably that she is talking to the Welsh Government and external organisations on how to improve the situation for women in Wales.
- **CO** points out that despite gynaecological cancer being a government priority, only 38 per cent of women are meeting the targets and no overall improvements have been made in the last year since the Inquiry was launched.
- **CO** notes the most important factor of her campaign is for women to be able to vocalise changes in their care and to be listened and feel supported in healthcare spaces.
- **AH** thanks **CO** for her presentation and lends his support to her campaign. He reiterates that patients are not being trusted and primary care services need to improve on this.
- **AH** points out that he has tried to get data on gynaecological cancer in Wales but was unable to find any. He also asks about information provided on fibroids.
- **SS** thanks **CO** for her presentation and invites **Roxanne Green (RG)** from the NHS Executive to begin her presentation.
- Before beginning, **RG** invites **Dr Geeta Kumar (GK)** to ask a question.
- **GK** comments that the Royal College of Gynaecology has reviewed information provided on fibroids and while deemed acceptable, she will be taking the issue back to the British Gynaecological Cancer Society to look into leiomyosarcoma warning signs. **GK** points out that information about leiomyosarcoma is provided on patient information leaflets when undergoing fibroid removal procedures.
- **GK** also explains that an audit is currently being undertaken on leiomyosarcoma in Betsi Cadwaladr UHB which will be published next year.
- **RG** begins her presentation by introducing herself on behalf of the National Cancer Recovery Programme and thanks **CO** for her earlier presentation.
- **RG** explains that gynaecology was scoped as a priority cancer site, and she provides an overview of the National Cancer Recovery programme.
- **RG** provides information on the programme's workstreams, including reducing the number of patients waiting for a diagnosis, reviewing the use of available capacity, digital and data availability, as well as best practice and quality standards, and innovation.

- **RG** summarises the programme approach by explaining that it will offer clinical, strategic and change management across three tiers, including regional solutions, working with health boards and trusts across Wales and defining good practice models to support the delivery of the national optimum pathways.
- **RG** explains there is also an element of transformation funding as part of the £2m budget, which has received over 90 applications.
- **RG** ends her presentation by explaining that the programme responds to new and existing strategic drivers collaboratively, an example being the recent ministerial-led tackling cancer innovation programme.
- **Dr Jeff Turner (JT)** begins his presentation by recognising the challenges that are being seen as part of the suspected cancer pathway performance, specifically the early cancer pathway where people are waiting for diagnostic tests for appointments and timely access to those, as well as workforce challenges and the fragility of oncology services to treat cancer in patient pathways once a diagnosis is made.
- **JT** provides an overview of the work to make pathways more efficient and streamlined within primary and secondary care, including the use of women's health hubs.
- **JT** explains there has been a discussion around guidance for women experiencing unscheduled bleeding on HRT, which is a recognised occurrence and presentation, and how people can gain timely access to diagnostic tests as part of that pathway.
- **JT** touches on how to free up capacity in the system.
- **JT** emphasises that there is an opportunity to improve data particularly around diagnostic waiting times and the importance of ensuring that primary care has consistent and equitable access to diagnostic tests across Wales.
- **JT** explains in further detail about demand and capacity for the provision of treatments and ensuring the patient's health is optimised so they are ready for treatment.
- **JT** finishes by emphasising the importance of collaborative working with different stakeholders and lends his support to the Unheard Report's recommendations.

### Questions:

- **SS** thanks the speakers and kicks off questions by asking **CO** to outline the next steps of her campaign.
- **CO** explains the aims of Claire's Campaign, including holding people to account effectively and ensuring patients know how to navigate the system following their diagnosis.
- **CO** emphasises the importance of timely referrals within primary care as it would allow for longer waiting times or delayed appointments in secondary care and of ensuring that primary care services are better informed and fully supporting women in their care.

- **AH** thanks presenters and highlights the importance of clinicians listening to their patients, to ask for help when required and having better access to diagnostic tests.
- **AH** also makes a point that referral letters should be individualised and sent to the relevant medical consultant by name to allow better prioritisation and continuation of care.
- **AH** raises a concern about a lack of data in Wales and recommends that measures need to be taken to address this.
- **JT** responds by emphasising the importance of facilitating electronic processes.
- **Dr Lee Campbell (LC)** explains that Cancer Research Wales has invested into primary care and has identified an inequity of how GPs use the NG12 guidelines. He notes this reinforces the need for uniformity across primary care and for the guidelines to be used to allow for timely referrals.
- **LC** also raises a point about institutional tension between primary and secondary care and explains a phase three cancer study has been launched to look at putting an implementation package in place within primary care services to address these concerns, as well as the introduction of cancer champions to help facilitate the patient's journey through secondary care.
- **SS** asks **LC** if he would be willing to share this work with the Wales Cancer Alliance or CPG.
- **LC** explains that up to 100 packages have so far been delivered to GP practices across participating areas of the UK and outcomes should be available in approximately 18 months.
- **AH** closes the meeting by thanking attendees and emphasising the importance of coming together to learn from each other and deliver impactful changes.

The meeting closes at 11:16am.