Minutes of the Cross Party Group on Cancer Meeting 17 March 2022

What: Cross Party Group on Cancer: *Taking Action on Less Survivable Cancers*
When: 17 March 14:00pm – 15:30pm Where: Microsoft Teams

Time	Item
14:00	**Welcome, David Rees MS (Chair)**
14:10	**Speaker presentation: Judi Rhys MBE (Chief Executive, Tenovus Cancer Care)**
14:20	**Speaker presentation: Anna Jewell (Chair, Less Survivable Cancers Taskforce)**
14:30	**Speaker presentation: Natalie Lewis (expert by experience).**
14:40	**Speaker presentation: Dr Dai Samuel (Consultant Gastroenterologist and Hepatologist, CTM HB)**
14:50	**Panel Discussion and Q&A, facilitated by David Rees MS (Chair)**
15:30	**Close, David Rees MS (Chair)**

Speakers
Judi Rhys MBE
Anna Jewell
Natalie Lewis
Dr Dai Samuel

Secretariat
Alaw Davies, CRUK

Topic
Around 19,500 people in Wales are diagnosed with cancer every year. Thanks to research, cancer survival in Wales is improving, with 58.5% of people surviving their cancer for five years or more.

However, not all cancers have seen these gains in survival. Only 16% of people diagnosed with one of the six less survivable cancers (lung, pancreatic, liver, oesophageal, brain and stomach) will survive the first five years from diagnosis. More than 4,400 people will be diagnosed each year in Wales with one of these six cancers and, because of the short prognosis, they make up over 40% of all deaths from cancer each year in Wales.

This aim of the session was to highlight the inequalities in prognosis between cancers and discuss what action is needed in Wales to improve survival rates and the quality of life for those affected by less survivable cancers. The session included speaker presentations, followed by a Q&A session. We heard from a range of speakers, including Judi Rhys (Chief Executive Officer, Tenovus Cancer Care) Anna Jewell (Chair, LSCT), Dr Dai Samuel (Consultant Gastroenterologist and Hepatologist, CTM HB) and Natalie Lewis (lay representative with lived experience of cancer).

1. Welcome
David Rees MS (Chair) opened the meeting and welcomed members.
The Chair briefly described the meeting agenda and etiquette.

The Chair introduced the panellists.
The Chair noted apologies from Joel James MS as he was not able to attend this meeting.

1. Presentation by Judi Rhys MBE (Chief Executive of Tenovus Cancer Care)

The Chair introduced the speaker. Judi Rhys MBE is currently Chief Executive of Tenovus Cancer Care and has held previous CEO roles at Arthritis Care and the British Liver Trust. Tenovus Cancer Care is a member of the Less Survivable Cancers Taskforce. Judi presented an update on the work to address lung cancer in Wales, which is one of the six less survivable cancers, of course, lung cancer, which claims more lives than breast and bowel cancer combined in Wales through the targeted lung health check project through Tenovus Cancer Care.

2. Presentation by Anna Jewell (Chair, Less Survivable Cancers Taskforce)

The Chair introduced the speaker. Anna Jewell is the Chair of the Less Survivable Cancers Taskforce, and is Director of Services, Research & Influencing for Pancreatic Cancer UK. Anna presented on the work of the Less Survivable Cancers Taskforce.

AJ noted why survival is lower for the six specific cancer sites:

- 5-year survival just 16%
- 4,400 people diagnosed each year (out of 19,500 total)
- 40% of cancer deaths in Wales
- Haven't seen the progress made in other cancers
- Need investment and research breakthroughs

AJ noted what action is needed to improve the following areas

Earlier diagnosis

- Thanks to research, cancer survival in Wales is improving, with 58.5% of people surviving their cancer for five years or more, but survival for LSCs is still at just 16%. A significant reason for this is problems with diagnosing the less survivable cancers early enough for treatment. We need a specific commitment or ambition for improving early diagnosis rates for less survivable cancers to drive improvements through awareness raising and improved ways to detect these cancers through screening or through finding better tools and tests to better triage those with vague symptoms and identify at-risk people who are asymptomatic and need further investigation.

Faster diagnosis

- Even when diagnosed at an early stage, less survivable cancers often still have poor outcomes due to delays in pathways, meaning that people have reduced treatment options and for example might move from being operable to inoperable due to rapid progression of their cancer**.** Meaning they no longer have a chance of being cured. This rapid progression also means that, while a 28-day target may be beneficial for other cancers, it is still too long for LSCs. The pathway from suspected cancer to confirmed diagnosis must be quick.

Optimal Pathways

- We too often hear through our services and through discussions with clinical specialists that there is variation in how care is delivered across the UK for our cancers and about problems with the clinical pathway. For example we hear about avoidable delays happening between initial

scans (diagnosis) and decision to treat. Sometimes delays occur due to inconclusive and outdated clinical tests or because it takes too long to do scans, fitness tests and biopsies and this can be because of lack of coordination between different hospitals as well as because of lack of standardised clinical pathways, workforce and resources.

- Diagnosing and treating people faster can help ensure more people diagnosed now get better outcomes, receive treatment, survive longer and have a better quality of life.
- An optimal pathway should cover the whole spectrum of care - from presentation of symptoms to diagnosis and access to best treatment and supportive care for those living with and cancer.

Better supportive care

- There is a dearth of information about the patient experience and quality of life of patients with a less survivable cancer. The most significant means of measuring experience of cancer care, the National Cancer Patient Experience Survey (CPES) fails to capture patient experience for the majority of people with LSCs (because of the timing of the survey), meaning that their specific needs, experiences and concerns can be overlooked.
- Health services can only effectively improve what they can understand and measure, meaning the NHS may be failing to understand and improve the experiences and quality of life of most people diagnosed with a less survivable cancer.

Boost investment in research

- Investment is needed in new diagnostic technologies and tests that can help to diagnose these cancers earlier, or help to triage those needing further investigation.
- For some less survivable cancers there is currently no simple test or a tool to timely identify symptomatic people who need further investigation. For example, pancreatic cancer presentation is characterised by vague and non-specific symptoms that have a low probability to be cancer.
- The development of new tests for cancer biomarkers could be truly transformational in helping to diagnose people with less survivable cancers earlier and faster. UK governments and research institutes should support trials of new early diagnostic biomarkers and help embed these into pathways when successful. For example, new diagnostic triage tools, such as the *Dxcover* test (in development), need additional investment. This test has shown promise in preliminary studies having recently been found to identify more than 90% of glioblastomas (the most common type of brain tumour) and more than 80% of all other brain tumours. [437 words]
- Or the Olympus/Guts UK's current research project using breath testing for pre-cancerous cell changes in patients with Barrett's oesophagus could save lives diagnosing oesophageal cancer early, when it is far more treatable. Cytosponge, a successful triage test to detect Barrett's oesophagus, which is far less invasive and resource-intensive than endoscopies, was first introduced 20 years ago but has still not been successfully rolled out or nationally implemented.
- Investment is also needed to find better ways to successfully treat the less survivable cancers.

AJ noted success in the following areas:

Optimal pathway development for pancreatic cancer

- Wales has pioneered in developing this, and is the first nation in the UK to have a specific optimal pathway for pancreatic cancer
- Good pathway, but it has not yet been implemented – this needs to be considered as part of future service integration work

- It’s crucial for pancreatic cancer to have a specific pathway, as it’s the deadliest common cancer so needs tailored steps from diagnosis to treatment and beyond

Service spec development for HPB cancers

- Integrated service for surgery, helping centres work together to become more aligned with guidelines and to deliver better, faster treatment
- If the Optimal Care Pathway for pancreatic cancer, and for other cancers when developed, was integrated into service specification – this would help with patient reviews, drive down waiting times, promote better cross-area working and increase capacity.

3. Presentation by Natalie Lewis (expert by experience)

The Chair introduced the speaker.

Natalie Lewis presented on the importance of reaching out to organisations that can help patients such as Tenovus and understanding you are not alone in your journey. Natalie was diagnosed with grade two astrocytoma in July 2016. Natalie had surgery in 2016, and in 2019 re appearance led to radiotherapy and chemotherapy. She is now living life to the fullest and having 6 monthly check up MRI scans. Natalie outlined the importance of listening to your body if you experience symptoms that could be a sign.

4. Presentation by Dr Dai Samuel (Consultant Gastroenterologist and Hepatologist, CTM HB)

The Chair introduced the speaker.

Dr Dai Samuel is a Consultant Hepatologist based at the Royal Glamorgan Hospital in Llantrisant. He is clinical lead for Gastroenterology and liver lead for the health board. He is an interventional endoscopist who performs numerous procedures relating to the management of upper GI Cancer. Dr Dai presented on "Improving and Optimising patient engagement in Cancer diagnosis and management".

DS outlined the challenges facing Welsh valleys patients as:

- Historical perception of Cancer and outcomes
- Fatalstic attitude reinforced by poor outcomes of friends and family (diagnosed at a late stage)
- Poor understanding of diagnostic and treatment options
- Lack of knowledge and understanding
- They are just scared! They are also stigmatised (esp. Liver Cancer patients)
- Our services don’t meet their needs; They serve our convenience

DS outlined what we are doing well and not so well to reverse late diagnosis:

- Probably not enough quickly enough
- Slow to embrace, lead and adopt practices piloted elsewhere
- Often view basic services established elsewhere as “specialised” (EUS)
- Lack of genuine, significant investment in workforce and infrastructure
- Trying to do everything rather than what we are genuinely really good at

DS noted what can we do to change late diagnosis in UGI Cancer:

- Use the next generation - Educate our children to educate their parents

- Celebrate success and survival - from the horses mouth
- Be bold and embrace new technology and screening tools
- Take our services to the patient - Give me a bus and I will travel
- Invest - without significant resource, expansion and investment (no more one year plans locally at UHB level) we will never achieve greatness. HCC MDT is a good example of this as is the regional pancreatic MDT
- Adopt best practice - no need to invent the wheel. We just need to buy more wheels
- Better networking, collaboration; less empire building and fear

Panel Discussion

Close

The Chair thanked all speakers and participants for their contribution.

Meeting closed 15:30

Attendees

1. Alaw Davies
2. Natalie Lewis (Guest)
3. David Rees
4. Joan Jeyes (Old Mill Foundation)
5. Judi Rhys
6. Anna Jewell
7. Katie Till
8. Kate Roberts
9. Stephanie Grimshaw
10. Mike Hedges (Guest)
11. Sarah Gwynne (Swansea Bay UHB - Oncology)
12. Noor (LSCT secretariat) (Guest)
13. Eleanor Mellor
14. Peter Henley (Velindre - CRW)
15. Sophie Baxter
16. Jane Cox (Guest)
17. Madelaine Phillips
18. Sarah Beard
19. Thomas Davies
20. Greg Pycroft
21. Chris ROWLAND
22. Joseph Woollcott
23. Ryland Doyle
24. Tracey Burke
25. Dawn Casey (CTM UHB - Patient Care & Safety)
26. Sian Morgan2 (Cardiff and Vale UHB - AWMGS)
27. Sarah Clark (Old Mill Foundation)
28. Emily Waller

29. Amy Case (Swansea Bay UHB - Clinical Oncology)
30. Richard Daniels
31. Robert Jones (Velindre - Consultant)
32. Angie Contestabile
33. Craig Lawton
34. Sara Bale
35. Heledd Roberts
36. Bethan Hawkes (NHS Wales Health Collaborative)
37. Tom Crosby (Velindre - Consultants)
38. Richard Pugh
39. David Samuel (CTM UHB - Gastroenterology)
40. Borrows, Maisie
41. Samantha Holliday
42. Martin Rolles (Swansea Bay UHB - Oncology)
43. Natalie Lewis
44. Amy Louise Smith (NHS Wales Health Collaborative)
45. Andy Glyde