

**Strategic Group**

Thursday October 7th 2021, 10.30am – 12.00pm, via MS Teams

**MINUTES**

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| **Patient & Carer Representatives:**Gill Tyrer (CPF Chair)Norma Williams ( Chair, Central)Kirsten Foster-Alexander (Vice Chair, Central)Peter Holloway (Laryngectomy support)Martin O’Donnell (Laryngectomy support)David Maitland-Price (North Wales ProstateCancer Support and Central)Michael Boyle (CHC and Central)Adrian Hattersley(North Wales ProstateCancer Support and Central)Roger Prince (Central)Val Wakefield (Joint Chair, North West)Vera Wilson (CHC and North West)Linda Pritchard (North West)Malcolm Budd (North West)Pam Wedley (Acting Chair, North East)Sarah Marshall (North East)Brian Lewin (GUTSY support, North East)Rosemary Birch ( North East)Barbara George (Wrexham Breast Cancer Support North East)Haydn Jones (Bowel Cancer Support North Wales, North East)Neil McKenzie (Strategic)Louise Andrews (Strategic)  | **Staff Representatives:**Dr Caroline Usborne, BCUHB Cancer Clinical DirectorGeraint Roberts, BCUHB, Divisional Manager, CancerCatrin Plews, Cancer Division Lead for Person Centred CareJackie Pottle, Cancer Division Lead for TherapiesEleri Anderson, BCUHB Deputy Head of Service User ExperienceSandra Anderson, BCUHB Engagement Officer, NE WalesKaren Owen, BCUHB Engagement Officer, NW WalesPat Evans, User Involvement Facilitator, BCUHB Cancer DivisionFiona Evans, Macmillan Cancer Support, Engagement Lead  |

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| **1.** | **Welcome, introductions and apologies**Gill Tyrer extended a warm welcome to patient, carer and staff representatives. **Apologies:** Betty Foster, Stuart Hatton, John George, Beryl Roberts, Laura Vernon | **Action** |
| **2.** | **Update from North Wales Cancer Services**Dr Caroline Usborne, Clinical Director for North Wales’ Cancer Services, highlighted the continuing impact of Covid-19. However, the many difficult challenges have also helped to accelerate positive change and innovation. BCUHB cancer services have performed well by comparison with other Health Boards across Wales.Following the retirement of Dr Simon Gollins, the Cancer Division has welcomed the appointment of two new Oncology Leads, Drs Claire Fuller and Cath Bale. The new BCUHB CEO, Jo Whitehead, is particularly committed to improving regional cancer services and Gill Harris, Deputy CEO, has replaced Adrian Thomas as Executive Lead for cancer services. Dr Usborne talked of the phenomenal effort by Lead Nurse Beryl Roberts and her teams in maintaining services on the Day Units and inpatient wards amidst Covid-19 outbreaks. It was noted that some Units across the UK have temporarily closed in the face of similar challenges.The main Acute Hospitals are under great pressure, but cancer surgery has been prioritised and has been impacted less than many other specialities.Dr Usborne shared positive news on the proposal to bring a **Maggie’s Centre** to North Wales, a vision driven largely by Forum member Haydn Jones. A few days previously, Caroline joined a team including senior members of the BCUHB Executive Team, Awyr Las, Maggies and the Steve Morgan Foundation on a walk-about of the Glan Clwyd Hospital site to consider possible locations for a new Centre. Several possibilities were identified. Jo Whitehead, Health Board CEO is optimistic that the Centre can be completed before the end of 2022.Although Glan Clwyd has to be the first choice for location of the main Maggie’s Centre, Dr Usborne, looking to the future, would like to see satellite centres located in North East and North West Wales.There have also been positive developments for the implementation of the **‘PSA Tracker’** a monitoring system that could prove to be a ‘game changer’ for prostate cancer patients, allowing them to self-manage their PSA levels. Dr Usborne emphasised that, whilst the technology is initially for prostate cancer patients, similar software could be used in the future for other cancers with well-defined tumour markers. This would be a great saving on clinic slots.The **Rapid Diagnostic Clinic** project, presented to the June meeting of the Forum Strategic Group, is progressing well. Funding has been secured to run a weekly clinic in each of the three Acute Hospitals, and are set to greatly improve early diagnosis of patients who present to their GP with vague symptoms that could be symptomatic of cancer. Dr Usborne recognised that **Hospital parking** is a big issue for patients of all specialities. Facilities for cancer patients were discussed during the recent walk-about of the Glan Clwyd site. The Hospital management team reiterated a commitment to develop reserved parking for cancer patients adjacent to the Radiotherapy Unit, to be accessed by a swipe-card system. Caroline acknowledged the commitment of Divisional Manager Geraint Roberts in pursing this.Dr Usborne conveyed particular thanks to **patient representatives** attending Clinical Advisory Groups (CAGs) and noted the value of their contributions to these meetings.**Discussion:** * **Roger Prince** (Central), a new member of the Forum, enquired about plans for the use of a large bequest for which he is executor. Roger emphasised that the wishes of the person who made the bequest were for the legacy to be used solely for improvements to the Heulwen Unit. He sought reassurance that these wishes would be respected. Staff on Heulwen would like to see part of the legacy used to purchase new chairs for the chemotherapy bays.

Dr Usborne explained that the Health Board demands that strict policies and due process must be followed for use of any gifts exceeding £5000, which can result in delays.Geraint provided assurances that the legacy would be spent on Heulwen and conversations with an architect were underway to explore the development of new clinic and triage areas. Geraint explained that pressures to maintain patient throughput during the pandemic meant that some Heulwen facilities had been moved to the ground floor of the Cancer Treatment Centre, including the League of Friends Café.**Action: Updates on options for improvements to Heulwen will be brought to the Forum** * **Pam Wedley** (North-East) welcomed news about the Maggie’s Centre for North Wales. However she highlighted the ongoing difficulties in dealing with capacity issues for the Shooting Star Cancer Treatment Unit based in the Wrexham Maelor Hospital.

Dr Usborne acknowledged these concerns and accepted that the ongoing challenges were related to funding. She emphasised that the Cancer Division had worked hard to resolve these challenges.There are big changes in the nature of cancer treatments which may reduce current demands on Units. For instance, Caroline anticipated that immunotherapies may soon overtake chemotherapies. However, alongside those changes, there are also concerns that the delayed impact of Covid-19 may cause a surge in cancer referrals, and patients being diagnosed with more advanced disease. Dr Usborne provided reassurances that the Shooting Star Unit remains a priority for her, and in general her focus would be on improvements to Day Units, where the majority of cancer patients are treated, rather than Inpatient Wards.Geraint confirmed that members of the cancer management team had recently met with an architect to discuss how existing facilities on the Shooting Star Unit could be re-utilised and improved to achieve required standards.**Malcolm Budd** highlighted particular challenges and anxiety posed by Hospital parking for people who live alone, and attend appointments alone. He suggested that special consideration should be given to this patient group.Dr Usborne understood Malcolm’s concerns. There are proposals to build a multi-storey car park on the Glan Clwyd Hospital site, but the main concern would be the disruption that would be caused by the construction.**Martin O’Donnell** conveyed his thanksto health professionals who work so hard to provide an excellent service, amidst huge challenges.His concern was around the sustainability of services in the face of the anticipated surge in cancer referrals, an increase in presentation of late stage cancers alongside difficulties in staff recruitment. He questioned whether the Covid-related increases in Welsh Government funding would increase.Dr Usborne confirmed that Covid-19 linked Welsh Government funding was short-term.In terms of recruitment, Geraint was pleased to share recent successes in recruitment, both at nursing and consultant level. Improvements to training programmes in North Wales were encouraging trainees to remain in North Wales and progress to consultant posts. Lead Oncologist, Dr Claire Fuller, is undertaking a review of medical manpower in cancer services to improve the recruitment of clinical fellows and consultants.**Rosemary Birch** confirmed that members of the North East Wales Cancer Patient Forum Group are meeting with the Health Board CEO on October 25th to share their views / concerns about the Shooting Star Unit development. She noted that the prospect of increasing cancer referrals reinforced the call for increased capacity for the Unit. | **Geraint** |
|  **3.**3.13.2 | **Minutes and matters arising****Minutes**: Minutes from the meeting of June 18th 2021 were agreed. **Matters Arising:*** **Macmillan ‘Transforming Cancer Services Together’: next steps**
* **Rapid Diagnostic Clinics for North Wales**

These matters were addressed by Dr Usborne’s presentation. Thanks were conveyed to Sarah Marshall and Martin O’Donnell for their involvement in the Rapid Diagnostic Clinic project. Sarah explained that the focus of the project was currently on logistics, and the extent to which patients could contribute was limited. However, the project team anticipated that patient involvement would be valuable in developing communication resources for service users.* **Robotic Surgery:** An update on progress in bringing robotic surgery to North Wales was requested at the June meeting.

Robotic surgery is now used routinely in many centres across the UK, particularly for urological surgery. The facility is expensive, but there is evidence of improved outcomes for patients. Also, with many junior doctors now being trained to use robotic techniques, this is becoming an important factor in attracting skilled clinicians.A robotic facility for North Wales has been under discussion for many years. Geraint confirmed that an implementation group has been set up and is meeting weekly to oversee the development of a North Wales robotic facility to be based in Ysbyty Gwynedd. * **PET-CT scanner:** Thanks were conveyed to Forum members who have contributed to a major consultation on the re-modelling of Nuclear Medicine and PET-CT services in North Wales.

The consultation continues with decisions required on the final location of either one or two specialist centres.Welsh Government has confirmed funding for a permanent PET-CT scanner for North Wales to replace the mobile facility currently located in Wrexham.  |  |
|  | **BUSINESS** |  |
| **4.** | **Cancer Patient Forum****Locality Groups: reports from Chairs** Locality Group Chairs provided a brief overview of recent meetings (draft Minutes to be circulated by email).**Pam Wedley, Chair of the North East Wales Locality:** *“Since the last Strategic meeting the North East Wales Group has primarily focussed on the Redevelopment of the Shooting Star Unit as already outlined.* *Ysbyty Maelor has half the number of day beds and no designated cancer inpatient wards compared with Ysbyty Gwynedd and Ysbyty Glan Clwyd, yet Wrecsam and Flintshire has a higher population profile. This has been of great concern to the North East Group and seen as inequity of provision.* *Discussions around a proposed extension and draft plans have been ongoing for over 4 years and initial plans and funding were approved in principle. A business case was developed to support the extension. However, as with all competing priorities, and Health Board discussions around a major redevelopment of the whole of the Wrecsam site (similar to Glan Clwyd), the extension plans were changed. Options for reordering of services within the Shooting Star Unit and extension of working days were discussed as well as the need to ensure staff have access to adequate space, e.g. isolation area for patients who attend unwell, increased toilet facilities and storage facilities.**Further delays and changes to the business case, and more recently the pandemic, has meant that funding the initial plan is no longer viable, as year on year delays and escalating costs have more than doubled the cost of the original plan.* *The issues need addressing urgently. The pandemic has affected cancer care, with missed diagnoses, delayed treatments, interruptions to cancer screening, delays in scans and diagnostics, on top of patient reluctance to seek medical care. These issues will no doubt increase demand and put even more pressure on service provision across North Wales, but could impact greatly in the North East where capacity is already over-extended.* *The North East Group has therefore arranged to meet with the Chief Executive Officer of BCUHB on October 25th to raise their concerns re the lack of equity and the urgent need to look at the capacity issues in the Shooting Star Unit.* *Despite these issues and concerns, I want to finish on a positive, and so thank the Cancer Management Team for working with us and offer thanks to staff at the Shooting Star Unit, as despite the challenges, the service received has remained of high quality and delivered with care and compassion.**I am also pleased to report that:** *A new Macmillan Information Coordinator has been appointed for the Centre at Wrexham.*

*.* * *the members continue to work with* ***Nightingale House Hospice*** *to dispel the stigma of hospice care and raise awareness of what the Hospice has to offer and how we can work together in our communities to share this information. Members were recently invited for a tour to visit the redeveloped and extended Hospice at Wrecsam.”*

**Norma Williams, Chair of the Central Locality:***“The central meeting of the Forum was well attended, and some excellent information relayed to the group.****Matters arising:***1. *Geraint Roberts, once again confirmed that the Hospital Estates have agreed in principal to providing protected parking for patients attending the Cancer Treatment Centre, using the area adjacent to the Radiotherapy unit, until temporary portakabins are removed, there can be no further progress. Geraint will continue to bring updates to the group.*
2. *Blue information Folder: review of the blue cancer information folder remains on the cancer division “to do list”, but pressures imposed by Covid, means there has been no further progress. There is funding to replenish stocks of the current folder, and essential updates have been made to ensure that information is updated and correct. Forum members, whilst recognizing the value of the information folder, reiterated that a review of the content was needed to ensure that it continues to be relevant to the patient needs.*

***Future of the Breast Services in Llandudno:****Geraint confirmed that the project to develop breast services in Llandudno has been brought to a close. Both Norma and Kirsten had contributed to the project team as patient representatives for a number of years and expressed their disappointment that the project had ended with very little communication or explanation. Geraint explained that plans for the future of breast services in North Wales were on hold and awaiting the Health Boards final decision on proposals to build 2 new diagnostic centres in North Wales.****Radiotherapy Services:****Patricia Evans, BCUHB radiotherapy Services Manager presented a brief overview of a report on the radiotherapy unit following an announced inspection by Health Inspectorate Wales in March 2021.* *The purpose of the inspection was to explore how the service complied with the Ionising Radiation (medical exposure) regulations 2017.**Met the health care standards 2015, in addition to finding excellent compliance with regulations and procedures, the report stated: there was evidence of an experienced and committed workforce with a good team working ethos overall, staff were happy with the level of support provided to them, and there was very positive feedback provided by patients around their experience in attending the department.”***Val Wakefield , Vice Chair of the North West Wales Locality***“The lack of psychotherapy services remains a long-standing problem in the North West and, despite continued pressure, nothing has improved the situation.**Some items, such as staff uniform status recognition and more informative text telephone reminders, were deferred for the time being due to Covid-19 pressures on the NHS staff whose involvement is needed to communicate or clarify the information.**The effectiveness of communications between hospitals and GPs was discussed, with reference to endpoints for repeat medication. Communication appears to be a common problem within the NHS.**The Forum members expressed their deep and sincere gratitude to Manon Williams for the cancer teams’ dedication and hard work, despite staff shortages and stressful working conditions, which Manon said were still as difficult as they had ever been.**An invited guest, Chas Muskett, the Chair of the Alaw Ward Charity Group, shared some recent examples of how charitable funds are used to improve cancer care. He was particularly excited about the EBUS (endobronchial ultrasound) Service developed by the North Wales Respiratory team, which could make a great difference to patients in North West Wales.**Chas has recently approached Awyr Las for some guidance and clarity around different ethical decisions about charitable funding versus BCUHB funding.* *The North West Macmillan information and support centre had reopened, although face-to-face appointments would be discouraged, with email and telephone support preferred.**Forum members have continued to work with the Chester University based international team working on the “Finding My Way” project which is expanding its trials to include many more patients nationally, still including Ysbyty Glan Clwyd, and despite Covid-19, good progress is being made.* *Mark Edwards, the North Wales ‘Patient Partner’ for the Wales Cancer Research Centre, has contributed to two projects. One is being carried out by Cardiff University; “Public attitudes to death and dying”, funded by Marie Curie and the other to NWORTH clinical trials unit (part of Health and Care Research Wales) based at Bangor University into “Public perceptions of clinical research”.**Mark also welcomed the recent news that the NHS has launched the world’s largest trial of a new blood test that aims to detect the earliest signs of cancer in more than 50 types of cancer before symptoms appear.”***Patient representation and involvement :** A brief overview of recent representation and involvement by Forum members was circulated for information.**CPF project groups: Communication / Website:**These groups have not met since the last Strategic Meeting.Updates to the Forum website continue and thanks were conveyed to Ian Sampson for his work in managing the website. The pop-up element on the website home page, inviting visitors to subscribe to the Forum email circulation, continues to attract new subscribers, approximately 3 / 4 every week.Thanks were also conveyed to Kirsten Foster-Alexander for her time and skills in maintaining the Forum social media pages.**Action: Members were invited to get in touch (via Pat) if they have any news that they would like to share on social media.****Arrangements for future meetings:**Consultation with the Forum meetings should continue to be conducted via Microsoft Teams, with review again in early 2022.**Annual General Meeting, November 25th 2021:****Action: Details of the forthcoming AGM will be circulated to all Forum members.** **The business part of the AGM will include elections for a new Chair and Vice Chair. Expressions of interest will be invited.**  | **All****Pat** |
| **5.** | **Any other business:**Sarah Marshall (North East Locality) proposed that Forum members should be given an opportunity to contribute to a draft document which aims to share ideas and suggestions from patients on possible efficiencies in Cancer Treatment Units, based on personal experiences. This work has arisen from discussions related to the Shooting Star Unit, but could be equally relevant to the other Cancer Treatment Units in North Wales. Sarah was keen that the exercise should focus on positive suggestions for improvement, rather than negative groans. These can then be shared and discussed with the Cancer Division.**Action: A paper will be circulated to all members and comments / ideas invited**  | **All** |
|  **6.** | **Date of next meeting : To be confirmed** |  |