

## Notes from ASW Cancer Network Survivorship Meeting

Friday 19 December 2014 – 14:10 – 15:40

Penny Brohn Centre, Pill, Bristol

	Agenda Item	Action
1.	<p><b>Welcome and apologies</b></p> <p><u>Present:</u>  <b>Dorothy Goddard (DAG) (Chair)</b>, Consultant Breast Radiologist and National Clinical Lead for Breast Cancer Survivorship            Jonathan Miller (JM), SW Cancer Network Manager NHS England            Belinda Ockrim, Lead Cancer Nurse, YDH            Carol Chapman, Lead Cancer Nurse, NBT            Catherine Neck, Macmillan Lead for AHP's &amp; Survivorship, ASW            Catherine Zollman, Macmillan GP &amp; Penny Brohn Cancer Centre            Cherry Miller, Breast Clinical Nurse Specialist, RUH            Elisabeth Summers, Assistant Psychologist, NBT            Jo Bailey, Gynae Surgical Oncology Consultant / Lead UHBristol            Karen Morgan, Macmillan Consultant Radiographer, TST            Lucy Thompson, Macmillan GP Advisor, Central South West England            Helen Dunderdale, Cancer Network SSG Support Manager, SWSCN            Maggie Crowe, Macmillan Development Manager, Avon &amp; Somerset            Michelle Jennings, Staff Development Lead HOPE Directorate, TST            Miranda Benney, Macmillan Uro-oncolgy CNS, RUH            Nick Ambler, NBT            Nikki Hawkins, Macmillan Sponsorship Lead, Glos CCG            Pat Turton, University of West of England            Rebecca Vermeer, PA to Dr C Gamlin, MD &amp; Admin Support SW SCN            Ruth Hendy, Lead Cancer Nurse, UHB            Samantha Cole, Specialised Clinical Psychologist, UHB            Samantha Larsen, South West SSG Admin Support, SWSCN            Sarah Warren, Senior Project Manager, SWCSU            Sarah Mathewson, Macmillan Survivorship Lead, Glos CCG</p> <p><u>Apologies:</u>            Alison Wint, Macmillan GP, South Glos CCG            Amelia Randle, Macmillan GP, Somerset CCG            Andrew Allison, Clinical Director – Cancer, YDH            Axel Walther, Consultant Oncologist, UHB            Ed Nicolle, Cancer Services Manager, RUH            Helen France, Project Manager, NBT            Helen Thomas, Clinical Director – Cancer, SW Strategic Clinical Network            Jeremy Braybrooke, Consultant Oncologist, UHB            Jo Wilson, Macmillan Survivorship Project Lead, TST            Jonathan McFarlane, Consultant Urologist, RUH            Kathryn Hall, Glos CCG            Kerry Sant, Lymphoedema Nurse Practitioner, RUH            Katy Horton-Fawkes, Gynae Oncology Specialist Nurse, UHB            Lynn Pearson, Taunton and Somerset NHS Foundation Trust            Mandy Bessant, Macmillan Breast Care Nurse, WAHT            Mike Osborn, Macmillan Clinical Psychologist, RUH            Nikki Thomas, SW SCN Cancer Clinical Lead            Olivia Donnelly, Macmillan Clinical Psychologist, NBT</p>	

	<b>Agenda Item</b>	<b>Action</b>
	Rachel Ainsworth, Consultant Oncoplastic Breast Surgeon, WHAT & NBT Rachel Linegar, EPR programme manager – IT, RUH Raj Persad, NBT Sarah Levy, Head & Neck, Brain & Sarcoma CNS/ Keyworker, YDH Sadaf Haque, Macmillan GP, Gloucestershire CCG Zoe Haines, Macmillan GP, BaNES CCG	
<b>2.</b>	<b>Notes and actions of last meeting</b>	
2.1	Meeting notes agreed as accurate	
2.2	<p><b>Actions:</b></p> <p>3.1 – completed – HD present at meeting</p> <p>3.2 – completed – JM has emailed group as well as CCGs detailing recommendations for commissioning intentions for Cancer including the survivorship agenda.</p> <p>7.1 – information and education re late effects – ongoing service developments in Taunton and at RNHRD in Bath</p>	
<b>3.</b>	<b>Strategic Clinical Network update</b>	
3.1	JM advised that SSGs should ensure MDT's had adopted the nationally advised pathways (as per Site Specific Clinical Reference Groups) to be worked through and agreed, implementing Health Needs Assessment, Care Plans and Treatment Summaries, considering how they are managed.	
	<b>ACTION: DAG to write to Chairs of SSGs re: having survivorship on their agenda.</b>	<b>DAG</b>
<b>4.</b>	<b>Recovery Package – Progress</b>	
4.1	<b>Penny Brohn:</b> The Health and Wellbeing Clinics are funded through Prostate UK and Macmillan. They have been invited by Birmingham Trusts, London, South East and North to model delivery.	
4.2	<b>NBT:</b> Surgery patients have HNA/TS at 6-8 weeks and are invited to Health and Wellbeing events. They currently have 6 a year, but are looking to move to quarterly. 35-45 patients attend the HWB Clinic. At the Nurse Clinic a HNA/TS is done with a copy sent to the patient and their GP. They have Prostate Living Well events which take place during a morning, as well as Moving on programme/Living Well courses which are funded by Prostate UK.	
4.3	<b>TST:</b> When patients are discharged they have appointments for the Health and Wellbeing Programme. There are generic events and then specific for four sites. Using an electronic HNA for breast and head & neck, but it takes time. Radiotherapy have the main treatment summaries.	
4.4	<b>UHB:</b> There is a CQUIN for the treatment summary and on target. This takes place at the end of surgery or treatment as well as staggered throughout treatment. Currently the paper version of the HNA is being used but they have secured funding for the electronic HNA and have identified teams who want to begin using it. However, they are looking at sustainability and resource to continue	

	<b>Agenda Item</b>	<b>Action</b>
	<p>this post-funding.  Macmillan has funded the Health and Wellbeing events. They are both site specific and generic. Teams decide who is invited and at which point to refer, but usually at the end of treatment. The events are held every two months. Support workers organise them.  The main hurdles for this are sustainability and there is a need for this to be commissioned.</p>	
4.5	<p><b>YDH:</b>  Have head and neck wellbeing event. There is a spring project which is being funded by Macmillan.  HNA do happen but not at a specific point in time.  AO team have communication with GPs.  Trying to use the Cancer Register  Have applied for the electronic HNA and just secured approval for this.</p>	
4.6	<p><b>Gloucs:</b>  They have a very supportive CCG and a recovery package has been agreed – yet to be implemented across the MDT's. They are engaging primary care through Macmillan and practice nurses.</p>	
4.7	<p><b>Bath RUH;</b>  Paper version HNA's still in use across breast, prostate, gynae, colorectal, with care plans sent to GP's. Working with IT to have Treatment Summary on the electronic patient record system (Millenium) – starting with prostate, then colorectal and breast. This will be completed at relevant points along the treatment pathway (surgeons, oncologists, CNS's) and sent electronically to GP's at end of primary treatment. Health and Well being programme well established for breast patients (3-4 per year), now also for colorectal and prostate (as per the prostate UK project), together with generic events.</p>	
<b>5.</b>	<b>Remote Surveillance – Progress</b>	
5.1	<b>YDH, RUH</b> – have prostate remote surveillance in place.	
5.2	<b>UHB:</b> there is an upper GI early research study with UWE re: remote surveillance taking place looking at follow up.	
	<b>ACTION: all providers to feedback remote surveillance programmes to DAG/RV</b>	<b>Providers</b>
<b>6.</b>	<b>Late Effects</b>	
6.1	<p>TST are sending a letter in January 2015 to 1500 patients from over a 5-year period with specific/target questions.  They have a Pelvic Steering Group.  There is pilot service for gastro-urology, which will be picked up by the Gynae SSG.</p>	
<b>7.</b>	<b>Primary/Secondary Cancer Care Integration</b>	
7.1	<p>There is a summary of the Macmillan Primary Care Conference event to be circulated soon. It was clear that there are issues around communication between the GPs and consultants, which needs to</p>	

	<b>Agenda Item</b>	<b>Action</b>
	be addressed and improved.	
<b>8.</b>	<b>Third Sector Update</b>	
8.1	Covered under agenda item 4	
<b>9.</b>	<b>Any Other Business</b>	
9.1	Penny Brohn: Working with community groups for active self-management.	
9.2	Macmillan: <ul style="list-style-type: none"> <li>– Pre-rehabilitation and Health Needs Assessment – working with community health team.</li> <li>– Lynne Cage Bristol – over 55s – bid is being made for looking at supporting people with cancer to reduce isolation.</li> <li>– Working with Sirona in BaNES around wellbeing coordination with the LTC team around cancer care.</li> <li>– Integrating with community care.</li> </ul>	
9.3	JM reported that there was development around practice nurses with CNS's going into primary care.	
9.4	MC requested that supported self-management be put on the next meeting's agenda. JM recommended that Ruth Hall, Quality Improvement Programme Manager for the SW SCN around rehabilitation be invited to attend the next meeting.	
	<b>ACTION: JM/RV to invite Ruth Hall to attend the next meeting for the supported self-management agenda item.</b>	<b>JM/RV</b>
	<b>ACTION: DAG to put supported self-management on the next meeting's agenda.</b>	<b>DAG</b>
9.5	YDH: have a substantively funded post to support the wellbeing events.	
	<b>ACTION: Belinda to send questionnaire form which YDH use to DAG/RV who will forward it to the membership.</b>	<b>BO DAG/RV</b>
9.6	Bristol CCG: Have a pathway commissioning strategy event end Jan/early Feb.	
	<b>ACTION: Sarah Warren to email event details to DAG/RV to share amongst membership.</b>	<b>SW DAG/RV</b>
<b>10.</b>	<b>Next Meeting:</b>  Monday, 9 March 2015 @ 14:00 – 15:30, MR1, S W House, Taunton  <u>Future dates:</u> Tuesday, 9 June 2015 @ 14:00 -15:30, Penny Brohn Centre Wednesday, 9 September 2015 @ 14:00 – 15:30, S W House, Taunton Thursday, 10 December 2015 : 14:00 – 15:30, <b>TBC</b> Penny Brohn	