Meeting of the Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Operational Group
Wednesday 11th December 2019, 10:00-12:00
Dining Room, PG Medical Education Centre, Royal United Hospital, Coombe Park, Bath BA1 3NG

Present:

Amy Smith	CAG Administrative Coordinator	SWAG CA CAG Support Service
Belinda Ockrim	Lead Cancer Nurse	Yeovil District Hospital NHS FT
Caren Attree	Lead Cancer Nurse	Taunton and Somerset NHS FT
Carol Chapman	Lead Cancer Nurse	North Bristol NHS Trust
Ed Nicolle (Chair)	Cancer Manager	Royal United Hospitals Bath NHS FT
Elaine Farley	SCR Analyst Co-ordinator	SCR
Gemma	SCR Trainer	SCR
Emilia Scutt	Cancer Services Manager	Salisbury NHS FT
Michelle Gregory	Deputy Cancer Manager	University Hospitals Bristol NHS FT
Helen Dunderdale	CAG Support Manager	SWAG CA CAG Support Service
James Curtis	Cancer Manager	Gloucestershire Hospitals NHS FT
James Withers	Data Liaison Manager	NCRAS
Nicola Gowen	Project Manager	SWAG Cancer Alliance
Patricia McLarnon	Cancer Alliance Programme Manager	SWAG Cancer Alliance
Rachel Butler	Genomics Lead	South West Genomics Laboratory
Suzanne Priest	Assistant General Manager	Weston Area HT
Tariq White	Cancer Alliance Managing Director	SWAG Cancer Alliance
Terri Agnew	Cancer Manager	North Bristol NHS Trust
Zena Lane	Cancer Manager	Taunton and Somerset NHS FT

Apologies:

Charlotte Kemp	MDT & Cancer Performance Manager	North Bristol NGS Trust
Claire Smith	Lead Cancer Nurse	Salisbury NHS FT
Corinne Thomas	Part-time and fixed-term Lead Cancer Nurse/Matron	Weston Area HT
Hannah Marder	Cancer Manager	University Hospitals Bristol NHS FT
Julia Stroud	Associate Director of Nursing (interim Lead Cancer Nurse)	Weston Area HT
Julie Armoogum	Senior Lecturer - Adult Nursing	UWE
Luke Curtis	Cancer Manager	Yeovil District Hospital NHS FT
Natalie Heath	Operational Manager for Cancer	Yeovil District Hospital NHS FT
Ruth Hendy	Lead Cancer Nurse	University Hospitals Bristol NHS FT
Ousaima Alhamouieh	Transformation Project Manager	SW Cancer Alliances
Sally House	Lead Cancer Nurse	Gloucestershire Hospitals NHS FT

1. Welcome and apologies

E Nicolle welcomed all group members. Apologies received prior to the meeting were noted.

From the agenda:

2. Notes and actions from the last meeting

Notes from the last meeting held on 16th October 2019 were accepted with no amendments needed.

040/19 Reimbursement of Historic Service Level Agreement Funding: There was some uncertainty whether underspend had been reimbursed to all Trusts. H Dunderdale had spoken with UH Bristol Finance Department and funding should have been received in June. This will be checked but the action is now closed to this meeting.

039/19 Clinical Advisory Group Service Level Agreement Final Sign Off: Some slight amendments are needed before recirculation to all Trusts and sign off by the Cancer Alliance. Sign off will occur by the February COG meeting.

038/19 Acute Service Provider Support Needed for Rapid Diagnostic Service: A summary of the Rapid Diagnostic Service is on the agenda for this meeting. N Gowen, Cancer Alliance Project Manager, has circulated an email response to concerns raised at the previous meeting to all COG members; action closed.

037/19 Cancer Alliance Member Attendance at Future COG Meetings: Terms of Reference is listed as an agenda item; action closed.

036/19 Remote Monitoring Service System Options: This will be discussed as an agenda item during this meeting; action closed to COG, although this is recognised as a more complex issue.

035/19 Personalised Care and Support (LWBC) Staff Contracts: H Marder was to draft a board paper with comment. It is understood this has been sent to all Trust boards for agreement; action closed.

034/19 Gloucester Next Steps Commissioning: update pending.

033/19 NCPES Presentation for Cancer Alliance Board December Meeting: B Ockrim, Lead Cancer Nurse (LCN) representative, forwarded last year's presentation to R Hendy for update. This was completed and presented at the Board meeting; action closed.

032/19 Attendance at National Cancer Advisory Workshops: No dates are available yet. R Hendy will circulate dates when available.

028/19 Benign Day 28 Template Letters: T Agnew had not realised this was an action but will circulate.

028/19 Action: TA to circulate NBT template letter

027/19 Development of Emotional /Psychological Support Roles: this action is still ongoing and will be followed up at the LWBC steering group meeting update. C Chapman has undertaken risk assessment work. B Ockrim raised the inequity of a lack of level 4 services in Somerset. STP support is needed to fund that going forward. Previously there was some money available for psychology level 2 training across Somerset and Weston. Clarification of whether this is being built into the Transformation plan was sought. Tariq White, new substantive Managing Director of the SWAG Cancer Alliance, will take this forward to a meeting held next Monday, 16th December 2019.

027/19 Action: T White to seek CCG clarification of funding

026/19 Remote Monitoring System: This action is scheduled on the agenda; action closed.

005/17 Network-wide Pharmacy and Oncology Posts: H Dunderdale confirmed this is virtually signed off; action closed.

3. Cancer Alliance & Transformation Funding

3.1 Cancer Alliance Update
Purpose: To agree any issues for escalation to the Alliance Board

The Cancer Alliance reorganisation is ongoing. Both administrative positions are not expected to be filled until towards the end of the financial year. Currently the team is Tariq, Patricia, Nicola Gowen and Ousaima Alhamouieh.

T White stated the Cancer Alliance's commitment to pick up circa £1 million funding for Personalised Care going forward. Details are being defined and he will work with STP Cancer Leads and teams to see what high level needs there are. There is commitment to fund on a tapering basis for the next four years.

Staff contracts remain a major concern for Cancer Alliance Board escalation. It is understood that this problem must be sorted well before March 2020. The final decision will be made at the Board, but a meeting to discuss this is being planned for mid-January 2020. From an Alliance perspective, the caveat is there was £2.7 million funding for Personalised Care this financial year, so there is a huge differential compared to a £1million budget next year. There is a total budget of £4.3 million available next year to cover Early Diagnosis funding too. The Alliance will work with Trusts and CCGs to look at commitment levels.

At RUH, the Trust has taken the decision to extend the contracts of the Living With and Beyond Cancer Staff currently funded through CTF for a further six months, until 30 September 2020, to maintain service until a longer term decision on funding is made. It was noted there was some underspend in this year's budget which will be small sums but returned to STPs. Carry over into the next financial year's budget will be for local determination. It was also noted that Personalised Care is a must do, it is to be delivered in secondary care. The system is going to have to find funding and pick up the funding gap.

There was a request to escalate Remote Monitoring. The national team acknowledge the complexity; further discussion of concerns will take place under Agenda Item 4.4.

Concerns were raised about data, particularly under-reporting what teams are doing. Difficulties are due to both systems and resource issues. NBT received feedback from NHS England that they were not using the correct field to collect data. The metric has been tweaked. NBT focus is on HNAs but it was noted many teams are doing much more cost-effective delivery.

P McLarnon confirmed all performance deliverables and funding plans have been approved, with only a slight delay to BNSSG plans, which are being picked up. COG members were advised to contact her with any issues. Funding must be spent on what was agreed, as there is a lot of scrutiny from national and regional colleagues. There is a lot of concern about getting Return on Investment. This is not really seen in current performance. Opinion is this is not just a regional issue; teams face similar problems nationally regarding performance levels. It was noted the Gynaecology service in Yeovil is not using the money as stated because the locum has just pulled out.

Most teams have submitted plans. The Yeovil, Bath, Weston, N Bristol (Swindon is in this but is not part of SWAG) UAN plan is awaited.

COG concerns about 28 day data had been compiled by H Marder and emailed to P McLarnon. COG members were advised to contact NHS England Data directly to clarify. For NBT, the outcome of contacting NHS England was an unclear 'How To' PDF guide. All COG members agreed the need for a very simple guide; currently teams are working to clock stops but this resulted in reporting errors. T White will raise this at the regional performance meeting next week and feedback.

P McLarnon apologised for the short notice request for 28 day data return but thanked all involved in data returns. The Alliance acknowledges there is a lot of hard work going on.

Following the recent 28 Day Event in Taunton, NHS England & Improvement and Health Education England (HEE) will put together 2 or 3 further events. These are expected to take place in February/March 2020 and will be for administrative teams – such as MDT coordinators. Locations are still to be decided as Dorset must be included. Events will include contributions from 2 patient representatives who have positive feedback about their pathway and 1 negative and a lung cancer discussion. There will also be a table top discussion on how to speed up processes. There will be some Trust presentations about sharing smart practices. HEE has agreed to fund a 3 day Oncology course run by David O'Halloran. There will be 10 funded places per Trust. Online Cancer Essentials Training will be shared at the events.

N Gowen thanked COG members for submitting August lung data. There are still a couple of September submissions outstanding. Continue to submit returns to the generic email but also cc N Gowen's email so she can access these. P McLarnon echoed the need to get up-to-date with data returns as these can show real-time performance and improvement.

Gloucester raised concern of receiving a request for Fit data negative values and asked for clarification on where data requests are coming from and the reasons for them. COG members acknowledged this is onerous additional workload. The request would be from the Fit Steering Group. P McLarnon advised COG members to contact her if/when additional data requests are received. Further evaluation of requests will take place from April onwards. There could be benefit in compiling a central list of all returns. Opinion included concern a central list is quite difficult to maintain but data requests being discussed at COG meetings would be beneficial.

041/19 Action: All COG members to develop a list of data requests and returns that are part of workload.

T White advised communication to steering groups that all requests should come through COG.

3.2 Rapid Diagnostic Service (RDS) Update

Purpose: To review acute service support needed

N Gowen thanked COG members for the group letter and hoped her response had answered all the questions raised. There were no further questions raised during this meeting.

Two pilots are being developed and both are rurally based. The RDS clinics will be run by a GP, with links to secondary care run by RUH. Project teams are in the process of setting up the service detail. E Nicolle confirmed he is working with Emma Finn from Somerset. CT is the only diagnostic tool being used.

Regarding CT accessibility and reporting timescales, treat this pathway in the same way as 1-week-wait. There will be a generic email flag that goes to the RDS clinic to say when results are available. The RDS Clinician and the navigator will be able to see these.

There is reasonable acceptance that patients are going to have a CT anyway. Patient numbers are going to be very small, with 2-3 CTs per week cumulative expected, and the RDS will not add extra demand. This service could support evidence of recognised CT demand for some postcodes. There may be increased CTs initially but this is likely to smooth out with service implementation. RDS has not been welcomed by Radiology services but there is general acceptance of the need to progress. If demand becomes wildly different from projections then reassessment will be needed. If this was a

whole catchment service it would be different. The Royal College of Physicians has been trying to push the lack of diagnostics for a decade. This is a way to evidence the case. Capacity issues are very acute in all Trusts; smaller Trusts may have greater difficulty to get appropriate scans done in time, as it can take 4-6 weeks for PET and bone scans.

R Butler questioned if we are looking to the future enough. In the USA there is a GRAIL circulating tumour DNA sequencing trial, which involves a simple blood test. This is an ideal opportunity for translational research. There is a good chance that tumour cells could be detected. That would be cheap, at £100 per sample, would identify cancer and would help direct appropriate scans. It was acknowledged blood tests are not 100% sensitive, are not suitable for germline testing and are better for patients with more advanced disease. This could be particularly helpful for ovarian and lung cancers (lung patients usually present with stage 3 disease.) N Gowen confirmed it is in the Alliance and national focus.

042/19 Action: N Gowen to share slides from last night's presentation

4. Network Issues

4.1 Cancer Registry Update

Purpose: To improve completion of data

James Withers, Data Liaison Manager National Cancer Registration and Analysis Service (NCRAS), provided a brief update. There is a Cancer Outcomes and Services Dataset (COSD) road show event to present version 9 in Exeter on 8th January 2020. Anyone interested should register ASAP. Invitations have been sent out to Alliances and to commissioners as well.

October Data Quality Report submissions have been received. There is a limited amount of time to sort out data quality issues and processing will begin in the New Year. CCGs and Alliances are looking at the data, so completeness is increasingly important. Current staging completeness nationally is 58.7% and in the SWAG region is 53% for 2019 so there are a few issues to resolve. If support for issues is needed, James is happy to visit. Use Data Views that ENCRAS has created. The new version of Data Views will be rolled out during 2020. This will be a lot clearer and easier to use. Again set-up support is available.

A TNM versions email has been circulated and responses are still needed. What TNM is listed as used in the schema and what is used for staging records may not match. The request is for all COG members to check they match and email NCRAS. Recommendations are in Appendix E COSD user guide.

043/19 Action: Check TNM versions used in your centres

H Dunderdale stated some research trials are still using TNM version 7; therefore some teams need to use that version and need it to be supported. This will not be possible globally but it is possible to set at individual patient record level or set at Trust level.

4.2 Genomics Laboratory Hub Update

Purpose: To review the detail of cost implications and provision of tests

R Butler, Genetic Scientist and Director of the North Bristol Genomics Laboratory Hub, provided a general overview of the service, based around cancer.

The provision of genetic and genomic test panels is transitioning from a project to a standard NHS service. The number of laboratories has been consolidated from 25 to a network of 7 Genomic Laboratory Hubs (GLHs), all processing a core set of samples according to the same standards. NBT was successful in the bidding process to become one of the GLHs in partnership with Royal Devon and Exeter Trust; 80% of genomics work done regionally will be in Bristol, while the Exeter spoke will focus on rare diseases. Each hub has been given the responsibility for processing a number of additional specialist tests, which are divided so it is clear who is doing what for each indication/disease; all cancer samples will be processed in NBT.

Although the south west is one of the smallest regions by population, it is a large region geographically. Geography will present difficulties in ensuring rapid transportation of fresh tissue samples and in turnaround times. Transport methods are in the process of being clarified. Results are sent back by email currently. Future developments need to enable results appearing on databases or systems so results can be copied into clinical notes. That will be a next step.

Genetics is a fast-changing area of medicine and constantly subject to updates. There has been a real explosion between assessing particular genetic markers and therapeutic response to chemotherapies. This could impact future treatments, especially immunotherapy (which is not suitable for all patients.) The test directory currently has 180 cancer tests to which oncologists and pathologists have access. These will be made available via NHS England at some point in the near future (potentially April 2020). The plan is to update the test database annually. R Butler has applied to be part of the national group overseeing this. The American Society for Clinical Oncology (ASCO) and the European Society for Medical Oncology (ESMO) regularly update guidance for tumour types but EGFR, ROS and ALK will be among the tests done.

The pan-solid tumour gene panel will test for everything. There is a separate panel for haematological malignancies. The gene panel strategy was discussed and tumour block samples will remain viable for future testing. Results will be reported either via MDT report, or if particularly complex, can be reviewed by a central Genetic Tumour Advisory Board (GTAB).

Through to 2021, testing will be highly selective for specific tumour types – namely acute leukaemias and lymphomas, paediatric tumours and sarcomas. From 2021/22 testing is expected to expand rapidly – through to prostate, pancreatic and breast cancers and relapsed cancers. Pathway inhibitors are going to be approved. These could include: BRCA plus 500 gene panel; prostate path inhibitors; and Neurotropic Tyrosine Receptor Kinase (NTRK) gene alteration inhibitor drugs for all relapsed cancers.

Service developments are a major challenge for pathologists. There is a need to ensure they have the resources to do it. Evidence shows that targeted treatment gives better outcomes.

Results can be complex and will be unrelated to a patient's germline. This requires education, clinical engagement and upskilling of clinical teams. MDT structures will need to provide results support. There will be a need to meet NICE guidance, particularly if treating patients with path inhibitors. Genomics England will be involved with some of the sequencing and informatics. HEE will be involved with training and education events.

Concerns were raised about protocol procedures and patient information leaflets if blood tests are included in testing. Potential delays for pathways such as ovarian, which already breach 62 days, were discussed. From an Alliance perspective a massive conversation would be needed; R Butler

agreed this would be a different patient conversation and a different protocol and part of a bumpy service development.

Other concerns included access to the appropriate drug, difficulties keeping abreast of all treatment/test changes and patient informed consent. Different clinical groups must focus on their area; oncologists need to check drug NICE approvals, diagnostics need to keep up in their specialist area. The aim should be to gather the best information to treat patients. R Butler will answer any further questions via email.

4.3 COG Terms of Reference

Salisbury is not included in the Terms of Reference (ToR) but should be included for COG meetings, although it is separate for Clinical Advisory Group/SSG activities. Circulate proposed questions and changes. The Alliance should remain within core membership of COG meetings.

044/19 Action: H Dunderdale to update Terms of Reference and recirculate

4.4 Progress of the Remote Monitoring Business Case

Purpose: To review regional template development

T Agnew had been asked to do a lift and shift business case at the last COG meeting. This would have been ready for the end October/beginning November 2019. However, after attending the Outpatients Transformation board meeting, it was evident the Remote Monitoring case is STP led, as a deployed system could release cash for follow-ups. NBT need to save 30% of outpatient follow-ups using systems. This is not a "cash saving" but an "efficiency". Decision-making is needed through the Outpatient Transformation board, the STP board and the internal NBT Outpatient Transformation board, as well as the Cancer Alliance board. The business case template will be signed off by STPS, as it underpins the digital plan. COG members would be able to present a version to their Trusts with a costed business case etc. The caveat is this has a My Medical Record focus, so if COG members/Trusts are not looking at that, the template will need adaptations.

Also there are licencing issues. Initial quotes were on a cost per service basis, which is expensive. NBT and outpatient for long-term condition patients tiered licensing is being worked out based on figures for stratified pathways and outpatient figures on savings needed. The completed business case will be ready by the end of December 2019. Technically the STP and Cancer Boards don't meet until March 2020 but there will be email commitment to support to meet deadline submission.

Somerset has Somerset Cancer Register. Service costings are based on what was agreed. There are concerns about My Medical Record changing the pricing structure for this template.

There is national recognition of complexity. However, the Alliance cannot accept a remote monitoring plan for prostate, breast and colorectal which includes long-term condition patients. COG business case status is as follows: Somerset have submitted a business case (not My Medical Record); Salisbury has submitted quotes from My Medical Record; Gloucester is preparing a business case using My Medical Record for Prostate which is integrated with Pathology. This is not automated. BNSSG will use My Medical Record but UH Bristol will not need prostate or breast pathways. RUH will continue to use My Medical Record for the prostate pathway until an in-house patient portal is fully operational.

A decision by the Alliance Board in March 2020 would be made too late for funding. This funding must be allocated by mid-January 2020 or it will be lost. It is still to be worked out when funding will be available or how it will be split. It is clear £600K will not cover costs, based on quotes received. There is a need for economies of scale and a proposal was to base costings on the number of users per Trust.

My Medical Record is a referral and treatment system. However, there are safety issues for clinical follow-up. Outpatient appointments are saved as virtual clinics. There is a dedicated CNS Team cross-checking these in Southampton which is time-consuming. The tariff is changing to release less to the provider because virtual clinics incur smaller charges.

P McLarnon advised any outstanding Trusts to submit figures as soon as possible, using £30k as a basis.

5. Lead Cancer Nurse Update

5.1 Personalised Care and Support (LWBC)/CNS Workforce

Purpose: To review LWBC activity and sustainability plan

B Ockrim had sent a long list of proposed agenda items to HD. These included comparing LCN roles and responsibilities around the region. About half the SWAG COG LCN membership comprises LCNs who are also performing Matron roles. Some work part-time. LCNs undertake most of the Personalised Care work. The workload makes it difficult to support board meetings, CAGs and other meetings.

045/19 Action: HD to circulate table of CAG meetings and who should attend; add to agenda for next meeting

Discussion of job descriptions and roles and responsibilities could be written into COG ToR but is a Trust, not just a COG, issue. Confirmation of absolute shoulds regarding roles is sought. There are some new Macmillan posts.

046/19 Action: include in ToR; include agenda item for ToR and Macmillan

Changes to CPES PICKER questionnaires means results should be returned quicker. The cohort dataset which was just sent back will be reported in March. New question inclusions were, "When was your diagnosis?" and "How long have you had your diagnosis for?"

J Curtis had spoken with Kathryn Hall who understood Gloucester is the only area where CNS funding comes from LWBC budget. This was confirmed by all COG members present. In Yeovil there is some LWBC budget funding for other posts such as Allied Health Professionals; NBT stated similarly, posts such as dietitians had been funded from this budget.

6. Any other business

P McLarnon reminded COG members that performance should be on future meeting agendas. The Alliance would welcome hearing the true reflection of challenges faced by COG members and their teams.

Date and time of next meeting: 10:00-12:30 Wednesday 12th February 2020, Brentree Room, Level 2 Seminar Tower, Green Zone, Southmead Hospital, Bristol N.B. This meeting will be extended by half an hour to allow for the pre-meeting discussion of LCN job roles and responsibilities.

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