**Wednesday 30th March 2022, Holiday Inn Taunton, Dean Gate Avenue,  
Taunton, Somerset, TA1 2UA or via MS Teams, 10:00-16:15**

**REPORT**

**Chair: Consultant Oncologist Clare Barlow (Immunotherapy Lead, Somerset Foundation Trust)**

|  |  |
| --- | --- |
| **NOTES**   1. **Introduction:**   Following an initial scoping meeting last year, there was found to be significant interest across the region to work as a regional multidisciplinary group to inform the rapidly developing Immuno-Oncology (IO) services.  Since then, C Barlow and H Winter had presented a proposal to the Cancer Alliance for SWIG to be formally recognised as a Cancer Clinical Advisory Group (CAG). This has been agreed by the Cancer Operational Group and is now under the remit of CAG Manager H Dunderdale.  It was not felt to be appropriate to limit membership to a portion of the South West, and following another meeting with the Clinical Directors for the SWAG and Peninsula Cancer Alliance (H Winter, and J Renninson) it was agreed to be appropriate to include the Peninsula team plus South West Wales.  A National IO Clinical Network Group is also in the process of being developed. C Barlow and R Frazer are part of a small steering group led by A Olsson-Brown (Clatterbridge) with the first scoping meeting to establish the clinical priorities due to convene in Birmingham tomorrow (31st March 2022).  It will be important for SWIG to recognise the developments that will be most appropriately informed by this National forum.  The objective of the meeting today is to gather everybody’s views within the room to identify priorities, decide on the structure of future meetings, and to define what needs to be taken forward by the region, and the support required locally and nationally.  The focus of the group will be operational; educational content will be reserved for the newly formed SWAG and Velindre IO monthly forum, which is proving to be very popular, and highlights from the forum will be summarised at each SWIG meeting.   1. **Immunotherapy service provision and workforce development:**   **Please see the presentation uploaded on to the SWAG website**  **Presented by C Barlow**  The Somerset FT (SFT) IO Service Business Case, submitted in 2018, led to the development of a service that has now been operational for two and a half years. The business case has generated a significant amount of interest and has been shared with multiple centres.  R Dylan Frazer, on behalf of Velindre, has developed a recently approved 10-year plan for the IO service that is more extensive and reflects the size of the South Wales service.  It has now been possible to compare the SFT Business Model with Clatterbridge; both centres had independently produced very similar models.  Data from the SFT Service shows that it has been successful in managing an exponential increase in patient treatment numbers and provides a service that is safe, reduces Grade 3/4 toxicities and inpatient stays, is integrated and collaborates with other oncology treatment services. It also dramatically reduces the need for medical clinics, as it is led by IO Nurse Specialists who prescribe and manage a toxicity tracking system, with supervision from C Barlow.  The increase in patient numbers is expected to continue to rise dramatically with the additional number of drugs and indications that have been licenced and approved since 2018.  It is necessary to carefully plan how to manage the increasing workload associated with IO treatment, toxicity recognition and management which differ from alternative SACT treatments. It will not be possible to sustain this with existing resources.  All oncology treatment modalities overlap, making it essential to work collaboratively to ensure patient management is optimised.  The main components of the service:   * Treatment (managed by 2 x IO Band 7 Clinical Nurse Specialists) * Toxicity Management (managed on a daily basis) * Education * Governance.   Although there is no formal Peer Review for the service, a local operational policy, Annual Report and Work Plan have been produced to match governance arrangements in line with other cancer services.  Outputs from the service show the number of patient indications that have come on board over the last few years and the number of preassessment clinic appointments that would otherwise have had to be undertaken in medical clinics (>1000) avoiding the need for extra consultant capacity.  The service commenced with single agent PD1, but very quickly included combination therapies.  Patients are referred to the IO CNS clinic after their first two cycles. This does not deskill the site-specific team, who are still involved in the patients’ care at poignant time points but removes this extra activity away from the medical clinics.  C Barlow provides support to the IO Clinic by holding a pre-clinic huddle to discuss any relevant issues that may arise. There is also a joint clinic huddle with the site-specific team where all issues are raised and collaboratively discussed.  Toxicity follow up activity shows that over two thirds of patients require some toxicity management. Everything is triaged via Acute Oncology and moved across to the IO toxicity clinic until the toxicity is managed.  Numerous education events are held by the IO team, including at junior doctor induction.  **Action: SWIG to consider how local governance is to link with the regional forum; to be added to SWIG Work Programme.**  There is now an adjuvant follow up clinic for patients who have finished IO and have ongoing needs, and there are plans to hold a late effects clinic in the future.  **Action: SWIG to consider the appropriate format of late effects clinics, plus how to support models of care and workforce development; to be added to SWIG Work Programme**  It was recognised that not all services will adopt an identical model than the SFT service, although the model has been proven to work well.  SWAG Lead Cancer Nurses (LCN) had reviewed the role of IO CNS and provided a recommendation that this should remain combined with the role of general SACT nurses.  Given the need for specific expertise to manage IO toxicities and advice from the national forum to provide an IO service that is integrated with, and supports the rest of oncology services, the recommendation needs to be reviewed.  **Action: LCN C Levett will ask the regional LCNs to review the recommendation regarding provision of a specific IO Specialist Nurse workforce.**  At present, RUH do not have the required workforce in place, and it would help to benchmark the service in comparison with all centres across the region, looking at number of staff per patient population.  It is hoped that the SFT data can contribute towards business cases to support staffing needs, which are increasing rapidly.  RD&E started with one 0.8 Whole Time Equivalent (WTE) IO CNS; the team has since expanded to 1.5 WTE and held 1600 clinic appointments, 5 days per week over the last year that would have otherwise been Consultant led.  Recently, the Band 7 nurses in SFT have been promoted to 8A Advanced Nurse Practitioners (ANPs) and an additional Band 6 will be appointed soon. Three clinics are held per week.  Velindre plan to appoint a Band 8A, Band 7 and Band 6.  Patient feedback from IO toxicity clinics has been positive.  **Action: SWIG members will send details of the current provision of IO Nurse Specialists and the clinics they provide to H Dunderdale**  **To provide a baseline understanding of current workforce and models of care.**  Management of follow up processes differ across the region.  **Action: SWIG members will send details of follow up processes to H Dunderdale**  **Action: SWIG will share processes on patient pathways between other specialist services for varied indications; to add to Work Programme**  It was noted that access to essential investigations is widely variable, for example it is currently only possible to arrange urgent flexi-sigmoidoscopy in some centres if the patient is admitted.  Funding for the optimal treatment for colitis needs to be clarified to ensure equity of access across the region, particularly with regard to second line/beyond immunosuppression.  **Action: Urgent access to sigmoidoscopy needs to be investigated collectively - requires consensus with the regional Gastroenterologists.**   1. **Further IO service developments:**   **Please see the presentation uploaded on to the SWAG website**  **Presented by C Barlow on behalf of V Fountain**  *Provision of Adjuvant Follow Up Clinics:*  Adjuvant follow up clinics have been arranged in SFT to manage ongoing toxicities following IO treatment once a patient has been discharged from general oncology back to their site specific teams.  Side effects can persist many months after treatment and can have a significant effect on Quality of Life and psychological wellbeing.  Prospective data was captured on the clinic activity to evaluate how the clinic was working, and this highlighted the need for a more formalised service.  The nurse-led clinic is run by the 2 ANPs (with medical supervision) once a week, with 6 clinic slots, in collaboration with the skin cancer practitioners.  A set of blood tests are undertaken, as is a clinical examination if required, every three months for 1 year.  Toxicities are managed as per Clatterbridge / UKONS guidelines.  Patients are referred on to other services for ongoing support and non-IO related concerns.  All patients to date (33) have been treated for melanoma.  The vast majority of patients completed treatment. Reasons for stopping treatment include toxicities, disease progression or due to other comorbidities.  Following the presentation the group noted it would be helpful if SWIG collected data on the number of patients completing treatment and the reasons why treatment was stopped.  Some centres manage late effects in a shared care system with site-specific teams. Importantly the different models all recognise the monitor and manage ongoing or late-onset toxicities.  **Action: SWIG to collect data on adjuvant follow up to compare who completes treatment and, if not, why not, plus what toxicities are being picked up**  *Provision of Late Effects Clinics:*  There are two aspects to consider: management of those patients with ongoing grumbling toxicities and management of unexpected late effects.  Patients need to be informed so that they can recognise when they need to seek help.  A late effects clinic could be provided via a telephone advice and guidance route for General Practitioners, who would be provided with an end of treatment summary that would include a list of symptoms that suggest a cancer relapse or a late toxicity.  There is no clear cut off time for when late effects can occur with IO. With chemotherapy, the cut off time is 6 weeks, but there are some papers that suggest IO late effects can happen as late on as 5 years post treatment.  An end of treatment wallet sized alert card needs to be developed to ensure that patients know when to contact their GP with symptoms and get advice / access to IO services.  **Action: R Dylan Frazer will draft an ‘Alert Symptoms’ card for review by SWIG.**  **Action: SWIG members are invited to email any ideas on management of late effects, or any data that would be considered helpful to collect, to H Dunderdale**  *Psychological Support & Ongoing Care:*  It is known that patients have unmet needs in terms of the psychological consequences of a cancer diagnosis and the subsequent treatment, and additional access to psychological support is required.  A cohort of patients will have been given a life expectancy of within a few months who now, with the intervention of IO, may live for many years; this will be complicated to process.  Some toxicities have life changing consequences.  It was not possible for a representative from the regional psychology network to attend today, however, Consultant Psychologist M Osborne from RUH asked SWIG to provide information on the following:   * Profile of side effects * Initial impressions regarding the psychological legacy * Have any surveys been undertaken or does this need to be an action from SWIG?   It will be straightforward to provide the profile of side effects.  A patient experience survey, undertaken by IO Specialist Nurse N Jones, had been presented at the most recent IO education forum, aiming to find out if patients knew of any gaps in the support given.  The survey was sent to 170 patients treated with IO in 2020 across all disease sites and a high response rate was received.  Questions on the psychological aspects of treatment included how people found living with uncertainty and if there were times when anxiety increased, for example, when waiting for results of surveillance scans.  It was appreciated that patients receive the National Cancer Patient Experience Survey, and so the survey was designed specifically to look at unmet needs from an immunotherapy point of view as this was not currently captured.  **Action: SWIG will replicate the patient experience survey across the region to baseline the current patient experience and repeat after a set period of time – to be confirmed.**  **Action: A second survey for patients 5 years post-treatment for assessment of Quality of Life will be produced.**  **Action: C Barlow will provide the psychology network group with information on side effects.**   1. **Governance:**   **CAG Service overview**  **Please see the presentation uploaded on to the SWAG Website**  **Presented by H Dunderdale**  The SWAG Cancer Clinical Advisory Group (CAG) Service comprises 15 groups which are managed by CAG Manager H Dunderdale and CAG Administrative Coordinator A Smith. The groups officially meet twice a year and ad hoc as and when required.  In addition, CAG service supports an annual meeting of the MDT Leads (postponed recently due to the pandemic) from all groups to discuss cross-cutting issues such as MDT reforms, plus the bi-monthly Cancer Operation Group (COG).  Ideally, there would be an additional Acute Oncology CAG. It is not possible for CAG service to provide this with existing resources, and so the Cancer Alliance has been asked to consider providing this service once they have their full complement of staff.  CAG service involved balancing the preparation for upcoming CAGs with reporting on outputs from previous CAGs, which can cause some delays, although actions are initiated and reports are finalised as soon as possible prior to the next meeting to push things forward on the CAG Work Programmes.  *Recurrent arrangements for the CAGs*  Acute providers of Cancer Services fund and manage the Cancer Clinical Advisory Group Service, which protects it from potential future changes to Cancer Alliances (the previous Cancer Networks were disbanded following a change in Government). CAG Service is owned by the clinical teams / managers.  The Cancer CAG Manager is accountable to report to the Cancer Alliance Delivery Group (which comprises provider Trusts, CCGs, Cancer Alliance core team representatives) on local priorities from CAGs and to report back the priorities of the NHS Long Term Plan ‘ambitions for cancer’ to the CAGs.  The Cancer Alliance Delivery Group will consult with CAGs and respond to issues raised by the groups.  *Remit of the CAGs: Provision of expert advice*  Statement of Purpose: To deliver equity of access to the best medical practice for our patient population.    CAG Activity   * Undertake work to facilitate compliance with network elements of Quality Surveillance requirements (individual Trusts are responsible for overall compliance) by agreement of regional guidance * Meet/liaise regularly as a network group to identify service requirements:   + Review of MDT / Network Service (MDT meetings / workforce etc)   + Assess compliance with the most up to date NICE / other Clinical Guidelines   + Coordination of patient care pathways across centres / services   + Ensuring patient’s advice is sought (24 patient representatives) on development of services   + Agreement of personalised care and support initiatives   + Agreement of evaluation processes (network audits / service evaluations / data dashboards etc.)   + Coordination of research to optimise recruitment opportunities   + Share best practice (reduce duplication of work wherever possible)   + Provision of educational opportunities / discussion of potential innovations   + Provision of advice to Trusts/CCGs/CAs to influence service developments.   *CAG Performance measures:*   * Attendance records * Agenda items discussed * Record of agreed outcomes (meeting reports) and completion of actions * Performance of organisations against agreed clinical outcomes (review of National audit data for example, although this measure is always hampered by data quality) * Performance in Quality Surveillance assessments (Peer Review of the regionally agreed guidance) * CPD accreditation * Website activity (SACT protocol service for example).   CAG priorities often align, making it possible to raise issues as a collective.  CAGs can influence priorities for Service Developments; numerous examples are listed in the presentation.  Following C Barlow’s presentation at the CA Friday morning meeting on the needs of the rapidly developing immunotherapy service, it was evident that there was a need to prioritise formally adopting SWIG as a CAG; this has been agreed by the Cancer Operational Group.  **Action: H Dunderdale will draft Terms of Reference for SWIG for review by the group.**  There is not thought to be an equivalent service in Wales, but for the purpose of SWIG, South Wales is included.  As part of the CAG service, SWIG has the means to escalate priorities to the various appropriate stake holders.   1. **IO Specialist Nurse Group:**   It is thought that the South West are positive outliers in recruitment of  IO Specialist nurses – more in SW.  It has previously been possible to meet as a group with support from a pharmaceutical company.  A pharmaceutical company is also starting up what is likely to be a National IO group, with the next one planned in May 2022.  The IO Specialist Nurse Group will reconvene to combine data and share information on their services in a format to be agreed by the IO Nurses; potentially linked to future SWIG meetings.  **Action: IO nurses to define ideal IO Specialist Nurse Group format.**  Specific item brought to the agenda for discussion: In the absence of evidence on the safe administration of IO by pregnant staff, SWIG recommend that SACT protocols are followed.  **Action: SWIG recommendation to be reviewed by SACT nurse group**  Alternative training for pregnant workers could be considered so that appropriate nursing-related tasks can be completed (toxicity clinics for example) when it is not possible to administer SACT/IO.  **Action: For local SACT services to consider alternative training for pregnant workers dependant on the workforce needs of individual departments.**   1. **Regional Data:**   Data collection and audit may be informed by the National IO forum.  Tangible Key Performance Indicators (KPIs) need to be defined to measure IO service outcomes  One initial proposal:  It would be helpful to gather data on G3/4 toxicities and review patient management to see if any lessons can be learned to improve toxicity management. For example, one service has implemented a safety check to ensure that any patient on IO that calls the helpline with diarrhoea is reviewed by an IO Specialist Consultant.  Data from Clinical Trials on G3/4 toxicities could be used as a baseline. Although Clinical Trials all refer to CTC toxicity definitions, local definitions may vary, but if considered G3/4 by the assessing clinical team, this will be accepted.  For the purpose of ensuring that there is equity of access across the region, the dataset will include details on administration of biologics and other immunosuppressants, including who was responsible for giving them and if there were any barriers to accessing the drugs. This should be flagged up by the National forum as well; often there are differences in access across the devolved nations.  **Action: A proposed G3/4 data collection spreadsheet will be sent for the opinion of the group**.  A second proposal regarding prophylaxis: prospective data could be collected on those patients who had other treatment related toxicities such as PCP, fungal infection or a fracture, to then assess if appropriate prophylaxis had been prescribed.  Cumulative steroid dose data would also be useful to review along with outcomes.  **Action: Data collection proformas to be developed**   1. **Network audits:**   **Action: Ideas for regional audits will be sent to H Dunderdale**   1. **Research:**   **Action: Provision of a list of open immunotherapy trials available, containing contact details of Principal Investigators will be investigated, aiming to improve cross-referrals across the region.**  **Action: The ability to refer patients to trials in the devolved nations will be investigated.**  Ideas for future research topics will probably be best addressed by the National forum – to be discussed at meeting 31.3.22.  Potential colitis trials are being discussed in the near future by R Dylan Frazer and N Powell and will be fed back to SWIG.  It is possible to refer patients to any other centre in England.   1. **Equity of access to therapy for toxicity management:**   As previously discussed, biologic treatments are not accessible with equity across the region. It is vital that SWIG addresses this.  **Action: SWIG members are to send details of current access and barriers to treatments for toxicity management.**   1. **Education:**   **Please see the presentation uploaded on to the SWAG website**  **Presented by R Dylan Frazer**  The current Education Forum, held on the first Thursday of every month from 13:00-14:00, has had brilliant feedback and is a well-attended national meeting. It is free of charge and non-promotional and has had several useful outputs such as agreement of audits and surveys.  Complex cases are discussed in general terms rather than providing advice on management of specific patients.  The varied topics discussed over the last 6 months are listed in the presentation; any steer on helpful topics for future meetings would be welcomed.  Another education forum, Practical Management of your Immuno-Oncology Patient (PMI-OP) is held every 4 months and provides expertise on management of different toxicity groups. The next meeting (which is also free) is at 6pm on Wednesday 11th May 2022.  Further work will be undertaken to promote the IO Education Forum and encourage wider participation. SWIG are asked for feedback on how to optimise the forum.  It is not possible for some key members of SWIG to attend the Thursday afternoon meeting.  **Action: A survey will be sent to establish an optimal alternative meeting date and time every other month while maintaining the Thursday afternoon forum.**  H Winter is looking at developing micro-learning packages (3 minutes long) that can be accessed in the workplace.  An IO curriculum is also being developed; the draft will be circulated for the opinion of the group.  Ideally, a recording of the events could be made available on a password protected page on the SWAG website.  **Action: H Dunderdale will contact the Cancer Alliance Comms Team to see if recordings can be improved and the Web Master to see if a secure area for recording of the meetings is possible.**  **Action: GP Education Packages on Immunotherapy will be explored with the Cancer Alliance Communications Team if not on the immediate national agenda**  The CA plan to develop an IO Leadership course and run an oral targeted therapy training course.  R Dylan Frazer recorded a podcast which is an interview with a GP to explain what IO is and what GPs need to know.  **Action: A link to the podcast will be shared.**   1. **Complex Case Multi-Disciplinary Team Meetings:**   Provision of an MDT meeting for timely opinions on complex cases will be investigated.  **Action: To raise with the regional Cancer Operational Groups.**  **Action: To compile a South West Directory of Specialist contacts.**  **Action: SWIG members to provide feedback on the management of complex cases at future SWIG meetings.**   1. **Any other business / date of next meeting.**   Actions identified in the meeting today will be fed back to the national forum tomorrow.  **Action: A Doodle Poll will be sent to find the optimal date for the next SWIG meeting.**  **-END-** | **ACTIONS**  **H Dunderdale**  **H Dunderdale**  **C Levett**  **SWIG / H Dunderdale**  **SWIG/H Dunderdale**  **SWIG/H Dunderdale**  **IO Leads / Gastroenterologists**  **SWIG members**  **R Dylan Frazer**  **SWIG members**  **SWIG members**  **C Barlow/ SWIG members**  **C Barlow**  **H Dunderdale**  **IO Nurses**  **H Dunderdale**  **SACT CAG**  **C Barlow/H Dunderdale**  **To be allocated – volunteers required**  **SWIG members**  **Clinical Research Network/s**  **R Dylan Frazer**  **SWIG members**  **R Dylan Frazer**  **H Dunderdale**  **To be confirmed**  **R Dylan Frazer/H Dunderdale**  **H Dunderdale**  **H Dunderdale**  **SWIG members**  **H Dunderdale** |