



NCRI

National
Cancer
Research
Institute

NCRI Teenage & Young Adults (TYA) and Germ Cell Tumour (GCT) Clinical Studies Group

Annual Report 2016-17



Partners in cancer research



NCRI Teenage & Young Adults (TYA) and Germ Cell Tumour (GCT) CSG Annual Report 2016-17

1. Executive Summary (including top 3 achievements in the year)

The Teenage & Young Adults (TYA) and Testis CSGs merged at the beginning of 2017 to form the TYA & GCT CSG, co-Chaired by Angela Edgar and Jonathan Shamash. The CSG has a strategic objective to improve opportunities for TYA (13-39 years) to enter disease-specific cancer studies and, specifically, to develop germ cell cancer trials (for both males and females). We will continue to carry out research to develop evidence-based guidance into the optimal provision of cancer care for TYA (16-24 years), facilitate opportunities for precision medicine and address survivorship issues. This strategy was supported by the NCRI at the TYA CSG Quinquennial Review (QQR) in October 2016.

Achievements

1. Clinical trials: recruitment, access and availability: We have shown that 10 year recruitment data (2005-2014) for TYA to selected NIHR CRN: Cancer trials for the commonest diseases in TYA, including male germ cell tumours, has fallen (since 2010 to 25%, 12% and <10% for 15-19, 20-24 and >25 year olds). NIHR now requires each LCRN to report its TYA recruitment to cancer trials and NHS England aims for at least 50% of TYA with cancer to be recruited to clinical trials by 2025. We continue to collaborate with NIHR LCRN TYA Subspecialty Leads (SSLs) and NIHR CRG to achieve this.

NIHR has identified major gaps in the trial portfolio that particularly disadvantage TYA. There are no first line intervention studies for intermediate/high risk metastatic or salvage therapy for relapsed/refractory testicular GCT. Two new studies (P3BEP and TIGER) have been developed to address this. Preliminary results of the recently closed 111-BEP study were presented at GU ASCO and the results of the TE-3 study were published.

2. National evaluation of TYA cancer services (BRIGHTLIGHT study): Recruitment closed in 2015 and the study ends in 2019 with >1,000 young people from ~100 NHS Trusts. Case study results were presented at the 9th International Conference and 1st Global AYA Cancer Congress in December 2016 and a number of papers have been published (see Appendix 5). In collaboration with the Department of Performing Arts at Chichester University, Contact Youth Group in Manchester, the Christie Hospital, and funded by The Wellcome Trust, a live performance "There is a light" has been created with young people's interpretation of results so far. Members of the Group were involved in the

production process taking part in five workshops. The performance is followed by an interactive talk back discussion to raise awareness of TYA cancer and has been performed in a number of cities throughout England.

3. Collaboration with the CCLG Tissue Bank Group with a view to extending tumour banking facilities up to age 25 years. A collaborative initiative with EORTC is in development to characterise the spectrum of targetable mutations in poor prognosis TYA cancer under the umbrella of SPECTArare. This will develop a bank of clinically annotated tissue sample for sequencing against a panel of targetable mutations with a view to identifying eligibility for clinical trials.
4. Survivorship and quality of life: The Teenage and Young Adult Cancer Survivor Study is the largest TYA survivorship study (200,945 survivors) has led to five publications in the last 12 months which have authoritatively shown the morbidity and mortality associated with TYA cancer care and emphasises the need to do more.

Challenges

1. Opening clinical trials: P3BEP opened in the UK in May 2017. It is imperative that multiple centres participate if TYA are not to be deprived of adequately powered trials and their chance to benefit clinically from trial participation.
2. Early diagnosis studies: Exploration of pathways to diagnosis study has been presented at international conferences and showed that there are challenges along the diagnostic pathway, not just in primary care. Funding has been secured for in-depth analysis of the routes to diagnosis for the BRIGHTLIGHT cohort. Securing funding for such studies remains challenging and no clear interventions have been defined. A new focus will be how young people use primary care and how to interact with and reintroduce these patients into primary care post-treatment.
3. Early onset carcinomas: Early onset carcinomas accounts for the largest group of cancers in the TYA age group. It is currently unknown whether the portfolio of trials for carcinoma are appropriate for this age group, or indeed whether the research questions are being addressed. The CSG wishes to establish a working party scope this for the more common carcinomas in this age bracket, with a view to ensuring the needs of TYA are considered by the site specific CSGs when developing clinical trials. This will involve collaboration with a number of CSGs.
4. Fertility studies: Fertility issues remain a major concern for young people with cancer, yet baseline assessment of reproductive function, documented discussion with patients regarding risk to fertility, suppression of ovarian function during treatment, fertility preservation uptake and outcomes and impact of new therapies on reproductive function is often ignored in clinical trial development. Further research in this area is required and collaboration with CSGs and other stakeholders is necessary to ensure this is addressed within clinical trials.

Opportunities

The diversification of the membership has broadened research opportunities and new collaborations, in partnership with other CSGs, will include:

1. Collaboration on improving quality of life for patients living with and beyond cancer.
2. To establish a Working Party to explore unanswered research questions in early onset carcinomas; this will involve collaboration with site-specific CSGs.
3. Exploiting the NIHR network agenda around e-Health to seek funding from NIHR and the Department of Health (DH) to support aftercare using an IT based system.

4. BRIGHTLIGHT will co-host the TYAC conference on 6-7 July at the Horizon Centre Leeds and emerging results from all workstreams will be presented. BRIGHTLIGHT will host a session at the NCRI Conference 2017 and the outcomes of the James Lind Alliance exercise will be presented.
5. UK and European collaborations will improve access to stratified medicine.

1. Structure of the Group

In January 2017, the TYA and Testis CSGs amalgamated to form one CSG, and the remit of the testis group expanded to incorporate all germ cell tumours (male and female, intracranial and extracranial germ cell tumours, GCT). The Group is currently known as the TYA & GCT CSG and is co-Chaired by Dr Angela Edgar and Dr Jonathan Shamash (former TYA and Testis CSG Chairs, respectively). The Group membership incorporates all the members (37) from both CSGs, including: five consumers, 12 medical oncologists, five paediatric oncologists, two academic paediatric oncologists, a pathologist, a research development coordinator, a NIHR CRN theme lead and a senior lecturer in cancer care (Appendix 1).

Dr Clare Rowntree stepped down from the Group in March 2017 having been a member since its inception in 2008. The Group would like to thank Dr Rowntree for her enormous contribution to the productivity of the TYA CSG and, in particular, for leading on and developing the Biological Studies Subgroup which she chaired until 2013. Dr Rowntree remains a member of the Biological Studies Subgroup.

The Group welcomed two new consumer members, Miss Lara Veitch and Mr Max Williamson, in September 2016. The Group also continues to benefit from the enormous support from full time Research and Development Coordinator, Dr Lorna Fern, appointed in 2006 and funded by Teenage Cancer Trust, with an extension of further funding until 2018. The role and funding agreement is reviewed bi-annually.

The Group has four Subgroups: Health Services Research (HSR) Subgroup (Chair, Dr Lorna Fern), Biological Studies Subgroup (Chair, Dr Martin McCabe), Survivorship (Chair, Professor Hamish Wallace) and Quality of Life Subgroup (Chair, Dr Danish Mazhar). Membership of the Subgroups is detailed in Appendix 1.

The first meeting of the CSG was held in March 2017 to set the priorities of the Group and discuss plans for future working. There is significant overlap in the Survivorship and Quality of Life Subgroups, which will function as one Subgroup henceforth. A prime function of the CSG is germ cell tumour clinical trial development; how this will be reflected in the overall structure of the Group is under discussion.

2. CSG & Subgroup strategies

Main CSG

The current CSG strategy incorporates the aims of the former TYA and Testis CSGs, and accommodates the overlap between the Groups. The overarching strategic aims are to:

1. Ensure that teenagers and young adults are considered for and have opportunities to enter disease-specific NCRI CSG research studies.
2. Develop clinical trials for GCT for all stages of disease.
3. Research into the optimal provision of health care for TYA (16-25 years) and to provide

- the evidence base for the present and future guidance for young people with cancer.
4. Further exposition of tumour biology in TYA and facilitate opportunities for personalised medicine.
 5. Address survivorship and quality of life issues.

Further details of the overarching strategic objectives, outputs and outcome measures, with timelines and leaders for each workstream, are provided in Appendix 2. The CSG will hold a strategy meeting in early 2018 to develop the future strategic direction of the Group. We will continue to work with other CSGs, the National Institute for Health Research (NIHR), funders and other stakeholders.

Health Services Research (HSR) Subgroup (Chair, Dr Lorna Fern)

The Subgroup has had two face-to-face meetings and regular teleconferences.

Aims

1. Improving understanding of the pathways to accessing research for TYA.
2. Improving understanding of the barriers to recruitment to research studies.
3. Improving routes to diagnosis.
4. Evaluating specialist care for young people (aged 16-25 years) with cancer.

The Subgroup is responsible for a James Lind Alliance (JLA) research priority exercise – due to complete December 2017.

Achievements

- Phase I of the evaluation of the FYSOT conference has been accepted for publication in the British Medical Journal Open.
- Phase II of the evaluation of the FYSOT conference has recruited 228 patients, 68 significant others and 48 healthcare professionals.
- The online study has recruited 20 young people and eight healthcare professionals.
- The JLA project attracted over 300 respondents with an equal split of young people, professionals and significant others.
- BRIGHTLIGHT dissemination continues to be prolific.
- Securing £40K from the Wellcome Trust to perform BRIGHTLIGHT results with the Contact Youth Theatre.
- Analysis of REFER_ME is underway.

Aims for the next 12 months

1. To develop transition as an area of research, including supporting young people at the end of treatment; this will involve collaboration with the merged Survivorship and QoL Subgroup.
2. Submission of a NIHR Programme Development Grant in autumn 2017 examining the delivery of psychosocial support delivered by multidisciplinary members of the team.
3. Top 10 research priorities identify from the JLA exercise.
4. Completion of the systematic review of E-Health project: Assessing the Quality, Feasibility, and Efficacy of Electronic Patient Platforms Designed to Support Adolescents and Young Adults with Cancer.
5. Closure of the BRIGHTLIGHT study and ongoing analysis.

Biological Studies Subgroup (Chair, Dr Martin McCabe)

The Subgroup meets twice per year face-to-face and several times by teleconference. The

Subgroup strategy is detailed in Appendix 2 and involves three major cross-cutting analyses and additional disease-specific projects.

Achievements

- Improving access to banked tissue for research: Our survey (2012-2014) identified approximately 1,500 tissue samples from cancer patients aged 13-39 currently held in Confederation of Cancer Biobanks, with CCLG tumour bank accounting for the majority of specimens from young people aged 13-19 (presented at the UK biobanking showcase conference, November 2016). Discussions to extend the CCLG tissue bank age limit to 25 years have had agreement in principal and possible funding sources have been identified.
- Exploring the contribution of biological and non-biological factors to differential survival in TYA compared to children and older adults: Subgroups of international clinical trialists have been convened to examine trial data for synovial sarcoma, acute myeloid leukaemia and germ cell tumours with regard to examining age-related outcome variation with treatment intensity. Extending this to include Ewing sarcoma and high grade glioma is being explored. A UK wide all-age trial of pharmacokinetic profiles and toxicity biomarkers of commonly used cytotoxic agents is recruiting well and define age-specific pharmacokinetic profiles with a view to describing age-related variation in drug handling in Ewing sarcoma.
- Increasing access to precision medicine: Significant progress has been made to enrol an AYA (adolescent/young adult) cohort into the EORTC stratified medicine platform SPECTA. EORTC has identified funding for a pilot study of poor risk patients with recurrent bone and soft tissue sarcomas and high grade brain tumours. The draft protocol is in circulation and UK centres have been approached.

Survivorship Subgroup (Chair, Professor Hamish Wallace)

Unfortunately, for a number of reasons, the Subgroup has not met formally. The strategic aims of this Subgroup overlap with the vision of the Quality of Life (QoL) Subgroup and, given the commonalities, these two Subgroups will form a single Subgroup and will be chaired by Dr Mazhar (see Appendix 2 for details of the strategy).

Achievements

- Publication of five peer-reviewed papers from the TYA Cancer Survivor Study.
- To develop innovative strategies to empowering patients: We aim to develop an electronic platform delivered as an app to encourage independence after active treatment and support follow up. This will incorporate a large body of work being developed in Scotland around using mobile technologies to enhance cancer care for young people.
- To support enhanced population based studies: This will build on the cancer survivorship studies led by Professor Hawkins.
- To address fertility issues: We are developing collaboration with the British Fertility Society to explore how best to take this forward to ensure all young people have opportunities for fertility preservation considered up front. The Subgroup will develop selection criteria and available evidence for ovarian cryopreservation with a view to preparing a national proposal.

Aim for the next 12 months

To establish the joint Survivorship and Quality of Life Subgroup and develop a strategy for the next year.

Quality of Life (QoL) Subgroup (Chair, Dr Danish Mazhar)

The Quality of Life (QoL) Subgroup has a remit to provide an oversight on studies involving testis cancer patients (current and past) that focus on survivorship, treatment toxicities and quality of life issues. The further development of the QoL portfolio of studies is a key theme within the overall strategy. The Subgroup has a multidisciplinary membership and has developed collaborative links other CSGs and Subgroups, including the POS CSG and its Survivorship Subgroup. The Subgroup holds two meetings a year (usually teleconferences) and reports to the main CSG. Danish Mazhar has been Chair of the Subgroup since July 2011.

Achievements

- The leading role played by members of the Subgroup in the development of quality of life sub-studies to run alongside large international collaborative studies in germ cell tumour patients.
- Development of protocol for RESURGE study.

Aims for the next 12 months

1. To submit RESURGE protocol for HTA funding.
2. To gain funding for the MaGIC Quality of Life substudy.
3. To develop a study to assess the factors relevant in patient treatment decisions for stage I testicular germ cell tumours after orchidectomy.

3. Task groups/Working parties

The CSG currently has no working parties. An application will be made for a time-limited working party to collaborate with targeted site-specific CSGs to explore the TYA issues in adult cancers, such as melanoma, breast, CNS and gynaecology.

4. Patient recruitment summary for last 5 years

In the TYA & GCT CSG portfolio, two trials closed to recruitment and two opened. Currently there are two recruiting trials (P3BEP and Pharmacokinetic variation and toxicity in Ewing's sarcoma) and an additional one is due to open (TIGER); however, as both of these studies are for small subgroups of patients, recruitment is likely to be low. This is only going to improve if a more widely recruiting study can be opened.

The CSG remains a cross-cutting CSG, which is distinct from other CSGs, in that, other than for GCT, recruitment data is not a true reflection of Group activity. Over the last few years, the former TYA CSG has focused its efforts on developing studies to address additional important research questions relating to cancer biology, age-related pharmacokinetics and toxicity, fertility preservation, psychological impact of cancer during adolescence, optimum provision of cancer care and survivorship, and is beginning to build up a portfolio of studies as shown in Appendix 3. Over 600 participants have been recruited to HSR studies this year (300 young people, around 150 HCP and around 168 significant others) but is not captured in non-portfolio studies. Furthermore, the HSR Subgroup has employed a number of interventions to retain participants in the FYSOT study.

Table 1 Summary of patient recruitment by Interventional/Non-interventional**TYA**

Year	All participants		Cancer patients only		% of cancer patients relative to incidence	
	Non-interventional	Interventional	Non-interventional	Interventional	Non-interventional	Interventional
2012/2013	269	-		257	-	-
2013/2014	661	0	619	0	-	-
2014/2015	497	0	476	0	-	-
2015/2016	190	5	138	5	-	-

Testis

Year	All participants		Cancer patients only		% of cancer patients relative to incidence	
	Non-interventional	Interventional	Non-interventional	Interventional	Non-interventional	Interventional
2012/2013	1342	277	1335	259	59.8	12.4
2013/2014	1639	290	1495	290	67.0	13.0
2014/2015	1349	140	1269	140	56.9	6.3
2015/2016	752	20	686	20	30.73	0.90

TYA & GCT

Year	All participants		Cancer patients only		% of cancer patients relative to incidence	
	Non-interventional	Interventional	Non-interventional	Interventional	Non-interventional	Interventional
2016/2017	872	6	639	6	-	-

5. Links to other CSGs, international groups and network subspecialty leads

The CSG continues to strengthen its UK and European collaborations; these include:

- CSGs: Primary Care (Chair, Professor Neal), Psychosocial Oncology & Survivorship (Dr Hubbard and Dr Taylor), Sarcoma (Professor Whelan, Dr Edgar and Mr Gerrand), CCL (Dr Edgar) and Gynaecological Cancer. However, we are yet to secure funding to continue with meetings to develop further collaborative grant proposals.
- Drs McCabe and Fern are members of the Brain CSG. Dr Taylor, Senior Research Manager for BRIGHTLIGHT, is also a member of the POS CSG and our HSR Subgroup.
- Dr Fern is a member of the NCRI Screening, Prevention & Early Diagnosis (SPED) Advisory Group.
- NCRAS (formerly National Cancer Intelligence Network CTYA Site Specific Clinical Reference Group): Dr McCabe was co-appointed as clinical lead for childhood and TYA cancer in December 2016.
- EORTC through the Biological Studies Subgroup's collaboration to facilitate opportunities for stratified medicine for TYA.
- Experimental Cancer Networks: The Biological Studies Subgroup has developed collaborating to further their work on developing tumour banking facilities.

- The Group continues to work very closely with the NIHR to ensure young people are included in cancer clinical trials by understanding how TYA access cancer services and how those services recognise their needs.
- The European Network of Cancer Research in Children and Adolescents (ENCCA), led by Dr Stark and involving several CSG members, is a European project aimed at improving outcomes for young people with cancer across Europe.
- A number of members form part of the Malignant Germ Cell International Collaborative (MaGIC) which aims to further our understanding of the biology of the disease, to improve diagnosis, disease monitoring, risk stratification, identification of therapeutic targets and ultimately improve outcomes for childhood and adolescent extracranial germ cell tumours.
- TYAC (an organisation for professionals involved in the care and research of TYA): Most CSG members are members and Dr Edgar, Ms Smith, Ms Morgan, Dr Fern, Dr Michelagnoli sit on the TYAC board - TYAC has agreed to provide a bursary to cover the travel costs of two trainees per year.
- The James Lind Alliance Priority Setting Partnership is our first joint research project with Teenage Cancer Trust, Clic Sargent and Children with Cancer UK. Our links with charities such as Teenage Cancer Trust continue to be strong and the charity continues to support funding for Dr Fern. The CSG has respected links with the NCRI Consumer Forum and are grateful for their ongoing support.

6. Funding applications in last year

Table 2 Funding submissions in the reporting year

Cancer Research UK Clinical Research Committee (CRUK CRC)			
Study	Application type	CI	Outcome
May 2016			
None			
November 2016			
Carboplatin vs BEP vs PEP in metastatic good prognosis disease – reducing toxicity by risk-adapted therapy in men and women	Outline application	Dr Jonathan Shamash	Not invited to full
TRISST: A randomised phase III trial of imaging and schedule in Seminoma Testis (MRCTE24)	Full (Extension)	Professor Johnathan Joffe	Supported
Other committees			
Study	Committee & application type	CI	Outcome
Understanding barriers to participation in cancer trials amongst teenagers and young adults: qualitative study	Chief Scientist Office Research Grants/CRUK	Dr Angela Edgar	Successful
Improving outcomes for children and young adults with extra cranial germ cell tumours 2015-2020	St Baldrick's Grant	Dr Matthew Murray	Successful
GAMMA: a phase II study in relapsed germ cell tumours (2013-20)	Orchid Cancer Appeal	Dr Jonathan Shamash	Successful
CarPET: PET scan response guided therapy of carboplatin AUC 10 in metastatic seminoma (2012-17)	Orchid Cancer appeal	Dr Jonathan Shamash	Successful

7. Collaborative partnership studies with industry

The Group has no formal arrangements with industry at the moment and this will now come under the remit of the Biological Studies Subgroup. Links with TYA Experimental Cancer Networks will further serve to foster links.

8. Impact of CSG activities

The CSG's work around trial entry and young people continues to inform the research community about improving access to cancer clinical trials. The continued scrutiny of CRC applications serves to ensure that appropriate age eligibility criteria has been applied and that relevant studies will be available in treatment centres for young people. The Group has been particularly prolific this reporting year, reviewing around 20 CRC applications. With permission from CRUK, we have extended the review to include members of the Biological Studies Subgroup which allows us to draw on a larger group of relevant experts.

As a cross cutting CSG, the Group is in a unique position to work along-side all of the CSGs and influence research opportunities for young people across the disease spectrum. Over the last few years, the TYA CSG focused its efforts on developing studies to address additional important research questions relating to cancer biology, age-related pharmacokinetics and toxicity, fertility preservation, psychological impact of cancer during adolescence, optimum provision of cancer care, and survivorship and is beginning to build up a portfolio of studies. We believe this can be built on with the merged CSG.

BRIGHTLIGHT will co-host the TYAC conference on 6-7 July at the Horizon Centre in Leeds and emerging results from all workstreams will be presented. BRIGHTLIGHT will also host a session at the NCRI Conference and the outcomes of the James Lind Alliance exercise will be presented.

The Group was the first to advocate CRUK to ask investigators to justify the use of age as an inclusion or exclusion criterion on new studies. In January 2017, the US Food and Drug Agency released a report recommending duplication of the "European Experience" in lowering the age eligibility criteria of adult studies (<http://clincancerres.aacrjournals.org/content/23/1/9>) (see page 11).

9. Consumer involvement

The CSG has five consumer members: Max Williamson, Stephen Thomas, Vincent Wolverson, Lara Veitch and James Adams.

James Adams (mentored by Dr Cutter) is a great ambassador for young people with cancer. James, a medical student from Manchester, is leading an awareness raising campaign to education young people about cancer which has been endorsed by Teenage Cancer Trust and will be adopted by other higher education institutions. James founded and leads Cancer Awareness in TYA (CATS), a student-run charity which started in Manchester and has been rolled out to other universities with an aim to increase cancer awareness among young people. He has contributed to applications submitted to CRUK's funding bodies (CRC and PRC).

Max Williamson (mentored by Dr Fern) has been a consumer member since September 2016 and is a member of the HSR Subgroup, James Lind Alliance TYA Group and the Innovation

Agency's Patient Involvement and Engagement Senate for Liverpool and the North West of England (IAPIE). He contributes to the review of research applications and has written a blog for IAPIE on the appropriate use of patient data. Max also featured as part of the NIHR International Clinical Trials day:

<https://www.nihr.ac.uk/news/being-involved-in-research-and-in-something-that-changes-lives-is-a-good-thing-to-be-part-of/6128>.

Stephen Thomas (mentored by Professor Stuart) and Vincent Wolverson (mentored by Dr Mazhar) represent the testicular patient perspective. Stephen is a member of various committees and panels across the UK (predominantly in Wales) acting as a bridge for the CSG with groups such as the Welsh Cancer Bank and the NIHR IPP. Stephen chairs the testis charity "The Big C" and regularly goes into schools/colleges to provide advice and knowledge. He has previously voiced struggles to engage with young males past secondary school age and hopes the merger of the two CSGs will bring insight and collaboration in this area.

Lara Veitch will join as a consumer member in April 2017 and is due to attend her first main meeting in September 2017. Lara has attended a HSR Subgroup meeting and is currently a member of James Lind Alliance TYA Group. She is also writing up data with Dr Fern on biological sample collection for TYA as part of her university coursework.

The BRIGHTLIGHT study has a user group of approximately 17 young people called the YAP who meet through face-to-face workshops, a closed Facebook page, social media and email. Dr Fern is PPI lead for BRIGHTLIGHT. The CSG also disseminates the results of BRIGHTLIGHT to young people with cancer via the Find Your Sense of Tumour (FYSOT), the annual patient conference ([YAPPERS at FYSOT](#)). Additionally, the JLA exercise further serves to increase outreach to young people and allows the opportunity to think more creatively about PPI involvement. "There is a light" provided us a unique opportunity to involve young people without cancer in BRIGHTLIGHT and will perform at the NCRI Conference and FYOST this year. Drs Fern and Taylor wrote a blog about their PPI experience for the NIHR international clinical trials day:

<https://www.nihr.ac.uk/blogs/does-patient-and-public-involvement-and-engagement-ppie-in-research-really-make-a-difference/6264>.

10. Open meetings/annual trials days/strategy days

The CSG has not hosted any open meetings, annual trials days or strategy days over the last 12 months.

The CSG participated in two SSL meetings in March 2017 hosted by the NIHR CRN: Cancer. The Group was represented at the joint Urological Cancers SSL meeting by co-Chair Dr Shamash where the differing needs of patients with germ cell tumours were apparent. In particular, the difficulty of securing funding and the lack of interest from industry making finding funding for trial support increasingly difficult. Last year's submission for a new metastatic germ cell good risk study was a case in point and it is hoped this can develop with SSL support.

The Teenage and Young Adults (TYA) Cancer Summit meeting was led by Dr Amos Burke (National Specialty Lead for Children and Young People's Cancer) and a number of current and former TYA CSG members attended, together with key stakeholders including TYA SSLs, Research Delivery Managers (RDMs), SSLs, charities, funders, the National Cancer Registration and Analysis Service (NCRAS), patient representatives and members of other CSGs. The meeting

explored the perspectives of TYA trial participation from the various stakeholders and developed a strategy for how we improve this through developing infrastructure and embedding research into service configuration. Drs Burke and Anwar carried out an analysis of the entire UK CRN cancer portfolio to identify access to studies that may be relevant to the TYA population and will aim to develop a core TYA portfolio. Metrics will be determined to facilitate scoping and current practice around clinical trial delivery and data collection across the regions.

The Group would like to explore a TYA trials event in the next two years and this will be considered at our strategy day in 2018. Raising awareness of TYA appropriate trials for young people is an important part of our strategy and a “core TYA” portfolio has been developed. This would involve collaboration and input from our colleagues in site-specific CSGs and a number of stakeholders, including, NIHR LCRN and CRN devolved nations.

Angela Edgar and Martin McCabe are members of the NHSE Clinical Reference Group Task and Finish Group for the Clinical Trials and Tumour Banking Workstream. The aim of this short-life group, convened in March 2017, is to advise the NHS to be able to produce an environment and infrastructure to facilitate clinical trials research and tumour banking.

11. Priorities and challenges for the forthcoming year

Priorities

1. Carry out a strategy day for the CSG in early 2018.
2. Maintaining a close working relationship with the NIHR and developed national cancer networks will be essential to ensuring equity of access to the clinical research portfolio.
3. Broadening the Survivorship and Quality of Life Subgroup portfolio to include fertility studies
4. To ensure TYA have opportunities to benefit from advances in personalised medicine.
5. To strengthen UK partnerships - ongoing collaborations with NCRAS is imperative if we are to improve our understanding of and outcomes for non-trial patients or for patients with refractory or recurrent disease.
6. To open AGCTAGCT1531, the first international, phase III, randomised controlled trial for low and standard risk extra-cranial germ cell tumours (GCT) in children, teenagers and young adults (up to 25 years old).
7. Re-submit the proposal for metastatic good risk seminoma/dysgerminoma based on feedback from the previous submission for IGCCCG good risk disease.

Challenges

1. Establishing a Working Party and developing collaborations with other CSGs to develop studies to look at early onset carcinoma.
2. Raising awareness of the TYA agenda in the traditional adult site-specific oncology community remains a challenge. This will require active engagement with other CSGs and the CSG will again visit the value of a national TYA trials meeting. Developing a greater profile must be seen as a priority and will require the efforts of all CSG members.
3. Securing funding for current and new research proposals is always challenging for our CSG given the small patient numbers and disease spectrum. We feel the challenges around funding early diagnosis projects will become less as the Refer Me project is underway, with plans for re-submission and incorporation into a larger programme grant.
4. Improving recruitment to research studies including early phase studies: Improving our understanding of patient recruitment to clinical trials from both a patient and health

professional perspective may require identification of a new model of thinking if we are to understand health behaviours. Exploring partnerships with medical anthropology to help us understand behaviour may provide insight into a necessary cultural shift.

5. Developing opportunities for personalised medicine in TYA necessitates European working due to the rarity of TYA cancers and the small TYA research community in the UK.

The co-Chairs would like to thank all of the CSG members for their valued contribution to the working of the CSGs over the past 12 months and for their patience and support of the merger. We feel that this is an exciting venture which will bring new opportunities and allow greater collaboration.

12. Appendices

Appendix 1 - Membership of main CSG and subgroups

Appendix 2 – CSG and Subgroup strategies

Appendix 3 – TYA & GCT CSG studies

Appendix 4 - Portfolio Maps

Appendix 5 - Publications in previous year

Appendix 6 - Major international presentations in previous year

Appendix 7 - Strengths & Weaknesses from the TYA CSG 2016 Quinquennial Review (QQR)

Dr Angela Edgar and Dr Jonathan Shamash (Teenage & Young Adults (TYA) and Germ Cell Tumour (GCT) CSG co-Chairs)

Appendix 1

Membership of the Teenage & Young Adults (TYA) and Germ Cell Tumour (GCT) CSG

Name	Specialism	Location
Dr David Cutter	Clinical Oncologist	Oxford
Mr James Adams	Consumer	Stoke on Trent
Mr Stephen Francis Thomas	Consumer	Cardiff
Miss Lara Veitch	Consumer	London
Mr Max Williamson	Consumer	Bedford
Mr Vincent Wolverson	Consumer	Norwich
Professor Mike Hawkins	Epidemiologist	Birmingham
Dr Jane Beety	NIHR CRN: Cancer, CCL Lead	London
Dr Linda Evans	Medical Oncologist	Sheffield
Dr Peter Hall*	Medical Oncologist	London
Professor Johnathan Joffe	Medical Oncologist	Huddersfield
Dr Danish Mazhar	Medical Oncologist	Cambridge
Dr Okezie Ofor*	Medical Oncology	
Dr Andrew Protheroe	Medical Oncologist	Oxford
Dr Alison Reid	Medical Oncologist	Surrey
Dr Naveed Sarwar	Medical Oncologist	London
Dr Jonathan Shamash (Co Chair)	Medical Oncologist	London
Dr Dan Stark	Medical Oncologist	Leeds
Dr Matthew Wheeler	Medical Oncologist	Southampton
Professor Jeremy Whelan	Medical Oncologist	London
Ms Sue Morgan	Nurse	Leeds
Dr Chris Barton*	Paediatric Oncologist	Liverpool
Dr Angela Edgar (Co Chair)	Paediatric Oncologist	Edinburgh
Dr Martin McCabe	Paediatric Oncologist	Manchester
Dr Maria Michelagnoli	Paediatric Oncologist	London
Dr Matthew Murray	Paediatric Oncologist and Translational Scientist	Cambridge
Dr Sara Stoneham	Paediatric Oncologist	London
Professor Hamish Wallace	Paediatric Oncologist	Edinburgh
Dr Shaun Wilson	Paediatric Oncologist	Oxford
Dr Clare Verrill	Pathologist	Oxford
Dr Lorna Fern	Research Development Coordinator	London
Dr Lisa McCann	Senior Lecturer in Cancer Care	Glasgow
Dr Tom Maishman	Statistician	Southampton
Ms Veronica Moroz	Statistician	Birmingham
Dr Kenneth Rankin	Surgeon	Newcastle
Mr Benjamin Thomas	Urologist	Cambridge
Dr Rebecca Ling*	Paediatric Oncology Trainee	London

* denotes trainee member

Membership of the Subgroups

Health Services Research (HSR) Subgroup		
Name	Specialism	Location
Miss Lara Veitch	Consumer	London
Mr Max Williamson	Consumer	Bedford
Dr Lisa McCann	Lecturer	Strathclyde
Dr Dan Stark	Medical Oncologist	Leeds
Ms Sue Morgan	Nurse	Leeds
Dr Rachel Taylor	Nursing/Clinical Trials	London
Dr Rebecca Ling*	Paediatric Oncology Trainee	London
Dr Lorna Fern (Chair)	Research Development Coordinator	London
Dr Anne-Sophie Darlington	Senior Research Fellow	Southampton
Dr Rachel Dommett	TYA Consultant	Bristol

Biological Studies Subgroup		
Name	Specialism	Location
Dr Clare Rowntree	Haematologist	Cardiff
Dr Dan Stark	Medical Oncologist	Leeds
Dr Frederik van Delft	Paediatric Oncologist	London
Dr Angela Edgar	Paediatric Oncologist	Edinburgh
Dr Martin McCabe (Chair)	Paediatric Oncologist	Manchester
Dr Matt Murray	Paediatric Oncologist	Cambridge
Dr Bob Phillips	Paediatric oncologist	Leeds
Dr Rachael Windsor	Paediatric Oncologist	London
Dr Gareth Veal	Pharmacologist	Newcastle
Professor Sue Burchill	Professor of paediatric and adolescent cancer research	Leeds
Dr Lorna Fern	Research Development Coordinator	London

Survivorship and Quality of Life (QoL) Subgroup		
Name	Specialism	Location
Dr Jenny Harrington	Clinical Fellow	Cambridge
Dr Rob Huddart	Clinical Oncologist	London
Mr James Ashton	Consumer	
Professor Mike Hawkins	Epidemiologist	Birmingham
Dr Ed Wilson	Health Economist	Cambridge
Dr Danish Mazhar (Chair)	Medical Oncologist	Cambridge
Dr Dan Stark	Medical Oncologist	Leeds
Professor Nick Stuart	Medical Oncologist	Gwynedd
Dr Jeff White	Medical Oncologist	Glasgow
Mrs Sue Brand	Nurse	Bristol
Ms Nicola Thomson	Nurse	Glasgow
Dr Sara Stoneham	Paediatric Oncologist	London
Professor Hamish Wallace	Paediatric Oncologist	Edinburgh

* denotes trainee member **denotes non-core member

Appendix 2

CSG & Subgroup Strategies

CSG Principles	Strategic Objectives	Strategic Outputs	Outcome measures	CSG Leads	Dates
Portfolio development (general)	<ol style="list-style-type: none"> To submit new study concept proposals To raise awareness & promote recruitment to TYA research studies in cancer networks To ensure trials developed for TYA Germ cell tumour clinical trial development 	<ol style="list-style-type: none"> Each subgroup to submit new SCP Collaborate with NIHR LCRN TYA leads/CRG To collaborate with other CSGs Clinical trials for first line treatment for intermediate and poor risk disease and salvage therapy for relapsed / refractory GCT. 	<ol style="list-style-type: none"> Subgroup submission of new SCP 2.1 Regular meetings with in NIHR CRN TYA Leads 2.2 Promotion of portfolio maps To apply for working party to explore early onset carcinomas Opening of studies throughout the UK 	All	Ongoing
Portfolio development (Subgroup specific)	<p>Health Services Research</p> <ol style="list-style-type: none"> Improving understanding of the pathways to accessing research for TYA Improving understanding of the barriers to recruitment to research studies Improving routes to diagnosis Evaluating specialist care for young people (aged 16-25 years) with cancer 	<ol style="list-style-type: none"> 1.1 Audit: improve national reporting processes for trial recruitment 1.2 Access: Collaboration with NIHR and devolved nations CRN. Scoping resources regionally 1.3 Availability: 'core TYA portfolio' of trials 2.1 Funding secured for further studies 3.1 Complete and publish closed studies 4.1 Complete BRIGHTLIGHT study and sub-studies 	<ol style="list-style-type: none"> 1.1 Publication and dissemination of 10 year trial accrual study results 1.2 Collaboration with PHE CRG / CTU determine timelines for trial opening and understand barriers 2.1 To open national study in Scotland 3.1 Disseminate study results and further studies 4.1 To provide evidence on for policy makers on the optimum provision of specialist TYA cancer care 	<p>LF, JW</p> <p>All</p> <p>AE RD, LF, JW JW, LF, RD</p>	Ongoing
	<p>Biological studies</p> <ol style="list-style-type: none"> Improve access to biological samples of TYA cancers. Explore the contribution of biological and non-biological factors to differential survival in TYA compared to children and older adults. Facilitate opportunities for personalised medicine. 	<ol style="list-style-type: none"> 1.1 Identify and establish links with existing groups 1.2 Report results of 2012-2014 biobank survey 1.3 Develop funding application to expand CCLG tissue bank 2.1 Establish collaborations to study contribution of dose intensity to age-related outcomes 2.2 Working groups to study individual tumour types 3.1 Agreement with EORTC to include AYA cohorts within SPECTA 3.2 Development of funding application beyond SPECTA pilot study 3.3 Investigate other opportunities for TYA precision medicine projects 	<ol style="list-style-type: none"> 1.1 Ongoing discussion with CCLG tissue bank 1.2 Peer reviewed journal article with results of survey 1.3 Completion and submission of funding application 2.1 Completion of agreed analytical protocol for each disease-specific working group 2.2 Formation of subgroups for all planned diseases 3.1 Ratification of SPECTA AYA protocol by EORTC 3.2 Completion and submission of funding application 	<p>MM MM, CR</p> <p>MM</p> <p>BP</p> <p>DS</p> <p>MM, DS, LF</p>	Ongoing
	<p>Survivorship and Quality of Life</p> <ol style="list-style-type: none"> Develop innovative strategies using mobile technologies to enhance care and support greater independence To support enhanced population based studies To develop fertility studies To develop QoL studies To improve understanding of treatment toxicities and limit where possible 	<ol style="list-style-type: none"> Explore existing patient facing platforms Identify nested control studies from TYACSS Explore TYA views on fertility issues and explore how to incorporate fertility issues into new clinical trials GCT QoL study open in UK To ensure this is considered in development of new clinical trials - 	<ol style="list-style-type: none"> 1.1 Proof of concept study for electronic passport 1.2 Secure funding for risk-stratified follow up study 2.1 SCP on nested control studies from TYACSS 3.1 SCP - Explore TYA views on fertility issues 3.2 Proposal to recommend consideration of fertility issues incorporated into new clinical trials 4.1 Secure funding for additional QoL studies 5.1 To develop proposal on how to address this and to ensure data collection 	<p>HW DM MH HW HW HW DS HW DM</p>	Ongoing
Portfolio development (cross cutting)	<ol style="list-style-type: none"> Develop links with other CSGs, Advisory Groups - CCL, S&PC, SPED Identify CSG members on other CSGs 	<ol style="list-style-type: none"> 1.1 To attend CCL CSG 2.1 To promote TYA in other CSGs 		All	ongoing

CSG Principles	Strategic Objectives	Strategic Outputs	Outcome measures	CSG Leads	Dates
CSG structure and function	Subgroups 1. To establish three SG and define responsibilities 2. To recruit trainee to each subgroup	1.1 SG Chairs to prepare Terms of Reference 1.2 To set meeting dates 2.1 To invite trainees to join SG and assign to project	1.1 SG Terms of Reference 1.2 Meeting dates for the next 12 months 2.1 Trainees join SG and assigned to project	MM, HW, FG	done ongoing ongoing
	Trainee scheme 1. To develop guidance for mentor/mentees 2. To secure ongoing funding for trainees	1.1 To assign mentors to trainees 1.2 Trainee reports 2.1 To negotiate ongoing funding from TYAC	1.1 Plan for support of trainees 1.2 Trainee report/feedback at 18 months	AE AE	ongoing
Strengthen UK and European partnership collaborations	NCIN CTYA SSCRG 1.To establish regular contact with NCIN 2.To improve our understanding of non-trial patients 3.To improve our knowledge of relapsed patients 4.To explore development of collaborative studies 5.To support development of TYA research staff in PTCs	1.1 Chair to represent NCRI at NCIN CTYA SSCRG 1.2 To explore collaboration with NCIN		AE, MMc	Ongoing
	NIHR LCRN and devolved nation CRNs 1.To establish regular contact with CRN subspecialty leads 2.To work with subspecialty leads in England to ensure equity of access to the clinical research portfolio 3. To strengthen links with devolved nation CRNs 4. To use PMs to determine overview of trial availability 5. To support delivery of studies to time and target	1.1 To work with CRNs and PTCs in England to ensure equity of access to clinical trials 2.1 To work with subspecialty leads to develop portfolio and support CRN objectives 3.1 To engage with CRN in devolved nations 4.1 To develop an understanding of local portfolios 5.1 To collect data for study opening in CRNs	1.1 To contact/arrange meetings with CRNs 2.1 To engage with CRNs and PTC research nurses/data managers 3.1. As above for devolved nations 4.1 To work with CRNs to build picture of local portfolio and research support 5.1 To link with CTUs	AE, LF, SA AE AE, LF,	Ongoing
	Industry 1. To ensure appropriate age eligibility criteria	1.To establish links with ABPI		AE, LF, JW	Ongoing
	ENCCA 1.To strengthen collaboration with ENCCA	1.To identify links with ENCCA 2.To explore possibility of collaborative studies	1.To identify CSG member to lead this	DS	Ongoing
	JLA 1.To identify research priorities for TYA	1.Priority setting exercise underway	1.Due to complete end of 2017 2.Update at CSG meetings	FG, LF	ongoing
Consumer involvement	Consumer 1. To provide mentoring support 2.To assist in identifying research priorities for TYA	1.To ensure support from mentor 2.To provide input to CTAAC applications 3.To be involved in subgroup activities 4. To be involved in research priority setting	1.To assign mentor to each trainee 2.To provide input to CTAAC applications 3.To be involved in subgroup 4. To be involved in research priority setting	All	Ongoing
Raising awareness	1. To improve dissemination of results of studies 2. To consider annual 'trials' meeting 3. To encourage submission of abstracts to meetings 4. To have annual presence at NCRI conference	1.1 To report study results in Annual Report 1.2 To disseminate results to other CSGs/website 2. To explore possibility of annual TYA research day 3. Abstract submission 4. To explore options for greater profile at NCRI	1.Annual Report updates 2.To prepare summary of study results 3.To consider extending meeting to facilitate this 4. To contact NCRI	All	Ongoing

Appendix 3

CSG studies

Study	CSG involvement	Type	Open	End date	Status	Funding Body	PI / leads	Publication
Open / ongoing								
P3BEP - First line treatment for intermediate and poor-risk metastatic testicular GCT	GCT	Interventional	03/17	03/21		CRUK	Dr Danish Mazhar	
TIGER - Salvage therapy for relapsed/refractory GCT	GCT	Interventional						
BRIGHTLIGHT: Do specialist services for children and young adults with cancer add value?	HSR Subgroup	Programme of research Qualitative	2011	2018	Closed to recruitment - in follow up Data analysis	National Institute for Health Research £1,999,995.46	Prof Whelan	Multiple
BRIGHTLIGHT: The Culture of TYA Care across Five Principal Treatment Centres	HSR Subgroup	PhD Qualitative	2013	2018	Ongoing	NIHR £1,999,995.46	Prof Gibson	In preparation Abstract: Yes
When cure is not likely - BRIGHTLIGHT companion study	HSR Subgroup	Qualitative	2013	2015	Closed to recruitment Data analysis	Marie Curie £300,000	Professor Whelan	Yes
Pathways to diagnosis in Teenage and Young Adult	HSR Subgroup	Quantitative and qualitative	2014	2016	In analysis	FP-7	Dr Stark	Abstract: yes
REFER_ME: secondary analysis of routes to diagnosis from BRIGHTLIGHT survey	HSR Subgroup	Qualitative	2016	2017	In analysis	UCLH/UCL	Dr Fern	n/a
ACE study: 'Too young to get cancer'	HSR Subgroup	Qualitative		2016	analysis	CRUK	Dr Rachel Dommett	Manuscript in preparation
Understanding barriers to participation in cancer trials amongst teenagers and young adults: qualitative study	HSR Subgroup	Qualitative	09/17	5/19	In set up	Chief Scientist Office/CRUK £130,367	Dr Edgar	
An evaluation of 'Find Your Sense of Tumour' (FYSOT).	HSR Subgroup	Qualitative and quantitative	2015	2017	Ongoing	Teenage Cancer Trust £81,274	Drs Fern & Taylor / Martin	Yes
INFORM_ME: Online information and support needs for young people with cancer.	HSR Subgroup	Qualitative	2016	2017	Ongoing	Teenage Cancer Trust £27,120.6	Dr Fern	In preparation
HRQoL in Adolescents and Young Adults with Cancer	HSR Subgroup	Qualitative	Open	Dec 2016	Ongoing	EORTC Quality of Life Group	Dr Ann-Sophie Darlington	Abstract

Access to research for young people: 10 year accrual data	HSR Subgroup			2016	analysis		Dr Fern/ Prof Whelan	Manuscript in preparation
Assessing the Quality, Feasibility, and Efficacy of Electronic Patient Platforms Designed to Support AYA With Cancer	HSR Subgroup	Systematic review			Ongoing		Dr Lisa Mccann / Gemma Pugh	yes
James Lind Alliance: patient and professional research priority setting exercise	HSR Subgroup			Dec 2017	Ongoing		Dr Lorna fern / Prof Faith Gibson	
Pharmacokinetic variation and toxicity in Ewing's sarcoma	BS Subgroup	Translational	2014	2019	Open to recruitment		Dr Quentin Campbell-Hewson	
Late CT study	Quality of Life Subgroup							
Vascular effects of chemotherapy for testis cancers	Quality of Life Subgroup							
P3BEP Quality of Life substudy	Quality of Life Subgroup		2017			CRUK	Dr Danish Mazhar	
In development								
Integrated care for psychosocial distress in TYA who develop a major chronic illness.	HSR Subgroup	Complex intervention / implementation study				Exploring programme development grant with NIHR	Dr Stark	
Culture of recruitment to cancer research for TYA – BRIGHTLIGHT companion study	HSR Subgroup					CRUK Kids and teens - unsuccessful Exploring others	Dr Rachel Taylor	
SPECTArare	Biological Studies Subgroup	Translational				Exploring with EORTC	Drs McCabe/ Fern	
Stratified Medicine for TYA	Biological Studies Subgroup	Translational				Exploring with CRUK	Dr McCabe	
To improve access to tumour banked samples for research	Biological Studies Subgroup	Translational				Exploring	Drs McCabe / Fern	
To explore interaction between treatment intensity and toxicity across age spectrum	Biological studies Subgroup	meta-analyses				Exploring	Drs Stark/ Philips	
To develop national proposal for female fertility preservation	Survivorship Subgroup	Translational				Exploring	Prof Wallace/ Anderson	
To develop longitudinal study with UK Assisted Conception Units to	Survivorship Subgroup	Epidemiological				Exploring	Professors Wallace &	

determine fertility outcomes from cryostorage							Anderson/ Dr Davies	
To explore barriers to widespread use of fertility preservation	Survivorship Subgroup	Qualitative				Exploring	Prof Wallace	
RESURGE: REmote SURveillance in GErm cell tumours: Evaluation of Quality of Life - Comparing remote surveillance vs. the current standard hospital-based surveillance in patients with good prognosis testicular cancer	Quality of Life Subgroup							
Patient reported outcomes/ quality of life study as part of MaGIC collaborative study	Quality of Life Subgroup	Qualitative				Exploring	Dr Dan Stark	
De-escalation of therapy in metastatic seminoma/dysgerminoma	Testis CSG	Interventional				exploring	Dr Jonathan Shamash	
MaGIC Quality of life sub study							Dr Dan Stark	

Appendix 4

Portfolio maps

TYA

<http://csg.ncri.org.uk/portfolio/portfolio-maps/> - there are 26 maps for this cross cutting area.

Testis

See next page:

NCRI portfolio maps

Testicular Cancer

Map A – Germ cell tumours

Click ↓ below to reset map

		Advanced disease - 1st line	Biology and genetics	Early stage	Follow-up and quality of life	Salvage therapies	Translational	
Non-seminomatous germ cell t.	All					EA/001		
					Late CT Study			
			The Leeds Testi					germ stem cell
				GeMCoS				
		TIGER			Vascular Effects of Chemotherapy for Testicular Cancer			
		UK P3BEP Trial			Effects of Chemotherapy for Testicular Cancer			
Seminomatous germ cell tumours	All		The Leeds Testi					
							germ stem cell	
				GeMCoS				
			TIGER			Vascular Effects of Chemotherapy for Testicular Cancer		
		UK P3BEP Trial			Effects of Chemotherapy for Testicular Cancer			

Filters Used:

Active Status: All, CSG Involvement: All, Funding Type: All, Phase: All

- Open Multi CSG
- In Setup, HRA Ap..
- Open Single CSG
- In Setup, HRA Ap..
- In Setup, Waiting ..

Appendix 5

Publications in the reporting year Subgroup

Study	Conference details
Health Services Research Subgroup	
BRIGHLIGHT and companion studies	Taylor R, Feltbower R, Aslam N, Raine R, Whelan J, Gibson F. A modified international e-Delphi survey to define healthcare professional competencies for working with teenagers and young adults with cancer. <i>BMJ Open</i> 2016;6(5);e011361
	Taylor R, Fern L, Aslam N, Whelan JS. Application of Section 251 of the NHS Act (2006) to directly access research participants. <i>BMJ Open</i> 2016;6:e011847
	Ngwenya N, Kenten C, Jones L, Gibson F, Pearce S, Flatley M, Hough R, Stirling C, Taylor R, Wong G, Whelan JS. Experiences and Preferences for End-of-Life Care for Young Adults with Cancer and Their Informal Carers: A Narrative Synthesis. <i>J Adolesc Young Adult Oncol.</i> 2017. Epub 2017/01/12. Doi 10.1089/jayao.2016.0055
Early diagnosis	Gibson F, Pearce S, Fern L, Martins A, Kelly D. Improving the identification of cancer in young people: A scoping review. <i>Expert Review of Quality of Life in Cancer Care</i> Volume 2, 2017 - Issue 2
E-HEALTH	Pugh G., McCann L., Assessing the Quality, Feasibility, and Efficacy of Electronic Patient Platforms Designed to Support Adolescents and Young Adults With Cancer: A Systematic Review Protocol <i>JMIR Res Protoc</i> 2017;6:e4
Find Your Sense of Tumour Evaluation	A Martins, Taylor RM, Morgan S, Fern L.A. Being normal, not vulnerable - process evaluation of a two-day conference for teenagers and young people with cancer. <i>British Medical Journal (open)</i> In press
ENCCA	Pini SA, Gibson F, Fern LA, Morgan SJ, Phillips RS, Stark DP. Multi-Professional Perspectives on Adolescent and Young Adult Oncology Across Europe: An e-Delphi Survey. <i>J Adolesc Young Adult Oncol.</i> 2017;6:178-185.
Biological studies Subgroup	
Toxicity studies	Lindner OC, Mayes A, McCabe MG, Talmi D. Acute memory deficits in chemotherapy-treated adults. <i>Memory.</i> 2017 Mar 13:1-13.
	Musgrave KM, van Delft FW, Avery PJ, Clack RM, Chalmers EA, Qureshi A, Vora AJ, Biss TT. Cerebral sinovenous thrombosis in children and young adults with acute lymphoblastic leukaemia - a cohort study from the United Kingdom. <i>Br J Haematol.</i> 2016 Jul 8. PMID: 27392277
	Forster VJ, van Delft FW, Baird SF, Mair S, Skinner R, Halsey C. Drug interactions may be important risk factors for methotrexate neurotoxicity, particularly in pediatric leukemia patients. <i>Cancer Chemother Pharmacol.</i> 2016;78(5):1093-1096.
	Panagiotopoulou N, van Delft FW, Hale JP, Stewart JA Fertility Preservation Care for Children and Adolescents with Cancer: An

	Inquiry to Quantify Professionals' Barriers. J Adolesc Young Adult Oncol. 2017 Feb 10. PMID: 28186840
Survivorship Subgroup	
TYA Cancer Study	Bright C, Hawkins M, Guha J, Henson K, Winter D, Kelly J, Feltbower R, Hall M, Cutter D, Edgar A, Frobisher C, Reulen R. Risk of Cerebrovascular Events in 178 962 Five-Year Survivors of Cancer Diagnosed at 15 to 39 Years of Age: The TYACSS (Teenage and Young Adult Cancer Survivor Study). Circulation 2017;135:1194–210 .
	Henson K, Reulen R, Winter D, Bright C, Fidler M, Frobisher C, Guha J, Wong K, Kelly J, Edgar A, McCabe M, Whelan JS, Cutter D, Darby S, Hawkins M. Cardiac Mortality Among 200,000 Five-Year Survivors of Cancer Diagnosed Aged 15-39 Years: The Teenage and Young Adult Cancer Survivor Study. Circulation 2016;134:1519-1531.
	Clare Frobisher, Emma Lancashire, Helen Jenkinson, David L. Winter, Julie Kelly, Raoul C. Reulen, Michael M. Hawkins, On behalf of the British Childhood Cancer Survivor Study (BCCSS) Steering Group. Employment status and occupational level of adult survivors of childhood cancer in Great Britain: the British Childhood Cancer Survivor Study. Int. J. Cancer, 2017doi:10.1002/ijc.30696
	Miranda M. Fidler, Raoul C. Reulen, David L. Winter, Julie Kelly, Helen C. Jenkinson, Rod Skinner, Clare Frobisher, Michael M. Hawkins, on behalf of the British Childhood Cancer Survivor Study (BCCSS) Steering Group. Long term cause specific mortality among 34,489 5 year survivors of childhood cancer in Great Britain: population based cohort study. BMJ 2016; 354:i4351 doi:10.1136
	Miranda M. Fidler, Raoul C. Reulen, Katherine Henson, Julie Kelly, David Cutter, Gill A. Levitt, Clare Frobisher, David L. Winter, Michael M. Hawkins, on behalf of the British Childhood Cancer Survivor Study (BCCSS) Steering Group. Population-based long-term cardiac-specific mortality among 34,489 5-year survivors of childhood cancer in Great Britain. Circulation 2017; 135(10):951-963.
	Bright C, Hawkins M, Guha J, Henson K, Winter D, Kelly J, Feltbower R, Hall M, Cutter D, Edgar A, Frobisher C, Reulen R. Risk of Cerebrovascular Events in 178 962 Five-Year Survivors of Cancer Diagnosed at 15 to 39 Years of Age: The TYACSS (Teenage and Young Adult Cancer Survivor Study). Circulation 2017;135:1194–210 .
Germ cell tumour studies	
TE-3	Shamash J, Sarker SJ, Huddart R, Harland S, Joffe JK, Mazhar D, Birtle A, White J, Chowdhury K, Wilson P, Marshall MR, Vinnicombe S. A randomised phase III study of 72 hour infusional versus bolus bleomycin in BEP (bleomycin, etoposide and cisplatin)

	chemotherapy to treat IGCCCG good prognosis metastatic germ cell tumours (TE-3). Ann Oncol. 2017 Feb 21. doi: 10.1093/annonc/mdx071. Epub ahead of print
Postchemotherapy changes in testicular germ cell tumours	Berney DM, Lu YJ, Shamash J, Idrees M. Postchemotherapy changes in testicular germ cell tumours: biology and morphology. Histopathology 2017;70(1):26-39.
The efficacy of irinotecan, paclitaxel, and oxaliplatin (IPO) in relapsed germ cell tumours with high-dose chemotherapy as consolidation	Badreldin W, Krell J, Chowdhury S, Harland SJ, Mazhar D, Harding V, Frampton AE, Wilson P, Berney D, Stebbing J, Shamash J. The efficacy of irinotecan, paclitaxel, and oxaliplatin (IPO) in relapsed germ cell tumours with high-dose chemotherapy as consolidation: a non-cisplatin-based induction approach. BJU Int. 2016;117(3):418-23.
Is adjuvant chemotherapy indicated in ovarian immature teratomas?	Pashankar F, Hale JP, Dang H, Krailo M, Brady WE, Rodriguez-Galindo C, Nicholson JC, Murray MJ, Bilmire DF, Stoneham S, Arul GS, Olson TA, Stark D, Shaikh F, Amatruda JF, Covens A, Gershenson DM, Frazier AL. Is adjuvant chemotherapy indicated in ovarian immature teratomas? A combined data analysis from the Malignant Germ Cell Tumor International Collaborative. Cancer. 2016;122(2):230-7.
Others (through links with other CSGs)	
UK guidelines for the management of bone sarcomas	Gerrand C, Athanasou N, Brennan B, Grimer R, Judson I, Morland B, Peake D, Seddon B, Whelan JS. UK guidelines for the management of bone sarcomas. Clinical Sarcoma Research. 2016;6:7. Epub 2016/05/06.
UK guidelines for the management of soft tissue sarcomas	Dangoor A, Seddon B, Gerrand C, Grimer R, Whelan J, Judson I. UK guidelines for the management of soft tissue sarcomas. Clinical Sarcoma Research 2016;6:20 DOI: 10.1186/s13569-016-0060-4.
EURAMOS-1 trial	Marina N, et al, Whelan JS. Randomised Comparison of MAPIE vs MAP in patients with a Poor Response to pre-operative chemotherapy for newly-diagnosed high-grade osteosarcoma: results from the EURAMOS-1 trial. Lancet Oncol 2016
An observational study of the Euro-E.W.I.N.G group	Foulon S, Brennan B, Gaspar N, Dirksen U, Jeys L, Cassoni A, Claude L, Seddon B, Marec-Berard P, Whelan J, et al. Can postoperative radiotherapy be omitted in localised standard-risk Ewing sarcoma? An observational study of the Euro-E.W.I.N.G group. Eur J Cancer. 2016;61:128-36. Epub 2016/05/14

Appendix 6

Major international presentations in the reporting year

Study	Conference details
Cancer genes - a game changer for developing new therapies for TYA	Oral presentation to 2nd International paediatric congress in Dubai, Nov 2016
Pathways to diagnosis in teenage and young adult cancers in Europe: results from a pilot study	L Fairley, S Pini, RG Feltbower, A Ferrari, PR Olsen, D Yeomanson, G Kertesz, R Hough, L Gofti-Laroche, I Schiff, D Stark. Teenage Cancer Trust 9th International Conference and 1st Global AYA Cancer Congress December 2016, Edinburgh
Early Diagnosis: ACE “Too young to get cancer”	Domett R– Teenage Cancer Trust 9th International Conference and 1st Global Adolescent and Young Adult Cancer Congress, 5th-7th December 2016, The Assembly Rooms, Edinburgh, Scotland
Teenage and Young Adult Cancer Survivorship – maximising benefits and minimising harm	Hawkins MM. (2016) Plenary Lecture – Teenage Cancer Trust 9th International Conference and 1st Global Adolescent and Young Adult Cancer Congress, 5th-7th December 2016, The Assembly Rooms, Edinburgh, Scotland
PanCareSurFup: Risk of Subsequent Primary Neoplasms in Childhood Cancer Survivors	Hawkins MM. (2016) Plenary Lecture – European Symposium on Late Complications after Childhood Cancer (ESLCCC16), 22nd-23rd September 2016, Copenhagen, Denmark
Causes and prevention of further cancers: Potential future directions for ‘outcomes’ research relating to survivors	Hawkins MM. (2016) Two Plenary Lectures – PanCareSurFup for Childhood Cancer Survivors European Conference, 23rd-24th May 2016, Brussels, Belgium
Ten year trends of participation of teenagers and young adults (TYA) in selected NIHR National Cancer Research Network trials	Fern L.A., Whelan JS. Teenage Cancer Trust 9th International Conference and 1st Global Adolescent and Young Adult Cancer Congress, 5th-7th December 2016, The Assembly Rooms, Edinburgh, Scotland
	Fern L.A., Whelan JS. - National Cancer Research Institute Conference Liverpool, November 2016
BRIGHTLIGHT What can we learn from cross country comparisons of cancer care for adolescents and young adults (AYAs) to improve cancer outcomes	Fern L.A. Global Cancer Control World Cancer Congress, Paris, November 2017.
BRIGHTLIGHT STUDY Using patient reports and treatment data to evaluate the effectiveness of AYA services in the UK.	Taylor R.M. Global Cancer Control World Cancer Congress, Paris, November 2017
NSGCTT: A single-arm trial evaluating one cycle of BEP as adjuvant chemotherapy in high-risk, stage 1 non-seminomatous or combined germ cell tumors of the testis	Robert Anthony Huddart, Johnathan K. Joffe, Jeff D. White, Paul Hutton, Rebecca Lewis, Danish Mazhar, J Clin Oncol 35, 2017 (suppl 6S; abstract 400) GU ASCO February 2017

CarPET: Carboplatin AUC 10 in metastatic seminoma: Role of early PET scanning to reduce the amount of treatment while maintaining outcome—A phase 2 study

Shamash J, et al
J Clin Oncol 34, 2016 (suppl; abstr 4545) 2016 ASCO Annual Meeting

Appendix 7

Strengths & Weaknesses from the TYA CSG 2016 Quinquennial Review (QQR)

Strengths

- The Group is generating a wide variety of work, which was commended.
- The direction of work of the Biological Studies Subgroup, especially plans to improve molecular understanding for early onset carcinomas.
- The breadth of work carried out by the HSR Subgroup.
- The international visibility of the HSR Subgroup and its work.

Issues for the CSG to consider

- Establishing links with the ECMC network as a mechanism to drive change.
- Exploiting the NIHR network agenda around e-Health to seek funding from NIHR and DH.
- Considering survivors of childhood cancers as well as TYAs when carrying out survivorship research – is age relevant here, or should all patients with many years ahead of them be looked at together, particularly with regards to the medical consequences of survivorship.
- Given a lack of momentum over the past year in establishing the planned Survivorship Subgroup, approval for this is now deferred; NCRI will await the outcome of the forthcoming Living With and Beyond Cancer Workshop, then reconsider the optimum configuration of survivorship research across the CSG structures.

Issues for the NCRI/NIHR CRN to consider

- Ensuring that the merger with the Testis CSG is successful, and managing any conflicting priorities that arise.
- Whether the Survivorship Subgroup in its current form is the most appropriate structure or whether this should be absorbed into the NCRI's wider work on Living With & Beyond Cancer.