

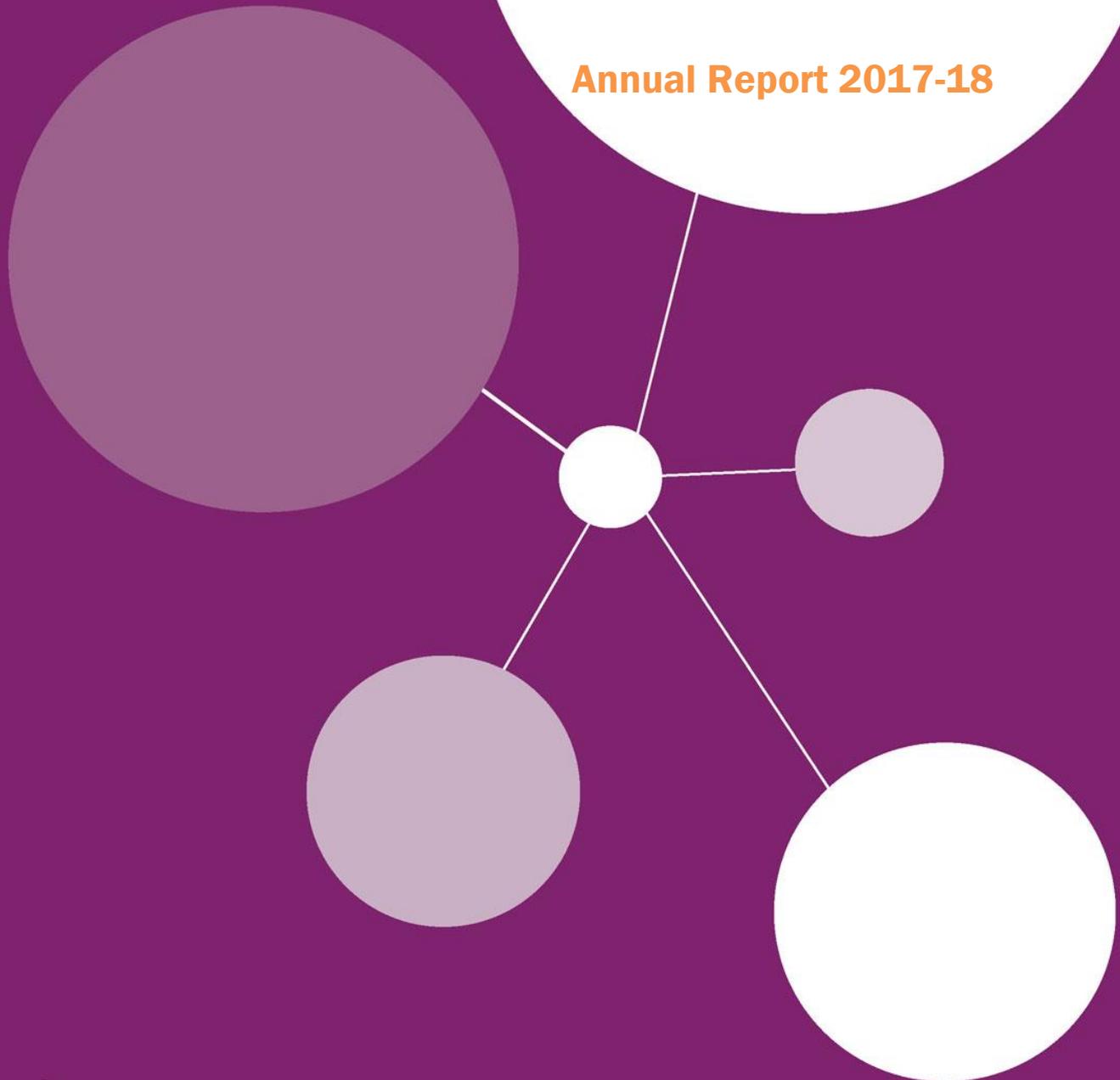


NCRI

National
Cancer
Research
Institute

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

Annual Report 2017-18



Partners in cancer research



NCRI Teenage & Young Adults (TYA) and Germ Cell Tumour (GCT) CSG CSG Annual Report 2017-18

1. Top 3 achievements in the reporting year

Achievement 1

Funding secured for international extracranial germ cell tumour trial

Funding has been awarded for the first ever international collaborative trial for low and standard risk extracranial germ cell tumours, AGT1531 study, led by Dr Sara Stoneham, which will address a trial gap. This work builds on a new risk stratified classification system based on data analysis carried out by the Malignant Germ Cell International Consortium (MaGIC): the first successful trans-Atlantic collaboration between the paediatric and medical oncology GCT groups.

Achievement 2

National evaluation of TYA cancer services (BRIGHTLIGHT study)

Emerging data has been widely disseminated at national and international conferences. The first phase of REFER_ME - the largest worldwide study on early diagnosis in young people - was published in the Lancet. In collaboration with the Youth Theatre Arts groups, young people's interpretation of emerging results from BRIGHTLIGHT was transformed into a critically acclaimed theatre production, "There is a light", which toured the UK and was shortlisted for Manchester Theatre Awards, March 2018.

Achievement 3

Facilitating opportunities for personalised medicine

A European pilot cohort of clinically focused genomic analysis specific to Adolescents and Young Adults (AYA) patients with high grade gliomas and sarcomas will open in the UK this year, and other European countries, funded within the EORTC SPECTA study. Tumour samples collected under informed consent will undergo molecular testing against a commercial cancer

gene panel and, following discussion at an international molecular tumour board, a clinical report will be prepared for referring clinicians.

2. Structure of the Group

The group is co-chaired by Dr Angela Edgar and Dr Jonathan Shamash (former TYA and Testis CSG Chairs, respectively). Rotation of the Chair is due and both Chairs have elected not to stand for re-appointment; Dr Dan Stark was appointed as the new Chair in April 2018. The current Co-Chairs will step down from the CSG following the Strategy Day in May 2018.

The TYA & GCT CSG membership incorporates 34 members: 5 consumers, 11 medical oncologists, 5 paediatric oncologists, 2 academics paediatric oncologists, pathologist, research development coordinator, NIHR CRN lead, and a senior lecturer in cancer care (Appendix 1). This is based on former membership of the CSGs prior to merger, and will be gradually reduced through natural attrition.

The Group benefits from the enormous support of full-time Research and Development Coordinator, Dr Lorna Fern, appointed in 2006, funded by Teenage Cancer Trust, with an extension of further funding until 2019. The role and funding agreement is reviewed bi-annually.

Professor Jeremy Whelan (former Chair) and Ms Sue Morgan stepped down from the Group in 2017, having been integral and productive members of the Group since its inception in 2008; we extend our sincere thanks to both. Dr Jane Beety, also stepped down from the Group and we thank her for bringing the NIHR CRN perspective and her valuable contribution to the Group.

The Group has three Subgroups: 1) Health Services Research (HSR, Chair Dr Lorna Fern), 2) Biological Studies (Chair Dr Martin McCabe), and 3) Quality of Life and Survivorship (Professor Mike Hawkins succeeded Professor Hamish Wallace and Dr Danish Mazhar in November 2017). 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 will be determined at the forthcoming strategy day in May. An Early Onset Carcinoma Working Party was also established in the reporting year.

3. CSG & Subgroup strategies

Main CSG

The TYA & GCT 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). The current overarching strategic aims will be adapted following the Strategy Day in May but currently 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 and facilitate opportunities for personalised medicine in TYA;
5. Address survivorship and quality of life issues.

The James Lind Alliance (JLA) Teenage & Young Adult (TYA) Priority Setting Partnership (PSP) completed in January 2018 and the top ten research priorities were identified: specific questions within the domains of early diagnosis, access to research, improved survivorship, and palliative care were highlighted as areas to address. The areas of research identified by the JLA exercise will inform the Strategy Day, scheduled for May 2018. We will continue to collaborate with other CSGs, the National Institute for Health Research (NIHR), funders and other stakeholders.

Biological Studies Subgroup (Chair, Dr Martin McCabe)

Facilitate opportunities for personalised medicine

A European pilot cohort of AYA patients with high grade gliomas and sarcomas will open this year in the EORTC SPECTA study. UK sites have been identified and are either open (n=2) or in set up. The overall SPECTA programme recruits patient samples and data to be held in the IBBL tissue bank, Luxembourg for future molecular testing against a commercial cancer gene panel. For the AYA cohort the Subgroup has negotiated collaboration between EORTC and the German Cancer Research Centre at Heidelberg to use the same per-patient funding to perform exome sequencing on tumour and blood, RNA sequencing and methylation profiling. Cases will have central pathology review. A panel of expert sarcoma and glioma pathologists have been recruited and a process agreed and tested for central path review.

A molecular tumour board is in setup which will meet monthly and will issue a clinically verified report back to referring clinicians. The pilot study will open to recruitment this year throughout the UK.

In parallel, we are under negotiation to work with the Foundation Medicine Programme (Roche) to analyse and publish the results of Foundation medicine molecular profiling of AYA patients worldwide. The future goals of this project are:

1. Obtain funding for a larger AYA molecular profiling study building on the experience of the pilot

2. Use the molecular profiling results of this initiative and/or the Foundation Medicine results to develop a molecularly directed European AYA basket study.

Explore the contribution of biological and non-biological factors to differential survival in TYA compared to children and older adults

This study is collating and meta-analysing multiple existing global clinical trial datasets in key TYA cancers to examine interactions between treatment intensity, age and toxicity to determine whether these factors can explain any of the differences in outcome observed between children, TYAs and adults.

The study is progressing very significantly in soft tissue sarcoma, acute myeloid leukaemia and germ cell tumours. Data-sharing agreements have been agreed and 8 datasets obtained. A PhD student is analysing this work, and analyses should be available in 18 months. Collaborations could not be established in Ewings Sarcoma, Lymphoma or Brain tumours. Delays were due to the prolonged negotiations with the trialist groups. This study should clarify whether the established dose and toxicity effect in TYA with osteosarcoma affects other disease groups. With the analyses, the group will design the next study.

Improve access to biological samples of TYA cancers

The most pressing strategic aim, with the SPECTA study nearing implementation, is to embed tissue banking into routine research activity and standard NHS clinical practice for all aged 16-24, as recommended by the Independent Cancer Taskforce. To achieve this, the Subgroup has worked with the CRUK funded Children's Cancer and Leukaemia Group (CCLG) tissue bank to target this age group. Funding has been identified from the existing CRUK grant to appoint an experienced adult research nurse to visit existing CCLG tissue banking centres that treat adults, and TYA principal treatment centres that do not currently submit tissue to the CCLG bank. The purpose of this role is to meet key MDT members in each centre and respective pathology departments to identify and work to break down potential barriers. A small working group of young people was held in February, funded by Teenage Cancer Trust and led by the Subgroup Chair to discuss how to optimise recruitment either by face-to-face or online approaches. As a result, an amendment is underway that includes, among other things, changes to the current tissue bank Patient Information Sheets and consent form taking into account the young people's views. An online PIS and consent form is in development, anticipated to be ready later this year.

There are currently no active strategies to increase tissue banking in over 25s. This is an area for development.

Health Services Research Subgroup (Chair, Dr Lorna Fern)

James Lind Alliance Research Priority Setting Partnership

The JLA TYA PSP, led by Dr Fern and former HSR Chair, Professor Faith Gibson, was completed in January 2018 and the top ten research priorities were identified. The exercise attracted 300 respondents, submitting over 800 questions and members of the steering group refined the questions according to the JLA methodology. The study was more resource intensive than anticipated and the input of Susie Aldiss, University of Sussex was gratefully appreciated and integral to study completion. The Top 10 has already been widely disseminated through press releases, blogs and newsletters, and presented at scientific meetings. Report writing is underway.

Top Ten Research Priorities

1. What psychological support package improves psychological well-being, social functioning and mental health during and after treatment?
2. What interventions, including self-care, can reduce or reverse adverse short and long-term effects of cancer treatment?
3. What are the best strategies to improve access to clinical trials?
4. What GP or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?
5. What are the best ways of supporting a young person who has incurable cancer?
6. What are the most effective strategies to ensure that young people who are treated outside of a young person's Principal Treatment Centre receive appropriate practical and emotional support?
7. What interventions are most effective in supporting young people when returning to education or work?
8. How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?
9. What is the best method of follow-up and timing which causes the least psychological harm, while ensuring relapse/complications are detected early?
10. What targeted treatments are effective and have fewer short and long-term side-effects?

<https://www.teenagecancertrust.org/about-us/news/top-research-priorities-teenage-and-young-adult-cancer-identified>

<http://www.ncri.org.uk/ncri-blog/top-10-research-priorities-for-teenage-and-young-adult-cancer-identified/>

Improve understanding of the pathways to accessing research for TYA

Improving access to clinical trials has been rated as a top research priority by the James Lind Alliance (JLA) "Teenage and Young Adult Cancer Priority Setting Partnership", (JLA).
<http://www.jla.nihr.ac.uk/priority-setting-partnerships/recruitment-to-clinical-trials/top-10.htm>.

Examining barriers to recruitment for young people with cancer in BRIGHLIGHT

Following publication of this study in BMJ Open, November 2017, a review of existing interventions to improve recruitment of young people to cancer trials was completed (in press Paediatric Blood Cancer) and a workshop is planned for 2018 to explore potential interventions.

Understanding barriers to recruitment to cancer trials amongst TYA in Scotland

This national study opened in 13 participating Scottish Health Boards in November 2017 and 24 health professionals, TYA and caregivers have been recruited. Recruitment of TYA is skewed towards non-trial participants due to limited trial availability. Further REC approval has been granted to increase the size and diversity of the sample pool. From emerging data, permission has also been granted to extend the interviewee pool to non-clinical professionals involved in clinical trial delivery.

'Find your sense of tumour' two-day residential programme: evaluation of understanding access to research and biobanking among attendees

Data collected from surveying 200 young people about access to research and biobanking was analysed by consumer, Lara Veitch for her dissertation thesis and presented at the NCRI Conference 2017. The study was awarded the Social Impact prize by King's College London.

Improve routes to diagnosis

Further study into improving early diagnosis for young people with suspected cancer was identified as a research priority in the JLA exercise.

REFER_ME

Collaboration with University College London ECHO department continues to thrive and the first Phase of REFER_ME was fast tracked for publication in the Lancet Child and Adolescent Health Journal with accompanying comment and editorial. This paper is the largest description of times to diagnosis of young people worldwide and serves as a benchmark for future interventions and further strengthens the evidence base for the proposed programme of early diagnosis research. The data has also been presented at two conferences. REFER_ME is an example of the group using secondary data analysis from emerging BRIGHTLIGHT results to inform new studies.

The second Phase of REFER_ME is underway which examines symptom profiles of times to diagnosis. This has been accepted as an oral presentation at the forth coming Cancer Outcomes Conference and as an e-poster for the Cancer and Primary Care International Research Network Conference. We anticipate a full publication to be submitted during the summer. Phase 3 of REFER_ME will begin in the summer of 2018 and look at times/routes to diagnosis and outcomes.

Evaluate specialist care for young people (aged 13-24 years) with cancer

BRIGHTLIGHT study: Do specialist cancer services for young people add value?

The NIHR funded programme grant, BRIGHTLIGHT, continues to be one of the subgroups greatest achievements. Data collection from young people was completed in March with results anticipated by the end of the 2018, presented at a BRIGHTLIGHT conference (TBA). Meantime, dissemination is prolific: jointly with TYAC, emerging findings were presented at an education day in 2017 (#BLTYAC2017); oral presentation at the NCRI Cancer Conference 2017; and presentation of five posters at the AYA global accord, Atlanta 2017 (#AYAGlobalCancer).

In collaboration Youth Theatre Arts groups, young people's interpretation of emerging results from BRIGHTLIGHT was transformed into a critically acclaimed theatre production – "There is a light", which toured the UK, disseminating results to >2000 people; with and without cancer, general public and professionals. The production was shortlisted for Manchester Theatre Awards, March 2018. Drs Fern and Taylor are now in discussions with Napier University to use recordings of the performance to inform an education tool for professionals and young people.

Sex, body image and relationships have been identified as areas of unmet need and, with publication in press, further work is planned.

Quality of Life (QoL) & Survivorship Subgroup (Chair, Professor Mike Hawkins)

Risks and causes of adverse health (physical and psychological) and social (including education and employment) outcomes among survivors of TYA cancer

The Teenage and Young Adult Cancer Survivor Study (TYACSS) provides the largest such study worldwide (>200,000 survivors) which benefits from being population-based. We have demonstrated that there are excess risks of new cancers, cardiac conditions and strokes among survivors, but the extent to which these are caused by previous cancer treatments, lifestyle factors or genotypic factors has not yet been investigated. Lifestyle factors are potentially modifiable with effective interventions. The identification of genotypic characteristics conferring large excess risks of adverse effects of specific treatments would be useful for both risk stratification of existing survivors and their clinical follow-up and in planning future treatments in a way which avoids treating high risk genetic subgroups with, what is for them particular toxic treatments. The TYACSS cohort should be viewed as a national resource which could be used as a starting point for more detailed investigations.

It is also important that we explore the widest possible potential research landscape to develop our strategy. Investigations relating to the development of cost-effective models of clinical follow-up which are well regarded by survivors would be very welcome.

4. Task groups/Working parties

Remit of Early Carcinoma Onset Working Party (Chair, Dr Angela Edgar)

The aim of the Working Party, approved in September 2017, is to establish collaborations between a number of CSGs, including Breast, Colorectal and Gynaecological, to consider the following areas:

1. To review the NIHR trials portfolio for the common carcinomas occurring in young adults;
2. To determine if the current trials explore the contribution of biological and non-biological factors to differential survival in young adults compared to older adults;
3. To improve access to biological samples and improve opportunities for personalised medicine;
4. To explore access to cancer trials for carcinomas in this age group.

Engagement with our Working Party will involve one face-to-face meeting and six teleconferences over a two-year period. Research generated from this group will hopefully be sustained by the relevant CSGs.

Progress to date

The core group has been established with representation from relevant CSGs and the initial meeting by telephone conference set out the aims and objectives. The aim of the initial phase is to evaluate our current knowledge of clinic-pathological features of early onset carcinomas; breast, colorectal and ovarian, in order to inform development of preventative, screening and management strategies, to improve outcomes. A proposal has been developed and funding is being explored. A face-to-face meeting will be held in the Summer.

5. Funding applications in last year

Cancer Research UK Clinical Research Committee (CRUK CRC)				
Study	Application type	CI	Outcome	Level of CSG input
May 2017				
ProVINCe: Prospective Validation of Prognostic Factor index in stage I non seminomatous germ cell tumours	Full application	Dr Robert Huddart	Not supported	No CSG involvement
November 2017				
AGCT1531: A Phase 3 Study of Active Surveillance for Low Risk and a Randomized Trial of Carboplatin vs. Cisplatin for Standard Risk Paediatric and Adult Patients with Germ Cell Tumours	Late Phase Study (Full Application)	Dr Sara Stoneham	Supported	GCT CSG (Stoneham / Murray)
Other committees				
Study	Committee & application type	CI	Outcome	Level of CSG input
April 2018				
Multicentre implementation trials with embedded evaluation to improve NHS outcomes for teenagers and young adults (TYA) with psychological distress and physical illness.	Programme Grants for Applied Research (£3,522,311.00)	Dr Dan Stark	Not Known	HSR Subgroup study (Stark/Fern/Morgan)
March 2018				
Impact of cancer diagnosis on social reintegration	Economic & Social and Research Council Full application (£798055.73)	Dr Dan Stark	Not Known	HSR Subgroup study (Stark/Taylor/Morgan)

Development of a module to supplement the EORTC Core instrument for the assessment of Health Related Quality of Life in Adolescents and Young Adults (AYAs) aged 14-39 years with cancer & Validation of the EORTC QLQ-C30 with 12-17 year olds with cancer.	EORTC (£202,763.83)	Dr Anne-Sophie Darlington	Funded	HSR Subgroup Study (Darlington/Fern/Taylor/Stark)
September 2017				
Information and support needs when active treatment ends	Teenage Cancer Trust (£40,048.48)	Dr Rachel Taylor	Funded	HSR Subgroup Study (Taylor/Fern/Morgan)

6. Consumer involvement

The work of the consumers is integral to the success of the TYA/G CSG particularly within the HSR Subgroup. BRIGHTLIGHT has young people central to its feasibility work, study operation and dissemination. This was exemplified by the creation of 'There is a light' which toured round the UK this year. There is a link to the video documentary of 'There is a Light' featuring Amy Riley. <https://vimeo.com/238045094>.

Lara Veitch

Lara is currently travelling with the 'Pacific's guide to cancer' in Australia. Lara is a member of the HSR Subgroup and is mentored by Dr Fern. She has made an excellent contribution to the Subgroup - attending meetings, teleconferences and conferences. She is a member of the JLA Steering Group and has attended meetings, contributed to data cleaning, sorting and dissemination of the survey. Lara attended the NCRI Conference on full bursary.

Lara analysed data collected from Find Your Sense of Tumour where 200 young people answered questions around access to research and biobanking. This was submitted as her final year dissertation, which was marked very high, and presented at the NCRI Cancer Conference 2017. The study was awarded the Social Impact prize by King's College London. Lara Co-Chaired a session with Dr Dan Stark at the BRIGHTLIGHT conference in July 2017 and she was invited to be an Expert Panel member at the Find Your Sense of Tumour conference in November 2017.

Max Williamson

Max has been a Consumer Forum member and member of the HSR Subgroup since September 2016, and, more recently, the Quality of Life and Survivorship Subgroup. Max has been a co-applicant for funding proposals, procured funding for TYA focus groups and is developing a London-based charity event for the TYA cancer awareness charity, CATS, with founder, James Adams.

Max has played an integral role on the James Lind Alliance TYA PSP Steering Group; publicising the survey, data collection, cleaning, analysis and dissemination. He is developing collaborations with consumers in the CCL and Primary Care CSGs to address the research questions identified.

Through his work for Paediatric Oncology Referee Team, editing and advising on paediatric clinical trial documents, he is in collaboration with the CCL CSG to develop strategies to improve clinical trial participation. He is also a patient representative on the FAIR trials working group, working towards lowering age limits on adult clinical trials to 12 years in Europe.

Max is the lead patient representative for a number of regional and national organisations, including; NIHR, MRC CTU at UCL, UK Health Research at European Health Innovation Collaborative, participating and promoting international trials days, contributing to strategy development, clinical trial portfolio, and dissemination and presentation at international conferences. Max attended the NCRI Cancer Conference 2016 and 2017 on full bursaries.

James Adams

James has been a Consumer Forum member since November 2014 and is also a member of the NCRI consumer liaison group (CLG). James is the founder and head of Cancer Awareness in Teenagers and Young People Society (CATS), a charity based in Manchester, Cambridge, Birmingham, Liverpool, Leicester and Salford which aims to deliver awareness within a higher education setting.

As a member of the CSG, James worked alongside Martin McCabe to deliver the completion of the YPCAM validation process and evaluation of the public health campaign. James was largely involved by working with a statistician in Manchester to prepare the YPCAM validation and the CATS evaluation in preparation for publication.

James continues his work on a project which evaluates communication experiences of TYA cancer patients. The project uses key themes from interviews with patients and to design a workshop which will be fed into the Manchester Medical School undergraduate curriculum. It is hoped that this project will improve communication skills of future medical students and its results will be published on its completion in 2019.

James will be rotating off the group in June 2018

Stephen Thomas

Stephen has been a Consumer Forum member since November 2014. His position on the CSG has been extended to 2020 to ensure continuity of testes consumer representation during the transition from single site CSG to the combined Testes/TYA CSG. Stephen has used his experience as a CSG member and former patient to contribute to the Wales Cancer Bank and trial management groups in oesophageal cancer research. He has also contributed as a patient/public representative to the HTA as part of the NETSCC primary care panel, which has a brief to recommend research into improving diagnosis and care in this sector.

Vincent Wolverson

Vince has been a Consumer Forum member since November 2014. His position on the CSG has been extended to 2020 to ensure continuity of testes consumer representation during the transition from single site CSG to the combined Testes/TYA CSG.

Vince has been a co-applicant for funding proposals, and the Testis Tumour GeCIP Domain Application.

Vince is the Chairman of It's On The Ball, a Norwich based testicular cancer awareness and support charity, and regularly gives presentations and lectures in school, colleges and workplaces throughout East Anglia to emphasise the importance to young men of self-examination for the symptoms of testicular cancer.

Vince is a founding member of the Testicular Cancer Network (TCN), a collaboration of testicular cancer support groups throughout the UK. The TCN will be launched at the National Germ Cell Group Conference in April 2018.

7. Priorities and challenges for the forthcoming year

Priority 1

Strategy Day May 2018

The timely completion of the JLA TYA PSP provides an excellent opportunity for the TYA & GCT CSG to develop an exciting workplan for the next five years. Development of a robust and realistic strategy around the top ten areas of research identified will strengthen funding applications. Early agreement on a clear operational policy for the structure and functioning of the Group, ensuring the needs and remit of the former GCT CSG are encapsulated, will be essential to the success of the strategy day.

Priority 2

Improve health and social outcomes among survivors

Survivorship issues have been rated as the top research priority by the JLA TYA exercise: five of the top 10 research priorities address improving health (physical and psychological) and social (including education and employment) outcomes among survivors. The Teenage and Young Adult Cancer Survivor Study (TYACSS), led by Professor Hawkins, the largest TYA survivorship study worldwide has provided clear evidence of excess risks of further cancers, cardiac conditions and strokes among survivors of TYA cancer. It is a priority for us to understand the causes of these excess risks and particularly the role of previous cancer treatments, lifestyle factors and genotypic factors to enable interventions to be developed to reduce the risks.

Priority 3

Build on the growing international interest in AYA-directed research to drive forward international collaborative studies in biological, outcomes research / observational studies and psychosocial studies.

It has long been established that programmatic research, as achieved by BRIGHTLIGHT and the TYACSS, is the key to the development of wide-ranging impact. The Group should work together to highlight and develop opportunities for joint programmatic cross-cutting research, using the existing infrastructure such as NCRAS, tumour banks and Patient-reported outcomes in clinical practice.

Challenge 1

The travel from a merger to a functioning and committed mutually supportive CSG

The diversification of the membership through the merger of the two CSGs 12 months ago, has broadened research opportunities and allowed new collaborations to develop, in partnership with other CSGs: The Quality of Life and Survivorship Subgroup is under new leadership with renewed vigour and enthusiasm; the Early Onset Carcinoma Working Party has engaged a number of site specific CSGs with projects underway. The new Chair will need to continue to sustain this enthusiasm and encourage and drive new research projects from external applicants. Populating the CSG with new members across a range of degrees of research experience, to provide the balance of expertise, energy and capacity will be necessary.

Challenge 2

The challenging nature of the funding environment for patients for rare cancers and with good survival outcomes

NIHR has identified major gaps in the trial portfolio that particularly disadvantage TYA. There are no first line studies for some of the commonest TYA cancers and there is difficulty in driving new clinical trials built around site specific questions.

Challenge 3

Improving recruitment to clinical trials

NIHR now requires each LCRN to report its TYA recruitment to cancer trials, with NHS England aiming for at least 50% of TYA with cancer to be recruited to clinical trials by 2025. 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). Development of intervention strategies to improve recruitment for young people with cancer and continued collaboration with NIHR LCRN TYA Leads and NIHR CRG to achieve this is imperative.

8. Appendices

Appendix 1 - Membership of main CSG and subgroups

Appendix 2 – CSG and Subgroup strategies

Appendix 3 - Portfolio Maps

Appendix 4 – Top 5 publications in reporting year

Appendix 5 – Recruitment to the NIHR portfolio in the reporting year

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 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	London
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
Mrs Kath Jones	NIHR Cancer Research Network	London
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

Biological Studies Subgroup		
Name	Specialism	Location
Dr Dan Stark	Medical Oncologist	Leeds
Dr Chris Barton*	Paediatric Oncologist	Liverpool
Dr Angela Edgar**	Paediatric Oncologist	Edinburgh
Dr Martin McCabe (Chair)	Paediatric Oncologist	Manchester
Dr Maria Michelagnoli**	Paediatric Oncologist	London
Dr Matt Murray	Paediatric Oncologist	Cambridge
Dr Bob Phillips	Paediatric oncologist	Leeds
Dr Frederik van Delft	Paediatric Oncologist	London
Dr Shaun Wilson	Paediatric Oncologist	Oxford
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
Dr Kenneth Rankin	Surgeon	Newcastle

Health Services Research Subgroup		
Name	Specialism	Location
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

Quality of Life & Survivorship Subgroup		
Name	Specialism	Location
Dr Jenny Harrington**	Clinical Fellow	Cambridge
Dr Rob Huddart	Clinical Oncologist	London
Mr James Ashton	Consumer	
Professor Mike Hawkins (Chair)	Epidemiologist	Birmingham
Dr Ed Wilson	Health Economist	Cambridge
Dr Danish Mazhar	Medical Oncologist	Cambridge
Dr Dan Stark	Medical Oncologist	Leeds
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

A – Main CSG Strategy

The current CSG strategy incorporates the aims of the former TYA and Testis CSGs, and accommodates the overlap between the Groups. The CSG will hold a strategy meeting in May 2018 to develop the future strategic direction of the Group. The current 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 and facilitate opportunities for personalised medicine for TYA;
5. Address survivorship and quality of life issues.

Biological Studies Subgroup (Chair, Dr Martin McCabe)

Aims

1. Facilitate opportunities for personalised medicine.
2. Improve access to biological samples of TYA cancers.
3. Explore the contribution of biological and non-biological factors to differential survival in TYA compared to children and older adults.

The biological studies subgroup has been in existence since 2011. It has an extended membership comprising scientists, medical and paediatric oncologists, a surgeon and an R&D coordinator Dr Fern. Membership is managed such that travel costs are available to core members who need to travel to meetings from outside London. Several members have been in attendance since the subgroup formed. The balance of membership is heavily weighted in favour of paediatric oncologists. Dr Clare Rowntree, the first subgroup chair, stepped down during the year. The subgroup sincerely thanks her for her input since its inception.

The subgroup has met three times since the last annual report, twice by teleconference and once face to face to discuss future strategy in advance of the main CSG strategy day. The group recognises the imbalance in its membership. Stronger representation from scientific representatives with specific expertise would be desirable.

Health Services Research Subgroup (Chair, Dr Lorna Fern)

Aims

1. To complete the James Lind Alliance research priority exercise
2. Improving understanding of the pathways to accessing research for TYA
3. Improving routes to diagnosis
4. Evaluating specialist care for young people (aged 16-25 years) with cancer

Appendix 3

Portfolio maps

TYA

<http://csg.ncri.org.uk/portfolio/portfolio-maps/>- there are 27 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
Non-seminomatous germ cell t.	All				Late CT Study	
			The Leeds Testi			
		CANC- 3681 LEE011 in relapsed, refractory, incurable teratoma				
					Vascular Effects of Chemotherapy for Testicular Cancer	
					Latent Vascular Effects of Chemotherapy for Testicular Cancer	
		TIGER				
		UK P3BEP Trial				
Seminomatous germ cell tumours	All		The Leeds Testi			
					Vascular Effects of Chemotherapy for Testicular Cancer	
					Latent Vascular Effects of Chemotherapy for Testicular Cancer	
			TIGER			
			UK P3BEP Trial			

Filters Used:

Active Status: All, CSG Involvement: All, Funding Type: All, Phase: All, LCRN: None

In Setup / single re..
 Open / single rese..

 Open / multi resea..

Null



Designed and maintained by NCRI Clinical Research Groups (CRGs) & NIHR

Appendix 4

Top 5 publications in the reporting year

Trial name & publication reference	Impact of the trial	CSG involvement in the trial
1. BRIGHTLIGHT: Qualitative study to understand the barriers to recruiting young people with cancer to BRIGHTLIGHT: a national cohort study in England. Kenten et al. <i>BMJ Open</i> 2017;7:e018291.	Largest study of young people worldwide. This paper reveals new barriers to recruitment within the research networks	HSR Subgroup trial
2. BRIGHTLIGHT: Diagnostic timeliness in adolescents and young adults with cancer: a cross-sectional analysis of the BRIGHTLIGHT cohort. Herbert et al, <i>The Lancet Child and Adolescent Health</i> .2018; 2: 180-190.	Largest study of routes and times to diagnosis for young people with cancer. Identifies groups at particular risk where more work and intervention can focus	HSR Subgroup trial
3. Experiences and preferences for end of life care for young adults with cancer and their informal carers: a narrative synthesis. Ngwenya N, et al. <i>J Adolesc Young Adult Oncol</i> . 2017; 6: 200-12.	Only end of life study for young people aged 16-39 years including partners, carers and professionals.	Previous CSG and Subgroup members (Whelan J (PI), Faith G., Taylor RM., Pearce S.)
4. COAST (Cisplatin ototoxicity attenuated by aspirin trial): A phase II double-blind, randomised controlled trial to establish if aspirin reduces cisplatin induced	Aspirin did not protect from cisplatin-related ototoxicity. Cisplatin and gentamicin may therefore have distinct ototoxic mechanisms, or cisplatin-induced ototoxicity may be refractory to the aspirin regimen used here.	GCT CSG

hearing-loss. Crabb SJ et al, Eur J Cancer. 2017; 87:75-83.		
5. Outcome of Men With Relapse After Adjuvant Carboplatin for Clinical Stage I Seminoma. Fischer S et al, J Clin Oncol. 2017; 10; 35:194-200.	Has determined how to manage stage 1 relapses- indicates that overall adjuvant therapy should not affect subsequent therapy	Outcome of patients treated in TE 19 and other adjuvant patients treated with carboplatin

Appendix 5

Recruitment to the NIHR portfolio in the reporting year

In the Teenage & Young Adult (TYA) and Germ Cell Tumour (GCT) CSG portfolio, 4 trials closed to recruitment and 20 opened.

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	-	-
2017/2018	321	193	231	193	-	-