NCRI
National
Cancer
Research
Institute

NCRI Teenage & Young Adults Clinical Studies Group

Annual Report 2015/2016

Partners in cancer research

NCRI Teenage & Young Adults CSG
Annual Report 2015/16

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

The Teenage and Young Adult Clinical Studies Group (TYA CSG) has had another productive 12 months. The Group is chaired by Dr Angela Edgar, Paediatric Oncologist, Edinburgh, and continues to be supported by full time researcher, Dr Lorna Fern, appointed in 2006 and funded by Teenage Cancer Trust. The Group is truly multidisciplinary with national representation. The remit of our cross-cutting CSG, which is different to the site-specific tumour CSGs, focuses on:

1. Improving recruitment and access to clinical trials for young people.
2. Understanding and improving pathways to diagnosis.
3. Biological studies.
4. Survivorship and quality of life issues.

Crucial to delivering our strategy will be strengthening links with other CSGs, developing links with National Institute for Health Research (NIHR) Clinical Research Network (CRN) Subspecialty Leads, funders and other stakeholders.

Achievements:

1. Established collaboration with NIHR CRN to understand how TYA access cancer services and how those services recognise their needs

To improve opportunities for TYA to participate in clinical trials, a 'core' TYA relevant trials portfolio and metrics for benchmarking are in development. These will measure recruitment targets, including time-to-recruit, time-to-first patient, eligibility, screening, and the infrastructure available to do this. In Scotland, similar measures are ongoing via the Managed Service Network for Children and Young People with Cancer (MSN CYP Cancer) TYA Group in collaboration with NHS Research Scotland. A core TYA trials portfolio will improve visibility of clinical trials for this age group and identify gaps in the portfolio.

2. Ten-year clinical trial recruitment data for TYA (2005-2014)

Analysis of ten year recruitment of clinical trial recruitment for children, TYA and older adults to selected NIHR CRN cancer clinical trials (2005-2014) for the most common cancers in the 0-24 years age bracket has been completed and a manuscript is in preparation. Early dissemination has begun including NIHR CRN specialty leads and Association of British Pharmaceutical Industry (ABPI). Ongoing recruitment studies will be developed in collaboration with NIHR CRN and NCIN SSCTYA CRG.

3. Waves one and two of BRIGHLIGHT are now completed, data cleaning and analysis is underway with results anticipated late 2016.
4. Three papers have been published; one under review and two are in preparation.
    - James Lind Alliance Priority Setting Exercise fully operation.
    - Confederation of cancer biobanks scoping exercise completed and paper in preparation.
    - Collaboration with European community to develop strategy for personalised medicine for TYA established and draft proposal being considered.

Challenges:
Reduced availability of clinical trials for common TYA cancers and regional variation in access to clinical trials has been highlighted by the Managed Service Network for Children and Young People with cancer in Scotland and NIHR audit of UK CRN Portfolio (personal communication NIHR CRN, report due June 2016). The CSG will collaborate with other CSGs to promote the importance of developing studies for first line treatment for the common cancers in TYA. Recognising the challenges of clinical trials in rare cancer, Professor Seymour will facilitate meetings with CRUK to prioritise these trials as an unmet need.

Working towards earliest possible diagnosis for young people with cancer is firmly entrenched in the principles of the Group. Pursuant of this end is a key strategic aim of the Pathways Subgroup. Identifying measurable and meaningful interventions remains a challenge when applying for funding. It is the ambition of the Group that this work is incorporated into a larger programme grant looking at pathways to diagnosis, led by Dr Fern, over the next 36 months.

Initial enthusiasm and commitment to establish an Experimental Cancer Medicine Centre (ECMC) TYA virtual network has not come to fruition, the proposed TYA Network is currently on hold as the ECMC Network is undergoing its quinquennial review in October 2016. The CSG will engage with the ECMC in early 2017 to ensure the needs of TYA entering early phase studies are being considered.

2. Structure of the Group

Membership of the main CSG is drawn from across the UK and currently consists of 18 multidisciplinary members with a broad range of expertise, reflecting the complex nature of cancer care for young people: haematologist, clinical academic surgeon, epidemiologist, clinical oncologist, two medical oncologists, five paediatric oncologists, Assistant Theme B Lead NIHR CRN, one consumer member, one expert TYA nurses, two trainees, senior lecturer in cancer care, and dedicated researcher for the Group.

Professor Faith Gibson and Ms Sam Smith have stepped down from the Group. Professor Gibson joined the group in 2008 with Ms Smith in 2011 and have made an enormous contribution to the Group, leading the way in the nursing arena and pioneering qualitative research in the field of TYA cancer.

The CSG would like to thank our two trainees, Dr Karan Manias, Paediatric Oncologist, Birmingham and Ms Gemma Pugh, PhD Student, London, for their contribution to the Group as they step down from their positions. Two new trainees have been appointed, Dr Chris Burton, Paediatric Oncology, Liverpool, and Dr Rebecca Ling, Academic Clinical Fellow. A call for three new members including a consumer member is underway and is advertised with greater use of social media.

The CSG has three Subgroups: Health Services Research (HSR) Subgroup which has been chaired by Professor Faith since the HSR Working Party was disbanded in 2009 and created the HSR Subgroup, Biological Studies Subgroup chaired by Dr Martin McCabe and a new third Subgroup which will address Survivorship chaired by Professor Hamish Wallace. Professor Gibson has stepped down from her position as Chair of the Health Services Subgroup and we are delighted to welcome Dr Fern who has been appointed as the new Chair of the HSR Subgroup.

3. CSG & Subgroup strategies

Main CSG

The definition of TYA age range is variable, often reflecting epidemiological studies or service provision, and is generally set at 16-24 years when defining age appropriate care. For the purposes of this Group, it refers to a lower age limit of around 16 years, with younger teenagers incorporated into the paediatric group, and an upper limit of around 39 years. Our vision is to improve outcomes for teenagers and young adults (TYA) with cancer through high quality medical research. Our remit, which is different to the cross-cutting tumour specific CSGs, is detailed below:

1. To ensure that teenagers and young adults are considered for and have opportunities to enter disease-specific NCRI CSG research studies.
2. To research into the optimal provision of health care for patients in that age group and to provide the evidence base for the present and future guidance for children and young people with cancer.
3. To ensure that the research agenda is set with young people.

The CSG three-year strategy (2015-2018, Appendix 2) details the overarching strategic objectives, outputs and outcome measures with timelines and identifies leaders for each workstream. The remit of our Group has changed over the last 12 months from improving recruitment of young people into clinical trials to working closely with NIHR CRN to support delivery of the trials portfolio. Our most recent analysis of TYA inclusion in cancer trials has shown a fall in recruitment rates and the CSG will focus efforts on understanding the barriers to recruitment which may form the basis for a systematic approach to design and conduct of clinical trials in this age group.

Biological Studies Subgroup (Chair, Dr Martin McCabe)

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

Aims:

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

Strategy:
The Subgroup's strategy is to concentrate for the coming five years on its three major aims. In addition, initial contact made with CTRad group to scope areas of joint interest, e.g. predicting radiation-induced toxicity in children and TYA.

Achievements:

- Confederation of cancer biobanks scoping exercise completed. Article to describe existing TYA banked samples in preparation.
- Involvement of NCRI group members to the Cancer Taskforce resulted in recommendation 44 of the Taskforce recommendations.
- Collaborative agreements to study the contribution of delivered dose intensity to age-related outcomes for TYA synovial sarcomas and germ cell tumours.
- Initiation of discussions with UK paediatric stratified medicine steering group and EORTC to develop stratified medicine strategies for TYA. EORTC discussions have been initiated by the subgroup and brokered by CRUK. A draft protocol is in development. The European ENTYAC network is supportive of the project.

Challenges:

- Working effectively with site-specific and other cross-cutting strategic groups without duplication.
- Reaching patients treated outside of large, research-active cancer centres.
- Small pool of research-active professionals in the UK with focus on TYA cancers. Some projects need to be European.
- Cancer Taskforce recommendation 44 (consenting all TYA at diagnosis for data and tissue samples will be challenging to meet. Several subgroup projects (tumour banking, stratified medicine) will inform the debate.

Health Services Research (HSR) Subgroup (Professor Faith Gibson stepped down as Chair in April 2016; Dr Lorna Fern has been appointed as Chair)

The Subgroup meets quarterly with two face-to-face meetings and two teleconference meetings per year. The Subgroup interacts regularly via email and members meet when required to develop proposals.

Aims:

1. Improved understanding of the pathways to accessing research for TYA.
2. Improved understanding of the barriers to recruitment to research studies.
3. Improving routes to diagnosis.

Strategy:
The HSR Subgroup held a strategy day in January 2016 identifying the future direction of the group. The Subgroup will focus on the aims above and additionally will continue with the current studies, namely BRIGHLIGHT and its companion studies, James Lind Alliance research priority exercise and social media projects.

Achievements:
In line with the CSG strategy, the Subgroup has submitted two new CSPs this year, one examining the use of social media in young people with cancer and another on examining the culture of recruitment to cancer clinical trials. Funding has been secured from Teenage Cancer Trust for the social media project to carry out a period of feasibility work, this will commence in July 2016. We submitted a brief study outline to CRUK Kids and Teens funding stream to determine suitability for 'RECRUIT_ME: Examining the culture of recruitment to cancer clinical trials' however this is out of remit and we will continue to pursue funding elsewhere.

- Ten year recruitment data (2005-2014) for the common TYA cancers has been analysed and shows a decline in clinical trial participation across all ages, including TYA. Reasons for this will be explored.
- Waves one and two of the BRIGHTLIGHT Study have been completed and data analysis is underway. Three papers published and two papers in preparation. Further studies in development exploring culture around trial recruitment.
- 'When cure is not likely' has been completed despite difficult recruitment and analysis of results is underway.
- The James Lind Alliance Steering Group was slow to progress due to administrative difficulties. The group secured external resources to overcome these difficulties. The JLA priority setting exercise is now well established, with a full steering group which includes five committed consumer members. Three face to face meetings have been held this year and the survey is ready to be disseminated. The top 10 research priorities in TYA cancer will be ready by Autumn 2017.
- Completion of the POPP study: an exploration of young people and health professionals' experience around enrolment in clinical trials for bone sarcoma. Results were published in the European Journal of Cancer and the study went onto be awarded the RCNi Excellence in Cancer Research Award, sponsored by Cancer Research UK.
- Completion and publication of 'How young people describe the impact of living with and beyond a cancer diagnosis: feasibility of using social media as a research method.'

New studies:
A Grant £81,274 to evaluate Find Your Sense of Tumour being led by Dr Fern and Dr Taylor has been secured from Teenage Cancer Trust. The three year study includes ethnographic observation of the conference, in-depth qualitative interviews with professional attendees and steering group members and a one year longitudinal study of young people attending, significant others and healthcare professionals. Dr Ana Martins is the lead researcher for the study, with Quality Health being responsible for data collection.

Challenges:

- REFER_ME and early diagnosis studies have continued to prove challenging to secure funding with a lack of existing research on which to base interventions or identify potential outcomes associated with time to diagnosis. An alternative approach is to examine existing data collected within BRIGHTLIGHT and in collaboration with early diagnosis expert Dr Yoryos Lyratzopoulos, Cancer Research UK Advanced Clinician Scientist Fellow & Reader in Cancer Epidemiology, University College London. Negotiations are underway with Teenage Cancer Trust and Dr Fern/Professor Whelan for funding for this which will be crucial to informing a Programme Grant.
- Collaborative working with other CSGs to encourage development of TYA relevant clinical trials
- Working efficiently with NIHR LCRN to support delivery of the TYA trial portfolio and to explore reasons for decline in trial recruitment.

Collaborative studies:
Collaborative study with Leeds Teaching Hospitals, funded by Burdett, exploring difficulties implementing transition processes in order to map out pathways is underway. Members of the Group are also involved in developing a number of studies with European collaborators.

Survivorship Subgroup (Chair, Professor Hamish Wallace)

The Survivorship Subgroup was established in October 2015 and is in the process of finalising the multidisciplinary membership, including external representation, ahead of the first meeting (Appendix 2). The Subgroup will meet quarterly: two face-to-face and two teleconference meetings per year.

Aims:

1. 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. We are working with a number of stakeholders to take this forward.
2. To support enhanced population based studies - this will build on the cancer survivorship studies led by Professor Hawkins.
3. 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 review selection criteria and available evidence for ovarian cryopreservation with a view to preparing a national proposal.

4. Task groups/Working parties

The CSG currently has no working parties. The Group will support Dr Fern to develop and lead her own research programme around early diagnosis and access to cancer clinical trials. This will build on the successful work she has achieved around understanding and improving clinical trial recruitment in the TYA population and will incorporate the work of the early diagnosis project. The first step towards this will require an application for a working party in early 2017 following results of REFER_ME.

5. Patient recruitment summary for last 5 years

The CSG remit, which is distinct from other CSGs, means that recruitment data is not a true reflection of Group activity.

Table 1 Summary of patient recruitment by RCT/Non-RCT

Year	All subjects		Cancer patients only		% of cancer patients relative to incidence	
	Non-RCT	RCT	Non-RCT	RCT	Non-RCT	RCT
2010/2011	-	-	-	-	-	-
2011/2012	39	-	21	0	-	-

Table 2 Summary of patient recruitment by Interventional/Non-interventional

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	191	5	139	5	-	-

In the TYA CSG portfolio, 5 trial closed to recruitment and 2 opened.

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

The CSG continues to strengthen its UK and European collaborations. It has links with the Primary Care CSG (Chair Professor Richard Neal), Psychosocial Oncology & Survivorship CSG (Dr Gill Hubbard and Dr Rachel Taylor), Sarcoma CSG (Professor Whelan, Dr Angela Edgar and Mr Craig Gerrand) and CCL CSG (Dr Angela Edgar). However, we are yet to secure funding to continue with meetings to develop further collaborative grant proposals.

Dr Fern is a member of the NCRI Screening, Prevention & Early Diagnosis (SPED) Advisory Group, ensuring the needs of TYA are considered by this Group. Dr Martin McCabe and Dr Fern are members of the Brain CSG. Dr Dan Stark sits on the Testis CSG Quality of Life Subgroup. Dr Rachel Taylor, Senior Research Manager for BRIGHTLIGHT, is also a member of the POS CSG and our HSR Subgroup providing direct links between the TYA and POS CSGs. This serves to continue to raise awareness of our Group amongst other relevant CSGs as outlined in our strategy.

The CSG has good representation and links with the National Cancer Intelligence Network CTYA Site Specific Clinical Reference Group; Dr Martin McCabe Chairs the Group, with Dr Edgar, Professor Whelan and Dr Fern also being members.

The Group is working very closely with NIHR CRN to ensure young people are included in cancer clinical trials by understanding how TYA access cancer services and how those services recognise their needs. Dr Jane Beety is the Assistant Theme B Lead NIHR CRN.

The European Network of Cancer Research in Children and Adolescents (ENCCA) is a European project aimed to improve outcomes for young people with cancer across Europe. The project is led by Group member Dr Stark, with involvement from most of the TYA CSG.

The CSG has strong links with TYAC (an organisation for professionals involved in the care and research of TYA) with most CSG members also being TYAC members and membership of the TYAC board (Dr Edgar, Ms Smith, Ms Morgan, Dr Fern, Dr Michelagnoli). 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 Liaison Group and are grateful for their support with recruitment to the family and carer workshops for ‘When Cure is Not Likely’.

7. Funding applications in last year

The CSG has had a number of successful applications for funding and a number of study concept proposals have been submitted with a view to these being expanded to full applications. The Group

submitted a funding application to the Brain Tumour Trust to explore the use of mobile phone based system to improve symptom management in teenagers and young adults diagnosed with a primary brain tumour but were unsuccessful. Alternative funding bodies are being explored.

A funding application was submitted to the Chief Scientist's Office (CSO) to explore barriers to participation in cancer trials amongst teenagers and young adults. This application has been invited to progress to a full funding application and will be funding jointly by CSO and third sector. This study will be adopted on to the portfolio if successful.

Funding totalling £108,394.60 has been secured from Teenage Cancer Trust for two projects arsing through the HSR subgroup (see above).

The CSG continues to be considerably active in commenting on relevant CRC applications. In the last 12 months we have commented on nine applications with input from many Group members. In addition, the CSG has extended its pool of reviewers to include subgroups members (with permission from CTAAC), to broaden the expertise. The CSG considers this activity to part of core business in ensuring that relevant studies are considering the needs of young people and will be available in centres where young people are most likely to be treated.

This year we have also been approached by investigators prior to submission to CRC for comments and letters of support, this is a good move forward for the Group in being connected to other CSGs and researchers and groups.

Table 3 Funding submissions in the reporting year

Other committees			
Study	**Committee & application type**	**CI**	**Outcome**
Adaption and feasibility testing of a mobile phone based system to improve symptom management in teenagers and young adults diagnosed with a primary brain tumour	Brain Tumour Trust Quality of Life awards Application	Lisa McCann	Unsuccessful
Understanding barriers to participation in cancer trials amongst teenagers and young adults: qualitative study	Chief Scientist Office Research Grants	Angela Edgar	Successful – to submit full application
An evaluation of 'Find Your Sense of Tumour' (FYSOT).	Teenage Cancer Trust	Lorna Fern	Successful (£81,274.00)
Online information and support needs for young people with cancer.	Teenage Cancer Trust	Lorna Fern	Successful (£27,120.60)

8. 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 Experimental Cancer Networks TYA Network Group will further serve to foster links.

The CSG initiated conversations with the Association of British Pharmaceutical Industry Cancer Working Party in May 2013 with little official engagement since. We were invited to attend their Cancer Working Group meeting in May 2016. Dr Fern and Professor Whelan attended and presented the ten year accrual data. The Group is chaired by Dr David Montgomery, Medical Director Oncology, Pfizer and has representation from BMS, AstraZeneca, Takeda, Janssen, Servier

and Amgen. The Group were enthusiastic to implement the lower age eligibility criteria across industry studies and recognised they may not be best placed to initiate this and committed to assist in putting us in contact with the correct global people who could influence. They suggested that it would only take a few of the main players to implement the lower age of 16 and many would follow suit.

9. Impact of CSG activities

The CSG does not have a portfolio of trials, however, its 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. Ongoing analysis and dissemination of recruitment to NIHR cancer trials by age continues to change practice. Since 2014, application to CRUK has required investigators to justify age restrictions. This has resulted in most CRC applications we have since reviewed having either removed age eligibility criteria or lowered their age eligibility criteria to 16 years. Notably some studies had removed upper age eligibility criteria therefore also impacting in improving access to research for the elderly. Following on from this, the NCRI Executive issued a statement to NCRI partners to consider following suit of CRUK and asking for justification of age related exclusion and inclusion criteria. Through our links with the ENNCA project we will adapt the statement to funders and send out via our European stakeholders. This is re-iterated in Dr Fern's book chapter on access to clinical trials which also includes the statement from CRUK as a model of international funders to follow.

In March 2016, we were contacted by Dr Georgina Jones Health Economics and Decision Science, University of Sheffield after their Ethics committee had asked them to raise the age eligibility of a fertility study 'The development and evaluation of a fertility preservation decision aid to support women with cancer 'from 16 to 18 years. The CSG provided a letter of support (see appendix 3) and the decision was over turned.

In February and November 2015 in Scotland, Dr Edgar and Dr Fern participated in Parliamentary Roundtable discussions with relevant stakeholders; clinical and academic institutions representing paediatric and adult oncology, third sector, governmental agencies, clinical research, pharmaceutical industry and clinical trials expertise, to identify barriers to making more trials available to young people and factors hindering recruitment. The findings are echoed by others and include limited availability for trials for TYA cancers, limited access to trials for TYA in Scotland, low visibility of trials, low referral rates to specialist centres, physician related attitudes, regulatory and institutional barriers, poor collaboration between paediatric and adult services and unique psychosocial needs of TYA with cancer. This has led to the Chief Scientist Office (CSO) adopting CRUK's approach around age appropriateness in trial design, collaboration with NHS Research Scotland to improve trial availability and visibility, and collaboration between the Managed Service Network for Children and Young People with Cancer (MSN CYPC) around the trial portfolio maps.

Furthermore, a full funding application has been invited by CSO to explore attitudes of TYA and health professionals around clinical trial participation; a necessary step if we are to improve recruitment rates.

10. Consumer involvement

The CSG had two consumer members, Mr James Adams and Matthew Cooke who attend our CSG meetings, subgroup meetings and also the main Consumer Liaison Group meetings. Sadly, Matthew Cooke passed away this year and the CSG is very grateful to his enthusiastic and enormous contribution to the CSG. Mr Adams is mentored by Dr David Cutter. The CSG has recently advertised for a new consumer member. Mr Adams has stepped down from his role within the HSR Subgroup to concentrate on his academic studies. The CSG is currently advertising for a new member, however, representation of TYA on the Group remains to be optimised as we have currently one member and three subgroups.

Mr Adams is the founder and head of Cancer Awareness in TYA based in Manchester (CATS), an education programme aimed at raising awareness of cancer in young people, aimed at university students in Manchester. This programme has been very successful and has recently been endorsed by Teenage Cancer Trust as part of their higher education programme and will provide money to evaluate the project. CATS will be launched in other universities, including Cambridge and UCL. Mr Adams is preparing an abstract for the NCRI conference in November.

The BRIGHTLIGHT study has a user group called the YAP, of approximately 17 young people, 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) this year; the annual patient conference (YAPPERS at FYSOT). Additionally, the JLA exercise further services to increase outreach to young people and allows the opportunity to think more creatively about PPI involvement.

11. Open meetings/annual trials days/strategy days

The CSG has not hosted any open meetings/trials days or strategy days over the last 12 months. However, several of our members have played an integral part in the NCRI Sarcoma Strategy Day and Professor Whelan presented the ten year recruitment data for the commonest TYA cancer, highlighting the gaps in frontline trials for this age group. The CSG also participated in a meeting with NIHR CRN, hosted by Dr Amos Burke, National Specialty Lead for Children and Young People's Cancer and Dr Shamilia Anwar, Specialty Cluster Manager (Cancer, Surgery and Oral & Dental Health) and attended by a number of Local CRN TYA Subspecialty Leads. Drs Burke and Anwar have 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.

12. Progress towards achieving the CSG's 3 year strategy

The CSG is making progress with the three year strategy and is detailed in the strategy document (Appendix 2). The CSG has successfully established the Survivorship Subgroup and Chair, appointed a new Chair to the HSR Subgroup and expanded our membership to include a broader range of professionals. The first phase of BRIGHTLIGHT has been completed; data analysis is underway and dissemination of emerging results back to young people is ongoing and companion studies closed for analysis. Progress had been made towards improving access to biological samples for TYA cancers and opportunities for personalised medicine are being explored. Ten year

recruitment data has been collated and manuscript preparation underway. National clinical trial recruitment is now required and will be the remit of NIHR CRN. Collaborative work with NIHR is well established and will involve joint working to ensure our strategic objectives around ensuring research opportunities for young people are met. The work of the CSG has been extensively disseminated through high quality journals and presented at national and international conferences. The CSG made less progress with securing funding for the early diagnosis workstream but there is a clear direction going forward.

13. Priorities and challenges for the forthcoming year

Priorities:

1. To strengthen UK partnerships - Developing collaborations with NCIN CTYA SSCRG is imperative if we are to improve our undertsanding of and outcomes for non-trial patients or for patients with refractory or recurrent disease. Close working relationship with NIHR LCRN and developed nations cancer newtroks will be essential to ensure equity of access to the clinical research portfolio.
2. To ensure TYA have opportunities to benefit from advances in personalised medicine.
3. To secure funding for the feasibility work to inform a Programme grant on Diagnosis.

Challenges:

1. 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, NCRI Conference 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.
2. 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.
3. 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 a identification of new model of thinking if we are to understand healht behaviours. Exploring partnerships with medical anthrolopogy to help us understand behaviour may provide insight into a necessary cultural shift.
4. Developing opportunities for personalised medicine in TYA necessitates European working due to rarity of TYA cancers and the small TYA research community in the UK.

14. Concluding remarks

The CSG Chair would like to thank all the CSG members for their valued contribution to the work of the Group over the past twelve months and for their instrumental role in ensuring delivery of the CSG strategy. The CSG would particularly like to thank Professor Faith Gibson and Sam Smith for their enormous contribution to the Group. The CSG would also like acknowledge the contribution of Mathew Cooke to the Group and extend our condolences to his family and friends at this time.

15. Appendices

Appendix 1 - Membership of main CSG and subgroups

Appendix 2 – CSG and Subgroup strategies

- A – Main CSG Strategy
- B – Health Services Research (HSR) Subgroup Strategy
- C – Biological Subgroups Subgroup Strategy
- D – Survivorship Subgroup Strategy

Appendix 3 - Letter of to Dr Georgina Jones

Appendix 4 - Portfolio Maps

Appendix 5 - Publications in previous year

Appendix 6 - Major international presentations in previous year

Dr Angela Edgar (TYA CSG Chair)

Appendix 1

Membership of the TYA CSG

Name	Specialism	Location
Dr David Cutter	Clinical Oncologist	Oxford
Mr James Adams	Consumer	Stoke on Trent
Mr Mathew Cooke	Consumer	Cambridge
Professor Mike Hawkins	Epidemiologist	Birmingham
Dr Clare Rowntree	Haematologist	Cardiff
Dr Jane Beety	NIHR CRN: Cancer, CCL Lead	London
Dr Dan Stark	Medical Oncologist	Leeds
Professor Jeremy Whelan	Medical Oncologist	London
Ms Sue Morgan	Nurse	Leeds
Ms Samantha Smith	Nurse	Manchester
Dr Angela Edgar (Chair)	Paediatric Oncologist	Edinburgh
Dr Martin McCabe	Paediatric Oncologist	Manchester
Professor Hamish Wallace	Paediatric Oncologist	Edinburgh
Dr Shaun Wilson	Paediatric Oncologist	Oxford
Dr Karen Manias*	Paediatric Oncologist	Birmingham
Professor Faith Gibson	Professor of CYP Cancer Care	London
Ms Gemma Pugh*	PhD Student	London
Dr Lorna Fern	Research Development Coordinator	London
Dr Lisa McCann	Senior Lecturer in Cancer Care	Glasgow
Dr Kenneth Rankin	Surgeon	Newcastle

* denotes trainee

Membership of the Subgroups

Health Services Research (HSR) Subgroup		
Name	**Specialism**	**Location**
Ms Sue Morgan	Nurse	Leeds
Ms Sam Smith	Nurse	Manchester
Dr Dan Stark	Medical Oncologist	Leeds
Professor David Walker	Paediatric Oncologist	Nottingham
Professor Faith Gibson (Chair)	Professor of CYP Cancer Care	London
Dr Lorna Fern	Research Development Coordinator	London
Dr Anne-Sophie Darlington	Senior Research Fellow	Southampton

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

The Survivorship Subgroup membership is to be finalised.

Appendix 2

CSG & Subgroup Strategies

A – Main CSG Strategy

CSG Principles	Strategic Objectives	Strategic Outputs	Outcome measures	CSG Leads	Dates
1.1 Portfolio development (general)	1.To submit new study concept proposals 2. To development of TYA CPMS database 3 To raise awareness & promote recruitment to TYA research studies in cancer networks 4 To improve dissemination of study 5. To ensure trials developed for TYA 6. Development of TYA CSG Programme Grant	1.1 Each subgroup to submit new SCP 2.1 To link with NIHR CRN/EDGE – age data 2.2 To explore PM of common TYA tumours 3.1 To link with CTYA subspecialty leads 4.1 To incorporate into CSG agenda 5.1 Identify trial gaps and collaborate with CSGs 6.1 To develop Programme Grant	1.1 Subgroup submission of new SCP 2.1 Contact with lead in NIHR CRN/EDGE re age data 2.2 List of common TYA tumours and available trials 3.1 Contact/meet with CTYA subspecialty leads 4.1 Present study results at CSG meetings 5.1 Identify trial gaps and collaborate with CSGs 6.1 Proposal outline for programme grant	MM, FG, HW AE, SA NIHR AE AE, LC AE, LC LF	7/17 ongoing done Done/ongoing Ongoing ongoing In progress
1.2 Portfolio development (Subgroup specific)	**Health Services Research** 1. To improve our understanding of the pathways to accessing research for the one diagnostic group, with transferrable benefits to other groups 2. To improve recruitment to research studies 3. To ensure TYA included in early phase studies 4. To continue with ongoing studies	1.1 To develop study proposal: Refer Me 1.2 Explore studies with NHS Choices 2.1 Determine regional availability of trials 2.2 Explore timelines for trial process 2.3 To study cultural barriers to trial recruitment 3.1 To develop links with ECMC 4.1 To report on studies 6 monthly 4.2. To submit funding application for Refer Me	1.1 Develop proposal and explore funding 1.2 Update on usage of NHS Choices website 2.1 Develop collaboration with CTU/NIHR 2.2 To contact trials units: explore remote trial opening 2.3 To develop study proposal and submit for funding 3.1 To re-engage with ECMC on TYA 4.1 To report on studies 6 monthly 4.2.Update at next CSG on proposals for funding	LF TBC AE AE, LF AE, JW, LF JW, AE All	ongoing Done/ongoing 11/16 In progress 12/16 Ongoing Ongoing
	Biological studies 1. To expand access to biological samples of TYA cancers 2.To explore the contribution of biological and non-biological factors for differential survival in TYA compared to children and older adults 3.To facilitate opportunities for personalised medicine 4. To explore the impact of dose intensity/toxicity on patient outcomes	1.1 Identify and establish links with existing groups 1.2 Explore clinical trial tumour banks/access 1.3 Identify tumours where there is no bank 1.4 Submit paper for publication 2.1To establish collaboration to study contribution of dose intensity to age-related outcomes 3.1 Establish links with existing networks: SPECTA 4.1 CTRad/CCLG & TYA CSG – develop radiation toxicity study 4.2 To identify site-specific groups to work on this 4.3 To identify clinical trial data to pool for analyses 4.4 To apply for funding to do meta-analysis	1.1Report on tissue collection plans from CTAAC funded studies 1.2 Complete analysis for results section 1.3 Submit paper for publication 3.1 Explore collaboration with UK SPECTA +/-others 3.2 Initiate discussions with Pharma to access targeted agents for teenagers 3.3 If successful; proposal for tumour sequencing 4.1 Coordinate stakeholders' meeting to explore CTRad/TYA & CCL CSG joint RT toxicity study 4.1 Work with subgroups to explore this 4.2 A collaboration agreement 4.3 A trials list 4.4 A grant application		12/15 done 12/16 10/16 08/15 12/15 08/16 07/15 10/15 10/15 04/16 04/16 07/16
	Survivorship 1. To develop innovative strategies to empower patients 2. To support enhanced population based studies 3. To develop fertility studies	1.1 Explore existing patient facing platforms 1.2 Explore patient views on introduction of above 1.3 Explore the best psychological assessment tool 2.1 Identify nested control studies from TYACSS 3.1 Explore TYA views on fertility issues 3.2 Explore how to incorporate fertility issues into new clinical trials 3.3 Develop cohort studies for non-trial patients	1.1 To prepare report for CSG meeting 1.2 Exploration of TYA views on electronic passport 1.2 Identify the core functionality of what TYA want 1.3 Report on psychological assessment tool 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 3.3 To develop proposal on how to address this	LM LM, HW HW DS HW/MH HW HW HW	10/16 done 04/17 11/16 10/17 07/16 02/17 2/18
1.3 Portfolio development (cross cutting)	1.Develop links with other CSGs, Advisory Groups - CCL, S&PC, SPED 2. Identify CSG members on other CSGs	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
2 Improving TYA representation in clinical trials	**NCRI TYA CSG Researcher – Programme Grant** 1. Pilot studies – examine data from BRIGHTLIGHT 2. To develop programme grant around earrl diagnosis	1. To establish working group 2. To prepare proposal for programme grant 3. To submit application for funding	1.Identify working group 2. Explore feasibility of incorporating existing project 3. Complete pilot study 4. Outline project proposal and SCP 5. Submit funding application	LF	10/16 Done 12/16 3/17 6/17
3 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	11/16 ongoing ongoing
	Trainee scheme 1. To develop guidance for mentor/mentees 2. To identify 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 LG, KM AE	ongoing
4.1 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.Steering group established and priority setting exercise underway	1.Update at CSG meetings	FG, LF	ongoing
5 Consumer involvement	**Consumer** 1. To develop guidance for mentor/mentees 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 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	AE JA, MC JA, MC JA, MC	Ongoing
6 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	AE, LF LC, AE, LF AE, LC All AE	Ongoing

B – Health Services Research (HSR) Subgroup Strategy

Please see the main CSG strategy document.

C – Biological Studies Subgroup Strategy

Since its inception, developing a strategy to improve access to tissue for research has been the Subgroup's main priority. Beyond that the Subgroup has struggled to agree whether it should develop and encourage cross-cutting, age-directed studies or to focus on biological studies of the cancers that peak during teenage and young adult years. Most of the latter research is performed at an international level by European and US disease consortia. This issue, and the Subgroup's future direction, was discussed at length during the main CSG's strategy day in April. Three main strategic focuses arose from those discussions and were agreed for the next 3-5 years:

1. To improve access to banked tumour samples for biological research

The Subgroup has spent two years collating data on over 4,000 existing tumour samples from young people aged between 13 and 40 banked in recognised UK tissue banks. During the next six months, we will complete the descriptive analysis of those data and prepare them for publication. As part of that analysis we will identify the tumour types that are poorly represented in existing collections. Of note, our survey has considered only whether tissue was available, without any assessment of quality.

Over the next two to three years we will use the data from the survey analysis to develop a strategy relating to the availability of samples representative of the spectrum of TYA cancer. The Subgroup has considered three broad solutions: to set up a specific tissue bank, to develop a virtual repository of available tissue, or to develop a strategy to increase the deposition of tissue samples to existing, quality-assured tissue banks. We agreed in advance that a survey of existing tissue was a necessary step in that decision-making process.

In parallel, recognising that samples aligned to clinical trials have particular value deriving from their associated metadata, we plan to assess the impact of the CRUK CRC committee's policy to specify access policies for the sample collections they fund. We plan to work with CRUK to survey the plans of CRC applicants, and to assess how straightforwardly external investigators should be able to access samples in those collections.

2. To facilitate opportunities for personalised medicine in TYA patients

The increasing availability of high throughput -omics technologies and the scope to increase the availability of targeted therapies for this age group is an attractive area for development. Members of the group are already involved in biological studies and clinical trial groups at a national and European level. We have agreed three areas to take forward over the next 3-5 years:

- To establish patient views about the acceptability of clinical trials at first line or relapse that rely on tissue sampling over and above what is needed to make a diagnosis, particularly relating to molecular phenotyping –
  In the era of targeted therapy, trials increasingly require additional samples to be taken at screening to identify the molecular phenotypes most likely to respond to treatment. In the relapse setting, particularly for poor prognosis diseases, such biopsies may limit the acceptability of clinical trials to patients. We will work with our patient representatives and existing TYA patient groups to survey patients' opinions about tissue biopsies in this setting.
- To develop links with existing, clinically accredited sequencing platforms or research groups –
  We do not yet have a clear idea of the proportion of TYA patients at a population level who have targetable mutations. We plan to develop a clinical trial, working with established, clinically

accredited sequencing laboratories, to access tissue from patients' initial diagnosis and relapse for high throughput, targeted sequencing to identify that proportion. In the longer term, we plan to use that knowledge to develop therapeutic clinical trials of targeted therapies in the relapse setting, and to encourage Pharma companies to improve access of teenagers to agents that are available to adults. The anticipated work flow for this long-term project would be:

- establish relationship with clinically accredited sequencing lab
- sequencing study of patient samples
- establish relationships with one or more Pharma companies to support a Phase I/II study, possibly under the auspices of the combinations alliance
- design a multi-arm Phase I/II study of specific targeted agents, across a selection of poor prognosis diseases

- To work with other relevant CSGs to work on proposals of joint interest –
  There is some interest in the Subgroup to work with the CCL CSG and CTRad to look into the feasibility of a cross-cutting radiogenomic study assessing the impact of germline characteristics on radiation toxicity including children, teenagers and young adults. We plan to set up an initial discussion with members of the CTRad group to assess how feasible such a study would be, and if there is an appetite to take it forward, to work with members of the CCL CSG to develop a study protocol for submission for funding.

3. To explore the impact of age-related variation in dose intensity and toxicity on patient outcomes

For most of the poor prognosis diseases in TYA patients, children have better outcomes than adults. For decades there has been debate about the relative contributions to this phenomenon of tumour and host biology, the evolution of different treatment strategies in adults and children, and issues relating to the intensity of delivered treatment. For a small subset of diseases, it is clear that differing treatment clearly results in differential survival. For others the situation is less clear.

The LIVESTRONG collaboration between several large, cooperative bone sarcoma groups, has shown through meta-analysis of several that for osteosarcoma, adults have lower treatment intensity, fewer side effects and worse outcomes than children. Thus, worse survival in adults is not dictated solely by differing biology, and the evidence does not support the idea that adults, at least in the young adult age range, do not physiologically tolerate chemotherapy as well as children.

We intend to work with international clinical trial groups to perform a series of meta-analyses across certain poor prognosis diseases to specifically study the issue of dose intensity across the age spectrum, in terms of the intensity of different treatment regimens, and in the differential delivery of dose-intensive treatment by age. Several subgroup members are members of relevant international trial consortia. Specifically, we plan to approach individual cooperative trial groups and set up collaboration agreements over the next year, with a view to developing funding proposals to support the meta-analyses in the following years.

D – Survivorship Subgroup Strategy

Please see the main CSG strategy document.

Appendix 3

Letter of to Dr Georgina Jones

Dr Georgina Jones

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18th March 2016

Dear Dr Jones,

Re: Cancer, Fertility and Me:

The development and evaluation of a fertility preservation decision aid to support women with cancer

Thank you for your recent correspondence regarding the age eligibility criteria for the above study. It is somewhat surprising and also unacceptable to hear that the ethics committee have requested that the lower age of the study should be raised to 18 years, therefore excluding young girls aged 16 and 17 from participation.

The National Cancer Research Institute's Teenage and Young Adult Clinical Studies Group have carried out a considerable amount of work around age inequalities in access to research for young people and in particular the arbitrary use of age as an exclusion criteria applied to many studies (please find attached our recent Lancet Oncology publication). In light of this work Cancer Research UK are now asking all new investigators to justify the use of age as an inclusion or exclusion criterion on all new funding application and if a lower age must be used that this should be 16 years rather than 18 years. We also attach a recent statement from the NCRI to its member partners to advocate the same approach.

Fertility issues are pertinent to young females and discussions around sex, intimacy and fertility preservation will have routinely taken place during consultations prior to chemotherapy. As such, there is no increased sensitivity or risks posed by making this study available to them. Indeed, we would view it as unethical to exclude 16 and 17 year olds from this study.

We trust this is sufficient information to support your response to the ethics committee however should you require further discussion with any of the group members or our patient representatives then please feel free to contact us.

Yours sincerely

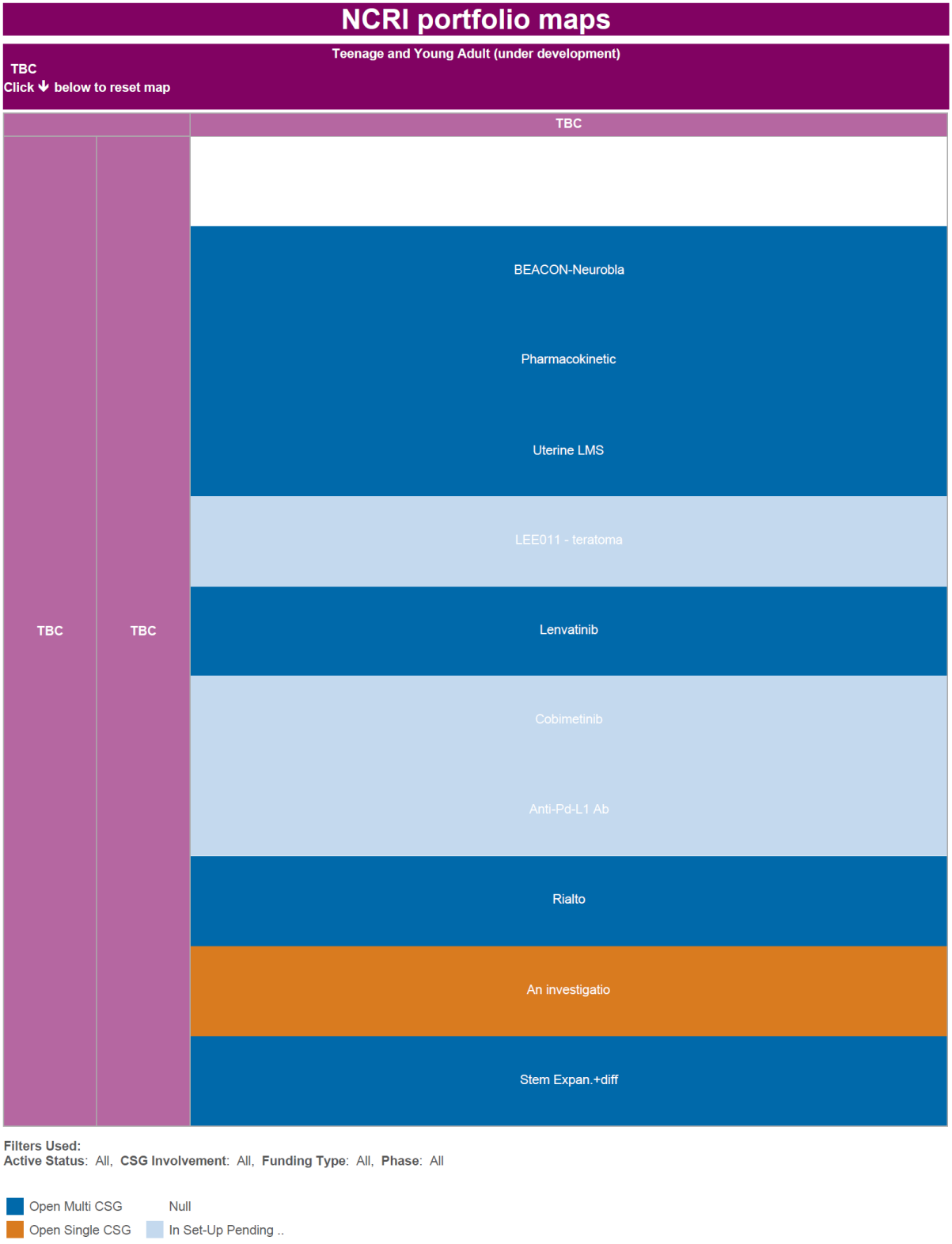
Dr Lorna A Fern PhD

Research Development Coordinator on behalf of the National Cancer Research Institute Teenage and Young Adult Clinical Studies Group

Appendix 4

Portfolio maps

Please note that this portfolio map is under development.



Appendix 5

Publications in the reporting year

The perceptions of teenagers and young adults and professionals in the participation of bone cancer clinical trials
Pearce S., Brownsdon A, Fern L.A., Gibson F. Whelan J., Lavender V. Eur J Cancer Care (Engl). 2016 Mar 3. doi: 10.1111/ecc.12476. [Epub ahead of print]

A participatory study of teenagers and young adults views on access and participation in cancer research
Taylor RM, Solanki A, Aslam N, Whelan JS, Fern LA. Eur J Oncol Nurs. 2016 Feb;20:156-64. doi: 10.1016/j.ejon.2015.07.007. Epub 2015 Aug 4.PMID: 26251363

How young people describe the impact of living with and beyond a cancer diagnosis
Gibson F, Hibbins S, Grew T, Morgan S, Pearce S, Stark D, Fern LA., How young people describe the impact of living with and beyond a cancer diagnosis: feasibility of using social media as a research method. Psychooncology. 2016 Jan 8. doi: 10.1002/pon.4061.

BRIGHTLIGHT
Taylor RM, Fern LA, Solanki A, Hooker L, Carluccio A, Pye J, Jeans D, Frere-Smith T, Gibson F, Barber J, Raine R, Stark D, Feltbower R, Pearce S, Whelan JS. Development and validation of the BRIGHTLIGHT Survey, a patient-reported experience measure for young people with cancer. Health Qual Life Outcomes. 2015 Jul 28;13:107. doi: 10.1186/s12955-015-0312-7

Direct access to potential research participants for a cohort study using a confidentiality waiver included in UK National Health Service legal statutes
Taylor RM., Fern LA., Aslam N., Whelan J. British Medical Journal Open. Outcome: Accept minor revisions

BOOK CHAPTERS
Nathalie Gaspar & Lorna Fern, Increasing access to clinical trials and innovative therapy for teenagers and young adults with cancer – A multiple stakeholders and multiple steps process. In 'Tumors in Adolescents and Young Adults', PROGRESS IN TUMOR RESEARCH, First Edition. KARGER books, In press

Annette Hay, Lorna Fern, Ralph Meyer, Nita Seibel, Ronald Barr, Cancer in Adolescents and Young Adults, Clinical Trials. Second Edition. Springer. In press

Lorna Fern & Jeremy Whelan, Cancer Research and Adolescents and Young Adults. A practical approach to the care of Adolescents and Young Adults with cancer. First Edition, Springer. In preparation

Appendix 6

Major international presentations in the reporting year

Edgar AB, Ritchie S. The Trial Gap: Reduced access to cancer trials for children and young people in Scotland. NCRI Cancer Conference 2015: B150. http://www.bbc.co.uk/news/uk-scotland-34700082. http://www.cancerresearchuk.org/about-us/cancer-news/press-release/2015-11-03-scotlands-youth-missing-out-on-trials-of-cancer-treatment

Fern L.A. Involving young people in longitudinal research, 'more than post it notes and glitter'. CLOSER Conference – The importance of early years, childhood and adolescence: Evidence from longitudinal studies, January 2016.

Fern L.A., Taylor R.M., Worrall S., Neal RD. Medical negligence claims for 'delays' or failures in cancer diagnosis and treatment for children and young people, costs to the National Health Service and impact on patients. Inaugural International Adolescent and Young Adult Oncology Congress, Sydney, December 2015.

Fern L.A. on behalf of the BRIGHTLIGHT Team 'OK to ask': young people's views about access to and participation in research. Inaugural International Adolescent and Young Adult Oncology Congress, Sydney, December 2015.

Fern L.A., Taylor R.M., Worrall S., Neal RD. Medical negligence claims for 'delays' or failures in cancer diagnosis and treatment for children and young people, costs to the National Health Service and impact on patients. Teenage and Young Adult Cancer, Education Day, Leicester, INVITED SPEAKER

Fern L.A. Building on Teenage and Young Adult Networks. 18th European Cancer Congress (ECCO), 25th-28th September 2015, Vienna. September 2015.