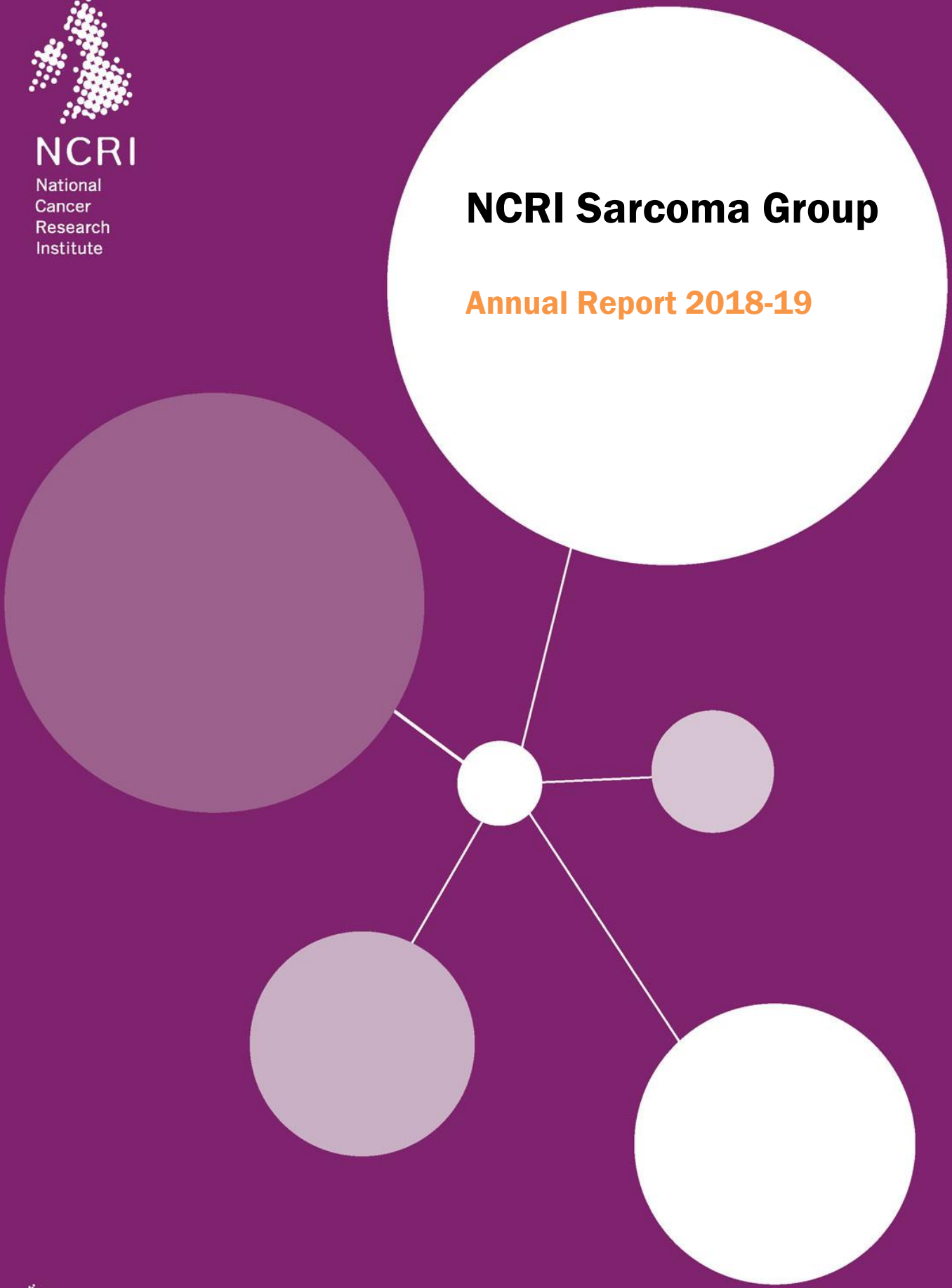
NCRI
National
Cancer
Research
Institute

NCRI Sarcoma Group

Annual Report 2018-19



Partners in cancer research

NCRI Sarcoma Group
Annual Report 2018-19

1. Top 3 achievements in the reporting year

Achievement 1 A positive outcome for EpSSG RMS 2005 second randomisation experimental arm, with median follow up of 5 years in surviving pts, 3 yr EFS and overall survival (OS) in M-arm vs Std-arm were respectively: EFS 78.4% (95% IC -71.5-83.8) vs 72.3% (95% IC -65.0-78.3) (p 0.061) and OS 87.3% (95% IC 81.2-91.6) vs 77.4 (95% IC 70.1-83.1) (p = 0.011). This was practice changing results of a study developed within the CSG, as a result it is now standard of care for all patients to receive maintenance chemotherapy. This is the first ever positive outcome in RCT trials in paediatric/TYA population in 25 years.
Achievement 2 The CSG undertook a successful Quinquennial Review (QQR) with an impressive report and positive feedback during the meeting and in the reviews.
Achievement 3 Flag ship trials developed within the CSG have proven popular with clinicians, as the recruitment is ahead of planned or finished recruiting early to trial in 'Does circulating DNA predict the grade and disease burden of chondrosarcoma? A nationwide Collaborative study' (105/130 patient recruited) and EE2012 has completed recruitment in 2019. This proves that the CSG are designing studies that clinicians think are important and need exploration.

2. Structure of the Group

The membership of the Sarcoma CSG continues to evolve every year. The feedback from the Quinquennial Review Panel Report highlighted the number of different specialities within the Group, in particular the Bone Subgroup, which was described as a great asset to the group. The main CSG group now consists of 4 clinical oncologists, 4 surgeons (including a retroperitoneal sarcoma surgeon), 3 medical oncologists, 2 paediatric oncologists, 2 consumer representatives, 2 pathologists, 2 scientists, 2 trainee representatives (clinical research fellow and trainee orthopaedic surgeon), a medical physicist, a statistician and a clinical nurse specialist from a wide geographical distribution throughout the UK. The diversity of membership is also represented within the YOSS, Bone & Soft Tissue Sarcoma (STS) Subgroups.

A major recommendation from the Quinquennial Review Panel Report was for NCRI Executive to approve a Soft Tissue Sarcoma Subgroup as this was deemed more appropriate than a Working Party due to the large proportion of patients this group represents. Dr Aisha Miah who is chairing this sub-group, has identified a multidisciplinary membership including consumers, and has organised the first meeting. This group will focus on trial development for STS patients, but will also address local control questions including surgery, the role of rehabilitation and use of medication around surgery to reduce the inflammatory micro-environment which may reduce local recurrence.

The group welcomed new members Prof Nischalan Pillay, Dr Susanne Gatz, Dr Quentin Hewson, Mr Anant Desai, Dr Phil Green (Consumer Representative) as well as Mr Christopher Anthony and Dr Elizabeth Roundhill as new trainee representatives.

Dr Beatrice Seddon, Dr Paula Wilson, Dr Louise Carter, Dr Sandra Strauss, Dr Rajesh Botchu and Mrs Sharon Forsyth rotated off the group and were thanked for their hard work and contributions made whilst members of the Group.

3. Sarcoma Group & Subgroup strategies

Sarcoma Group Strategy

Increase the number of trials available for sarcoma patients in the UK

The group continues to see growth in the number of trials available for sarcoma patients within the portfolio and the number patients recruited to trials. There has been an increase in recruitment to sarcoma studies every year since 2015 with now 19% of new sarcoma patients recruited to trials. There are currently 17 bone sarcoma trials listed on the portfolio and 24 STS trials listed on the portfolio. There are several large trials that are currently in set up and will start recruitment in 2019 including ICONIC and Far-RMS studies which were funded recently.

A key strategic aim for the CSG following the Strategy Day was to develop studies which gave an opportunity for the sarcoma community to take part in trials. This was seen with the opening of the new bone sarcoma trials and Sarcoma Assessment Measure trial. The opportunity to further develop STS trials through a new STS Subgroup is intended to lead to new trials being developed in STS, advanced disease and local control.

The CSG took part in the International Osteosarcoma Research Symposium in January 2019 co-sponsored by Children with Cancer and Bone Cancer Research Trust. This day gathered experts from around the world to design a follow-on study from ICONIC and other study ideas.

Develop new trials with both interventional and non-interventional arms and allow as many patients with sarcoma to enter data into studies

The primary focus of the CSG remains to develop new studies with both interventional and non-interventional arms. The CSG developed a study, SARC-MET (A longitudinal cohort study of patterns of care for patients presenting with metastatic soft tissue sarcomas), which held the ideals of both intervention and observation, which unfortunately was not funded by RfPB. It did however, receive useful feedback and alternate funding streams are being investigated. It was also presented to Supportive & Palliative Care CSG with favourable feedback.

The newly formed STS subgroup is continuing to hone the protocol to a point where it can obtain funding. This new sub group will also work on studies focusing on local control issues including surgery with interventional, translational and observational arms.

The CSG has recently developed ICONIC, FaR-RMS and EpSSG NRSTS 2018 trials which all have interventional, translational and observational arms which have been funded and are due to open for recruitment shortly.

Increase studies in bone sarcoma

For the first time the CSG has developed studies in the four major types of bones sarcoma:-

1. Osteosarcoma – ICONIC was funded last year and is due to open to recruitment imminently and is awaiting formal REC approval. The CSG participated in the

International Osteosarcoma Research Symposium 2019, hosted by Children with Cancer UK and the Bone Cancer Research Trust, which brought together researchers from across the globe to identify research progress, challenges that need to be overcome and opportunities to move research forward. This year Children with Cancer UK will be committing £500,000 to future osteosarcoma research.

2. Ewings – Euro Ewings 2012 continues to be an important study for the CSG. It has recruited to target early and discussions are continuing with the EuroEwings Consortium for a follow up study. rEECur has also recruited to target early.
3. Chondrosarcoma – ctDNA and cartilage tumours has been a phenomenal success recruiting 105/130 planned patients ahead of target. A study of IDH1/2 mutations in the serum of chondrosarcoma patients has been funded and will open this year.
4. Chordoma – Two studies are open for chordoma but currently one does not show on the portfolio map. Guiding Chordoma Treatment Through Molecular Profiling: A National Cohort Study has recruited 40/100 planned patients. A new study, A Phase 2, Single Arm, European Multi-center Trial Evaluating the Efficacy of Afatinib as First-line or Later-line Treatment in Advanced Chordoma opened in 2019.

Further develop the Sarcoma CSG portfolio

The CSG's primary focus remains to develop studies which give opportunity for the whole sarcoma community to take part in trials. Several studies including the Sarcoma Assessment Measure (SAM) study are designed to recruit as many sarcoma patients as possible, and the recruitment figures show that 19% of new sarcoma patients are recruited to trial. The aim of the CSG is to increase this figure.

Following the QQR report a new subgroup, the STS sub group, is being developed to develop new studies specifically for soft tissue sarcomas. The group will take over the SARC-MET (A longitudinal cohort study of patterns of care for patients presenting with metastatic soft tissue sarcomas), which unfortunately not funded by RfPB in 2018. Several new projects are under development within the CSG including Stratification Of Sarcoma Pathways; improving diagnostic and follow up pathways for patients with extremity sarcoma.

The CSG has changed the structure of the main meetings to give ample time for trial development and updates. The Group had 5 study proposals presented to the CSG in 2018 prior to funding submission for feedback, awareness and endorsement of the CSG. The CSG has also regularly invited funder representatives from CRUK, Sarcoma UK and BCRT to attend meetings to try to harmonise future applications with research calls, to maximise the chance of successful application and allow a two-way dialogue with funders. The CSG continues to support funders, NICE and other organisations in reviewing applications.

Raise awareness and profile

The CSG continues to present abstracts at international and national meetings for studies developed within the CSG. The CSG has a regular section at the British Sarcoma Group (BSG) to disseminate the new trial ideas and studies which are opening, this also allows the CSG to

engage with the sarcoma community to uncover areas of unmet research need from the sarcoma community.

The CSG engaged with Sarcoma UK to develop a trainee research scheme, similar to Breast Cancer Trainee Research Collaborative (BCTRC) and this scheme will have small grants available for pilot studies for junior researchers. The project aims to develop new projects but also engage with young researchers to encourage participation with the CSG.

The interaction between the NIHR Sub-Specialty Leads (SSLs) and the CSG remains variable. Highlights from the CSG meeting are disseminated to the SSLs and there have been attempts to hold meetings with the SSLs and invite them to the main CSG meeting, however, this has been with limited success, a further meeting is planned for 2019.

Develop trials in key research priority areas

The CSG has made good progress on many areas of the key research priority areas set in 2016:-

1. Surgery - The CSG has developed "Whispar" study of wound complications which was not funded by RfPB. The group hold a surgical studies sandpit, but the lack of specific surgical questions that could be answered by a randomised question makes securing funding difficult for a stand-alone study. The CSG has focused therefore on adding surgical and radiological questions regarding surgical margins, function of reconstruction and radiological assessment of response to the upcoming ICONIC study for Osteosarcoma and views this as a viable alternative strategy to stand alone surgical studies. The STS working party is interested in incorporating a randomised question on identifying biomarkers of poor wound healing and randomising interventions prior to surgery, especially as pre-operative radiotherapy has a wound healing problem in over 30% of cases.
2. Osteosarcoma/Chondrosarcoma – The CSG has developed studies for both of these tumour types, which have been funded and are open or opening shortly. Follow up studies are currently being discussed.
3. Advanced Disease - SARC-MET (A longitudinal cohort study of patterns of care for patients presenting with metastatic soft tissue sarcomas), was developed by the CSG but was unfortunately not funded by RfPB in 2018. The STS sub-group will take over further development of this trial.
4. QOL/Follow up – The SAMs trial is focused on PROMS for sarcoma patients. This aims to recruit 1000 patients and has already recruited 289 patients, moving into the second phase of the trial. Stratification Of Sarcoma Pathways; improving diagnostic and follow up pathways for patients with extremity sarcoma study is currently under development.
5. Translational – The CSG has excelled in increasing translational research in either stand alone studies or embedded to larger studies. Translational studies are available in Osteosarcoma, Chondrosarcoma, Ewings, Chordoma and STSs. The group engaged above incidence with 100,000 genomes and continues to engage with GECiP and SPECTA.

Strengthen UK wide and international working

Given the size of the national and international community the CSG has always benefitted from close links with national and international organisations. This is clearly seen within the studies in the portfolio and in development. The CSG has representatives on key research organisations such as European Organisation for Research and Treatment of Cancer (EORTC), Children's Oncology Group (COG), Scandinavian Sarcoma Group (SSG), European paediatric Soft tissue sarcoma Study Group (EpSSG), Euro Ewing Consortium (EEC), IOC and Chordoma Foundation. This remains a strong and important priority for the CSG.

The CSG also regularly interacts with other NCRI groups with members sitting on Consumer Forum, SPED Advisory Group and Teenage & Young Adult (TYA) & Germ Cell Tumours (GCT) CSG and Dr Sandra Strauss is the Sarcoma Site Specific Clinical Reference Group (SSCRG) Chair for National Cancer Registration and Analysis Service (NCRAS) for sarcoma. The CSG has benefitted from interaction with Children's Cancer & Leukaemia CSG, Gynaecological Cancer CSG, Primary Care CSG, Psychosocial Oncology & Survivorship CSG, Supportive & Palliative Care CSG and TYA & GCT CSG either in the main meetings or via interaction with subgroups.

CSG structure and function

The membership of the Sarcoma CSG continues to evolve every year. The feedback from the Quinquennial Review Panel Report highlighted the number of different specialities within the Group, in particular the Bone Subgroup, which was described as a great asset to the group. The main CSG group now consists of 4 clinical oncologists, 4 surgeons (including a retroperitoneal sarcoma surgeon), 3 medical oncologists, 2 paediatric oncologists, 2 consumer representatives, 2 pathologists, 2 scientists, 2 trainee representatives (clinical research fellow and trainee orthopaedic surgeon), a medical physicist, a statistician and a clinical nurse specialist from a wide geographical distribution throughout the UK. The diversity of membership is also represented within the YOSS, Bone & new STS subgroups.

The strength of the CSG lies in the diversity of its membership; with several members holding academic positions undertaking basic science research, as well as clinical positions, thus giving expertise for both clinical and biological research. Several of the members have been involved in devising, gaining funding, running and concluding large national and international trials, which serves as a great inspiration and an invaluable resource for the group. Representatives of two of the main charitable funders of sarcoma research, Sarcoma UK and BCRT, attend the meeting, which provides valuable feedback to the members and helps the charities consider areas of unmet research needs. The CSG regularly debate the skills within the group and areas which could be strengthened. The Chair has pro-actively approached several individuals with skills in areas under-represented and encouraged them to apply for to join the CSG or subgroups. This year has seen the development of the STS sub-group following the QQR.

Patient and Public Involvement and Impact

The consumer involvement within the CSG remains good with Mr Michael Maguire, Mr Roger Wilson CBE and Dr Phillip Green being involved as consumer representatives. Both Roger and Michael have been involved in the development of studies with the last year, as well as being active in the NCRI Consumers Forum 'Dragons Den'. A major coup for the CSG was the membership of Dr Phillip Green, who joined the CSG this year. Dr Green was diagnosed with an Osteosarcoma at the age of 17 years old and underwent an amputation. He is a General Practitioner and works with BCRT, this combination of patient and medical experience will be invaluable to the CSG. He has already been involved in several projects and subgroups. The CSG will be recruiting a new consumer member this year. The CSG has worked with Sarcoma UK and BCRT to identify patients active in their organisations that may be suitable to join the CSG and subgroups. The CSG is hopeful for a positive response to the current advert for consumer members.

Address Recommendations from the Quinquennial Review (QQR) Panel Review

The CSG had a successful QQR panel review and a number of recommendations were suggested.

- **The Group needs to define their strategy on interacting with the TYA & GCT CSG to ensure that the TYA age group is successfully incorporated and recruited into sarcoma studies**
    - Several members of the CSG are members of the TYA & GCT CSG including Dr Angela Jesudason, Mr Kenneth Rankin and Dr Sarah Pratap has just joined. The YOSS sub group interacts regularly with the TYA CSG and TYA patients are well represented in the portfolio.
- **Given the relatively small sarcoma community, the Panel stressed the importance of engaging with the next generation of sarcoma clinicians and suggested having trainees on trials as 'deputy CI's' to encourage research engagement and inspire the next generation.**
    - The CSG has taken this advice on board and together with Sarcoma UK is sponsoring a Sarcoma Trainee Research Collaborative, to encourage junior researchers into Sarcoma research.
    - The trainee representatives have also been invited to attend the RAC meetings for Sarcoma UK.
- **The significance of having sarcoma patients as consumer members on the Group was highlighted. It was suggested that the Group should interact more with site-specific charities like Sarcoma UK and BCRT to engage the patient community.**
    - As previously stated this has been undertaken, with the appointment of Dr Green.
- **The Panel suggested that the Group should take a more ambitious approach to integrate translational research into their strategy, perhaps in the form of adding sarcoma studies into other bucket trials.**
    - The CSG has a strong translational element to its portfolio and continues to develop further studies.
- The Groups lack of work in surgery was highlighted.

- The lack of specific surgical trials is recognised, and further studies are in development, however, the strategy of the CSG has been to embed surgical questions into bigger trials such as ICONIC.

- **The Panel suggested that the Group should engage more with other funders outside of Sarcoma UK and BCRT and look to create a diverse funding portfolio.**
  - The CSG continues to work with other funders, such as CRUK, who are invited to attend the main CSG meetings, however, the success in funding applications for Sarcoma remains a concern.

Bone Tumour Subgroup (Chair, Mr Craig Gerrand)

Develop studies in bone sarcoma through wide engagement, including involvement with charitable partners and national collaboration

The Bone Subgroup has continued to engage widely with centres and charity partners. There has been an open door policy, meaning that interested partners can attend meetings. There is regular attendance from representatives of the Bone Cancer Research Trust, Sarcoma UK, the Anticancer Fund and British Sarcoma Group. The relationship with BCRT has been pivotal in the development and funding of the ICONIC study by BCRT.

In January 2019, the first International Osteosarcoma Research Symposium was held in order to explore further research in osteosarcoma. This meeting, chaired by Sandra Strauss, was supported by BCRT, Children with Cancer, the Frankie Biggs family and the NCRI. Children with Cancer subsequently announced a funding call to which osteosarcoma research proposals have subsequently been submitted by members of the group.

Develop studies where there were none, for osteosarcoma and chondrosarcoma

A major achievement this year has been the further development of the ICONIC study as it gets closer to recruitment. This study will recruit all patients with osteosarcoma and the Phase 1 pilot and feasibility component will open in 2019.

The study of circulating tumour DNA in chondrosarcoma has recruited over 100 patients against a target of 120 nationally. A workshop is planned later in 2019 to explore further studies in chondrosarcoma which may follow this one.

A paper from the EURAMOS-1 study is online.

Promote national collaboration in the development and delivery of studies

National collaboration has been a key strategic aim, and is evidenced by the attendance at meetings and the development of multicentre research.

Develop the next European Ewing Study EE 20XX

This is an ongoing process, with regular meetings supported by the European Ewing's Consortium. Funding for the Consortium is at an end, and the infrastructure to further develop the trial is therefore lacking. However, an outline for the next Ewing's study is under development, although there are considerable challenges to its delivery.

A CRUK application to extend the rEECur study has been submitted, as well as an abstract to ASCO.

Young Onset Soft tissue Subgroup (YOSS) (Chair, Professor Bernadette Brennan)

Open a first line study in Rhabdomyosarcoma across all ages in UK centres and European centres 2. Build in current relapse studies in RMS using VIT as the backbone

The FaR-RMS: A multiarm-multistage study for children and adults with localised and metastatic Frontline and Relapsed Rhabdomyosarcoma. This study is about to be opened in the first UK centre.

Trial summary: The FAR-RMS Study is an overarching clinical trial that explores several aspects of treatment for RMS, both for patients newly diagnosed with the disease and also at the time of relapse. It is open to patients of all ages (children, teenagers/ young adults (TYA) and adults) across Europe who are newly diagnosed with RMS or in whom the disease recurs.

To develop an all age European study in specific soft tissue sarcomas which occurs in paediatric, TYA and adult age group e.g. Synovial Sarcoma, MPNST, leiomyosarcoma and liposarcoma

Work has begun to set up a subgroup of YOSS and main NCRI group to develop an all age study in STS. The European agenda is on hold due to the negative results of the ANNOUNCE Olaratumab study.

Build on the outcomes of other rare sarcomas from the NRSTS 2005 study to develop further clinical trials, specifically Rhabdoid tumours at all sites, and Desmoids

Work is ongoing for both these tumours to obtain a targeted drug to add on to a backbone of chemotherapy or to compare with standard chemotherapy for Desmoid tumours. Protocols for Rhabdoid tumours are at a mature point of development.

To embed biological studies, biomarkers and novel targets into clinical trial portfolio

This will be achieved in FaR-RMS as above and EpSSG NRSTS 2019 - a successor to EpSSG NRSTS 2005 which will be a prospective cohort study with a biological question, which may be useful for all the NRSTS subtypes, leading to a therapeutic interventional trial.

Increase the TYA population in sarcoma studies

This will be achieved by extending the upper age range for study entry in all proposed studies above.

4. Task groups/Working parties

Remit of Gynaecological Sarcomas Working Party

The aim of the Working Party is to gain a better understanding of the different treatments gynae-sarcoma patients receive across the UK. The group wishes to produce guidelines for every gynae-sarcoma patient to be seen by a sarcoma MDT from a gynae-sarcoma questionnaire.

Progress to date

The working party has recently attended the Gynaecological CSG to discuss studies about Uterine leiomyosarcoma and a national survey has been undertaken. Further discussions and development of a trial are ongoing.

Remit of Lung Metastases Working Party

The main focus of this Working Party is to deliver a trial on metastatic sarcoma, the SARC-MET programme.

Progress to date

This working party has been dissolved and research into advanced disease has been taken over by the soft tissue sarcoma sub-group. SARC-MET (A longitudinal cohort study of patterns of care for patients presenting with metastatic soft tissue sarcomas), was developed by the CSG but was unfortunately not funded by RfPB in 2018. Work continues to get this study funded.

5. Funding applications in last year

Table 2 Funding submissions in the reporting year

Cancer Research UK Clinical Research Committee (CRUK CRC)					
Study	**Application type**	**CI**	**Outcome**	**Level of CSG input**	**Funding amount**
May 2018					
Not applicable					
November 2018					
ACCESS: Atr inhibitor Combinations AllianCe study in Ewing and Synovial Sarcoma	Clinical Trial Award	Dr Sandra Strauss	Not Supported		
VMPRASS (Validation of a Molecular Signature of Pazopanib Response in Advanced Soft tissue Sarcoma)	Biomarker Project Award	Dr Paul Huang	Not Supported		
Other committees					
Study	**Committee & application type**	**CI**	**Outcome**	**Level of CSG input**	**Funding amount**
ICONIC – Improving Outcomes through Collaboration in Osteosarcoma	BCRT - Clinical / Translational Grant	Dr Sandra Strauss	Supported	Developed within CSG	£275,000
Modelling Ewing sarcoma heterogeneity and tumour microenvironment to improve outcomes	BCRT - Explorer	Professor Sue Burchill	Supported	Developed alongside CSG by member	£67,414
Biological tissue collection infrastructure grants	BCRT	Collaboration from Primary Bone Centres	Supported	Developed with CSG	£81,452

Improving outcome in sarcoma through analysis and interrogation of national cancer data	Sarcoma UK	Dr Sandra Strauss	Supported	Developed with CSG input	£118,791
GeCIPing Sarcoma: A UK-led initiative to personalise sarcoma treatment	Sarcoma UK	Professor Adrienne Flanagan	Supported	Developed with CSG input	£250,000
In vivo and in vitro evaluation of novel gallium doped bioactive glasses for the management of osteosarcoma	Sarcoma UK	Professor Lee Jeys	Supported	Developed with CSG input	£118,918
Deconstructing the sarcoma matrisome for drug target and biomarker discovery	Sarcoma UK	Dr Paul Huang	Supported	Developed with CSG input	£120,000

6. Consumer involvement

Phil Green

Phil is currently the only Consumer Member of the NCRI Sarcoma Group and has been in post since August 2018. Sarcoma UK have been encouraged to approach their patient body in this regard and Phil has likewise approached the Bone Cancer Research Group with similar intention. He has yet to be invited to join the soft tissue or bone sarcoma subgroups but has expressed a willingness to participate if required.

Phil is the Consumer Member of the Trial Management Group for the ICONIC Study led by Sandra Strauss and funded by the Bone Cancer Research Trust. He has critiqued and edited the patient information drafts, resulting in an improved publication that is now perceived to be optimal to ensuring patient understanding of the study concepts, with the aim that patient recruitment will be maximised. Phil has also completed a similar exercise by commentating on and modifying the trial documentation intended to be sent to patient's GPs; the purpose being to collate information relating to the pre-diagnostic patient journey. GP supplied data, will be key to the success of one component of the study.

Phil is a member of the SOS Study Group and has participated in refining the documentation for presentation at the Consumer Forum Dragons Den event which took place in March 2019. Along with the trial leads, he helped to facilitate the session as a study group member and also further contributed suggestions as a Consumer. The NCRI Sarcoma Group recognises that this study concept is a priority not for only sarcoma, but also as a template for other cancer studies. A role for qualitative and quantitative review of diagnosis and follow-up, is in-line with the NCRIs priority area of Living with and Beyond Cancer.

Phil has become an active member of Sarcoma PAtient EuroNet (SPAEN); a well established pan-European sarcoma patient advocacy group. Having attended the annual conference in Athens and generating a number of excellent European patient and professional contacts, he has been selected to participate in a European-wide project, that aims to develop a strategy to improve outcomes for sarcoma patients. In a collaborative effort of patient advocates, patients, carers and sarcoma experts (represented by the EORTC Soft Tissue and Bone Sarcoma Group) the intention is to create a Sarcoma Research White Paper, or similar publication, highlighting the top 10-20 consumer-determined research priorities in sarcoma. The NCRI Sarcoma Group are keen for regular updates on the progress of this work, to influence its trial portfolio going forwards.

Phil has established regular contact with his scientific mentor via NCRI Group Meetings, Trial Management Group Meetings and via telephone. She has informally but positively commentated on his contributions to CSG activities to date and these have been formally recognised by the group as a whole, during its meetings.

7. Priorities and challenges for the forthcoming year

Priority 1 To develop the soft tissue sarcoma sub-group to effectively develop an overarching study on STS, including SARC-MET trial and stratified sarcoma follow up trials.
Priority 2 To launch ICONIC study and FaR-RMS by engaging with Sarcoma community to obtain recruitment. To liaise with Children with Cancer regarding a new initiative on funding osteosarcoma trials.
Priority 3 To increase participation of the TYA population in trials, indeed extending all our trials and research to the adult age group.
Challenge 1 To have greater representation at the NCRI conference for 2020. This meeting often clashes with the Connective Tissue Oncology Society meeting, however, Dr Phil Green, our new consumer representative has highlighted the need for greater involvement.
Challenge 2 To liaise with funders and develop a new study on soft tissue study in the absence of any new drugs worthy of investigation following the disappointing results as the primary endpoint of overall survival (OS) benefit with the combination of olaratumab (Lartruvo) plus doxorubicin was not met for patients with advanced or metastatic soft tissue sarcoma (STS) in the phase III ANNOUNCE clinical trial.
Challenge 3 To obtain large scale funding from national funders for a rare cancer type, in which there are few new drugs available, making a randomised intervention difficult.

8. Collaborative partnership studies with industry

The CSG continues to work with industry to identify new drugs in development which may be useful to treat sarcomas. Dr Strauss applied for a CRUK grant as part of the ECMC Combination Alliance and NIHR CRN: Cancer Clinical Alliance, but unfortunately the application was unsuccessful. The CSG has been in discussion regarding novel agents for several tumour types in 2018-19.

9. Appendices

Appendix 1 - Membership of the Sarcoma Group and subgroups

Appendix 2 – Sarcoma Group and Subgroup strategies

A – Sarcoma Group Strategy

B – Bone Tumour Subgroup Strategy

C – Young Onset Soft-tissue Sarcoma Subgroup Strategy

Appendix 3 - Portfolio Maps

Appendix 4 – Top 5 publications in reporting year

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

Appendix 6 – Feedback from the Quinquennial Review Panel

Professor Lee Jeys (Sarcoma Group Chair)

Appendix 1

Membership of the Sarcoma Group

Name	Specialism	Location
Dr Laura Forker*	Clinical Oncologist	Manchester
Dr Susanne Andrea Gatz	Clinical Oncologist	Birmingham
Dr Quentin Campbell Hewson	Clinical Oncologist	Newcastle
Dr Aisha Miah	Clinical Oncologist	London
Mr Christopher Anthony*	Orthopaedic Surgeon	Yorkshire
Dr Elizabeth Roundhill*	Clinical Research Fellow	Leeds
Dr Phil Green	Consumer	Leicester
Mr Michael Maguire	Consumer	London
Dr Charlotte Benson	Medical Oncologist	London
Dr Louise Carter	Medical Oncologist	Manchester
Dr Sarah Pratap	Medical Oncologist	Oxford
Professor Luc Bidaut	Medical Physicist	Lincoln
Mrs Helen Stradling	Nurse	Oxford
Dr Bernadette Brennan	Paediatric Oncologist	Manchester
Dr Angela Jesudason	Paediatric Oncologist	Edinburgh
Dr Malee Fernando	Pathologist	Sheffield
Professor Nischalan Pillay	Pathologist	London
Professor Sue Burchill	Scientist	Radiologist
Dr Paul Huang	Scientist	London
Mr Piers Gaunt	Statistician	Birmingham
Mr Anant Desai	Surgeon	Birmingham
Mr Craig Gerrand	Surgeon	Newcastle
Mr Jonathan Gregory	Surgeon	Manchester
Professor Lee Jeys (Chair)	Surgeon	Birmingham

* denotes trainee member

Membership of the Subgroups

Bone Tumour Subgroup		
Name	**Specialism**	**Location**
Dr Fiona Cowie	Clinical Oncologist	Glasgow
Mrs Kelle Vernon	Consumer	Birmingham
Dr Sandra Strauss	Medical Oncologist	London
Professor Jeremy Whelan	Medical Oncologist	London
Dr Bruce Morland	Paediatric Medical Oncologist	Birmingham
Professor Bernadette Brennan	Paediatric Oncologist	Manchester
Professor Donald Salter	Pathologist	Edinburgh
Professor Sue Burchill	Scientist	Leeds
Mr Matthew Sydes	Statistician	London
Professor Keith Wheatley	Statistician	Birmingham
Mr Craig Gerrand (Chair)	Surgeon	Newcastle
Mr Kenneth Rankin	Surgeon	Newcastle

Young Onset Soft Tissue Sarcoma Subgroup		
Name	**Specialism**	**Location**
Dr Henry Mandeville	Clinical Oncologist	London
Dr Aisha Miah	Clinical Oncologist	London
Dr Palma Dileo	Medical Oncologist	London
Dr Katherine Cooper*	Paediatric Oncologist	Liverpool
Dr Julia Chisholm	Paediatric Medical Oncologist	London
Dr Maddi Adams**	Paediatric Oncologist	Cardiff
Professor Bernadette Brennan (Chair)	Paediatric Oncologist	Manchester
Dr Merial Jenney	Paediatric Oncologist	Cardiff
Dr Jennifer Turnbull**	Paediatric Registrar	Oxford
Dr Anna Kelsey	Pathologist	Manchester
Mr Ross Craigie	Surgeon	Manchester
Mr Tim Rogers	Surgeon	Bristol
Dr Janet Shipley	Translational Scientist	London

* denotes trainee member

**denotes non-core member

Appendix 2

Group & Subgroup Strategies

A – Sarcoma Group Strategy

Sarcoma CSG Strategy: May 2016 – May 2018

This strategy timeline has been produced to define the Sarcoma Research Strategy Plan and its implementation and will be reviewed and updated at each CSG meeting (NB supported by All)
The document is composed of the following:

Page 2 – 6: NCRI Sarcoma CSG Strategy: plan of implementation, containing agreed strategic objectives (1-6), specific actions, CSG leads and proposed deadlines.

Sarcoma CSG Members		Responsibility
LJ	Lee Jeys	CSG chair
BB	Bernadette Brennan	Young Onset Soft Tissue Sarcoma Subgroup Chair
CG	Craig Gerrand	Bone Sarcoma Subgroup Chair
RB	Ramesh Bulusu	Clinical Oncology
AM	Aisha Miah	Clinical Oncology
BS	Beatrice Seddon	Clinical Oncology
PW	Paula Wilson	Clinical Oncology
MM	Michael Maguire	Consumer representative
RD	Ray Davis	Consumer representative
MF	Malee Fernando	Histopathology
CB	Charlotte Benson	Medical Oncology
HH	Helen Hatcher	Medical Oncology
SP	Sarah Pratap	Medical Oncology
SS	Sandra Strauss	Medical Oncology / NCRAS Chair
JW	Jeremy Whelan	Medical Oncology
JM	Jane Margetts	Medical Oncology
AE	Angela Edgar	Paediatric Oncology / TYA Chair
RBo	Rajesh Botchu	Radiology
RW	Roger Wilson	Sarcoma Charity / Comsumer Representative
SF	Sharon Fortsyth	Trial Co-ordinator
PG	Piers Gaunt	Statistical Lead
JG	Jonathan Gregory	Surgery / SPED CSG
JS	Jonathan Stevenson	Surgery
MW	Mary Wells	Psychosocial CSG
SA	Sam Ahmedzai	Supportive and Palliative Care CSG Chair
DH	Dominque Heymann	Sarcoma Basic Scientist
UV	Ulla Ventham	PA
NK	Nicola Keat	NCRI Exec

Strategic objective	Action	CSG Lead	Date	Outcomes
1a. Portfolio development (general)	Establish a set of priorities for the development and set up of studies that takes account of the NIHR portfolio, international agenda, available funding opportunities and clinical need	ALL	Document key priorities at Strategy Day 5th May 2016 Review Dec 2016	Review Portfolio priorities 6-monthly at CSG meetings
1b. Portfolio development – Advanced disease	Develop a new portfolio study of advanced disease. New study proposed to include all patients with bone and soft tissue sarcoma with a new presentation of metastatic disease. Aim of study is to investigate current treatment with goal to improve quality of life for advanced disease in a longitudinal cohort study with randomisation of local control options, utilising innovative study design . Study to include :- • Supportive care studies with QOL outcomes • Transitional studies with molecular biomarkers • Local control randomisation • Interaction with CRN subspecialty leads • Cross cutting with other CSGs	AM, JW, SS, SA	Identified at Strategy Day 5th May 2016 Progress review 6 monthly at CSG meetings	Working group to develop study / initial feasibility study/ application for programme grant/ leads to fill gaps in portfolio/ leads to engage with other CSGs.
1c. Portfolio development Osteosarcoma	Develop a new portfolio study of osteosarcoma following the hiatus left by a lack of follow up study to EURAMOS. The lack of a new drug has hampered a follow up study, however, many questions remain. Aim of study is recruit all new patients with osteosarcoma in UK. Study to include :- • Molecular biomarkers which predict outcome • Validation of novel classification of surgical margins • Imaging predictors of response to therapy pre-operatively • Randomisation of induction chemotherapy MiniMap vs AB • Interaction with CRN subspecialty leads • Cross cutting with other CSGs • QOL outcomes for patients	BB, SS, AE, SP, RBo, LJ, PG	Identified at Strategy Day 5th May 2016 Progress review 6 monthly at CSG meetings	Working group to develop study / initial feasibility study/ application for programme grant/ leads to fill gaps in portfolio/ leads to engage with other CSGs.
1d. Portfolio development Chondrosarcoma	Develop a new portfolio study of chondrosarcoma. Chondrosarcoma is now most common primary bone sarcoma in UK and has no studies on the portfolio. Aim of study is to recruit all patients presenting to bone sarcoma treating centres with benign or malignant cartilage tumours into longitudinal cohort study with randomisation of local control options for low grade cartilage tumours. Study to include :- • Biobank of cartilage tumours for future research • Investigation of molecular biomarkers (IDH 1 /2 mutation ratio) • Radiological studies of aggressive behaviour (fMRI) • Randomisation local control options for low grade tumours • Ability to include new drugs from on-going Phase 1/11 studies	LJ, JG, JS, CG, Rbo, PG, DH	Identified at Strategy Day 5th May 2016 Progress review 6 monthly at CSG meetings	Working group to develop study from 5 primary bone centres / initial feasibility study with bone sarcoma charity/ application for programme grant/ leads to fill gaps in portfolio/ leads to engage with other CSGs.

Strategic objective	Action	CSG Lead	Date	Outcomes
1e. Portfolio development – Follow up	Develop a new portfolio study to identify optimal methods of follow up of sarcoma patients following treatment, leading to risk stratification and personalised treatment plans. Current methods of post treatment surveillance is variable. Given the large geographic distances travelled to follow up clinics, novel methods of follow up may have benefit. Currently all types of sarcoma are followed up in a similar schedule, risk stratification may allow personalised regimes. Aim of study would be to recruit all new patients with sarcoma in UK to a follow up study. Study to include:- • Molecular & genetic biomarkers of outcome for sarcoma types • PPI involvement of preferences to follow up • Rationalisation of Imaging efficacy in detection of advanced disease • Cost benefit analysis of follow up methods • Novel methods of follow up strategies (distance, nurse led) • QOL outcomes for cancer survivors	JG, BS, CG, MW, RW, RD, MM, PG, FM,	Identified at Strategy Day Day 5th May 2016 Progress review 6 monthly at CSG meetings	Working group to develop study / initial feasibility study/ application for programme grant/ leads to fill gaps in portfolio/ leads to engage with other CSGs.
1f. Portfolio development – Surgical wounds	Continue to develop a surgical study (Whispar) which is a randomised trial of surgical dressings for soft tissue sarcoma wounds. The study randomises between traditional occlusive dressings and topical negative pressure dressings. Initial pilot study has been undertaken winning a prize at the British Sarcoma Group meeting 2016. Aims to recruit patients undergoing surgery for soft tissue sarcomas at units across UK.	JG & WHISPaR study group	Identified at surgical studies meeting 2014 Progress review 6 monthly at CSG meetings	Working group to apply for an RfPB or HTA grant / leads to fill gaps in portfolio
1g. Interaction with international research groups	Identify leads within the CSG to link with the following research groups: EORTC COG euroSARC Conticanet	LJ	May 2016	To keep under review at 6 monthly CSG meeting
1h. Interaction with Cross Cutting groups	Identify leads within the CSG to link with the following cross cutting CSGs and advisory groups: •Primary Care CSG •Biomarker Advisory group •Screening, Prevention and Early Diagnosis (SPED) Advisory Group •CTRAD •Supportive and Palliative Care CSG	LJ	May 2016	To keep under review at 6 monthly CSG meeting

Strategic objective	Action	CSG Lead	Date	Outcomes
1i. National Cancer Registration and Analysis Service (NCRAS)	Establish clear link with Sarcoma Clinical Reference Group Maintain clear links with NCIN the use of data to inform study design and take over long term follow-up	SS / ALL	Report 6 monthly at CSG meeting	NCRAS to have standing item on 6 monthly CSG meetings
2. Key research priority areas	**Surgery** • Increase number of surgical trials within portfolio • Set up a surgical studies subgroup to stimulate research ideas • Local control for chondrosarcoma • Prospective evaluation of surgical margins for osteosarcoma **Osteosarcoma / Chondrosarcoma:** • Establish further trials for these tumour types **Advanced disease :** • Establish further studies for metastatic disease **QOL / Follow up:** • Embed QOL questions into all sarcoma studies • Establish further studies for post treatment surveillance • Embed supportive care studies into future protocols **Translational:** •Work with key clinical and scientific groups to develop embed translational questions into all studies and build translational research platform	LJ JG LJ BB/LJ BB/LJ AM MW JG SA All	May 2016 May 2016 May 2016 May 2016 On-going	Outline proposals to CSG DEC 16 update on progress 6 monthly CSG meeting s
3a. Raising awareness and profile	Regular dissemination of study recruitment activity and outcomes through newsletters, annual meetings and Annual Report and submission of meeting abstracts Communications about new studies with CRN subspecialty leads Engage with sarcoma charities to promote NCRI work during Sarcoma awareness week Have regular NCRI sessions at sarcoma national meetings (BSG, BOOS)	LJ/All UV/All RW/All LJ/All	On-going 2016 2016 On-going	LJ to feedback Participate in future NCRI Subspecialty leads / CSG meetings Discuss next CSG meeting Dec 2016

Strategic objective	Action	CSG Lead	Date	Outcomes
3b. Ensuring successful delivery of studies through integration with NIHR CRN: Cancer	• CSG members to commit to delivering studies developed by the CSG • Interaction with LCRN Subspecialty Leads to determine placement of new studies and address barriers to actively recruiting patients • Monitor recruitment to portfolio studies, esp those developed by the CSG to ensure delivery to time and target • Contribute as far as possible to NIHR CRN: Cancer Speciality Objectives so they reflect what LCRNs need to deliver to ensure lung cancer patients can access the full portfolio of studies within UK	ALL ALL ALL ALL	On-going On-going On-going On-going	Recruit CSG-led studies to time and target Good regional placement of studies Meet NIHR CRN Speciality Objectives
3c. Maximise output from clinical trials	• Establish working groups for new studies within 6 weeks of funding award to facilitate swift set up, including representation from CI, CRCTU, NIHR CRN: Cancer • Ensure Translational, QOL & supportive questions embedded into all studies opened • Design studies which aim to recruit as many sarcoma patients as possible by asking multiple questions within same study	CI/CTUs All All	On-going	Update at six monthly CSG meetings
4. Strengthen UK wide and international working	Refine prioritisation process for international clinical trials to be submitted for funding to optimise the timing and success of applications Identify UK selling points for sarcoma research to identify and promote the flagships studies on the portfolio Work to badge academically sponsored NCRI CSG studies as 'NCRI study into x' Work to ensure research remains core to NHS service and is recognised in all job plans .	All All All	On-going On-going May 2016 May 2016	Update at six monthly CSG meetings

Strategic objective	Action	CSG Lead	Date	Outcomes
5. CSG structure and function	Establish Surgical Studies subgroup	JG/CG/LJ	May 2016	Establish appropriate representation at CSG meetings to foster research ideas and new studies Diversify portfolio studies to include areas of unmet need
	Working Party for new study proposals from strategy day	LJ/JG/BB/AM	May 2016	
	Diversify membership of CSG to include Basic scientist, Psychosocial, Specialist nursing experience in membership to reflect need for portfolio studies in these areas.	LJ/NK	May 2016	
	Regular invitation to attend CSG from other relevant CSGs, NCRAS and Advisory Groups depending on agenda items & proposals	LJ/NK/UV	May 2016	
	Identify mentors for future trainee registrars in the CSG / subgroups	LJ	May 2016	
	Identify mentors for new PPI members in CSG / subgroups	LJ	May 2016	
6. Patient and Public Involvement and Impact	Ensure consumers remain associated with the development of every new study at an early stage	All	On-going	Ensure studies have relevance to consumers through CSG meeting / reports
	Consider developing research studies to address key questions of concern to PPI representatives and other consumers	MM/RD to bring questions to the group	On-going	

B – Bone Tumour Subgroup Strategy

Strategic priorities

1. To develop and deliver a study in chondrosarcoma.
2. To develop and deliver a study in osteosarcoma.
3. To support the delivery of studies in Ewings sarcoma.
4. To promote national collaboration in the development and delivery of studies.

Progress against priorities

1. A study of IDH1/2 mutations in the serum of chondrosarcoma patients has been funded and will open this year.
2. A proposal for funding of a large umbrella study in osteosarcoma is being developed with a view to a submission to BCRT later this year.
3. Recruitment to EE2012, REECUR and related studies has been supported by the Subgroup. Adoption to the portfolio has increased the opportunity to recruit to the GenoEwings and Predict studies.
4. The Subgroup is able to engage with a larger number of members increasing its national reach thanks to BCRT funding. All studies under development are either multicentre or will become so, including the chondrosarcoma study, the osteosarcoma study in development and the Sarcoma PROMS study.

C – Young Onset Soft-tissue Sarcoma Subgroup Strategy

The group recognises the continuing challenges:

• To increase participation of the TYA population in trials, indeed extending all our trials and research to the adult age group.

• The necessity for stable international consortia to develop trials where patient numbers in the UK are small.

• Obtaining access to new agents from pharma companies for younger patients, and indeed in sarcomas.

• Funding the parallel biological studies in international trials

Agreed strategic priorities for YOSS:

1. To open a first line study in Rhabdomyosarcoma across all ages in paediatric, TYA and adult sites in UK and indeed European countries who are part of the EpSSG

2. To build on current relapse studies in RMS using VIT as backbone- this strategic aim is incorporated into the FaR-RMS study

3. To develop an all age European study in specific soft tissue which occur in paediatric, TYA and adult age group e.g. Synovial Sarcoma, MPNST, leiomyosarcoma and liposarcoma.

4. To build on the outcomes of other rare sarcomas from the NRSTS study to develop further clinical trials specifically Rhabdoid tumours at all anatomical sites.

5. To embed biological studies, biomarkers and novel targets into clinical trial portfolio

6. To open a prospective cohort study with a biological question that may be useful for all the NRSTS subtypes in particular those which mainly occur in the paediatric age group.

7. To increase the TYA population in sarcoma studies.

Planned implementation:

1. FaR-RMS: A multiarm-multistage study for children and adults with localised and metastatic Frontline and Relapsed RhabdoMyoSarcoma new study proposal has been funded by CRUK and will be opened by spring 2019.

2. See above

3. To develop an all age European study in specific soft tissue sarcomas. We have started to work in the UK first to open an all age STS study in view of the fact there was a negative outcome to the Olaratumab phase III study. We will lower the traditional age limit of 18 to include TYA and paediatric subjects.

4. To build on the outcomes of other rare sarcomas from the NRSTS study to develop further clinical trials (EURO RHABDOID 2017 study in planning).

5. To embed biological studies, biomarkers and novel targets into clinical trial portfolio. This will be achieved in FaR-RMS and EpSSG NRSTS 2018

6. To open a prospective cohort study with a biological question that may be useful for all the NRSTS subtypes. This will be achieved with EpSSG NRSTS 2019.

7. To increase the TYA population in sarcoma studies- this will be achieved by extending the upper age range for study entry

Appendix 3 - Portfolio maps

NCRI Portfolio Maps

Sarcoma

Map A – Soft tissue

ê below to reset map

		a) Primary treatment	b) 1st line advanced	c) 2nd line advanced/Palliative	d) Observational / translational
a) All soft tissue	All	IMRiS CANC 5271 PASART 2 patients with advanced solid	Pharmacokinetic ANITA (EORTC 1506)	APPLE SEAL Study: Selinexor in Advanced Liposarcoma	ISKS study TRuST characteristics of high grade soft Circulating tumour cells in soft tissue sarcoma
b) Gist	All	SSG XXII	BLU/285 CANC / 4893	Deciphera Pharmaceuticals DCC-2618-03-002 INTRIGUE	
c) rhabdo myosarc..	All	CANC 5271			
e) Kaposi's	All				Karposis Sarcom
f) Other	All		EORTC/1202/STBS GEMMK	EORTC/1202/STBS	n'blastoma & sts cells Developing and validating SAM QUEST Nirogacestat Versus Placebo with DTs/AF

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

Open / multi resea.. Suspended / singl..
In Setup / single re.. Open / single rese..

NCRI National Cancer Research Institute

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

Developed by **Mayden®** Analytics

NCRI Portfolio Maps

Sarcoma

Map B – Bone

ê below to reset map

		a) Primary treatment	b) 1st line advanced	c) 2nd line advanced	d) Observational / translational
All bone sarcoma	All	IMRiS			ISKS study Explant model HIFU - Bone Developing and validating SAM QUEST
Chondros arcoma	All		Afatinib in Chordoma	Afatinib in Chordoma	ctDNA and Cartilaginous tumours Understanding Chordoma: A National Cohort Study
Ewing's	All	Euro Ewing 2012 Pharmacokinetic	Euro Ewing 2012 Investigation of Antitumor Activity of INCB059872 in Ewing Sarcoma	rEECur ESPRIT ESP1/SARC025	Genotype and ph
Osteosarc oma	All				Functional Assessment of Bone Metastases 2 (FABB2)

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

Open / multi resea.. Suspended / singl..
In Setup / multi res.. Open / single rese..

Appendix 4

Top 5 publications in the reporting year

Trial name & publication reference	Impact of the trial	CSG involvement in the trial
1. Addition of dose-intensified doxorubicin to standard chemotherapy for rhabdomyosarcoma (EpSSG RMS 2005): a multicentre, open-label, randomised controlled, phase 3 trial. Bisogno G, Jenney M, Bergeron C, Gallego Melcón S, Ferrari A, Oberlin O, Carli M, Stevens M, Kelsey A, De Paoli A, Gaze MN, Martelli H, Devalck C, Merks JH, Ben-Arush M, Glosli H, Chisholm J, Orbach D, Minard-Colin V, De Salvo GL; European paediatric Soft tissue sarcoma Study Group.Lancet Oncol. 2018 Aug;19(8):1061-1071	This study demonstrates the ability to run prospective randomised paediatric studies in what is still a rare sarcoma RMS and included larger numbers of older patients in the TYA age group. Although the addition of doxorubicin did not contribute to the improvement in outcomes for those randomised to this arm, both arms in the first randomisation improved their EFS and OS by 10 %. The second randomisation from this study did have a positive result and hence changed practice so all patients now receive the experimental arm of maintenance chemotherapy	Members of the CSG were involved in the development of the EpSSG RMS study, recruited a significant number of patients, and co-wrote this paper from the data.
2. Jeremy Whelan, Marie-Cecile Le Deley, Uta Dirksen, Gw´ena¨el Le Teuff, Bernadette Brennan, et. al. High-Dose Chemotherapy and Blood Autologous Stem-Cell Rescue Compared With Standard Chemotherapy in Localized	The experimental arm demonstrated a benefit in outcomes for patients with high risk localised disease to receive HDT with Bu/Mel. This has now become a standard treatment and incorporated into current EE2012 trial	Members of the CSG were involved in the development of the EE99 study, recruited a significant number of patients, and co- wrote this paper from the data.

High-Risk Ewing Sarcoma: Results of Euro-E.W.I.N.G.99 and Ewing-2008. JCO 2018.36;		
3. Daniel Orbach, Bernadette Brennan, Gianni Bisogno et al. The EpSSG NRSTS 2005 treatment protocol for desmoid-type fibromatosis in children: an international prospective case series. THE LANCET CHILD ADOL 2017. 1;284-92	This established the practice of more conservative management of Desmiod tumours in the paediatric/TYA age group throughout Europe and indeed UK as the standard of care	Members of the CSG were involved in the development of the EpSSG NRSTS 2005 study, recruited a significant number of patients, and co-wrote this paper from the data.
4. Bas Vaarwerk, , Gianni Bisogno; Kieran McHugh et al. Indeterminate Pulmonary Nodules at Diagnosis in Rhabdomyosarcoma: Are They Clinically Significant? A Report From the European Paediatric Soft Tissue Sarcoma Study Group. J Clin Oncol 2019, 37:723-730	This study demonstrated for the first time, that indeterminate pulmonary nodules at diagnosis do not affect outcome in patients with otherwise localised RMS, and they should not be upstaged or receive extra therapy	Members of the CSG were involved in the development of the EpSSG RMS study, recruited a significant number of patients, and co-wrote this paper from the data.
6. Pasquali S, Pizzamiglio S, Touati N, Litiere S, Marreaud S, Kasper B, Gelderblom H, Stacchiotti S, Judson I, Dei Tos AP, Verderio P, Casali PG, Woll PJ, Gronchi ; EORTC – Soft Tissue and Bone Sarcoma	Patients of the EORTC-STBSG 62931 RCT with extremity and trunk wall STS and a low predicted pr-OS (high-risk patients) had better outcomes when treated with adjuvant chemotherapy. This may help reconcile the	Members of the CSG were involved in the development of the EORTC-STBSG 62931 RCT study, recruited a significant number of patients, and co-wrote this paper from the data.

Group. The impact of chemotherapy on survival of patients with extremity and trunk wall soft tissue sarcoma: revisiting the results of the EORTC-STBSG 62931 randomised trial. Eur J Cancer. 2019 Mar;109:51-60	disparate results of clinical studies on adjuvant/neoadjuvant chemotherapy in STS.	

Appendix 5

Recruitment to the NIHR portfolio in the reporting year

In the NCRI Sarcoma Group portfolio, 6 trials closed to recruitment and 9 opened.

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
2014/2015	145	115	145	115	-	-
2015/2016	58	130	58	130	-	-
2016/2017	208	206	184	206	-	-
2017/2018	360	223	346	223	-	-
2018/2019	569	154	569	154	14.88	4.03

Appendix 6

Feedback from the Quinquennial Review Panel

The panel thanked the Sarcoma CSG for the documentation provided and the openness with which they had engaged in discussions.

The Panel identified a number of strengths of the Group and issues that the CSG needs to consider:

Strengths

- The Panel was impressed with the content of the report and the demeanour of the CSG.
- Impressive standing in the international community.
- The Panel congratulated the Group on the significant progression of their strategy, developed in 2016, notably the shift in focus away from drug trials.
- The Group was commended on their positive response and attitude to feedback from the previous QQR and annual reports.
- The number of different specialities within the Group, in particular the Bone Subgroup, was described as a great asset to the group.
- The Group was congratulated on the scale of their involvement in the 100,000 Genomes Project in relation to their patient population.

Issues for the CSG to consider

- The Group needs to define their strategy on interacting with the TYA & GCT CSG to ensure that the TYA age group is successfully incorporated and recruited into sarcoma studies.
- Given the relatively small sarcoma community, the Panel stressed the importance of engaging with the next generation of sarcoma clinicians, and suggested having trainees on trials as 'deputy CI's' to encourage research engagement and inspire the next generation.
- The significance of having sarcoma patients as consumer members on the Group was highlighted. It was suggested that the Group should interact more with site-specific charities like Sarcoma UK and BCRT to engage the patient community.
- The Panel suggested that the Group should take a more ambitious approach to integrate translational research into their strategy, perhaps in the form of adding sarcoma studies into other bucket trials.
- The Groups lack of work in surgery was highlighted. Contact with Richard Shaw was suggested to further work in this area.
- The Group was encouraged to contact Professor Hisham Mehanna to discuss his ongoing work in elderly patients and the possibility of future collaboration. It was also suggested that the Group consider developing an overarching study in elderly patients, for example 'chemotherapy in the elderly', and approach other CSGs to develop a themed call.
- The Group was asked to update the strategy document to clarify the strategy on surgery and local control.
- The Panel suggested that the Group should engage more with other funders outside of Sarcoma UK and BCRT, and look to create a diverse funding portfolio.

Issues for the NCRI/NIHR CRN to consider

- The NCRI Executive will approve a Soft Tissue Sarcoma Subgroup as this was deemed more appropriate than a Working Party due to the large proportion of patients this group represents.
- The NCRI Executive will engage with Sarcoma UK and other suitable organisations to encourage sarcoma patients to apply for consumer positions on the CSG.
- The NIHR CRN will look into creating a fully open data platform to allow for easy access to recruitment data.

In concluding the Review, Professor Seymour thanked everybody for participating and the NCRI CSG Team for preparing the paperwork and organising the Review.

The business of the meeting took four hours. ***The Group will be reviewed in five years' time.***