

East Midlands Sarcoma Expert Clinical Advisory Group (ECAG)

ANNUAL REPORT

April 2016 – March 2017

Name: Mr Robert U Ashford MD FRCS (Tr. & Orth.), Consultant Orthopaedic & Musculoskeletal Tumour Surgeon, University Hospitals Leicester NHS Trust

ECAG Lead – East Midlands Sarcoma ECAG

East Midlands Clinical Network

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Annual Report

1.0 Introduction

This annual report relates to the operational period April 2016 to March 2017.

Number of meetings held: 1 (29/04/2016)

Membership

- The Group membership remains appropriate and in line with EMCN and Quality Surveillance (Peer Review) requirements
- Deputy lead, audit, education and research leads & NCRN speciality Clinical Lead posts are filled
- Deputy Chair in place, with plan for handover slowly evolving
- Attendance remains difficult because of clashing commitments, particularly for oncologists who have the requirement to attend multiple ECAGs in limited SPA time
- The Group no longer has a strong link with the national CRG. Due to recent restructuring of CRG's, NHS England has only one Sarcoma member in the Specialised Cancer Surgery (B03) CRG
- A SAG Chairs Forum has been established in an attempt to strengthen working between SAGs. Two meetings have occurred and been attended by Nicola Wilshaw & Dr Ivo Hennig

2.0 Key Achievements

Reducing variation

- Ongoing engagement of group in key issues facing sarcoma
- Identification of key barriers to improvement in care
- East Midlands Sarcoma Service (EMSS) database established & ongoing
- Referapatient.org funding for 1 year secured to try to improve access for retro-peritoneal Sarcoma patients
- Funding secured to appoint a Regional Sarcoma Co-ordinator

Pathway Issues

- NUH working group established to improve the patient experience & flow under the chair of Miss Raurell.

Research

- There is a drive from within the ECAG and the EMSS for research projects. Most are currently outcome based
- An EMSS multicentre study based at Leicester and Nottingham is open and recruiting on genetic soft tissue sarcoma (Telomere Study)
- Research projects:
 - Open & Recruiting:
 - Telomere lengthening in STS
 - 100,000 Genome Project
 - IMRiS
 - Approved for recruitment:
 - Functional outcome in STS (Approved UHL/ awaiting NUH)
 - Awaiting R & I Approval:

- Sarcoma PROMS
- Portfolio trial recruitment between 01/04/2016 and 31/03/2017 was as follows:

| | Total |
|--|-----------|
| Euro Ewing 2012 | 4 |
| rEECur | 2 |
| Genetic and telomere characteristics of high grade soft tissue sarcoma | 16 |
| IMRiS | 4 |
| Total | 26 |

3.0 Challenges

Reducing variation

- There is good access to expertise given the centralisation of the Sarcoma Service with diagnostics in Leicester and Nottingham and surgical treatment in Nottingham, however the services remain under pressure in terms of diagnostics and outpatients
- Two site pathology services presents issues in terms of access to reports at both centres and long term data capture

Service is under pressure

- The service's retroperitoneal surgeon is currently on maternity leave however, there is an interim plan in place
- The incidence of soft tissue sarcoma two-week wait referrals are continuing to increase

Resources need to be identified for:

- accurate data capture and submission
- development of a designated Desmoid Clinic

Data

- The accuracy of sarcoma service data submitted by NUH as host trust is at best poor with submitted overall numbers of treated patients considerably fewer than the actual number.
- The EMSS database now provides accurate contemporaneous numbers – work with the NUH Cancer Centre is ongoing to ensure correct data submission
- Having a full time Regional Sarcoma Co-ordinator for 2017/18 should help with data accuracy

4.0 Group Priorities/ Work Programme 2017/18

- To improve data capture
- To identify areas of need in terms of resources
- To develop the Desmoid Fibromatosis Clinic and Registry
- To work with the Sarcoma Chairs Forum and Clinical Reference Group particularly in terms of communication
- To support research both locally and nationally
- To agree local pathways for rapid and accurate diagnosis, staging and treatment

- To improve communications with the CCGs
- To analyse network radical treatment rates
- To perform local patient experience surveys
- To support education

5.0 Recommendations

- A national lead commissioner should be identified for sarcoma and perhaps for rare cancers in general
- It is essential that the quality of data available and provided by the host trust improves dramatically - the submitted data from NUH regarding the Sarcoma Service at present bears no resemblance to actual work done

6.0 Quality Surveillance (Peer Review)

The group QS measures have been reviewed by the group.

7.0 Education

An education day is planned for the 9 November 2017 to correspond with the business meeting.