First Draft

Meeting of the Sickle Cell Society, London Ambulance Service and the Patients Forum -LAS

Date: May 19th 2014

Attended by: Ann Radmore (CE-LAS), Dr Fionna Moore (Medical Director-LAS), Steve Lennox (Director of Nursing and Quality-LAS), John James (Sickle Cell Society-CE), Patrick Ojeer (Sickle Cell Society), Malcolm Alexander (Chair-Patient's Forum – LAS).

Ann Radmore welcomed colleagues to the meeting and expressed the wish that the meeting would help restore effective working relationships between the Sickle Cell Society and the LAS. Ann expressed regret that the constructive relationship between the LAS and SCS which had been developing 2 years ago had been undermined by lapses in communications.

1) The death of Sarah Mulanga

It was noted that the tragic death of SM, which was initially believed to be associated with a sickle cell crisis was later determined to be associated with other causes including a viral illness. The paramedics concerned with SM's initial care were found to be a fault by providing inadequate care and have since left the LAS.

2) a) Clinical Practice Guidelines - JRCALC

Noted that the JRCALC Project team is chaired by Dr Simon Brown, and has produced new guidelines in 2013, which include a section on the care of patients with a SC crisis, which update the 2009 guidlines. Fionna said that she and Dr Tullie Yeghen, Consultant Haematologist , from St Thomas/Lewisham have advised on the revision. Fionna said that advice from the SCS had contributed to the latest guidelines and agreed to provide the SCS with a copy of the latest version. Fionna said that she would be happy to work with the SCS to progress any further revisions of the Clinical Practice Guidelines. She said there was no specific history of public involvement in the work of JRCALC.

b) Collaboration between the LAS and SCS

John James welcomed this offer of collaboration and described the work recently undertaken by the SCS with NICE to produce new guidelines for sickle cell crises, which will ultimately become part of the Clinical Practice Guidelines. He added that the SCS worked closely with people with SCD, their families and clinicians and was therefore in a good place to advise on the care of people in SC crisis and on pain control. Fionna agreed to seek the society's advice on any future guidance.

3) Parent's Perspective

a) Patrick Ojeer said that as a parent of a young person with SCD, he found care and treatment provided by the LAS to be very variable and not systematic, and what was provided varied a great deal with which pre-hospital ambulance team was providing care. Patrick drew attention to the need to respond as quickly as possible to patients in SC crisis. He said that people in crisis will only call an ambulance as the last resort, so correct call categorisation was essential.

b) Fionna said that the quality of treatment provided might get better if the patient has their own written care plan, which paramedics could use to provide the most appropriate care, pain control and transfer to the most appropriate hospital. She added that current advice on pain control is to give subcutanious morphine and oral paracetemol. Fionna said that by 2016, all LAS front line vehicles will have a paramedic who can dispense morphine. She agreed that getting call categorisation right for the level of severity in a SC crisis was very important. She agree to share the 'LAS Conveyance of Patient Policy' with the SCS for their opinion.

4) Thalassaemia

In response to a question about the care of people with Thalassaemia, John James confirmed that the SCS had a close relationship with the UK Thalassaemia Society. He emphasized the importance of distinguishing between sickle cell disorders and thalassaemia.

5) It was agreed to:

a) Seek feedback from patients and patient stories who have sufferend a crisis and received LAS care.

b) Explore the use of written 'advance care plans' re pain control, clinical history and choice of hospital. It was acknowledged that the 'Coordinate My Care' system would not be available for sickle cell patients for some time. (refer to Julia Riley, Marsden Hospital).

c) Invite the SCS to contribute to the new LAS PPI strategy.

d) Invite the SCS to contribute to the development of any guidelines and policies regarding the care of people with a sickle crisis and their pain control. LAS agreed to forward JRCALC and patient conveyance policies for feedback from SCS

e) The SCS will brief Thalassaemia UK on the developing relationship with the LAS and seek to include them.

f) Look in more detail at the 999 response to patients in relation to the severity of their SC crisis.

Steve Lennox agreed to monitor progress to ensure that the SCS can establish an effective relationship with the LAS, with improved learning and enhanced clinical outcomes as the key objective.

End