**From:** Kye Gbangbola, Chair, Sickle Cell Society

**Sent:** Thursday, November 12, 2015 3:05 PM

**Subject:** Sickle Cell Society and LAS - Re-Launch Relationship

To: Dr Fenella Wrigley. Medical Director, LAS

Dear Fenella,

It was a pleasure meeting you at yesterday evenings LAS Forum Meeting, and may I thank Anne, Malcolm and yourself for the invitation to rekindle the relationship Steve Lennox wrote in his letter at the end of 2013.

May I take this opportunity to express how useful we at the Society found the meeting, it was apparent there was much that could inform the current LAS service delivery and CQUIN going forward.

We echo your sentiment that you need to hear from us and the people we serve, to which end I suggested the regular platform of dialogue proposed by Mr Hunt in the letter by Mr Lennox. To achieve such involvement and engagement to capture patient experiences we need to establish a regular platform to direct the change we all want to see.

You heard a range of issues yesterday, from those afraid and concerned that the incident they experienced could have cost them their lives, to those not receiving basic pain relief or transfer to the ambulance. The range of issues related to not receiving the care set in the guidance. Plus there were those people spoke of the stigma at being labeled a drug addict and being told the same. We also heard the good story’s especially in relation to children. We know all the sufferers present had concerns that are experienced across the Sickle Cell Community, their regular use of the service with this fluctuating disorder is a significant differentiator from other patient groups. It is for these reasons we at the Society reach out to help you identify, prioritise and then solve the issues to the benefit of an improved LAS.

The meeting was helpful in setting some actions including:

1     Asking for those presenting with SCD to have the same priority as those arriving by ambulance

2     Formulating quick brief of the latest guidelines for attendance categories, times, provision of pain relief, Oxygen, transfer into ambulance, delivery to preferred specialist Hospital/unit etc, plus the email address which takes complaints

3     The Society providing training support, especially with the projected increase of a third of your workforce, and also universities

4     Advance requests for a CQUIN

Complaints can be a constructive way to learn and change, and I thank you for raising it as no one knew the facility in 2 existed.

I look forward to hearing back. There is much we could do together under the banner ‘no decision about me without me’. Subject to your, Malcolm, and Anne’s thoughts perhaps the Society could attend the LAS Forum meetings; I do not know the meetings ‘Terms of Reference’ suffice to say well done for assembling such a committed group.

Best wishes,

Kye Gbangbola

Chairman – Sickle Cell Society