

**Minutes of the meeting held on**

**WEDNESDAY – NOVEMBER 11th 2015**

**ATTENDANCE: Forum Members**

Angela Cross-Durrant –Kingston - Vice Chair

Anthony John - Tower Hamlets

Arif Mehmood - Newham

Blessing Makanjuola

Catherine Gustaffe - Southwark

Christine Kenworthy – Kent

Colin Hill - Berkshire

Dave Payne – Southwark

Graeme Crawford – Healthwatch Ealing

Harbhajan Singh – Elderly Watch, Bexley and Greenwich

Inez Taylor – Southwark

Jacqui Fergusson – Barnet

Janet Marriott – Richmond/Hounslow

Jennifer Ogbata – Wandsworth Sickle Cell and Thalassaemia Group

John Larkin – Barnet – Company Secretary

Joseph Healy – Southwark - Forum President

Kathy West – Southwark

Louisa Roberts - Tower Hamlets

Lynn Strother – City of London HW and Forum Executive Committee

Malcolm Alexander – Forum Chair and Healthwatch Hackney

Maureen Patterson – Parent of children with sickle cell

Michael English – Healthwatch Lambeth

Rashid Ali Laher – Kingston Healthwatch

Robin Kenworthy – Kent

Sanora Abacchos – Southwark

Sheree Hall

Sister Josephine – Croydon – Vice Chair

Theresa Uwagboe

**SICKLE CELL SOCIETY:**

Kye Gbangbola, Chair of the SCS – Guest Speaker

Iyamide Thomas

Patrick Ojeer

June Okochi

**UK FORUM ON HEAMOGLOBIN DISORDERS:**

Dr Anne Yardumian, Chair

**LAS REPRESENTATIVES:**

Fionna Wrigley – Medical Director

Barry Hills

David Whitmore – Advisor to the Medical Director

Sally Easterbrook

M. Faulke

**LAS COMMISSIONERS:**

Stuart Ide

**NHS Trusts:**

Daniel Nyakutsey – Guy’s and St Thomas’

Liz Oden – King’s College Hospital

**APOLOGIES:**

Audrey Lucas – Healthwatch Enfield

Alhajie Alhussaine – Lambeth

Barry Silverman – Southwark

Carl Curtis –Southwark

Edith Okparaocha – Southwark

Gordon Kay – Healthwatch Croydon

Harbans Chahal - Redbridge

Kay Winn-Cannon – Healthwatch Waltham Forest

Margaret Luce - Head of Patient & Public Involvement

Mike Roberts – Hampshire Healthwatch

Natalie Teich – Healthwatch Islington

Pat Duke – Southwark

Viola Petrella, Healthwatch Newham

1. **MINUTES OF THE MEETING HELD OCTOBER 14TH 2015**

1.1 Minutes were agreed a correct record.

1. **MATTERS ARISING:**

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| **2.1** | **MEETING IN CROYDON REGARDING EMERGENCY CARE** | Forum to work jointly with Healthwatch Croydon to set up a community meeting to examine the problems with emergency care in Croydon. | Public meeting to be held on November 23rd. Sister Josephine and Malcolm Alexander to attend. |
| **2.2** | **PATIENTS WITH LEARNING DISABILITIES** | Members requested details of care provided by LAS to people with learning disabilities. PF to discuss with Zoe Packman, Dir of Quality and Nursing | Elizabeth Ogunoye requested to consider LAS CQUIN for improved care to patients with learning disabilities. Discuss with EO at next joint EC – EO meeting. |
| **2.3** | **STAFF SURVEY** | The staff survey results for 2014-5 were very poor and the new survey will be carried out in autumn 2015. | LAS asked for details of outcomes following action by the LAS to tackle the issues raised by staff.  Mark Gammage and Tony Crabtree. |
| **2.4** | **COMPLAINTS** | 1) Elizabeth Ogunoye reported that a ‘deep dive’ into complaints is taking place and the results will be presented to the Clinical Quality Review Group.  2) Could LAS produce more information about how to make complaints when patients have had poor care? | 1) Update requested from Gary Bassett and Elizabeth Ogunoye. Report awaited.  2) Raise this issue with Zoe Packman, Director of Quality and Nursing. Produce Forum leaflet for distribution to service users. |
| **2.5** | **MEMBERS SURVEY** | Natalie Teich has analysed results. | Response being prepared to members proposals and will be presented to December Forum. |
| **2.6** | **LAS PERFORMANCE – CQUINS (Commissioning for quality and innovation)** | Forum requested details of service improvements consequent upon the implementation of CQUINS, i.e. so that we can see how patient care is improving. | Review of progress at the end of Q3 (Oct-Dec), when the CQUINS have been up and running a while. Discuss new CQUINS for 2016-7 at Dec meeting. Forum proposals include sickle cell care and care of people with learning disabilities. |
| **2.7** | **FAITH SUPPORT FOR FRONT LINE STAFF AND ADVICE REGARDING RESPECTING THE FAITH OF PATIENTS** | Tony Crabtree leading work on developing multi-faith arrangements for supporting staff.  2) Recommend that Harbhajan Singh be invited to become a lay faith adviser on the LAS Equality and Inclusion Committee. | Equality and Inclusion now in Tony Crabtree’s team. Awaiting response from Tony re multi-faith support and Faith Adviser for the LAS. |
| **2.8** | **FORUM MEETING 2015** | Invite Dr Onkar Sahota, Chair of London Assembly Health Committee to December meeting at City Hall. | Dr Onkar Sahota, London Assembly, has agreed but no room available therefore transfer meeting to February 8th 2016 |
| **2.9** | **BARIATRIC CARE** | Concerns about care of bariatric patients. Questions to LAS:  Does LAS have adequate and appropriate ambulances in the fleet to provide the right care for bariatric patients? Is there specific and sufficient training re care and treatment of bariatric patients? | Zoe Packman asked to review complaint about bariatric care.  Forum to seek more information about care provided from patients who have used service.  Issue highlighted in the CQC report. |
| **2.10** | **SICKLE CELL DISEASE** | Joint meeting with the SCS and haematologists to be held in November. Invite clinical and operational staff from the LAS. LAS Medical Director and Deputy Director of Quality and Nursing will attend. | Report from Forum meeting to follow. |
| **2.11** | **CQC INSPECTION OF THE LAS** | CQC Quality Summit to examine the draft report on the LAS expected to take place in late November 2015. | Meeting held on December 2nd 2015 |
| **2.12** | **DEFIBRILLATORS** | Forum meeting with Mayor of Southwark and Southwark Diocese of the Catholic Church. | a) Update requested from Dora Dixon Fyle and the Southwark Diocese.  b) Agreed to raise issue about VAT on defibs.  c)Fenella reported on significant progress with installation of defibs in London and development of  d) Good Sam App being introduced to enable lay people and ambulances to respond better to cardiac arrest.  e) Promote defibs and training in local schools. |
| **2.13** | **EQUALITY AND INCLUSION COMMITTEE-LAS** | Kathy reported on the continuing failure of the Committee to consider the needs of people included within the scope of most protected categories of the Equalities Act. Kathy and Malcolm would prepare a report on the failure of the LAS to address equality and inclusion issues. Questions were put to July LAS Board meeting. | Discussed with Fionna Moore, Zoe Packman and Tony Crabtree. Agreed to share Forum’s report before publication. |
| **2.14** | **HANDOVER WAITS AT A&E** | a) Seek meeting with NHS England to discuss action to stop unacceptable waits.  b) FOIs to all trust and CCGs with one hour plus waits requesting a copy of their Serious Incidents investigations into these waits. Request sent to Northwick Park. | a) Letter sent to Prof Keith Willett, NHS England, re long wait for patients in ambulances outside A&E departments.  Response to Forum’s FOI to Northwick Park Hospital received and information being analysed before further action. |

2.14 Equality and Diversity: Agreed that it is essential for the LAS to promote careers in the LAS through active strategic engagement with six- forms in schools. Raise with Margaret Luce and Tony Crabtree.

2.15 Bursaries for paramedics: Noted that this issue is being actively pursued by the LAS commissioners and Health Education England.

2.16 Extended waits for ambulances: Noted that early November 2015 had been a particularly bad week for extended waits for ambulance. See data below.



A8 target = 75% in 8 minutes C1 target = 90% in 20 minutes

**3.0 SERVICES FOR PATIENTS WITH SICKLE CELL**

**3.1** Kye Gbangbola, Chair of the sickle cell society, described sickle cell as an autosomal genetic blood disorder, which can cause severe and debilitating pain when an affected person suffers a crisis. He said that the WHO describes SC as the most common genetic blood disorder and one of the most common illnesses alongside malaria and HIV. He said that according to the NHS Screening Programme 1:680 white British newborns carry the Sickle Cell gene, whilst it affects 1 in 7 Black Africans, 1 in 8 Black Caribbean's

Kye said that there are 15,000 people in the UK with SC and the work of the SCS involved providing assistance, support, information, training, advocacy, engagement and involvement. This includes work with people with SC who are in prison. The SCS also has regional workers, e.g. Iyamide Thomas who is the Regional Care Advisor for South London.

3.2 Dr Anne Yardumian, Chair, UK Forum on Haemoglobin Disorders, said that of the 15,000 people in London with SC, 80% live in London. She said the condition is variable, that the person may or may not suffer pain, and that most pain relief is dealt with at home – not in hospital. She said that people are reluctant to call an ambulance when they are in pain and cope at home if they possibly can. Although some people do call ambulances frequently, they tend to be people with co-morbidities (additional illnesses). Most SC patients who receive care from ambulance services are in an extreme situation, find crews sympathetic, supportive and helpful, and are very grateful for the care they receive. However, in some cases ambulance crew do not show a sufficient sense of urgency, and may not pick up symptoms of stroke which can occur with SC.

Anne said that it is important for the crew and patients to know what to expect when an ambulance is called, e.g. what type of treatment is most effective, which hospital usually provides care, what to expect and what to do when they is considerable pressure on the LAS. She added that patient’s expectations are sometimes not met and that this can be a problem.

**3.3 Contributions from people attending meeting:**

**3.4 Blessing Makanjuola** said that in her experience getting crew to take you to the correct hospital can be a problem. Also getting the right pain relief, dealing with breathing problems, being listened to and the transfer from home to the ambulance can all be problems if you are in a crisis.

**3.5 Jennifer Ogbata** from the Wandsworth Sickle Cell and Thalassaemia Group said many people in a crisis have positive experiences, but the problems areas are as follows:

* Time taken for the ambulance to respond to a 999 call
* Ensuring a reasonable waiting time for a person in significant pain
* Improving pain management
* Being treated as if you don’t need pain control
* Taken to the wrong hospital - not where you are usually treated
* Being taken to a hospital well outside your residential area
* Nerve wracking experiences when things go wrong.

**3.6 Jacqui Fergusson** said she has two sons with SC who are now over 18 years of age. She said that training and knowledge of SC for ambulance crew is paramount. In her experience 9/10 of experiences of the LAS were negative. The experiences included:

* Refusing to provide appropriate clinical care to her sons
* Lacking understanding of the seriousness of a sickle cell crisis
* Suggesting her sons wanted drugs, rather than treatment for pain
* Providing half a vial of pain killer instead of the full vial on the assumption that the pain was not the main issue

3.7 A contributor said that she has had no sickle cell crisis for three years, but on December 27th 2011 she went into SC crisis and suffered from difficulty in breathing at 2am. She believed she was suffering from pneumonia, which can be a sign of a SC crisis. She couldn’t walk and her pain management was not working. She was in terrible pain. Her brother carried her down three flights of stairs to wait for the ambulance but it did not arrive. Her brother therefore called a taxi to get her to hospital and when she arrived she remained on a trolley for three hours. When her brother phoned LAS to cancel the ambulance he was told that ‘he had no right to call an ambulance and then to cancel it’. She said that the failure of the LAS to appropriately prioritise her needs and provide adequate care could have cost her life.

3.8 Dr Fenella Wrigley responded to the statements made by contributors to the meeting. She said that she is an A&E consultant at the Royal London Hospital and had considerable experience of treating people in a sickle cell crisis.

**Dr Wrigley made a public apology to those who described poor experiences of SC treatment by the LAS. She said the LAS would listen and take forward any issues which would help to improve the service provided to people suffering from a SC crisis.**

Fenella described the situation from the LAS perspective. She said that the LAS receives 300-500 calls per hour and the LAS response is determined by the Ambulance Medical Priority Despatch System (AMPDS). She said that Cat A is used for people with a life threatened condition, whereas green calls (C1, C2, C3 and C4) are used for less severely ill patients. A sickle cell crisis would probably be categorised as C1 (should arrive within 20 minutes for 90% of calls). Fenella said that in some cases patients may describe their symptoms, but omit to say they have sickle cell, this is a problem because the AMPDS does not prioritise on the basis of the degree of pain experienced by the patient. It is important for the patient to inform the LAS that they suffering a crisis and the range of symptoms. For example if a person with SC had breathing difficulties or stroke-like symptoms they would be categorised at a Cat A (red 2) response. Thus sickle cell crisis is a C1 call and other symptoms can raise to a Cat A response.

**Action: 1) Arrange meeting between people with experience of sickle cell crises and Fenella Wrigley. 2) Develop opportunities for people with SC to participate in staff training.**

Fenella said that another problem was that because of a shortage of staff, response times were poor at the moment, e.g. C1 calls might have a 65-68% response instead of 90%, and a C2 call might have a 75% response rate within 30 minutes (stead of 90%). To improve the situation more staff are being employed and the LAS clinical hub (paramedics and nurses) review calls to see if a more appropriate, faster response is needed

With regard to getting the right kind of response, Fenella said that only paramedics can dispense morphine, so sending a non-paramedic crew to a person with a SC crisis could be the wrong decision. She said that non-paras can provide oxygen and transfer the person to an A&E, but in reality it is better to wait longer for a paramedic crew.

3.9 **David Whitmore** said that giving fluids is essential but that oral fluids are better than IV because veins get damaged from too many injections. He advised giving oxygen for all patients and emphasized the importance of acute signs.

The meeting discussed the use of the SC passport, which is a short form of the patients care plan and can be used to provide essential information to clinicians when a person is in crisis. **It was agreed that promoting the use of SC passports or agreed care plans was essential to improve clinical care.**

3.10 **Anne Yardumian** said that a mutual understanding between the patient and paramedics is essential. Protocols need to be patient focussed and in practice most A&Es in London have a great deal of experience of SC crises.

3.11 **Patrick Ojeer** said that the LAS system of response had changed a great deal and is pleased that the LAS and SCS are working closely together to resolve the problems highlighted by people with SC. He emphasized that people don’t call for an ambulance unless they are in a very bad way.

**3.12 Janet Marriott suggested that the experience of those who suffer sickle cell crises should be gathered together and a podcast produced as a training tool for staff.**

3.13 **Louisa Roberts** raised concerns about making complaints about poor treatment. She said there could be repercussions for patients and they might be blacklisted.

**3.14 Fenella assured Louisa that the LAS seeks to be open and transparent, welcomes complaints and that complainants would never be blacklisted. David added that if the LAS doesn’t know about the problems it can’t fix them.**

3.15 A participant said that her 8 year old son has SC and has been treated by King’s and Queen Elizabeth hospitals. Her experiences have been positive. Her son’s school also has a care plan for him in case he goes into crisis. When he collapsed at school the care plan was followed. She said the paramedics at King’s and QE provided a fantastic service. She has experienced no discrimination.

3.16 A participant said that when her children were kids the service was fantastic, but it changed dramatically when they became teenagers. **She proposed that a way is established to feed patients’ experiences into the LAS.**

3.17 **Anthony John** said that the LAS crew and hospital A&E services need to be more sensitive to the needs of people in crisis and to ensure that they provide the right care first time. He said he had had some appalling experiences when he was in crisis and needed care in an emergency.

3.18 **Blessing Makanjuola** described having to call the LAS on 3 occasions in a short space of time and on the third occasion the paramedic said to her: “Not you again”. She said she had to fight to get the pain relief she needed and usually had to wait a long time for an ambulance to arrive.

3.19 Iyamide **Thomas**, Regional Care Advisor Sickle Cell Society said it is important to highlight the important fact that when sickle cell service users call 999 they should ensure they tell the operator they have sickle cell so that the necessary fast track steps can go into gear

3.20 **Dr Anne Yardumian,** said that there is a register of most people in the UK with SC – it is called the National Haemoglobinopathy Register and that all those on the register have consented to being on it. This register could be a way of assessing, objectively, the quality of services and of developing a system of providing care plans to those on the register.

3.21 **Kye Gbangbola** said that a good and productive relationship between the LAS and SCS was essential. He said that things need to change, the gaps in services must be addressed and that there were now opportunities for action. He said that the SCS website would advise people what to expect when they call an ambulance when they are in a SC crisis. **He proposed that a working group be established by the SCS and LAS to optimise clinical practice and challenge the causes of stigma which people with SC often experience.**

3.22 **Fenella Wrigley** welcome to opportunities to work with the SCS and **proposed that a CQUIN should be developed between the LAS and commissioners to ensure that care is substantially improved for people who suffer a SC crisis.**

3.23 **Stuart Ide, LAS Commissioner** said that any proposed CQUINS suggested by Fenella on sickle cell would be considered by the commissioners and the 32 London CCGs.

3.24 Angela Cross-Durrant thanked all participants for their contributions; the speakers; Fenella and her team and the commissioners. She said that the change in culture at the LAS had facilitated an excellent meeting of a quality and openness that could not have happened in the past.

3.25 The Guest Speakers Kye Gbangbola, Chair of the SCS and Dr Anne Yardumian, Chair UK Forum on Haemoglobin Disorders were thanked for attending the Forum meeting.

**The Meeting Finished at 7.30 pm and was followed by the AGM of the Forum.**