**Insight Project – Sickle Cell and Thalassemia – Focus Group**

The following themes were discussed at the first focus group discussion – are these the right themes?

1. **When to call**
2. **Managing pain**
3. **Use of Entonox/Gas**
4. **Understanding Sickle Cell**
5. **Transfer to the ambulance**
6. **Choice of Hospital/Treatment Centre**
7. **Care Plans**
8. **Handover**

**When to call:** generally people spoke of a good experience when calling 999. People talked about leaving it until they could stand it no more, when pain was at a ’10’. Ideas included the use of ‘key’ words. Group members also talked about the number of questions asked at this stage and how the level of pain can make the questions very hard to answer.

**Managing pain and the use of Entonox/Gas:** this was a discussion topic that came up throughout the focus group. People talked about the need to address the immediate pain in order to be able to communicate with the ambulance crew. There was a range of different views about when and whether Entonox should be used as standard. Some group members talked about a perception (from service providers) that people with Sickle Cell want access to Entonox for reasons other than pain relief.

**Understanding Sickle Cell:** some group members spoke about a difficulty faced with explaining the situation and the symptoms of Sickle Cell to the call operator. Discussion focused on the value of personal care plans. Some in the group had them and had found them to be very helpful. People also talked about how sometimes the crew can be over familiar, making light of people who make multiple calls to the service. This was described as feeling of sarcasm.

**Transfer to the ambulance:** a number of group members described being asked to walk to the ambulance, sometimes down/up stairs, group members described how this created further pain and distress.

**Choice of Hospital and Treatment Centre:** discussions tended to focus on whether or not an ambulance crew should take patients to their designated treatment centre. A number of group members talked about crews taking them to other hospitals other than their treatment centre. The group discussed the severity of the clinical need and decisions about which hospital to go based on how life threatening a situation was. There was discussion about Sickle cell pain in the chest, strokes and other complications that might lead a crew to take a person to the nearest hospital.

**Care Plans:** the group talked about Care Plans in relation to, when to call, a better understanding of Sickle Cell, personal preferences, pain relief and choice of treatment centre. One group member had not called an ambulance for 8 years. He put this down to having a care plan that enabled him to build a relationship with his treatment centre and to make the best decisions about when to take himself there.

**Handover:** finally, the group discussed whether they felt involved in the process of handover from ambulance crew to staff at A&E. The group unanimously felt this was a process that they weren’t involved in.

**Possible Always Events**

For further discussion – are these the priorities? Are there any others? Are they suitable and realistic to implement consistently?

1.       Always offer pain relief (subject to care plan)

2.       Always (offer to) carry a patient in sickle cell crisis to the ambulance (to avoid permanent damage to bones and organs)

3.       Always (offer to) take a patient in sickle cell crisis to their dedicated treatment centre for expert care