Sickle cell workshop notes

4.1 Population

Is the population to be covered in 4.1.1 appropriate and correct?

GROUP 1

Change sickle cell crisis to 'an acute painful sickle cell episode (or event)'. Are we looking at just the pain of the acute painful event or the whole painful event?

The guideline title should include the word 'pain'.

It should read 'diagnosis of sickle cell disease with any geneotypes of ….'

GROUP 2

Definition of crisis needs to be changed-this can affect all organs. Acute painful crisis is also typically bony although some pain will not come from the bones (e.g. gallstones). Discussed using "acute painful episodes" throughout the scope. Group also discussed how some complications will cross-over to uncomplicated acute pain.

GROUP 3

The assumption that the pain is caused by sickle cell is the result of the sickling process, but there is no way of confirming this. Perhaps the problem is with the term *caused* and this could be changed to *painful sickle cell episode*.

4.1.2a – change to *adults and children who are sickle cell trait* and also exclude people with SC disease who present with a non painful episode.

Are there any other subgroups that should be added to section 4.1.1 (b) in addition to age-specific groups?

GROUP 1

- Add pregnancy as the management varies for pregnant women.
- Those with organ failure.
- Those already having chronic pain management as they will have an individual care plan.

GROUP 2

The group discussed adding pregnant women as an additional subgroup and to specifically exclude post operative patients with sickle cell if they are not having an acute painful crisis (If they are having a crisis they will fall under the main included

population). Also discussed that patients with renal failure in acute pain will also be included under the main population as long as they present with crisis and would not need to be specifically mentioned.

GROUP 3

Could potentially include those with renal failure as a sub group.

Are there any other populations that should be excluded in section 4.1.2

GROUP 1

Part (a) remove the remaining sentence from 'and'

Part (b) should read 'not related to acute pain'.

Should also add other sickle cell complications such as:

- Acute pricipism
- Sickle cell stroke
- Sickle cell chest syndrome

GROUP 2

10% of children are on long-term transfusions and sickling should not occur in these patients. The group discussed that this should not be a specific excluded population but should be considered as a special group as these patients effectively become carriers and shouldn't have crisis. This also includes adults who are transfused regularly.

3.2 Healthcare setting

Are the healthcare settings to be covered in section 4.2 appropriate and correct?

Group 1

Should read 'Care delivered (or directed) by secondary and tertiary care' to cover those where treatment is commenced prior or outside of the hospital, but using secondary or tertiary care staff. This treatment may include iv opioids.

Ambulatory day units.
Ambulances: sometimes treatment is started in the ambulance, including iv opioids.

Geographically – a day unit would not be practical.

- Paediatrics would usually go directly onto a ward fairly quickly after presenting in an A&E department.

- Paediatrics will have a different route than adults.

GROUP 2

Discussed that children would be admitted to paediatric ICU and HDU and that there is a need to be careful of referring patients early to specialist care. They also suggested that the expertise of people caring for patients was important but agreed that this was an issue to be covered in the GDG meetings.

May need to specify what teams should be looking after patients (in terms of experience and expertise rather than location). Suggested that we may need to look at different models of care (e.g. day case/ outreach). Networks of care may also need to be addressed.

GROUP 3

Acute pain would be managed in acute pain settings

4.3 Clinical management

(a) Should non-pharmacological management of acute pain be included and if so, which intervention should be considered?

GROUP 1

Need to be very what the starting point of this guideline is.

Should add co-analgesics as part of (a).

In part (c) need to remove the word ‘pain’. It’s the 5 vital signs that need monitoring and therefore needs to include all aspects for identifying the complications. This needs to be done you that parts (e) and (f) are possible.

(e) should include iv fluids and oxygen.

Should pharmacological interventions include Pethidine?

Pethidine should be included in the searches and if appropriate a recommendation should be made to say do not use it.

Are the clinical issues to be excluded in section 4.3.2 appropriate and correct?

The clinical issues to be excluded were appropriate and correct. In part (c) should removes the word ‘diagnosis’.

GROUP 2

Monitoring should be included specifically as this is needed when there are complications and when a patient deteriorates. There is psychological input in acute pain-e.g. in the form of distraction techniques which are used by patients.

Physical techniques include acupuncture, TENs and heat therapy. Also discussed the use of hypnosis although this may not be applicable to an acute pain setting.

Should pharmacological interventions include Pethidine?

This should be included in the literature searching so that if appropriate a do not do recommendation can be made. Need to consider that an acute episode of pain may also include some chronic pain. Other drugs to consider include fentanyl patches (opioid analgesic), morphine, diamorphine and pregabalin.

Are the clinical issues to be excluded in section 4.3.2 appropriate and correct?

Need to define a time scale for which the guideline will cover (first 24 hours? Not prolonged scale of for example 3 days) or this could be divided into time intervals (first 24 hours and on-going pain).

GROUP 3

a) There are many different pharmacological interventions to be used, and they are not limited to NSAIDS and opioids. For example, ketamine, lignocaine, clondine, amatriptlyne and pethadine are used as part of current practice.

b) Take out dosage, ideally include patient/nurse controlled administration (PCA/NCA) and look at the health economic implications around this. There is likely to be evidence around PCA/NCA, not related to SC, but more general. Also, intra-nasal administration and sugarfree lollipops.

The group also discussed non-pharmacological interventions, and whilst it would be interesting to look at some of these interventions (such as CBT), the main focus of this guideline should be on pharmacological interventions and therefore the non-pharma should be excluded. It is likely to take a great deal of IS/reviewer time and not lead to specific recommendations.

Also suggested taking out f) clinical signs and symptoms of acute complications associated with SC crisis. Regarding the optimal clinical setting, whatever is recommended for successful inpatient management of SC crisis, will need to be delivered in this setting.

Might be better to replace setting with something more helpful?

4.4 Outcomes

Are there any additional outcomes that should be included?

GROUP 1

Should add patient satisfaction.

(e) it needs to be made clear what is meant by ‘frequency’.

GROUP 2

Length of hospital stay may be complicated. Dependency on opioids should be included (this should be covered in adverse events). Chronic morbidities may be difficult to measure as they are incremental over a period of time. Patient satisfaction/experience/perceived quality of care should also be included as an outcome. Also may need to consider including re-admission rates as there is variation in how long it takes to settle pain across patients. Pain measurement should also include scales used for non-English speaking patients.

GROUP 3

A very useful outcome would be *time of arrival in hospital to pain being under control.* It would also be useful to have an objective way of working out where on the pain scale sickle cell pain is. Although, it is noted this is subjective and may be very difficult. Delete *chronic comorbidities.*

4.5 Health economics

Are the key health economic questions appropriate and correct?

GROUP 1

Remove the second paragraph about NSAIDS as it is not a realistic comparator. The comparison should be opiods v non opioid.

The use of PCA. There will be a rapid conversion to oral analgesia for those patients that use PCA, and as such they will leave hospital sooner.
A&E v day units.

There is s resource implications for those that are admitted directly to the ward (especially children).

GROUP 2

Comparisons should also include in-patient vs. day case settings