NICE Clinical Guideline

Schizophrenia in Children and Young People

Stakeholder Workshop Notes – 16th November 2010

Group A Group B Group C

1. **Suggested guideline development group composition – Are all the suggested members (and the numbers of each type of member) appropriate and important? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?**

Group A
The group suggested an education specialist should be included in the GDG constituency.

Group B
No comments.

Group C
The group came up with the following suggestions:
- Nurses
- Art Psychotherapist
- Family Therapist / Social Worker / CAMHS professionals
- Pharmacist
- Paediatrician
- GPs
- Educational Psychologist / Teachers who work in adolescent units

2. **Scope - Are we on the right track? Have we struck an appropriate balance between the need to keep the scope manageable and covering the most important clinical issues?**

Group A
The group agreed that the balance is right. They suggested looking at MHA, children's act, educational impact, neuropsychosocial assessment, family context (e.g. housing, accommodation, safe environment and how to collaborate with families), pharmacological interventions, drug interactions, and issues of pregnancy and contraception.

It was agreed that 'people' should be replaced by children and young people throughout the scope as currently it is not consistent.

Group B
The group made quite a few comments in regards to assessment e.g.
- Consider substance abuse during assessment. How does this influence management?
- How do we move from recognition to assessment to management?

- What are the risks of not doing an assessment or referral?
- What is the range of available settings for assessment?
- What are the recommended baseline assessments? The group felt that there should be standardised and shared risk assessments.

In the scope [section 4.2 (b)] the group felt that we should include possible ways to equip children for transition into treatment. Also consider a wider age band. Offer support and advice packages and consider the **choice** of the child and confidentiality e.g. from parents (this may incorporate legal issues).

Group C
The group felt that the scope is on the right track.

The scope should definitely cover:
- Treatment resistance
- Medical side effects of taking drugs in children and young people
- Awareness of process
- How important nurses are in the treatment process (should be added in 3.2 Current practice).

In section 4.3.2 – the title 'Clinical issues that will not be covered -The guideline will not "specifically" (should be added) cover'. Also, diagnosis should be addressed, particularly the variations in how diagnosis is made. Children and young people 'with coexisting learning difficulties, significant physical or sensory difficulties, or significant substance misuse' should not be excluded.

3. Do the topics listed in the scope (section 4.3.1) cover the most important areas? Are there any omissions or any topics on the list that should be deleted?

Group A
In 4.3.1 remove all 'or' and leave 'and'. The group felt that point (f) should be omitted and point (g) should be clarified as it is not clear what is meant. Point (j) should be modified to take into account drugs that do not have licensed indications due to evidence base.

Group B
The group requested that points (a) and (b) in section 4.3.1 should be combined. Also for point (a) the guideline should consider evidence of treatment initiation in development and young age (e.g. in relationship to dopamine receptors).

Point (d) should include mention of physical health issues. For point (g) the group thought that it should also include the **organisation** of early intervention services (as well as the use of services) in early treatment.

For point (h) the group thought it should include mention of other high-risk groups (other than B.E.M) such as socially excluded populations and looked after children.

The group also felt the need to highlight resistance to treatment as a clinical issue.

Group C
The group felt that it should be emphasised in (a) that the initiation of treatment has a very different interpretation for adults and those under 18 years old. In this area, the competence of staff is very important e.g. who delivers the interventions? / Are they able to do it effectively?

The group felt that (d) assessment and management of the known side effects of antipsychotic medication – is very important – e.g.

- Acute reactions / metabolic side effects
- Weight gain as a side effect
- Informed choice should be a priority e.g. children and young people should be made aware of the risks of not taking medication / they should be informed of what happens at all the stages of treatment / should they be given a choice to stop medication?
- Is 6-8 weeks of monitoring long enough to determine side effects?
- What about the effects of long-term medications?
- How long should treatment be?
- What are the lower maintenance treatments?
- Drs are keen to limit the side effects – treatment dose / maintenance dose
- Compliance in taking medication e.g. Are parents monitoring their children? What effect do parents have on teenagers?
- Awareness of transition of status's – what is happening in the young person's life e.g. examinations / hospitalisation.

4. Suggested clinical questions – ask the group the following general questions in order to agree/prioritise their selection.

a) There is a particular emphasis on recognition and management. Is this the right place to start?

Group A
The group felt that more detail with regard to recognition is needed in the scope. The group were concerned that 'pure' schizophrenia is not seen in clinical practice as there appears to be a blurring of the boundaries surrounding diagnosis especially with regard to Psychosis, Schizophrenia and Bipolar disorder. Suggested that GDG define clearly and explicitly what is meant by 'Schizophrenia' (e.g. heterogeneous disorder) at an early stage. The group were particularly concerned about how to address the limited evidence base for psychosis and substance misuse in children and young people. It was suggested that research recommendations can fill in any gaps in the literature and also by referring to existing guidelines

for recognition of other disorders (e.g. Psychosis and substance misuse guideline & Bipolar disorder). The group felt that training for HCP's should be included in the scope in order to improve recognition of important signs and symptoms.

Group B

The group would like to know if the clinical question in regards to recognition refers to recognition from different settings or different professionals. Who is the primary target?

The group would like to highlight the groups that need improved recognition e.g. school nurses/GPs/parents. Consider settings and screening tools.

The group thought that diagnosis would be a trigger of the care pathway so it should be highlighted. What the key features of the disorder are should therefore be considered. Also in terms of diagnosis, what diagnostic criteria will be used? What approaches to detection and recognition are useful?

Group C

There should be a clear definition of psychosis / schizophrenia. There are problems in society of labelling children and young people with 'schizophrenia' and so it was suggested that 'psychosis' be used as an overarching term.

b) How available/accessible are these services and should we set out appropriate care pathways?

Group A

No comments.

Group B

The group would like to know what the best way is and how children can enter the pathway. Also consider the difference between friendly or intimidating settings. Settings should be stable and home-like.

Group C

The group felt that with regard to access to services, the following should be looked at in particular:

- Children and young people who have dropped out of school – the suggestion was made that online education could be offered
- Those with offending backgrounds
- Those with homeless families
- Looked after children
- Those with a background of abuse or trauma
- The transition between CAMHS and adult services.

c) How many children and young people with schizophrenia /families will be affected and what might be the implications for social and educational provision beyond health care systems?

Group A

The group acknowledged it was important to address other settings such as educational, social care and voluntary agencies providing care for children and young people with schizophrenia in 4.2. Moreover, they suggested looking at the transition in healthcare that is received from CAMHS to early intervention services.

Group B

There should be education provision (linked with main outcomes) and what is the best way to help with integration back into education or employment (there is an available evidence base to support this). There should be a continuation of education provision, and this raises issues of funding and the nature of links with schools. There should be good communication and care planning with schools.

Group C

The importance of personalisation was emphasised (e.g. person centred care):

- Working with families
- Individualisation - concentrating on the development / social context of each child or young person.

The group discussed support from outside the family:

- Community placement
- Commissioners of care rather than providers
- Deprived families / those with a number of different mental health problems would benefit from community rehabilitation e.g. respite (although there is a problem of funding here).

d) What are the group's views about the available evidence base and how we might recommend changes in clinical practice?

Group A

The group were concerned that there may be a lack of evidence regarding schizophrenia in children. It was suggested that children with psychosis may act as a proxy if the evidence is lacking. The group agreed that much of the evidence may come from adult or mixed adult and young populations which will have to be accounted for in the strength of the recommendations made.

All agreed that long-term follow up is important when looking at the evidence base and will influence the recommendations for clinical practice. With regard to clinical management (4.3.1) the group were concerned that existing wording is very medical in nature and should incorporate a more multidisciplinary/holistic approach. The group suggested looking at the relevance of using MRI/CT scans and considering incorporating the TA into this guideline. Neuropsychosocial assessment should be included in the scope (in particular, the assessment and management of neurocognitive impact of schizophrenia). The group also proposed a baseline assessment when looking at the assessment and management of known side effects.

Group B

There should be an expert consensus for the section of the guideline on capacity and consent.

The group suggested looking for literature on the cost and economics of interventions vs usual care.

Group C

Evidence is hard to translate into health economic models:

- How is effective treatment defined?
- Is this group too hard to model?
- Is there a lack of economic data to support treatment?
- What is the cost of relapse and re-admission?
- Can evidence from other countries be looked at? (e.g. in particular, from the States, Europe, Australia, New Zealand).

e) What are the key outcomes to be considered (see also section 4.4 of the draft scope)?

Group A
Consider adding these to outcomes:

- Suicide
- Physical health
- Improving access, reducing the duration of untreated psychosis
- Engagement with services.

Consider omitting the following outcomes:

- Percentage of children and young people receiving appropriate treatment
- Measures of efficiency (but leave in cost-effectiveness).

Replace existing with:

- Replace first outcome with better recognition and earlier treatment of children and young people
- Replace health-related quality of life with social and educational well-being (including involvement with forensic services).

Amend:

- Last outcome: consider replacing ‘and incidence of’ with ‘related and other’.

Group B
One of the key main outcomes is improved recognition. The group would like to know who this is aimed at. Does it relate to an improved recognition and therefore an improved initiation of the pathway?

The group felt that the outcomes are too treatment focused and should relate more with the clinical issues listed in the scope.

The main outcomes should include:
- Family interventions
- Education
- Employment
- Training
- Educational **expectations** of a child/adolescent
- Improvement in the organisation of services (and in health costs)
- Physical health and well being (in addition to adverse events) such as reducing risk factors like smoking
- Reducing the duration of untreated psychosis (the gap between presentations to diagnosis)
- Maintain **engagement** through service transitions.
- Better outcomes in relation to **patient choice.**

Group C
The group felt that the outcomes are too clinically focused and they should also look at the following to aid recovery:
- Social life / life style – including relationships, active dietary management - e.g. dealing with fitness / weight
- Education / work
- Self confidence / self esteem
- Improved participation i.e. moving barriers and encouraging independence
- Decreasing levels of distress
- Family needs e.g. the effect on siblings

5. Equalities – how do inequalities impact on the provision of care for children and young people with schizophrenia? Should any particular subgroups of the population be considered within the guideline?

Group A
Perhaps children and young people with mild learning disabilities should be considered. Learning ‘difficulties’ should be changed to learning ‘disabilities’. Those with mild learning disabilities will be referred to standard services and will be included in the evidence base; however,

those with moderate-severe learning disabilities will receive specialist services and thus will not be included in the scope of this guideline.

Group B
The group would like to highlight the socially excluded populations such as looked after children.

Group C
It was agreed that complex comorbidities should be looked at but not dealt with specifically. The patient centred approach is particularly effective when used for those with comorbidities. It was emphasised that there should be a strong personalisation of needs as this leads to meaningful outcomes.

The group agreed that those with learning disabilities should not be excluded as this population has a higher risk of psychosis. These children and young people may or may not need the same care pathway. It was also suggested that children who are deaf should be covered in particular.

The group agreed that care pathways should be looked at for children of homeless families and those with offending backgrounds; there should be an emphasis on continuity of care – from CAMHS to adult services (i.e. importance of an effective transition).