NICE Clinical Guideline

Psychosis and schizophrenia in adults guideline (partial update) and quality standard

Stakeholder consultation workshop

1.

a) How available/accessible are services. Should the guideline set out appropriate care pathways?

Group 1

The raised several issues relating to transition between services, particularly between inpatient and community services, as this area of the care pathway can be variable.

The group also raised the issue that some service users are moved around services, leading to repeated and unnecessary assessment.

The group mentioned that it is important that organisations are clear on what is involved in improving service-level interventions and measuring quality. Service users often give feedback that the attitude of healthcare professionals is very important, particularly on acute wards.

The group mentioned that there are significant geographical disparities between services, for example assertive outreach teams.

Group 2

The group did not comment on this issue.

Group 3

- Some access problems are due to limited availability of early intervention services, as many areas cannot afford them.
- As many services cannot afford to set up any of the early services, the guideline needs to ask "how can generic services deliver early intervention and other early services?"
- Physical health checks
- Strong emphasis was placed on minority groups (BMEs)

b) Does the scope capture the appropriate range and nature of services?

Group 1

The group discussed the importance of informal services and other low intensity interventions, for example peer and other support groups, mentoring, and self-help groups. The group also mentioned that service-user organisations can provide important support.

Group 2

The group discussed the issue of 'complex cases':

- It was however agreed that there is little evidence supporting the specific management of coexisting conditions.
- The high prevalence of coexisting Asperger's was highlighted along with the need to increase awareness in the treatment of coexisting Schizophrenia and Asperger.
- The importance of cross referencing within guidelines was agreed.

A member of the group drew attention to the need to cover Social Care:

- Social care is, however, already covered in the current guideline.
- The importance of taking a broad look at social care was nonetheless highlighted (i.e. case management; employment).

The role of Primary Care was also brought up:

- General consensus was there has been very little in the form of new evidence since the last guideline update.
- Discussion was had concerning the use of audit and observational evidence. This was however disregarded due to the high number of confounding variables.

The importance of identifying the 'ingredients' that make up a successful intervention team was heavily discussed:

- Content covered;
- Team structure;
- Best methods to intervene;
- Befriending/ peer support/ Expert By Experience have all shown high response levels.
- A focus on 'Why' interventions work.

Group 3

The scope needs to include quality of life issues including

- Self care / self management
- Exercise
- Better information for people on side-effects

Comments were made about the exclusion criteria being too stringent. I.e. By excluding people with learning disabilities, how practical will the guideline be to implement? In the exclusion clause they would like to have the word 'organic' defined in its context and the implications/causes stated.

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

Group 1

The group mentioned several studies which the guideline development group could consider, including reviews of ACT and art therapy. However, the group acknowledged that there was not much new evidence in these areas.

Group 2

Very little discussion on this point was had by the group. Repeating above, some discussion was had concerning the use of audit and observational evidence. This was however disregarded due to the high number of confounding variables.

Group 3

- The Care Quality Commission have a great deal of helpful data.
- Two large projects – National Eden (Birmingham) and one in Australia (EPICS- Melbourne).
- It would be good to include research on specific early interventions to improve the patients quality of life, ie. Diet, exercise, self-management (LSE study)
- There were concerns raised around the issue of which services took responsibility for preliminary physical checks.
- Need for evaluated evidence on the cessation of treatment
- Clinicians need more training for monitoring the patient

d) What are the key outcomes to be considered?

Group 1

The group thought a consideration was that symptom measures might be hard to measure with service-level interventions.

The group suggested adding:

- volunteering/meaningful activity, to be considered alongside employment
- experience of carers
- stable housing
- physical health

Group 2

The group compiled a list of possible relevant outcomes:

- Quality of life
- Social functioning
- Physical functioning
- Symptom control
- Service user experience
- Side effects
- Weight gain
- Self-Harm
- Drug/ Substance/ SMOKING
- Suicide (Attempted and Completed)

- Rehospitalisation
- Employment
- Self-meaningfulness
- Social Support Network

Group 3

The groups concern focused on how the outcomes will be captured and realistically implemented into the real world

- Hospital admission and readmission
- Morbidity
- Duration of untreatedness – how able are they to seek help and how long does it take to attain?
- Satisfaction level, and how to give confidence to those who had a bad experience
- Regular physicals

e) Does the guideline scope cover all the important issues?

Group 1

The group thought that the scope covered the important issues, however a few additional comments were made about specific parts of the scope.

- Guideline title

The group agreed with the broadening of the guideline to include people with a diagnosis of psychosis. The group also thought that the explanatory part of the title should be broad, and not specific to the areas to be looked at in the partial update.

- 1.1

The group thought that it was important to explain in this section that the guideline will cover psychosis and well as schizophrenia.

- 2.2

The group suggested updating the service teams given as examples, and updating the economic statistics.

- 3.3.1

The group mentioned that the term ‘cognitive’ remediation’ can be used differently in different areas of health and social care, and so it may be appropriate to consider defining it broadly in the guideline.

Group 2

The group suggested possible new items for the scope.

- exercise
- self-Help was discussed with the emphasis on self-management and medication management. Such would develop independence and reduce stress through the attainment of control.

Group 3

The group would like to see the following measures/ considerations in the guideline and QS:

- cultural considerations
- occupational standards
- the effect of those coming on and off treatment
- the number of pathways into care
- the transition policy for those changing service groups.

2. Equalities – how do inequalities impact on the provision of care for people to schizophrenia? Should any particular subgroups of the population be considered within the guideline?

Group 1

The group mentioned that there are equalities issues relating to women of child-bearing age, for whom pregnancy can be a trigger for psychosis and for whom outcomes are often poor. There are also issues for pregnant women concerning pharmacological interventions.

Group 2

The group highlighted access and engagement as the critical factors in response to the topic of inequalities.

A study that looked at the intervention factors determining the level of access and engagement of minority groups found non-significant results in the patient level data was discussed. These findings meant that comment on access and engagement in the previous guideline was primarily based on expert recommendations.

The group suggested future discussion on differences between:

- individuals with differing social positions
- developing countries
- males and females
- employed and unemployed

The group also highlighted the importance of increasing cultural awareness across professional groups that come into contact with Schizophrenic individuals e.g. police and teachers.

Group 3

- Those largely affected by inequalities are refugees, asylum seekers, young people, BME's, the homeless and the over 50's.
- Inequalities are dependent on locations, population, the needs of the patient and the level of experience of the healthcare practitioner. Also in groups of people where mental health has a strong stigma attached to it means these people are less likely to uptake the care services available.

- Good links with the 3rd sector helps decrease these inequalities, however with the state of the economy and the current budget cuts, what will the consequences be?

3. Regarding the suggested guideline development group composition – are all the suggested members appropriate? Should we be including any other types of members for this guideline? Could there be a role for expert advisers in this guideline?

Group 1

The group suggested the addition of specialist team nurses, social workers, art therapists and representatives from the third sector.

Group 2

The group compiled a list of the types of members that should be included for this guideline:

- Community teams
- Service users who have had direct experience with community teams
- Professional groups-
  Community based psychiatric nurses
- Chief executive in a trust
- Commissioner
- Social worker
- Psychologist
- Ward based staff.

The group also held consensus that two separate groups may be necessary; one for the guideline update and another for the quality standards.

Group 3

The group would ideally like to see the following:

- educational/ vocational practitioner
- person from public health
- an assertive outreach representative
- someone to represent BME groups.