National Institute for Health and Clinical Excellence

Psychosis and schizophrenia in adults -Clinical Guideline and Quality Standard
Scope Consultation Table
8/12/11 – 9/1/12

PLEASE NOTE - NICE is revising its QS process and we are no longer required to develop the QS.

Type (NB this is for internal purposes – remove before posting on web)

SH = Registered Stakeholders. These comments and responses will be posted on the NICE website after guideline development begins.
GRP = Guidelines Review Panel member. These are added to this table for convenience but will not be posted on the web.
NICE = Comments from NICE. These are added to this table for convenience but will not be posted on the web.
Non Reg = Comments from organisations and people who have not registered as stakeholder. These are added for convenience but will not be posted on the web.

No	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
1	SH	**AstraZeneca UK**	1	General	AstraZeneca UK welcome the opportunity to comment on the draft scope to update the clinical guideline and develop the quality standard for Psychosis and Schizophrenia in Adults: core interventions in the treatment and management of psychosis and schizophrenia in primary and secondary care.	Thank you for your comments.
2	SH	**ISPS** **The International Society for the Psychological Treatments of the Schizophrenias and**	1	General	We very much welcome the inclusion of 'psychosis' in the title of the Guideline. Among other things, we think this could make the guideline much more accessible in practice for patients who would have been unwilling to consult a guideline which only mentioned 'schizophrenia'.	Thank you for your comments.

		other Psychoses				
3	SH	**ISPS**	2	General	Even more than in other areas of mental health, we are concerned that over-concentration on RCTs could restrict consideration of useful evidence, in particular regarding the nature of effective service-level interventions. We would encourage more emphasis on pathway studies, which can illuminate how clusters of individuals may be helped towards at least a degree of recovery. We would also encourage application of new concepts about translational medicine, in translating potentially useful research findings into effective interventions in actual settings.	Thank you for your suggestions. NICE guideline development process is that we look at the best available evidence and our first priority will therefore be to look at RCTs. Where RCT evidence is limited we will consider other studies and your suggestions are helpful. Thank you.
4	SH	**ISPS**	3	General	We think that there may now be sufficient further evidence to warrant the update also including psychological interventions. As well as papers mentioned below (notably Aaltonen et al 2011, Seikkula et al 2011, Brabban et al 2011), there is a new paper from the Danish National Study (Rosenbaum et al, 2012) showing effectiveness of Supportive Psychodynamic Psychotherapy against treatment as usual, with gains on both PANNS and GAFF measures. References: Aaltonen J, Seikkula J & Lehtinen K (2011) The comprehensive open-dialogue approach in Western Lapland: I. The incidence of non-affective psychosis and prodromal states. *Psychosis*, **3** (3), 179-191. Seikkula J, Alakare B & Aaltonen J (2011) The comprehensive open-dialogue approach in Western Lapland: II. Long-term stability of acute psychosis outcomes in advanced community care. *Psychosis*, **3** (3), 192-204. Brabban, A., Callcott, P., Christodoulides, T., Dudley, R., French, P., Lumley, V., Tai, S.J. and Turkington, D. (2011). Cognitive therapy for people with a schizophrenia spectrum diagnosis not taking antipsychotic medication: an	Thank you for your suggestion the only psychological interventions we have been asked to update is CRT.

					exploratory trial. *Psychological Medicine,* 1-8. Rosenbaum B, Harder S, Knudsen P, Koster A, Lajer M, Lindhardt A, Valbak K & Winther G (2012) Psychodynamic psychotherapy vs treatment as usual for first-episode psychosis: two years outcome. Accepted by *Psychiatry*, and awaiting publication.	
5	SH	**Otsuka Pharmaceuticals (UK) Ltd.**	3	GENERAL	An important facet of the management of Schizophrenia is the issue of poor adherence, that most studies point to non-adherence at 60-80% and that non-adherence is associated with poor outcomes in Schizophrenia. We believe that non-Adherence in Schizophrenia is of urgent importance to the improvement in the treatment of Schizophrenia. That lack of adherence is an inherent consequence of the disease, in addition to the more 'usual' reasons for lack of adherence. Strategies to improve adherence cut across each of the important avenues to be discussed within future workshops and it is sufficiently important to warrant special consideration. In the absence of new chemical entities or breakthrough therapies, the improvement in adherence (with existing chemical entities) and the various mechanisms to improve adherence provides the greatest current opportunity to improve the lives of patients with schizophrenia. The need for early treatment and compliance are known factors which improve the long term prognosis.	Thank you for your comment. Adherence will be considered by the GDG although we will not be updating the pharmacological section of the guideline.
6	SH	**Rethink**	1	General	Rethink Mental Illness welcomes the extension of the	Thank you for your comment.

		Mental Illness			guideline beyond a diagnosis of schizophrenia to include psychosis.	
7	SH	**Royal College of Nursing**	1	General	The Royal College of Nursing welcomes proposals to update this guideline and welcomes steps to produce quality standard statements to enhance the ability of the NHS to meet the needs of people with this condition. The draft scope seems comprehensive.	Thank you for your comment.
8	SH	**Royal College of Nursing**	2	General	The evidence for psychoeducation (PE) is that "education" and "health promotion" is suitable for primary care but complex PE interventions i.e. group interventions are given by experts.	Thank you. The GDG will be examining the evidence although we cannot pre-empt their findings at this stage.
9	SH	**Royal College of Psychiatrists**	2	General	Consider including guidance on quality assessment processes and tools e.g. AIMS programmes and Quality Indicator for Rehabilitative Care (www.quirc.eu)	Thank you. This will be considered by the GDG.
10	SH	**South London & Maudsley NHS Foundation Trust**	1	General	We welcome the proposals: 1) to review the evidence for team/service/organisational structures, particularly given the significant recent investments in service reorganisation 2) to review the evidence for interventions such as supported employment 3) to reconsider the evidence for CRT using different outcomes 4) to consider the evidence base for ‘psychosis’ rather than ‘schizophrenia’ as this better reflects practice	Thank you for your comment.
11	SH	**South London and Maudsley NHS Foundation Trust**	1	General	Although the scoping document specifies that psychological therapies will not be reviewed in the update, there is a developing evidence base for newer treatments, such as Acceptance and Commitment Therapy (ACT), indicating that these could be included as an intervention for consideration. The most recent National Institute for Clinical Excellence	Thank you for your comments. You are correct that psychological therapies will not be reviewed during this update. However we will suggest that new, emerging therapies should be included in the next update of psychological interventions. The information you have provided us with is useful and we will keep it on record for the future.

					(NICE) guidelines for Schizophrenia (NICE 2009) recommend the use of CBT for people with schizophrenia. Traditionally psychosis has been viewed in a biological manner and treatment aimed specifically to reduce psychotic symptoms, assuming that this will in turn improve functioning, despite unclear evidence to prove a link between improved functioning and reduced positive symptoms. This focus on trying to eliminate the symptoms of psychosis may not be the best approach, not least because those with psychosis often continue to experience symptoms and relapse. There is a growing breadth of evidence for the use of ACT in the treatment of psychosis. ACT is a behavioural therapy that incorporates mindfulness and acceptance strategies to develop psychological flexibility with the overarching aim of assisting individuals to develop and increase values-based actions and move towards recovery. The emphasis in ACT is therefore more on working towards meaningful life goals in the presence of ongoing symptoms A number of RCTs have now shown promising results for ACT interventions for psychosis, in terms of reducing relapse and rehospitalisation rates (Bach & Hayes, 2002; Gaudiano & Herbert, 2006). Furthermore these results have been found to be sustainable at 12 months follow ups (Bach, Hayes & Gallop, 2011). Published clinical case studies provide an in depth account of the nature and process of ACT as an intervention for psychosis (Bloy, Oliver & Morris, 2011). A recent feasibility study has demonstrated the potential for ACT to reduce depression, negative symptoms and usage of crisis services among service users who have experienced psychosis (White et al 2011). Recent research has also investigated the importance of acceptance and mindfulness processes as mechanisms of action in psychological treatments for psychosis (Gaudiano & Herbert, 2006;	

					Gaudiano, Herbert & Hayes, 2010). ACT and other third wave mindfulness based cognitive behavioural therapies offer an important development in the traditional CBT model of therapy for psychosis. There is a growing body of qualitative and quantitative evidence supporting the inclusion of mindfulness within psychological therapy for psychosis. The therapy goals adopted in ACT in terms of promoting acceptance, psychological flexibility and valued living are appropriate to the often long term nature of psychosis, fit well with a recovery framework, and represent a helpful shift from a more traditional approach in which symptom elimination would be viewed as the key criteria for measuring treatment effectiveness. **References** Ashcroft, K., Barrow, F., Lee, R. and MacKinnon, K. (2011), Mindfulness groups for early psychosis: A qualitative study. Psychology and Psychotherapy: Theory, Research and Practice. doi: 10.1111/j.2044-8341.2011.02031.x Bach, P., Hayes, S. & Gallop R. (2011). Long-term effects of brief acceptance and commitment therapy for psychosis. Behavior Modification. DOI: 10.1177/0145445511427193 Bach, P. & Hayes, S.C (2002) The use of acceptance and commitment therapy to prevent the rehospitalization of psychotic patients: A randomized controlled trial. *Journal of Consulting and Clinical Psychology. 70 (5) 1129-1139.* Bloy, S., Oliver, J.E. & Morris, E. (2011) Using Acceptance and Commitment Therapy with people with Psychosis: A case study. *Clinical Case Studies.* published online 15 September 2011. DOI: 10.1177/1534650111420863.	

12	SH	**The Meriden Family Programme**	11	General	Although we understand there is not a need to review psychological interventions we feel that there needs to be emphasis on the general support for families and carers. Carers who feel supported are better able to care for the family member who is unwell and this is extremely important as people transfer back to primary care and often their main support is the family.	Thank you for your comment. The experience of carers will be discussed during the development process and will feature as a main outcome in the management of psychosis and schizophrenia.
13	SH	**The Princess Royal Trust for Carers**	4	General	Our comments are as follows: The good practice cited in the Triangle of Care and the ongoing work on this project must be included in this work for it to have true value.	Thank you for your comment, which will be considered.
14	SH	**Welsh Government**	1	General	The draft scope should make specific mention of the patient or client with schizophrenia or psychosis who is a parent or carer of children, as this is a significant cause of child safeguarding problems. Numerous serious case reviews and professional reports have identified this as a significant issue in child safeguarding. Government guidance, Working Together to Safeguard Children , gives clear expectations of services and professionals where there are parental mental health problems: All professionals working in mental health services in the statutory, voluntary and independent sectors, should bear in mind the welfare of children, irrespective of whether they are primarily working with adults or children and young people Close collaboration and liaison between the adult mental health services and children's welfare services are essential in the interests of children. This will require the sharing of information where this is necessary to safeguard the child from significant harm It will therefore be important for the NICE review to include in its scope the situation of people with these mental health problem who are parents or carers of children. References: Royal College of Psychiatry report 2003 Child abuse and neglect - the role of mental health services	Thank you for your comment. We agree with you that this is a very important area and as you mentioned this concerns the safeguarding of children, which falls under the remit of Social Services and SCIE. The GDG may consider including a consensus statement but this is not an area where we will be looking at the evidence base.

					www.rcpsych.ac.uk/files/pdfversion/cr120.pdf Sharon Vincent CLCP 2009 Child Death and Serious case review processes in the UK www.clicp.ed.ac.uk/.../Briefing%205%20-%20Child%20Death%20SV.pdf	
15	SH	**South London & Maudsley NHS Foundation Trust**	2	1.1	Regarding the broadening to 'psychosis', how this affects the interface with the existing guideline and what is and is not being reviewed for this update should be considered. In other words, does the broadening indicate a review of the recommendations for medical and psychosocial interventions. In particular, affective psychoses may have different intervention implications, even at a service level, and may therefore require separate consideration.	Thank you for your comment. The term psychosis will be specified in the introduction (please also see reply to comment 19 below).
16	SH	**Royal College of Psychiatrists**	1	1.3.4 and 1.4.3	Update guidance on on arts therapy in light of findings of the MATISSE study (Crawford, Killaspy et al – In Press, BMJ)	Thank you for your comments. As outlined in the scope, psychological therapies (which include art therapies for this purpose) will not be reviewed during this particular update of the guideline.
17	SH	**South London & Maudsley NHS Foundation Trust**	6	Section 2	A lot of issues are raised in this section. Although they are all relevant to the care and experience of people with psychosis, it is not clear how they provide a rationale for the specific scope of the update.	Thank you for your comment. Section 2 of the scope sets out the background for this update which is why it is fairly broad. The rational for the guideline update can be found here: http://guidance.nice.org.uk/CG82/ReviewDecision/pdf/English
18	SH	**South London and Maudsley NHS Foundation Trust**		2	The online version of this article can be found at: tp://ccs.sagepub.com/content/early/2011/09/14/1534650111420863 Gaudiano, B.A. & Herbert, J. D. (2006) Acute treatment of inpatients with psychotic symptoms using Acceptance and Commitment Therapy: Pilot results. *Behaviour Research and Therapy.* 44, 415-437 Gaudiano, B.A. & Herbert, J.D. (2006) Believability of hallucinations as a potential mediator of their frequency and	Thank you for these helpful references.

					associated distress in psychotic inpatients. *Behavioural and Cognitive Psychotherapy. 34 (4) 497* Gaudiano, B.A., Herbert, J.D. & Hayes, S.C. (2010) Is it the symptom or the relation to it? Investigating potential mediators of change in acceptance and commitment therapy for psychosis. *Behavior therapy.* 41, 543-554 White, R.G., Gumley, A.I., McTaggart, J., Rattrie, L., McConville, D., Cleare, S, Mitchell, G. A feasibility study of Acceptance and Commitment Therapy for emotional dysfunction following psychosis. *Behaviour Research and Therapy (2011),* doi: 10.1016/j.brat.2011.09.003	
19	SH	**British Association for Behavioural and Cognitive Psychotherapies**	1	2.1	GH: The inclusion of psychosis is a good change to the guideline which previously was limited to schizophrenia (and related disorders). However, as other diagnostic conditions include symptoms of psychosis e.g. bipolar disorder, severe depression, PTSD, a tighter specification of what comes under the heading of psychosis should be included.	Thank you for your comment. The term psychosis will be clarified in the introduction. As a guideline already exists for Bipolar disorder, severe depression and PTSD they will not feature in this guideline.
20	SH	**Bradford District Care Trust (National Institute for Mental Health in England)**	1	2.1 a	The inclusion of 'psychosis' in the title and content of this document is very welcome and will increase its acceptability, value and use. The term 'schizophrenia' remains problematic for many and academic debate continues about its usefulness.	Thank you for your comment which we will bear in mind.
21	SH	**British Psychological Society**		2.1 a	The BPS welcomes the widening of the scope to include Psychosis, and hope that this can open the way to help being available to individuals undergoing anomalous experiences without the need to accept labels perceived by some as stigmatizing, as such acceptance can adversely affect their mental health. We would like to draw NICE's attention to research: suggesting that acceptance of diagnosis can adversely	Thank you for your comments and references.

					affect self image (Harder 2006); on self stigmatization (Read *et al*,2006 and Lysaker *et al,* 2007); and to the literature on changing terminology, e.g. Insel *et al* (2010) and Kingdon *et al* (2008). Please also see comment 4 below, relating to stigma. *References:* Harder, S. (2006). Self image and outcome in first-episode psychosis, *Clinical Psychology and Psychotherapy*, 13, 285-296. Insel T., Cuthbert B., Garvey M., Heinssen R, Pine D.S., Quinn K., Sanislow C. & Wang P. (2010). Research domain criteria (RdoC): toward a new classification framework for research on mental disorders, *American Journal of Psychiatry*,167(7):748-51. Cont'd/…. Kingdon, D., Vincent, Selvarej, Vincent, Sylvia, Kinoshita, Y. & Turkington, D. (2008). Destigmatizing schizophrenia: does changing terminology reduce negative attitudes? *Psychiatric Bulletin*, 32, (11), 419-422. Lysaker, P.H., Roe, D. & Yanos, P.T. (2007). Toward Understanding the Insight Paradox: Internalized Stigma Moderates the Association Between Insight and Social Functioning, Hope, and Self-esteem Among People with Schizophrenia Spectrum Disorders, *Schizophrenia Bulletin*, 33: 192-199. Read, J., Haslam, N., Sayce, L. & Davies, E. (2006). Prejudice and schizophrenia: a review of the 'mental illness is an illness like any other' approach, *Acta Psychiatrica Scandinavica*, 114, 303-318.	
22	SH	**ISPS**	4	2.1 a	We suggest adding "... and which may call for flexibility in services' response".	Thank you for your comment. This has been changed.
23	SH	**The Meriden Family Programme**	1	2.1 b	In the second sentence …."their carer and dependents" maybe this should specify the extended family to ensure that siblings are included and that the specific needs of children are addressed	Thank you for your comment**.** This has been changed.
24	SH	**British**	2	2.2 b	GH: Inpatient, secure forensic facilities and mild learning	Thank you for your comment. Inpatient

		Association for Behavioural and Cognitive Psychotherapies			disability services should also be covered here as they provide services to large numbers of people with schizophrenia and psychosis.	and secure settings are outside the scope of this guideline update, however people with mild learning difficulties will be covered (as they are in all our guidelines).
25	SH	**British Psychological Society**		2.2 b	The BPS believes that inpatient, secure forensic facilities and mild learning disability services should also be covered here as they provide services to large numbers of people with schizophrenia and psychosis.	Thank you for your comment. Inpatient and secure settings are outside the scope of this guideline update, however people with mild learning difficulties will be covered (as they are in all our guidelines).
26	SH	**Bristol-Myers Squibb Pharmaceuticals Ltd.**	1	2.2 c	While pharmacological treatments may not improve cognitive impairments associated with schizophrenia, they do have different effects on worsening cognitive impairment via sedating properties.	Thank you for your comment. We have amended the first sentence in this section to include: “usually have limited effects...”
27	SH	**Otsuka Pharmaceuticals (UK) Ltd.**	1	2.2 c	While pharmacological treatments may not improve cognitive impairments associated with schizophrenia, they do have different effects on worsening cognitive impairment via sedating properties. This is particularly true in the long term when a maintenance antipsychotic medication is needed. Moreover, impairment of cognitive functions induced by long term sedating agents may limit the impact/benefit of other concomitant non pharmacological interventions.	Thank you for your comment. We have amended the first sentence in this section to include: “usually have limited effects...”
28	SH	**British Psychological Society**		2.2 f	In order to ensure equality of opportunity regarding ethnicity and belief, we recommend that culturally aligned approaches to conceptualization and treatment of psychosis be considered. The revised guidelines note the problem of divergent explanatory models, presumably a contributory factor to the poor engagement with services by some minority groups, leading to over representation in admissions under section of the Mental Health Act. More specifically, a trend towards more spiritual and religious interpretations has been found among members of	Thank you for the comment and references. It is mandatory for us to assess equality issues regarding access to care and this will be discussed when looking into attaining good outcomes for service users in relation to their engagement with services and experience of care.

					some minority groups experiencing psychotic symptoms. We recommend attention to approaches sensitive to such cultural issues, e.g. Rathod *et al* (2010), Naeen *et al* (2011) and Clarke (2010). *References:* Clarke, I. (2010). 'What is Real and what is not': Towards a Positive Reconceptualisation of Vulnerability to Unusual Experiences. In I.Clarke, Ed. *Psychosis and Spirituality: consolidating the new paradigm.* (2nd Edition) Chichester: Wiley. Naeen, F., Waheed, W., Gobbi, M., Ayub, M. & Kingdon, D. (2011). Preliminary evaluation of culturally sensitive CBT for depression in Pakistan: Findings from developing culturally-sensitive CBT project (DCCP). *Behavioural and Cognitive Psychotherapy*, 39, 165-173. Rathod, S., Kingdon, D. Phiri, P. & Gobbi, M. (2010). Developing culturally sensitive cognitive behaviour therapy for psychosis for ethnic minority patients by exploration and incorporation of service users' and health professionals' views and opinions, *Behavioural and Cognitive Psychotherapy,* 38, 511-535.	
29	SH	**The Meriden Family Programme**	2	2.2 f	Could information be included on people from Asian communities accessing services be included. We are aware that there are issues with access and engagement with services.	Thank your comment we are committed to equality and equity of service provision. Issues of minority cultures have been included in the previous guideline and will be reviewed in this update.
30	SH	**RCGP Expert Resource: Clinical Innovation and research**	1	2.2 f	I think for psychosis and any mental health condition we have to look at the reasons for higher rates of admission of people from certain ethnic minorities for instance the mention about higher rates of compulsory admission in Afro-Carribeans. Racial inequality, access to health and cultural stereo-types may well be potential reasons for this and we need to a) accept they exist b) highlight them during training of health professionals and c) find ways to combat this bias which those of us who have worked in mental health all recognise. In the late 80s and early 90s this racial bias was an	Thank you for your comment. We agree with your concerns and this will be considered within the discussion on engagement with services and experience of care.

					"accepted" bias within the health service. I think things have changed recently and people from certain religious and ethnic backgrounds are now very often discriminated against so I think we need to have ways to increase tolerance of people from all faiths. These people are often stigmatised in receiving psychiatric services.	
31	SH	**British Psychological Society**		2.2 g	The BPS welcomes the identification of stigma as a social issue prejudicial to recovery. In addition to comments relevant to stigma made in (comment 1 above), we recommend attention to the research literature comparing diagnosed and undiagnosed groups reporting comparable anomalous experiences (e.g. Brett *et al,* 2009, Brett *et al,* 2007 and Heriot-Maitland *et al,* 2011). Cont'd/… Heriot-Maitland concludes: "*It is not the Out of the Ordinary Experience (OOE) itself that determines the development of a clinical condition, but rather the wider personal and interpersonal contexts that influence how this experience is subsequently integrated….. clinical implications for the validation and normalization of psychotic-like phenomena are proposed"*. The same arguments occur in service user experience-based literature (e.g. May, 2011) This research strand raises but does not fully answer the question: 'does the better adaptation to the same type of experiences revealed in this literature result from the undiagnosed group having more benign and easily managed symptoms, or does the negative impact of trauma and effect on self image of service contact exacerbate symptoms'? If the latter were robustly evidenced, there would be implications for socialization into the service and treatment approaches. *References:* Brett, C.M.C., Johns, L., Peters, E. & McGuire, P. (2009). The role of metacognitive beliefs in determining the impact of anomalous experiences: A comparison of help-seeking and non-help-seeking groups of people experiencing psychotic-like anomalies. *Psychological Medicine*, 39, 939-	Thank you for the references.

					950. Brett, C.M.C., Peters, E.P., Johns, L.C., Tabraham P., Valmaggia, L.R. & McGuire P. (2007). Appraisals of Anomalous Experiences Interview (AANEX): a multidimensional measure of psychological responses to anomalies associated with psychosis. *British Journal of Psychiatry*, 191, 23-30. Heriot-Maitland, C., Knight, M. & Peters, E. (2011 in press). A qualitative comparison of psychotic-like phenomena in clinical and non-clinical populations. *British Journal of Clinical Psychology*. doi: 10.1111/j.2044-8260.2011.02011.x. May, R. (2011). Relating to alternative realities. In M.Romme and S. Escher (Eds.), *Psychosis as a personal crisis: an experience-based approach* (pp. 140-152).	
32	SH	**The Meriden Family Programme**	3	2.2 g	In the second sentence..." the treatments they receive" we are not sure what this means. Should there be a specific mention of the limited availability of psychological treatments for example family interventions and CBT?	Thank you for your comment. This is intentionally non-specific as this sets the context of this update rather than defining the content of the guideline.
33	SH	**Royal College of Psychiatrists**	4	3.1	As part of minority group covered the scope should include looking at evidence relating to psychosis in adults with Learning Disabilities and Adults with autism spectrum conditions.	Thank you for your comment, however this falls outside of the scope remit and a specific guideline for adults with autism is currently being developed.
34	SH	**British Association for Behavioural and Cognitive Psychotherapies**	5	3.1.1 a	GH: The population to be covered includes a clinical working diagnosis of psychosis (needs to be defined better) or schizophrenia, including schizoaffective disorder and delusional disorder. The clinical working definition of psychosis should be defined better (see comment 1 above)	Thank you for your comment. We agree and both terms will be defined at length in the introduction of the guideline.
35	SH	**The Meriden Family Programme**	4	3.1.1 a	First sentence…"and those with a diagnosis of schizophrenia" people entering early psychosis services may not have an established diagnosis of schizophrenia, it may be referred to as psychosis. Is this will this be covered in the scope?	Thank you for your comment. People with psychosis or the early diagnostics of schizophrenia will be covered in the guideline.

36	SH	**ISPS**	5	3.1.1 b	This specification of early intervention services is a helpful clarification.	Thank you for your comment.
37	SH	**British Association for Behavioural and Cognitive Psychotherapies**	6	3.1.2	GH: Other groups who are excluded from the guideline who may have psychotic symptoms should be defined here e.g. severe depression, grief reaction, PTSD, those with neurological conditions who are experiencing psychotic symptoms	Thank you, the scope has been amended to exclude people with transient psychotic symptoms.
38	SH	**The Meriden Family Programme**	5	3.1.2 c	We have concern that not addressing or including substance misuse will have an impact on a large number of people	Thank you for your comment; we appreciate your concern, however a separate guideline on psychosis and substance misuse has recently been published.
39	SH	**Rethink Mental Illness**	2	3.2	We recommend that there should be a guideline for treatment of psychosis in forensic services.	Thank you for your comment. As stated in 3.2 b) the guideline will be relevant to the sectors but we will not be specifically examining the evidence in this area in detail. If you wish to recommend to NICE to develop a guideline specifically for forensic services please visit this link http://www.nice.org.uk/getinvolved/topicselection/topicselection.jsp
40	SH	**Royal College of Nursing**	3	3.2	Inpatient care needs to be included. Whilst specific evidence for the treatment of this condition may be sparse the guidance should reflect the impact of new evidence in other areas. For example the use of peer support workers is associated with inpatient settings (3.3.1 a)	Thank you for your comment. Inpatient and secure settings are outside the scope of this guideline update.
41	SH	**The Princess Royal Trust for Carers**	1	3.2	Our comments are as follows: as the Triangle of Care has been included in No Health without Mental Health as the key good practice guidance for mental health provision in relation to the inclusion of carers this guide should be	Thank you for your comment. We affirm the important role of carers, the delivery of care will be discussed at length

					considered when exploring the settings for the scope of this piece of work.	throughout the development process and should it be decided that the Triangle of Care is the best approach then it will be included in the guideline.
42	SH	**British Association for Behavioural and Cognitive Psychotherapies**	7	3.2 a	GH: Inpatient, secure and mild learning difficulty services should be included here	Thank you for your comment. Inpatient and secure settings are outside the scope of this guideline update, however people with mild learning difficulties will be covered (as they are in all our guidelines).
43	SH	**British Psychological Society**		3.2 a	The BPS recommends that inpatient, secure and mild learning difficulty services should be included here.	Thank you for your comment. Inpatient and secure settings are outside the scope of this guideline update, however people with mild learning difficulties will be covered (as they are in all our guidelines).
44	SH	**AstraZeneca UK**	2	3.3.1	We agree with the key issues that will be covered in the update to the clinical guideline, however as highlighted in our response to the earlier guideline review consultation (June 2011) we believe that the review should include an update on pharmacological interventions, given the emergence of new data since the last guideline was published in 2009, especially in relation to the specific licence indications of antipsychotic medications.	Thank you for your comment; however in the review of the evidence it was concluded that there is not sufficient new evidence to update the guideline recommendations about pharmacological interventions at this time. The review for a need of an update followed NICE's processes and was subject to consultation.
45	SH	**Bradford District Care Trust (National Institute for Mental Health in England)**	2	3.3.1	Reviewing the evidence for effective service models is also very welcome. The means by which treatments and interventions are delivered plays a huge part in their effectiveness. There is understandable pressure to organise services in the least costly way currently, but this risks being a false economy if effectiveness is compromised. Evidence has accumulated over the last ten years and an evidence base supported by NICE would be	Thank you for your comment. Members of the GDG will be aware of these crucial issues. We do not at this stage know how many RCT's look at these issues, but once we have reviewed any relevant evidence, we will consider them in our recommendations as appropriate.

					extremely helpful to commissioners and service providers and could be linked to pathways and packages. Although this guideline will not consider children's services, it would be helpful to identify the particular needs of younger adults (under 25) and consider the particular service delivery features necessary for effective care and treatment in this age group.	A guideline for children under 18 with Schizophrenia is currently under development. This guideline will look at services for those over 18.
46	SH	**British Association for Behavioural and Cognitive Psychotherapies**	4	3.3.1	TM: I assume 'The psychological management of previous trauma' should be 3.3.1.f, and, therefore, is within the scope. If so, could this not also include post-diagnosis trauma?	Thank you for your comment – this has been corrected. The psychological management of previous trauma will be included under section 3.3. 1 f. Post-diagnosis trauma is dealt with by the NICE guideline on Post Traumatic Stress Disorder, and therefore not covered by this guideline.
47	SH	**Royal College of Psychiatrists**	3	3.3.1	Endorse the need to review the evidence of service models, especially assertive outreach, early intervention and crisis response team, comparing these to care as usual by a community mental health team.	Thank you for your comment.
48	SH	**South London & Maudsley NHS Foundation Trust**	7	3.3.1 & 4.1.1	The anticipated coverage of the management recommendations & quality standards is very broad, and this update will be a very significant undertaking. No clear justification for each component to be reviewed is given in the introduction. The new evidence justifying review for each area should be referred to in order for stakeholders to comment on the necessity of review.	Thank you for your comment. The justification for the update is included in the review of the need for an update, carried out by NICE which was subject to consultation. Please see comment number: 17
49	SH	**British Psychological Society**		3.3.1 a	We welcome the inclusion of low intensity interventions in this scope, especially as it recognises individual difference in response to different interventions. By promoting variety of provision, such variation can be accommodated. It would also be useful to include telephone support, computerised and email support at this point.	Thank you for your helpful advice which will be considered by the GDG.
50	SH	**British Association for**	8	3.3.1 a	GH: Also could include telephone support, computerised and email support here	Please see the comment above.

		Behavioural and Cognitive Psychotherapies				
51	SH	**South London & Maudsley NHS Foundation Trust**	4	3.3.1 a	'Low-intensity' interventions – a distinction should be made between intensity of the therapeutic intervention (the level of complexity of the therapy being delivered and the training of the professional delivering it) and resource intensity (the need for care determined by the service user's presentation) – as both aspects of provision are being reviewed.	Thank you for your comment. Low intensity refers to the intensity (amount and complexity) of an intervention, not on how it is delivered in different settings. The GDG, with advice from IAPT SMI, will try to be clear about what will be included and excluded by this phrase.
52	SH	**The Meriden Family Programme**	6	3.3.1 b	Will the delivery of family interventions be included here? It would be useful to have guidelines services and teams on the effective implementation and delivery of recommended interventions. We know from our work that clinical staff are not delivering interventions even when they have the core skills.	Thank you for the comment. Family interventions were included in the 2009 update and will not be subject to update in this guideline. Implementation issues will be looked at via the QS process.
53	SH	**The Princess Royal Trust for Carers**	2	3.3.1 b & c	Our comments are as follows: service level interventions and the teams delivering these interventions cannot be looked at in isolation when carers play such a large part in any kind of intervention. It is crucial to look at the role of carers as well as the support they need to do this as part of the professional team and to ensure the intervention is being applied to its best level.	Thank you for your comment. We agree with your comment, and all of our guidelines are sensitive to the contribution of the carers. However we will not be focusing in this update, on specific interventions for carers.
54	SH	**British Association for Behavioural and Cognitive Psychotherapies**	9	3.3.1 b	GH: Inpatient, secure and mild learning disability services could be included here TM: Given that there is evidence that the efficacy of teams such as Early Intervention Teams is related to their capacity to deliver CBT and behavioural family interventions, the components of services should also be considered.	Inpatient and secure settings are outside the scope of this guideline update, however people with mild learning difficulties will be covered (as they are in all our guidelines). Thank you for your comment. We agree that this evidence is persuasive. This issue will be considered by the guideline development group. However, we will not be covering psychological interventions in this update.

55	SH	**British Psychological Society**		3.3.1 b	At a time when teams are being reconfigured, we recommend that the unique contribution of Early Intervention in Psychosis teams, through timely engagement and offering a range of individually tailored interventions to the service user and their social system, be recognised and considered within the review.	Thank you this will be considered at the guideline meetings.
56	SH	**British Psychological Society**		3.3.1 b	The BPS believes it would be useful to include inpatient, secure and mild learning disability services here.	Inpatient and secure settings are outside the scope of this guideline update, however people with mild learning difficulties will be covered (as they are in all our guidelines).
57	SH	**ISPS**	6	3.3.1 b	It would be helpful to make explicit mention here of inpatient services. Standards of care in inpatient mental health settings continue to be of concern to policy makers and care quality commissioners following the results of national and local audits and service user-led satisfaction surveys.[1] Much of the concern is around patient experience, with service users reporting a lack of regular, meaningful engagement with hospital ward staff; specifically, service users feeling they are not treated with due respect, dignity and understanding. Negative symptoms of schizophrenia are often associated with complex difficulties in communicating and relating interpersonally with others. To this end, the usefulness of the feedback provided by the arts therapists (art, dance movement/body oriented, drama and music therapists), in helping ward-based staff understand the bridge from non-verbal to verbal dialogue, which these therapies can provide for service users presenting with challenging behaviours, should perhaps be considered specifically as a component within acute multidisciplinary teamwork, in addition to the existing general recommendation that these therapies be offered to all people with schizophrenia, particularly for the alleviation of negative symptoms, and started either during the acute phase or later, including inpatient settings. [1] Relevant surveys can be found at www.cqc.org.uk and www.quality-health.co.uk	Thank you for your comment. We will be looking at the effectiveness of teams across a variety of settings. A number of issues you have referred to in relation to service user satisfaction have been covered in a guideline recently published called Service User Experience, which this guideline may make reference to. Regarding Arts therapy we are not updating psychological interventions in this update.
58	SH	**Rethink**	3	3.3.1 b	We welcome the inclusion of crisis houses in the scope,	Thank you for your comment to which we

		Mental Illness			particularly given recent bed closures across the country.	agree.
59	SH	**Royal College of Nursing**	4	3.3.1 b	The review of service level interventions is welcomed. Understanding the effects adherence to service fidelity and its relationship service costs and clinical outcomes is acutely important to service commissioners.	Thank you for your comment, we agree and this will be discussed.
60	SH	**British Psychological Society**		3.3.1 c	The BPS recommends that: The effect of psychological formulation on staff perceptions and efficiency of care planning be considered under this heading. While available and valued in clinical practice, research into this area is limited and to be encouraged. Berry *et al* (2009) have produced a pilot study. Team Environment, Team Structure, Team Processes and Individual Contribution that influence team effectiveness are reviewed under this heading as recommended by the British Psychological Society (2007). Psychological research evidencing the most effective ways of implementing guidelines is reviewed under this heading. The more precisely guideline behaviours are specified the more they are likely to be carried out (e.g. Michie & Johnston, 2004). *References:* Berry, K., Barrowclough, C. &Wearden, A. (2009). A pilot study investigating the use of psychological formulations to modify psychiatric staff perceptions of service users with psychosis. *Behavioural and Cognitive Psychotherapy*, 37, 39-48. British Psychological Society (2007) *New Ways of Working for Applied Psychologists in Health and Social Care – Working Psychologically in Teams*. BPS: Leicester. Michie, S. & Johnston, M. (2004). Changing clinical behaviour by making guidelines specific. *British Medical Journal,* 328, 343-345.	Thank you these points will be carefully considered.
61	SH	**ISPS**	7	3.3.1 c	It seems that a crucial element in effective multi-disciplinary team responses may be the extent to which an informed psychological attitude pervades the team's work as a whole (Aaltonen et al, 2011, and Seikkula et al, 2011). As well as	Thank you for your comments, these will be considered at the guideline development group meetings.

					psychological work thought of as a distinct activity, we think the recent evidence raises the question of ways in which training can enable a more psychologically responsive stance on the part of the service as a whole (ie, not only specialist psychological workers, but also a psychologically effective whole service). This would build on the advice in the 2009 Guideline that "psychoanalytic and psychodynamic principles may be considered to help healthcare professionals to understand the experience of people with schizophrenia and their interpersonal relationships". In keeping with comment 6 above, one would expect this to be at least as relevant to inpatient teams as to community-based ones. References: Aaltonen J, Seikkula J & Lehtinen K (2011) The comprehensive open-dialogue approach in Western Lapland: I. The incidence of non-affective psychosis and prodromal states. *Psychosis*, **3** (3), 179-191. Seikkula J, Alakare B & Aaltonen J (2011) The comprehensive open-dialogue approach in Western Lapland: II. Long-term stability of acute psychosis outcomes in advanced community care. *Psychosis*, **3** (3), 192-204.	
62	SH	**British Psychological Society**		3.3.1 d	The BPS welcomes the inclusion of interventions that improve the ability of people to work. We believe that supporting individuals who experience psychosis to live a valued life should be a priority aim of mental health services. Two issues that adversely affect the ability of individuals to return to work are: (a) problems with motivation to engage in psychological strategies to contain and cope with persisting psychotic symptoms; and (b) the linked issue of over-sedation and other side effects of medication that can interfere with employability. We would like to draw NICE's attention to the growing evidence base for three promising areas of psychotherapeutic practice that address these issues: Acceptance and commitment Therapy (ACT) in the	Thank you for your comment. We concur with your thoughts and will be discussing the issues and reviewing the evidence you have presented us with.

					treatment of psychosis. ACT uses mindfulness and acceptance techniques and encourages clients to reduce unhelpful struggle with psychological content to promote broadening of psychological flexibility and engagement in meaningful activities. Clients are supported to develop mindfulness skills to develop a present moment focused approach to distressing content. The explicit focus on valued living offers a useful platform from which to develop a motivational recovery-based intervention. (For the evidence base, please see comment 12 below) Cont'd/… Mindfulness group approaches for coping with psychotic symptoms similarly emphasize acceptance of symptoms, thus facilitating lower medication use and employability. Qualitative research (e.g. Goodliffe *et al*, 2010) as part of a broader research base (please see comment 13 below) evidences the broad acceptability of this approach and therefore its capacity to motivate, which is relevant to employability. Trials of Cognitive Behaviour Therapy for Psychosis for individuals not taking neuroleptic medication (for the evidence base, please see comment 14 below). *Reference:* Goodliffe, L. , Hayward, M., Brown, D., Turton, W. and Dannahy, L. (2010) 'Group person-based cognitive therapy for distressing voices: Views from the hearers', *Psychotherapy Research*, 20: 4, 447-461.	
63	SH	**Rethink Mental Illness**	4	3.3.1 d	We hope that any recommendations for this section also include occupational activity for those who cannot undertake paid work.	Thank you for your comment. Unpaid/ voluntary work and educational activity will be reviewed under this section.
64	SH	**ISPS**	8	3.3.2	We wonder if the heading here is the result of a layout mistake ("The psychological management of previous trauma. Key issues that will not be covered"). We take it that the heading should simply read "Key issues that will not be covered", and "The psychological management of previous trauma" was intended to feature in section 3.3.1.	Thank you for your comment and spotting an editorial error. The psychological management of previous trauma is in fact to lie under section 3.3.1 f). We recognise the importance of multi-

					On this assumption, the need to consider multi-disciplinary teams' psychological responsiveness and consistency, and their capacity to hear individuals' experience, are all the more pertinent.	disciplinary teams which will be examined in this section.
65	SH	**Royal College of Psychiatrists**	5	3.3.2	Given the title of this scope is 'core interventions in the treatment and management of psychosis in primary care puzzled that this excludes looking at pharamacological treatment and interventions in primary care. This is surely a guideline on models of service delivery and non-pharmacological secondary interventions	The original schizophrenia guideline was titled 'Core interventions...' this was updated and published in 2009, where pharmacological and psychological interventions were updated but not service level interventions, i.e. team level interventions (normally still based in secondary care), which will be reviewed now.
66	SH	**South London & Maudsley NHS Foundation Trust**	5	3.3.2	The psychological management of previous trauma – again, we welcome this, as we believe there is confusion over what interventions are carried out under the general heading of 'trauma work', however, greater clarity is needed as to which psychological interventions will be reviewed and how this will interface with the psychological therapy recommendations in the existing guidance.	Some of this detail will be evaluated by the group as the evidence will be examined. The integration of any evidence for the psychological management of previous trauma, with previous recommendations for existing therapies for psychosis will be very carefully considered.
67	SH	**British Psychological Society**		3.3.2 a	While noting the intention to exclude most psychological interventions from this scope, the BPS urges reconsideration of this in light of the three areas of compelling and developing evidence base (comments 12, 13 and 14 below), as they offer: a new generation of possibilities for effective psychological intervention for psychosis; enhanced motivating and engagement power; and provide the possibility of engaging a wider spectrum of the service user group as partners in their own recovery. We have already mentioned Acceptance and Commitment Therapy (ACT), mindfulness based groups and medication-free trials in relation to employability (see comment 10 above). A fuller breakdown of the evidence follows under comments 12, 13 and 14 below.	Thank you for your comment. We have not been asked to update psychological interventions in this guideline but we will suggest that new emerging therapies be included in a future update. Your comments are helpful and have been noted.

68	SH	**British Psychological Society**		3.3.2 a	The BPS recommends that Acceptance and Commitment Therapy (ACT) be included (please see comment 11 above). ACT has shown encouraging results clinically in relation to psychosis in terms of reducing relapse rates (Bach & Hayes, 2002; Gaudiano & Herbert, 2006a). Published clinical case studies provide an in depth account of the nature and process of ACT as an intervention for psychosis (Bloy, Oliver & Morris, 2011). A recent feasibility study has demonstrated the potential for ACT to reduce depression, negative symptoms and usage of crisis services among service users who have experienced psychosis (White *et al,* 2011). Recent research has also investigated the importance of acceptance and mindfulness processes as mechanisms of action in psychological treatments for psychosis (Gaudiano and Herbert, 2006b; Gaudiano, Herbert and Hayes, 2010). Thus, ACT offers a viable alternative to the traditional CBT model of therapy for psychosis: ACT's therapy goals of promoting acceptance, psychological flexibility and valued living are appropriate to the often long term nature of psychosis, fit well with a recovery framework, and represent a helpful shift Cont'd/… from a more traditional approach in which symptom elimination would be viewed as the key criteria for measuring treatment effectiveness. *References:* Bach, P. & Hayes, S.C (2002). The use of acceptance and commitment therapy to prevent the rehospitalisation of psychotic patients: A randomized controlled trial. *Journal of Consulting and Clinical Psychology.* 70 (5) 1129-1139. Bloy, S., Oliver, J.E. & Morris, E. (2011). Using Acceptance and Commitment Therapy with people with Psychosis: A case study. *Clinical Case Studies.* published online 15 September 2011. doi: 10.1177/1534650111420863. Gaudiano, B.A. & Herbert, J. D. (2006a) Acute treatment of	Thank you for your comment. We have not been asked to update psychological interventions in this guideline but we will be submitting suggestions to NICE on new emerging therapies that may be included in a future update. Your comments are helpful and have been noted.

					inpatients with psychotic symptoms using Acceptance and Commitment Therapy: Pilot results. *Behaviour Research and Therapy.* 44, 415-437. Gaudiano, B.A. & Herbert, J.D. (2006b). Believability of hallucinations as a potential mediator of their frequency and associated distress in psychotic inpatients. *Behavioural and Cognitive Psychotherapy.* 34 (4) 497. Gaudiano, B.A., Herbert, J.D. and Hayes, S.C. (2010) Is it the symptom or the relation to it? Investigating potential mediators of change in acceptance and commitment therapy for psychosis. *Behavior therapy.* 41, 543-554. White, R.G., Gumley, A.I., McTaggart, J., Rattrie, L., McConville, D., Cleare, S, & Mitchell, G. (2011). A feasibility study of Acceptance and Commitment Therapy for emotional dysfunction following psychosis. *Behaviour Research and Therapy,* doi: 10.1016/j.brat.2011.09.003.	
69	SH	**British Psychological Society**		3.3.2 a	The BPS recommends that mindfulness based group approaches be included (please see comment 11 above). A growing body of research has demonstrated the beneficial effects of mindfulness groups for psychosis (Chadwick *et al,* 2005 and Chadwick *et al,* 2009). A recent, small scale, controlled replication study has produced good results (Langer *et al*, 2012). Person-Based Cognitive Therapy (PBCT) and mindfulness groups (Dannahy *et al,* 2011). The latter study evidenced significant improvement in general well-being, and reducing distress and voice omnipotence. Qualitative studies have further elucidated the process of such effects and demonstrated the acceptability and motivating elements of the approach (Abba *et al,* 2008 and Goodliffe *et al,* 2010). A randomised controlled trial is currently in progress promising a more secure evidence base for the approach in the near future. It is therefore recommended that this psychological approach be included in the scope.	Thank you for your comment. We have not been asked to update psychological interventions in this guideline but we will be submitting suggestions to NICE on new emerging therapies that may be included in a future update. Your comments are helpful and have been noted for this purpose.

					References: Abba, N., Chadwick, P., and Stevenson, C. (2008). Responding mindfully to distressing psychosis: A grounded theory analysis. *Psychotherapy Research*, 18, 77-87. Cont'd/… Chadwick, P., Hughes, S., Russell, D., Russell, I., and Dagnan, D. (2009). Mindfulness groups for distressing voices and paranoia: a replication and feasibility trial.*Behavioural and Cognitive Psychotherapy*, 37, 403-412. Chadwick, P., Newman-Taylor, K., and Abba, N. (2005). Mindfulness groups for people with psychosis. *Behavioural and Cognitive Psychotherapy*, 33, 351-359. Dannahy, L., Hayward, M.,Strauss, C., Turton, W., Harding, E. and Chadwick, P. (2011) Group person-based cognitive therapy for distressing voices: Pilot data from nine groups. *Journal of Behavior Therapy and Experimental Psychiatry*, 42, 111-116 Goodliffe, L. , Hayward, M., Brown, D., Turton, W. & Dannahy, L. (2010) 'Group person-based cognitive therapy for distressing voices: Views from the hearers', *Psychotherapy Research*, 20: 4, 447-461 Langer, A.I., Cangas, A.J., Salcedo, E. and Fuentes, B. (2012). Applying Mindfulness Therapy in a group of psychotic individiuals: a controlled study. *Behavioural and Cognitive Psychotherapy*, 40, 105-111.	
70	SH	**British Psychological Society**		3.3.2 a	The BPS recommends that the use of psychological interventions, such as CBT, in the absence of antipsychotic medication, be considered (please see comment 11 above). The potential harmful of effects of antipsychotic medication are now well established. Weight gain and extra-pyramidal side effects are reported by service users as reasons for discontinuing medication (Moncrieff *et al* (2009). Other serious effects include cardiovascular problems (Tandon *et*	Thank you for your comment. We have not been asked to update psychological interventions in this guideline but we will be submitting suggestions to NICE on new emerging therapies that may be included in a future update. Your comments are helpful and have been noted.

					al, 2008), increased risk of sudden cardiac death (Ray *et al,* 2009), and cerebral abnormalities (Ho *et al,* 2011). Up to 74% of service users discontinue their medication within 18 months, (Lieberman *et al,* 2005). There is also a question about effectiveness. One meta analysis (Leucht *et al*, 2009) reported that atypicals outperform placebos on the Positive and Negative Syndrome Scale (PANSS) by only 10 points (about 5%). Furthermore, choice of interventions is increasingly valued by patients, and indeed recommended by NICE. Owens *et al* (2008) reported that many inpatients retain treatment decision-making capacity, and service users report that they want their choices to include more than just medication (Warner *et al,* 2006). There is now an emerging literature that psychological interventions can be safe, acceptable and effective to service users, from case studies (Morrison, 1994, Hutton *et al*, 2012), to case series (Morrison, 2001; Christodoulides *et al,* 2008) to a recent open trial (Morrison *et al,* 2011). These are encouraging developments for health economic reasons and most importantly patient care, and as such would be a welcome inclusion to the guidelines. Cont'd/… *References:* Christodoulides, T., Dudley, R., Brown, S., Turkington, D., & Beck, A. (2008). Cognitive behaviour therapy in patients with schizophrenia who are not prescribed antipsychotic medication: a case series. *Psychology and Psychotherapy: Theory Research and Practice,* 81, 199-207. Ho, B., Andreason, N., Ziebell, S., Pierson, R. & Magnotta, V. (2011). Long term antipsychotic treatment and brain volumes: a long term longitudinal study of first episode schizophrenia. *Archives of General Psychiatry*, 68, 128-137. Hutton, P., Morrison, A.P. &Taylor, H. (2012). Brief Cognitive Behavioural Therapy for hallucinations: can it help people who decide not to take antipsychotic medication? A	

					case report. *Behavioural and Cognitive Psychotherapy*, 40,111-117. Leucht, S., Corves, C., Arbter, D., Engel, R., Li, C. & Davis, J. (2009). Second generation versus first generation antipsychotic drugs for schizophrenia: a meta analysis. *Lancet*, 373, 31-41. Lieberman, J., Stroup, T., McEvoy, J., Swatz, m., Rosenheck, R., Perkins, D., Keefe, R., Davis, S., Davis, C., Lebowitz, B., Severe, J. and Hsiao, J. (2005). Effectiveness of antipsychotic drugs in patients with chronic schizophrenia. *New England Journal of Medicine*, 353, 1209-1223. Moncrieff, J., Cohen, D. & Mason, J. (2009). The subjective experience of taking antipsychotic medication: a content analysis of internet data. *Acta Psychiatrica Scandinavica*, 120, 102-111. Morrison, A. (1994). Cognitive behaviour therapy for auditory hallucinations without concurrent medication: a single case. *Behavioural and Cognitive Psychotherapy*, 22, 259-264. Morrison, A. (2001). The interpretations of intrusions in psychosis: an integrative cognitive approach to hallucinations and delusions. *Behavioural and Cognitive Psychotherapy*, 29, 257-276. Morrison, A. P., Hutton, P., Wardle, M., Spencer, H., Barratt, S., Brabban, A., Callcott, P., Christodoulides, T., Dudley, R., French, P., Lumley, V., Tai, S.J. & Turkington, D. (2011). Cognitive therapy for people with a schizophrenia spectrum diagnosis not taking antipsychotic medication: an exploratory trial. *Psychological Medicine,* 1-8. Owens, G., Richardson, G., David, A., Szmuckler, G., Hayward, P. & Hotopf, (2008). Mental capacity to make decisions on treatment in people admitted to psychiatric hospitals: cross sectional study. *British Medical Journal*, 337, 448. Ray, W., Chung, C., Murray, K., Hall, K. & Stein, M. (2009). Atypical antipsychotic drugs and the risk of sudden cardiac death. *New England Journal of Medicine*, 360, 225-235.	

					Tandon, R., Belmaker, R., Gattaz, w., Lopez-Ibor Jr, J., Okasha, A., Singh, B., Stein D., Olie, J., Fleischhacker, W. &Moeller, H. (2008). World Psychiatric association Pharmacopsychiatry section statement on comparative effectiveness of antipsychotics in the treatment of schizophrenia. *Schizophrenia Research,* 100, 20-38. Cont'd/… Warner, L., Mariathasan, J., Lawton-Smith S. & Samele, C. (2006). *A review of the literature and consultation on choice and decision making for users and carers of mental health and social care services.* King's Fund/Sainsbury Centre for Mental Health: London.	
71	SH	**ISPS**	9	3.3.2 a	Might this update offer a timely opportunity to consider specifically the question: are there circumstances and categories of patient where neuroleptic medication is not helpful (Lehtinen et al, 2000), and where psychological intervention can be effective in its absence (Brabban et al, 2011; Bechdolf et al, 2012)? References: Lehtinen V, Aaltonen J, Koffert T, Rakkoloinen V & Sylvalahti E (2000) Two year outcome in first-episode psychosis treated according to an integrated model. Is immediate neuroleptisation always needed? *European Psychiatry*, **15**, 312-320. Brabban, A., Callcott, P., Christodoulides, T., Dudley, R., French, P., Lumley, V., Tai, S.J. and Turkington, D. (2011). Cognitive therapy for people with a schizophrenia spectrum diagnosis not taking antipsychotic medication: an exploratory trial. *Psychological Medicine,* 1-8. Bechdolf A, Wagner M, Ruhrmann S et al. (2012) Preventing progression to first-episode psychosis in early initial prodromal states. *British Journal of Psychiatry*, **200** (1).	Thank you for your comment we will not be updating pharmacology.
72	SH	**Rethink Mental Illness**	5	3.3.2 b	We suggest that the scope is extended to include primary care, as the interface between primary care and secondary care is currently weak. People may be managed in primary care and therefore recommendations and guidance on	Thank you for your comment. Both primary care and secondary care were reviewed in the previous guideline. This may however be reviewed in the Quality Standards – the

					referral and access to specialist services would be valuable.	proposed areas of care includes care across settings and continuity of care.
73	SH	**ISPS**	10	3.3.2 d	We would favour an adjustment to the wording to "The exclusive management of affective conditions where they do not interact with psychotic symptoms, or psychotic levels of social functioning".	There is now some good evidence that affective states may precede and subsequently interact with symptoms of psychosis and social functioning. The phrase was meant to exclude affective disorders that do not lead to such difficulties.
74	SH	**British Association for Behavioural and Cognitive Psychotherapies**	10	3.3.2 e	TM: There is recent evidence regarding the use of psychosocial treatments in people who do not take antipsychotics, which may be worth examination and is not considered in the main adult guideline	Thank you but we will not be updating either pharmacological or psychological interventions, or their lack in this update. We will ask NICE to review it in a future update..
75	SH	**West London Mental Health NHS Trust**	1	3.3.2 e	Our comments are as follows the exclusion of strategies for non - treatment responsive schizophrenia is disappointing.	Strategies for non-response to treatment were covered in the 2009 update of the guideline. They will not be covered in this guideline other than at service level interventions.
76	SH	**British Association for Behavioural and Cognitive Psychotherapies**	3	3.4	TM: Given that 2g mentions the high levels of stigma experienced, and that some of this may be related to treatment, it would be useful to examine the evidence for treatments aimed at reducing stigma as a primary outcome, and examine evidence regarding symptom-focused treatments that measure stigmatisation as a secondary outcome.	Thank you for your comment. We agree that stigma is a particular problem and it is covered in brief in our previous SUE guideline. However we will not be addressing it in this guideline.
77	SH	**South London & Maudsley NHS Foundation Trust**	3	3.4 & 4.1.1 d	The range of outcomes to be considered is broad and it is good to see service user and caregiver experience included. The inclusion of work and meaningful activity as outcomes is also welcome. The measurement of 'recovery' will need some clarification - days in recovery refers to symptomatic, rather than personal recovery, and how personal recovery will be defined (or, indeed, whether it can be defined) from the	Thank you for your comment. A definition of recovery will be included.

					remaining outcome measures will need specification.	
78	SH	**Bradford District Care Trust (National Institute for Mental Health in England)**	3	3.4	Linking outcomes to both treatments and the key aspects of teams delivering services is to be applauded. You have included a comprehensive list of outcome domains in section 3.4. You might consider adding offending behaviour, substance misuse and suicide/self harm.	Thank you for your suggestion.
79	SH	**British Association for Behavioural and Cognitive Psychotherapies**	11	3.4	GH: Main outcomes should also include positive outcomes e.g. positive impacts of symptoms, well being. Self esteem and stigma could also be covered. TM: Could the outcomes include internalised stigma and perceived discrimination, given 2g?	Thank you for your comment. The outcomes you refer to are broad and encompass all the issues you raise, especially under quality of life, functioning and symptom measures. The GDG will decide on the specific outcomes to be regarded as primary once the GDG have met. Internalised stigma and perceived discrimination are complex issues which are not within themselves easily measurable. They are nevertheless, important but we are unable to cover them in this guideline.
80	SH	**British Psychological Society**		3.4	The BPS recommends that main outcomes also includes positive outcomes e.g. positive impacts of symptoms, well being. Self esteem and stigma could also be covered.	The outcomes you refer to are broad and encompass all the issues you raise, especially under quality of life, functioning and symptom measures. The GDG will decide on the specific outcomes to be regarded as primary once the GDG have met.
81	SH	**ISPS**	11	3.4	Within the list of main outcomes, we would favour individuals' sense of 'personal meaning' (related to, but wider than, 'meaningful activity') near or at the top of the list.	Thank you for your comment. The order in which the outcomes are labelled is not meant to imply their level of importance.
82	SH	**Rethink Mental Illness**	6	3.4	We suggest that a social capital outcome measure, reflecting relationships, networks etc. is included in this section.	Elizabeth please advise Thank you for your comment. We have included quality of life as an outcome measure. We will also consider issues of

						wellbeing.
83	SH	**Royal College of Nursing**	5	3.4	The guideline scope has captured outcomes that reflect change in physical, social and psychological functioning. There is increasing interest in recovery and well being based measures which are to some extent captured under quality of life and which quality of life has a robust evidence base. However inclusion of recovery and well being measures will reflect policy and practice change.	Thank you for your comments we will pass your suggestions to the guideline development group.
84	SH	**South London & Maudsley NHS Foundation Trust**	8	3.4	A new set of outcomes is being considered for the interventions which are to be reviewed. The impact of interventions which are not being reviewed (psychological interventions other than CRT and around managing previous trauma; medication) on the new set of outcomes should also be considered.	Thank you for your comments we will pass your suggestions to the guideline development group.
85	SH	**The Meriden Family Programme**	7	3.4	Should the experiences of family and other carers be included as an outcome? We feel that it would be good if it was as this will provide a broad perspective on total health care.	Thank you for your comment. This is included as an outcome under 3.4g.
86	SH	**The Princess Royal Trust for Carers**	3	3.4	Our comments are as follows: the outcomes for carers must be embedded and integrated into the outcomes for service users as the two are integrally linked.	Thank you for your comment. We agree that the role of the carer is vital. The outcomes for service users and carers are referred to in the scope in 3.4f (for service users) and in 3.4g (for carers).
87	SH	**Bristol-Myers Squibb Pharmaceuticals Ltd.**	2	3.5 and 4.2	We feel it is important to ensure that the impact of physical health is considered as part of the clinical and cost-effectiveness evaluation. A holistic approach should be adopted, as well as evaluating the impact on other parts of the NHS. Physical health impacts other key outcomes being considered, i.e., quality of life, social functioning, employment, and service user experience, which further increase the long term burden on health care services. Prioritising quality statements relating to therapies that cause minimal impact on physical health (and weight gain) would help ensure clinical and cost-effective way care.	Thank you for your comment. The physical health of the Service User will be considered as a main outcome.
88	SH	**Otsuka Pharmaceuti**	2	3.5 and 4.2	We feel it is important to ensure that the impact on physical health is considered as part of the clinical and cost-	Thank you for your comment. We agree and

		cals (UK) Ltd.			effectiveness evaluation of medication. A holistic approach should be adopted, as well as evaluating the impact on other parts of the NHS. Poor physical health (both premorbidly and medication related) impacts other key outcomes being considered, i.e quality of life, social functioning, employment, service user experience and further increases the long term burden on health care services. Prioritising quality statements relating to therapies that cause minimal impact on physical health (weight gain, glucose and lipid levels) would help ensure clinical and cost-effective way care.	this will be evaluated during the development process.
89	SH	**Roche Products Ltd**	1	4.1	Roche welcomes the development of a quality standard for psychosis and schizophrenia in adults and supports the proposed scope for areas of care that will be considered. We would also request NICE and the Guideline Development Group (GDG) to consider including the following areas of care for quality statement development: Role of primary care: As point-of-access for many mental health service users, GPs should undergo improved training for mental health conditions to increase the speed and accuracy of diagnoses. Patients presenting in primary care with suspected psychosis or schizophrenia should be properly assessed and referred to appropriate secondary care if they meet specific clinical criteria set out in the NICE guideline. Physical healthcare including weight management, smoking cessation, alcohol misuse, and co-morbidities such as diabetes, cardiovascular disease, and hypertension. Patient choice and shared decision-making in treatment plans Support for carers and family Treatment adherence We request that equality of services for all ages be duly considered across the quality standard.	Thank you for your comment; and the suggested areas are covered in the key areas of care for consideration in the quality standard (for example, care across all phases, including continuity of care), subject to detailed discussion with the QS Topic Expert Group. All quality standards are required to consider equality issues during development (see the interim process guide at www.nice.org.uk)
90	SH	**AstraZeneca**	3	4.1.1	We agree with the areas of care of a patient's pathway set	Thank you for your comment; and the

		UK			out that will be used to inform the development of the quality statements. We believe that underpinning each of these clinicians should have access to a broad spectrum of treatment options in order to effectively individualise treatments to patient need. We continue to support the view that patient choice is an effective component of the delivery of high quality care in schizophrenia.	suggested areas are covered under the broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.
91	SH	**Central and North West London NHS Foundation Trust**	1	4.1.1	**Our comments are as follows:** Consider the inclusion of optimising physical health for people with schizophrenia and psychosis in the quality standard	Thank you for your comment and the suggested areas are covered under the broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.
92	SH	**Janssen**	1	4.1.1	We fully support NICE's reference to the Guidance on Medicines adherence NICE CG76. One of the key principles of adopting a patient-centred approach to treatment, must also recognise that non-adherence is common and that most patients are non-adherent sometimes. We would suggest that a specific quality statement on medicines adherence is included in the quality standards both as a core consideration at treatment decision phase and monitored regularly throughout the course of treatment.	Thank you for your comment; and the suggested areas are covered under the broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.
93	SH	**Roche Products Ltd**	2	4.1.1 a	Whilst service function remains broadly consistent throughout England, service configuration and management team names are regionally different. A number of different services offer care for psychosis and schizophrenia patients within primary and secondary care (and within the criminal justice system) but a patient's journey through these can be unclear and complex resulting in discontinuity of care. Patients may drop through the gaps or become disillusioned with the number of people they have to deal with and protocols they must pass through. We support development of quality measures that will improve continuity of care and would encourage the inclusion of primary, secondary, tertiary healthcare and	Thank you for your comment; and the suggested areas are covered under the broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.

					social care aspects, with particular attention to the patient journey between these phases. In addition we suggest that quality statements could be developed which ensure quality of information and communication between phases of care. For example patients (carers and/or family) should be supplied with appropriate information about the medications they are prescribed so that they can make an informed decision about their treatment. Such a step would also improve adherence. We recommend that a quality statement be developed to ensure patients have access to a key worker whose role is to provide continuity of care and support, offering referrals to psychological, health, and social services if required and liaison with other healthcare professionals, including the GP and specialist mental health services.	
94	SH	**The Meriden Family Programme**	8	4.1.1 a	Not sure from this statement if psychosis and substance misuse is being covered as an earlier statement indicates people with substance misuse are not being included.	Thank you for your comment; the quality standard will consider quality of care for people with psychosis and substance misuse, as described in the relevant NICE guideline**,** subject to detailed discussion with the QS Topic Expert Group.
95	SH	**Roche Products Ltd**	3	4.1.1 b	We suggest that early intervention and treatment adherence could be considered within the scope of initiating treatment (first episode), taking into consideration patient choice and shared decision-making about a patient's treatment plan. Evidence suggests a high prevalence of negative symptoms amongst schizophrenia patients[1, 2] and the association between negative symptoms and other outcomes[3, 4]. However services and treatment are usually set up to manage and care for the positive symptoms (usually because positive symptom manifestation is the reason for accessing services/initiating treatment). We would suggest the GDG consider any evidence around negative symptom	Thank you for your comment and the suggested areas are covered under the broad areas of care for consideration in the quality standard **,** subject to detailed discussion with the QS Topic Expert Group.

					assessment with the aim of potentially drafting a quality statement which address this aspect of schizophrenia. Bobes J, Arango C, Garcia-Garcia M et al. Prevalence of negative symptoms in outpatients with schizophrenia spectrum disorders treated with antipsychotics in routine clinical practice: findings from the CLAMORS study. *J Clin Psychiatry*. 2010; 71: 280-286 Waddington JL, Youssef HA, Kinsella A. Sequential cross-sectional and 10-year prospective study of severe negative symptoms in relation to duration of initially untreated psychosis in chronic schizophrenia. *Psychol Med*. 1995; 25: 849-857 Sachdev P, Hume F, Toohey P et al. Negative symptoms, cognitive dysfunction, tardive akathisia and tardive dyskinesia. *Acta Psychiatr Scand*. 1996; 93: 451-459 Selten JP, Wiersma D, van den Bosch RJ. Distress attributed to negative symptoms in schizophrenia. *Schizophr Bull*. 2000; 26: 737-744 Further, patients should have access to the treatment they require within an appropriately stipulated timeframe for the service/therapy requested.	
96	SH	**Roche Products Ltd**	4	4.1.1 d	The scope of 'Promoting recovery across all phases' should include promotion of meaningful activity and treatment adherence. Measures such as attendance to follow-up, could be taken to ensure patients are appropriately engaged with their treatment plan to improve compliance and concordance.	Thank you for your comment; and the suggested areas are covered under the broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.
97	SH	**The Meriden Family Programme**	9	4.1.1 b	In relation to referral of people with a diagnosis of schizophrenia, given that families often initiate the contact in the early phases, it is important that this is taken into account.	Thank you for your comment; and the suggested areas are covered under the broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.
98	SH	**The Meriden Family Programme**	10	4.1.1 j	Promoting recovery – we feel that recovery should be an important intervention for every person and not just those who are not responding to pharmacological or psychological treatments. We feel recovery should underpin and be an aim for intervention for every person and we should be guiding treating teams to consider recovery and people realising their potential as a key component of their intervention.	Thank you for your comment; and the suggested areas are covered under the broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.
99	SH	**ISPS**	12	4.1.1 b and	Often the way in which a diagnosis of schizophrenia is discussed with a patient itself constitutes a significant	Thank you for your comment and the suggested areas are covered under the

				4.1.2 b	positive or negative element in treatment. We feel strongly that some statement about how the discussion should be conducted should be included.	broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.
100	SH	**British Psychological Society**		4.2	Picking up some of the points made earlier the BPS recommends that a full estimation of costs both of treatment and of social outcomes are balanced. The following points will have bearing on motivation to engage, stigma, employability and therefore on economic outcome: (1.) (3.) (4.) (10.) (12.) (13.) (14.). We believe that the cost of medication and the effects of over-reliance on medication on social functioning and employability should be set against the costs of offering a greater variety of psychological treatments. This would probably (usually, but not necessarily) be accompanied by judicious use of medication, thereby providing choice to the service user. This calculation should take into account the longer-term benefits of engaging the individual as a participant in their own recovery and of conveying a more hopeful and less stigmatizing message about their condition from the outset.	Thank you for your comment and the suggested areas are covered under the broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.
101	SH	**Janssen**	2	4.2	We would request that the NICE Quality Standards encourage and measure the provision of choice for all patients with schizophrenia. Both commissioners and providers should demonstrate that they have made treatment choices bases on patient preference, value and cost effectiveness as opposed to acquisition costs as stated in NICE CG 82. NICE CG 82 “The results of the economic analysis demonstrated that drug acquisition costs do not determine the relative cost effectiveness of antipsychotic medications.”	Thank you for your comment; and the suggested areas are covered under the broad areas of care for consideration in the quality standard, subject to detailed discussion with the QS Topic Expert Group.
102	SH	**Bradford District Care Trust (National Institute for**	4	6.2	Should there be a reference to the U18 guideline for psychosis that is under development in the section about related guidance?	Thank you for your comment. The changes have been made to the scope.

		Mental Health in England)				
103	SH	**Roche Products Ltd**	5	6.2	In addition to considering related NICE Guidance we also suggest the GDG consider external data sources such as the National Audit of Schizophrenia (NAS), an initiative of the Royal College of Psychiatrist's Centre for Quality Improvement (CCQI). Available at: http://www.rcpsych.ac.uk/quality/nationalclinicalaudits/schizophrenia/nationalschizophreniaaudit.aspx NAS will enable clinicians who treat people with schizophrenia in the community to assess the quality of their prescribing of antipsychotic drugs and of their monitoring of service users' physical health. It will also support them to monitor service users' experience of treatment and its outcome plus carers' satisfaction with information and support. We believe the standards and indicators developed for this audit could be helpful in developing quality statements and used as a data source to measure outcomes.	Thank you for your comment. Your suggestion will get passed onto the guideline development group and the technical team.