

Rehabilitation in adults with complex psychosis and related severe mental health conditions

[I] Collaborative care planning

NICE guideline TBC

Evidence review

January 2020

Draft for Consultation

This evidence review was developed by the National Guideline Alliance which is part of the Royal College of Obstetricians and Gynaecologists

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#). All NICE guidance is subject to regular review and may be updated or withdrawn.

Copyright

© NICE 2020. All rights reserved. Subject to [Notice of Rights](#).

ISBN:

Contents

Contents	4
Collaborative care planning	6
Review question 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	6
Introduction	6
Clinical evidence	6
Economic evidence	6
Summary of studies included in the economic evidence review.....	7
Economic model.....	7
The committee’s discussion of the evidence.....	7
References.....	9
Appendices	11
Appendix A – Review protocols	11
Review protocol for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	11
Appendix B – Literature search strategies	12
Literature search strategies for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	12
Appendix C – Clinical evidence study selection.....	13
Clinical evidence study selection for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	13
Appendix D – Clinical evidence tables.....	14
Clinical evidence tables for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	14
Appendix E – Forest plots	15
Forest plots for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	15
Appendix F – GRADE tables	16
GRADE tables for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	16
Appendix G – Economic evidence study selection.....	17

Economic evidence study selection for review question 4.1: What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?.....	17
Appendix H – Economic evidence tables.....	18
Economic evidence tables for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	18
Appendix I – Health economic evidence profiles.....	19
Economic evidence profiles for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	19
Appendix J – Health economic analysis.....	20
Health economic analysis for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	20
Appendix K – Excluded studies	21
Excluded studies for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	21
Economic studies	21
Appendix L – Research recommendations	26
Research recommendations for review question: 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?	26
Appendix M – Evidence behind the reference recommendations.....	27

1 Collaborative care planning

2 Review question 4.1 What is the best way of involving people 3 with complex psychosis and related severe mental health 4 conditions, and their families and carers, in planning their 5 care collaboratively with practitioners and providers?

6 Introduction

7 Collaborative care planning is a central part of UK mental health practice, as people should
8 play a big part in deciding what happens to them. The aim of this review is to establish the
9 best way to involving people with complex psychosis and related severe mental health
10 conditions, and their families and carers, in planning their care.

11 Clinical evidence

12 A review of the clinical evidence was not conducted following a group decision by the
13 committee. Collaborative care planning is a well-established requirement of all care planning
14 in all UK mental health services, with substantial established guidance already in place.

15 The committee anticipated the available UK pool of evidence would be sparse, and agreed
16 the best approach would be to review the existing UK guidance and adopt, adapt or refer to
17 what is already in place.

18 A simple search was conducted by the reviewer on the NICE guidance website for all
19 guidelines related to the population and containing the words 'care planning'. Five relevant
20 guidelines were identified:

- 21 • NG53: Transition between inpatient mental health settings and community or care
22 home settings
- 23 • NG 86: People's experience in adult social care services: improving the experience of
24 care and support for people using adult social care services
- 25 • CG 136: Service user experience in adult mental health
- 26 • CG138: Patient experience in adult NHS services: improving the experience of care
27 for people using adult NHS services
- 28 • NG108: Decision-making and mental capacity

29 A total of 115 existing recommendations were identified in these publications related to care
30 planning - including family involvement and mental capacity. The committee reviewed them
31 all and agreed on the most relevant ones to adopt if they were suitable, or else adapt if
32 necessary. Where there were a cluster of several relevant recommendations that belonged
33 together the committee referred to these sections within the other guideline.

34 See Appendix M for a list of the existing recommendations that the committee agreed to
35 adopt, adapt, or refer to, and a summary of the supporting evidence behind these statements
36 as well as the committee's discussion of these recommendations.

37 Economic evidence

38 No review of the economic evidence was conducted, following the consensus of the
39 committee.

1 **Included studies**

2 A systematic review of the economic literature was conducted but no economic studies were
3 identified which were applicable to this review question.

4 **Excluded studies**

5 Studies not included in this review with reasons for their exclusions are provided in appendix
6 K.

7 **Summary of studies included in the economic evidence review**

8 No economic evidence was identified for this review (and so there are no economic evidence
9 tables).

10 **Economic model**

11 No economic modelling was undertaken for this review because the committee agreed that
12 other topics were higher priorities for economic evaluation.

13 **The committee's discussion of the evidence**

14 **Interpreting the evidence**

15 ***The outcomes that matter most***

16 The most critical outcome is that service users' care and treatment wishes should be sought
17 out and complied with by services. The other critical outcome is to uphold the statutory rights
18 of service users to advocacy, confidentiality and help with expressing themselves in
19 accordance with the Mental Capacity Act, the Equality Act, and the Care Act.

20 An important outcome was better collaboration with the family or other carers of the service
21 user – where appropriate. The other important outcome to the committee was that
22 practitioners and services would have a better idea of exactly what the law requires of them,
23 and what good practice is and where to look for further guidance.

24 ***The quality of the evidence***

25 Collaborative care planning is already established practice in all NHS mental health services.
26 Existing guidelines and legislation already determine that collaborative care planning should
27 be the norm, and set out how it should be done. As a result, the committee agreed that an
28 electronic search of evidence was not necessary on this topic. Instead it was agreed that the
29 most appropriate approach was to summarise the relevant existing guidance and legislation
30 for this population.

31 In cases where the recommendations pertained to the statutory rights of services users,
32 which practitioners and services are already obliged to comply with, the committee made
33 strong recommendations. Softer recommendations were formed based upon existing
34 guidelines designed to apply to a broader population such as 'NHS service users' or 'mental
35 health service users' which the rehabilitation population fall under. The current population is
36 already subject to these broader-targeted guidelines, but the committee and technical team
37 reviewed the underlying research to be certain about how relevant the supporting research
38 had been.

39 The details and evidence behind all recommendations adopted or adapted from other NICE
40 guidance is summarised in appendix M.

1 **Benefits and harms**

2 See appendix M for individual evaluations of the benefits and harms of the adopted and
3 adapted recommendations chosen from other NICE guidance.

4 The committee intended this section to bring together the legal requirements and existing
5 guidelines on collaborative care planning in rehabilitation and put them into one place for the
6 further reference of all. By doing so the committee hoped to increase awareness and practice
7 amongst services to uphold these rights.

8 First the committee wanted to emphasise the responsibility of staff to seek out and comply
9 with the treatment wishes of their service users, empowering them to recover and live their
10 life in the way they wish. The rehabilitation population is likely to have experienced an
11 extensive history of disempowerment because of past difficulties related to their symptoms
12 and various institutional treatment regimens. Working collaboratively may often involve
13 overcoming barriers to communication due to factors like language, knowledge and
14 understanding, disorganised or aphasic symptoms, and power imbalances. The committee
15 agreed they wanted to promote collaborative care and care planning, and encourage the use
16 of better communication tools and techniques and also advocacy.

17 The committee felt it was highly relevant to include a recommendation on decision making
18 and mental capacity in this guideline. They were aware this topic is already comprehensively
19 covered in NICE's guideline on decision-making and mental capacity so referred readers to
20 this guideline as a whole.

21 The committee considered the offer of independent advocacy to be a key aspect of
22 collaborative care-planning. A recommendation was identified in NICE's guideline on
23 people's experience in the adult social care services which worded this well. The Care Act
24 2014 sets the requirement for advocacy to be offered to all vulnerable groups (including
25 those in the current guidelines' population) and the wording of the existing recommendation
26 was considered succinct for this requirement. Therefore the committee adopted this
27 recommendation.

28 Family and other care figures may play a big part in a service user's life, and may also have
29 requirements or wishes of their own that staff should consider. They may also have insights
30 about the preferences of the service user which could contribute to better person centred
31 care. Establishing who the relevant people are in a service user's life and including them
32 appropriately in conversations about care, while remembering confidentiality and capacity,
33 was considered an important part of collaborative care planning. Because of a likely
34 extended history of social difficulties, relocations, homelessness etc. the committee noted
35 that the rehabilitation population is less likely to have close family and carers than other
36 populations.

37 Recommendations in the NICE guideline on service user experience in adult mental health
38 outline good practice on considerations for including families and carers in care-planning.
39 The recommendation applies to all people who use adult NHS mental health services. The
40 inclusion of families and carers in care planning can be challenging for the current population
41 because in some cases their inclusion may be greatly beneficial, but in other cases there
42 may be historical distress or some history of people taking advantage. The committee
43 reflected on the wording in the existing recommendation agreeing that it was highly relevant
44 to this area, applying readily to the current guideline.

45 The committee agreed that respect for confidentiality should be a standard part of a person's
46 care, including care planning that might involve family members or carers.
47 Recommendations in the NICE guideline on transition between inpatient mental health
48 settings and community or care home settings outlined key considerations around
49 confidentiality, based on evidence outlining potential problems amongst a population of
50 people with mental health problems and their families/carers generally. The committee

1 believed that these key considerations are directly applicable to the current population and
2 their family/carers and so adapted this recommendation.

3 Where families and carers are to be included in care-planning and care-giving the committee
4 wanted to adopt a recommendation which emphasised the need for them to have support of
5 their own. There was reasonable quality evidence that underlined recommendations in the
6 NICE guideline on transition between inpatient mental health settings and community or care
7 home settings, about the importance of support for the families and carers of people who use
8 adult inpatient mental health services. The committee felt this evidence was relevant and
9 fully applicable to the current guideline's population and so adopted this recommendation.

10 Families or other carers may be an important feature in a service user's care plans, and so
11 these carer's own needs are highly relevant. The Care Act 2014 specifies that all carers
12 should be offered a needs assessment, including those caring for people with psychosis in
13 rehabilitation. A recommendation was identified in the NICE guideline on dementia stating
14 the important considerations of this requirement succinctly so the committee decided to
15 adopt it

16 The committee wanted a recommendation that highlighted the importance of trying to
17 maintain community links when forming a care plan. They identified recommendation 1.1.6
18 from the NICE guideline on transition between inpatient mental health settings and
19 community or care home settings as a relevant recommendation that already applies to any
20 adult NHS mental health service users at times of transition.

21 The committee was aware that NICE's guidance on transition between inpatient mental
22 health settings and community or care home settings made recommendations (1.5.20 and
23 1.5.21) on a full list of considerations for a care plan at discharge. Rather than list all the
24 points again, the committee agreed to refer the reader to this guidance. They were satisfied
25 that the service users this guideline applies to fell under the remit of these broader
26 guidelines.

27 For every adopted or adapted recommendation the committee reviewed the background of
28 the guidance and used their experience to confirm its applicability to people with complex
29 psychosis and related severe mental health conditions using rehabilitation services.
30 However, in the case of the recommendation about discussing how much the person wants
31 their family or carer involved, the recommendation about respecting the rights and needs of
32 carers alongside the person's right to confidentiality, and the recommendation about enabling
33 the person to maintain links with their home community, the committee used their expertise
34 and experience to form a consensus about necessary wording changes to make the inpatient
35 guidance applicable to a rehabilitation context.

36 **Cost effectiveness and resource use**

37 The recommendations were formed based upon guidelines and statutory requirements which
38 are already established. They will not require resources or further cost except where these
39 are not already being followed. Some costs may be associated with additional training for
40 staff or with implementing better practice where necessary but the committee believed these
41 should already be accounted for and could be incorporated into the normal costs and
42 processes of a service's usual internal development.

43 **References**

44 **NICE 2011**

45 National Institute for Health and Care Excellence. Service user experience in adult mental
46 health: improving the experience of care for people using adult NHS mental health services.
47 NICE guidelines [CG136]. 2011.

1 **NICE 2016**

2 National Institute for Health and Care Excellence. Transition between inpatient mental health
3 settings and community or care home settings. NICE guidelines [NG53]. 2016.

4 **NICE 2018a**

5 National Institute for Health and Care Excellence. Decision making and mental capacity.
6 NICE guidelines [NG108]. 2018.

7 **NICE 2018b**

8 National Institute for Health and Care Excellence. People's experience in adult social care
9 services: improving the experience of care and support for people using adult social care
10 services. NICE guidelines [NG86]. 2018.

11 **NICE 2018c**

12 National Institute for Health and Care Excellence. Dementia: assessment, management and
13 support for people living with dementia and their carers. NICE guidelines [NG97]. 2018.

1 **Appendices**

2 **Appendix A – Review protocols**

3 **Review protocol for review question: 4.1 What is the best way of involving**
4 **people with complex psychosis and related severe mental health**
5 **conditions, and their families and carers, in planning their care**
6 **collaboratively with practitioners and providers?**

7
8 No clinical evidence search was conducted for this review question.

9

1 **Appendix B – Literature search strategies**

2 **Literature search strategies for review question: 4.1 What is the best way of**
3 **involving people with complex psychosis and related severe mental health**
4 **conditions, and their families and carers, in planning their care collaboratively**
5 **with practitioners and providers?**

6

7

8 No clinical evidence search was conducted for this review question.

9

10

1 **Appendix C – Clinical evidence study selection**

2 **Clinical evidence study selection for review question: 4.1 What is the best way of**
3 **involving people with complex psychosis and related severe mental health**
4 **conditions, and their families and carers, in planning their care collaboratively**
5 **with practitioners and providers?**

6

7 No clinical evidence search was conducted for this review question.

8

9

10

1 **Appendix D – Clinical evidence tables**

2 **Clinical evidence tables for review question: 4.1 What is the best way of involving**
3 **people with complex psychosis and related severe mental health conditions,**
4 **and their families and carers, in planning their care collaboratively with**
5 **practitioners and providers?**

6

7 No clinical evidence search was conducted for this review question.

8

9

1 **Appendix E – Forest plots**

2 **Forest plots for review question: 4.1 What is the best way of involving people with**
3 **complex psychosis and related severe mental health conditions, and their**
4 **families and carers, in planning their care collaboratively with practitioners and**
5 **providers?**

6

7 No clinical evidence search was conducted for this review question.

8

9

1 **Appendix F – GRADE tables**

2 **GRADE tables for review question: 4.1 What is the best way of involving people**
3 **with complex psychosis and related severe mental health conditions, and their**
4 **families and carers, in planning their care collaboratively with practitioners and**
5 **providers?**

6

7 No clinical evidence search was conducted for this review question.

8

9

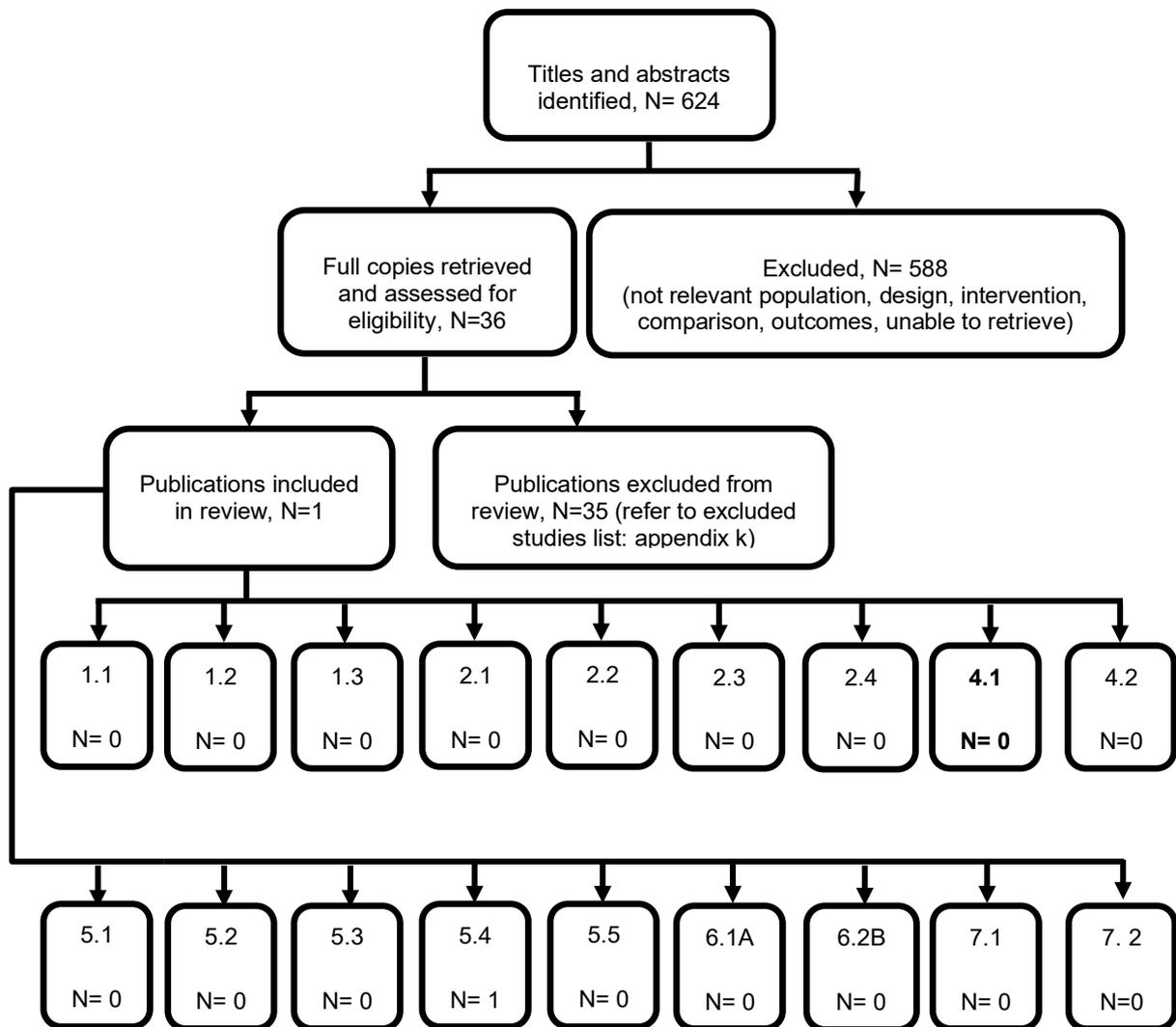
1 Appendix G – Economic evidence study selection

2 Economic evidence study selection for review question 4.1: What is the best way 3 of involving people with complex psychosis and related severe mental health 4 conditions, and their families and carers, in planning their care collaboratively 5 with practitioners and providers?

6 A global health economic literature search was undertaken, covering all review questions in
7 this guideline. However, as shown in Figure 1, no evidence was identified which was
8 applicable to review question 4.1.

9 **Figure 1: Health economic study selection flow chart**

10
11
12



1 **Appendix H – Economic evidence tables**

2 **Economic evidence tables for review question: 4.1 What is the best way of**
3 **involving people with complex psychosis and related severe mental health**
4 **conditions, and their families and carers, in planning their care collaboratively**
5 **with practitioners and providers?**

6 No evidence was identified which was applicable to this review question.

7

1 **Appendix I – Health economic evidence profiles**

2 **Economic evidence profiles for review question: 4.1 What is the best way of**
3 **involving people with complex psychosis and related severe mental health**
4 **conditions, and their families and carers, in planning their care collaboratively**
5 **with practitioners and providers?**

6

7 No evidence was identified which was applicable to this review question.

1 **Appendix J – Health economic analysis**

2 **Health economic analysis for review question: 4.1 What is the best way of**
3 **involving people with complex psychosis and related severe mental health**
4 **conditions, and their families and carers, in planning their care collaboratively**
5 **with practitioners and providers?**

6 No economic analysis was conducted for this review question.

7

1 Appendix K – Excluded studies

2 Excluded studies for review question: 4.1 What is the best way of involving 3 people with complex psychosis and related severe mental health conditions, 4 and their families and carers, in planning their care collaboratively with 5 practitioners and providers?

6 No clinical search was conducted for this review question.

7 Economic studies

8 A global economic literature search was undertaken for this guideline, covering all review
9 questions. The table below is a list of excluded studies across the entire guideline and
10 studies listed were not necessarily identified for this review question.

11 **Table 1: Excluded studies from the economic component of the review**

Study	Reason for Exclusion
Aitchison, K J, Kerwin, R W, Cost-effectiveness of clozapine: a UK clinic-based study (Structured abstract), British Journal of Psychiatry Br J Psychiatry, 171, 125-130, 1997	Available as abstract only.
Barnes, T. R., Leeson, V. C., Paton, C., Costelloe, C., Simon, J., Kiss, N., Osborn, D., Killaspy, H., Craig, T. K., Lewis, S., Keown, P., Ismail, S., Crawford, M., Baldwin, D., Lewis, G., Geddes, J., Kumar, M., Pathak, R., Taylor, S., Antidepressant Controlled Trial For Negative Symptoms In Schizophrenia (ACTIONS): a double-blind, placebo-controlled, randomised clinical trial, Health Technology Assessment (Winchester, England) Health Technol Assess, 20, 1-46, 2016	Does not match any review questions considered in the guideline.
Barton, Gr, Hodgekins, J, Mugford, M, Jones, Pb, Croudace, T, Fowler, D, Cognitive behaviour therapy for improving social recovery in psychosis: cost-effectiveness analysis (Structured abstract), Schizophrenia Research Schizophr Res, 112, 158-163, 2009	Available as abstract only.
Becker, T., Kilian, R., Psychiatric services for people with severe mental illness across western Europe: what can be generalized from current knowledge about differences in provision, costs and outcomes of mental health care?, Acta Psychiatrica Scandinavica, Supplementum Acta Psychiatr Scand Suppl, 9-16, 2006	Not an economic evaluation.
Beecham, J, Knapp, M, McGilloway, S, Kavanagh, S, Fenyo, A, Donnelly, M, Mays, N, Leaving hospital II: the cost-effectiveness of community care for former long-stay psychiatric hospital patients (Structured abstract), Journal of Mental Health J Ment Health, 5, 379-94, 1996	Available as abstract only.
Beecham, J., Knapp, M., Fenyo, A., Costs, needs, and outcomes, Schizophrenia Bulletin Schizophr Bull, 17, 427-39, 1991	Costing analysis prior to year 2000

Study	Reason for Exclusion
Burns, T., Raftery, J., Cost of schizophrenia in a randomized trial of home-based treatment, Schizophrenia BulletinSchizophr Bull, 17, 407-10, 1991	Not an economic evaluation. Date is prior to 2000
Bush, P. W., Drake, R. E., Xie, H., McHugo, G. J., Haslett, W. R., The long-term impact of employment on mental health service use and costs for persons with severe mental illness, Psychiatric ServicesPsychiatr Serv, 60, 1024-31, 2009	A United States costing analysis. Outcomes which relate to the Welfare system differs in substantial ways to a UK context.
Chalamat, M., Mihalopoulos, C., Carter, R., Vos, T., Assessing cost-effectiveness in mental health: vocational rehabilitation for schizophrenia and related conditions, Australian & New Zealand Journal of PsychiatryAust N Z J Psychiatry, 39, 693-700, 2005	Australian cost-benefit analysis - welfare system differs from UK context.
Chan, S., Mackenzie, A., Jacobs, P., Cost-effectiveness analysis of case management versus a routine community care organization for patients with chronic schizophrenia, Archives of Psychiatric NursingArch Psychiatr Nurs, 14, 98-104, 2000	Study conducted in Hong Kong. A costing analysis.
Clark, R. E., Teague, G. B., Ricketts, S. K., Bush, P. W., Xie, H., McGuire, T. G., Drake, R. E., McHugo, G. J., Keller, A. M., Zubkoff, M., Cost-effectiveness of assertive community treatment versus standard case management for persons with co-occurring severe mental illness and substance use disorders, Health Services ResearchHealth Serv Res, 33, 1285-308, 1998	Not cost-utility analysis. Cost-effectiveness analysis but does not consider UK setting. Date of study is prior to year 2000.
Crawford, M. J., Killaspy, H., Barnes, T. R., Barrett, B., Byford, S., Clayton, K., Dinsmore, J., Floyd, S., Hoadley, A., Johnson, T., Kalaitzaki, E., King, M., Leurent, B., Maratos, A., O'Neill, F. A., Osborn, D., Patterson, S., Soteriou, T., Tyrer, P., Waller, D., Matisse project team, Group art therapy as an adjunctive treatment for people with schizophrenia: a randomised controlled trial (MATISSE), Health Technology Assessment (Winchester, England)Health Technol Assess, 16, iii-iv, 1-76, 2012	Study not an economic evaluation.
Dauwalder, J. P., Ciompi, L., Cost-effectiveness over 10 years. A study of community-based social psychiatric care in the 1980s, Social Psychiatry & Psychiatric EpidemiologySoc Psychiatry Psychiatr Epidemiol, 30, 171-84, 1995	Practice has changed somewhat since 1980s - not a cost effectiveness study.
Garrido, G., Penades, R., Barrios, M., Aragay, N., Ramos, I., Valles, V., Faixa, C., Vendrell, J. M., Computer-assisted cognitive remediation therapy in schizophrenia: Durability of the effects and cost-utility analysis, Psychiatry ResearchPsychiatry Res, 254, 198-204, 2017	Cost effectiveness study, but population of interest is not focussed on rehabilitation for people with complex psychosis.
Hallam, A., Beecham, J., Knapp, M., Fenyo, A., The costs of accommodation and care. Community provision for former long-stay	Economic evaluation predates 2000. organisation and provision of care may have changed by some degree.

Study	Reason for Exclusion
psychiatric hospital patients, European Archives of Psychiatry & Clinical NeuroscienceEur Arch Psychiatry Clin Neurosci, 243, 304-10, 1994	
Hu, T. W., Jerrell, J., Cost-effectiveness of alternative approaches in treating severely mentally ill in California, Schizophrenia BulletinSchizophr Bull, 17, 461-8, 1991	A United States costing analysis. Outcomes which relate to the Welfare system differs in substantial ways to a UK context.
Jaeger, J., Berns, S., Douglas, E., Creech, B., Glick, B., Kane, J., Community-based vocational rehabilitation: effectiveness and cost impact of a proposed program model.[Erratum appears in Aust N Z J Psychiatry. 2006 Jun-Jul;40(6-7):611], Australian & New Zealand Journal of PsychiatryAust N Z J Psychiatry, 40, 452-61, 2006	Study is a New-Zealand based costing analysis of limited applicability to the UK.
Jonsson, D., Walinder, J., Cost-effectiveness of clozapine treatment in therapy-refractory schizophrenia, Acta Psychiatrica ScandinavicaActa Psychiatr Scand, 92, 199-201, 1995	Costing analysis which predates year 2000.
Knapp, M, Patel, A, Curran, C, Latimer, E, Catty, J, Becker, T, Drake, Re, Fioritti, A, Kilian, R, Lauber, C, Rossler, W, Tomov, T, Busschbach, J, Comas-Herrera, A, White, S, Wiersma, D, Burns, T, Supported employment: cost-effectiveness across six European sites (Structured abstract), World Psychiatry, 12, 60-68, 2013	Available as abstract only.
Lazar, S. G., The cost-effectiveness of psychotherapy for the major psychiatric diagnoses, Psychodynamic psychiatry, 42, 2014	Review of clinical and cost studies on psychotherapy. Studies cited do not match population for relevant review question.
Leff, J, Sharpley, M, Chisholm, D, Bell, R, Gamble, C, Training community psychiatric nurses in schizophrenia family work: a study of clinical and economic outcomes for patients and relatives (Structured abstract), Journal of Mental HealthJ Ment Health, 10, 189-197, 2001	Structured abstract. Not a cost effectiveness study.
Liffick, E., Mehdiyoun, N. F., Vohs, J. L., Francis, M. M., Breier, A., Utilization and Cost of Health Care Services During the First Episode of Psychosis, Psychiatric ServicesPsychiatr Serv, 68, 131-136, 2017	A United States costing analysis. Outcomes which relate to the Welfare system differs in substantial ways to a UK context.
Mihalopoulos, C., Harris, M., Henry, L., Harrigan, S., McGorry, P., Is early intervention in psychosis cost-effective over the long term?, Schizophrenia BulletinSchizophr Bull, 35, 909-18, 2009	Not a cost utility analysis. Australian costing analysis.
Perlis, R H, Ganz, D A, Avorn, J, Schneeweiss, S, Glynn, R J, Smoller, J W, Wang, P S, Pharmacogenetic testing in the clinical management of schizophrenia: a decision-analytic model (Structured abstract), Journal of Clinical Psychopharmacology, 25, 427-434, 2005	Structured abstract. Does not match any review question considered in this guideline.

Study	Reason for Exclusion
Quinlivan, R., Hough, R., Crowell, A., Beach, C., Hofstetter, R., Kenworthy, K., Service utilization and costs of care for severely mentally ill clients in an intensive case management program, <i>Psychiatric Services</i> Psychiatr Serv, 46, 365-71, 1995	A United States costing analysis. Outcomes which relate to the Welfare system differs in substantial ways to a UK context.
Roine, E., Roine, R. P., Rasanen, P., Vuori, I., Sintonen, H., Saarto, T., Cost-effectiveness of interventions based on physical exercise in the treatment of various diseases: a systematic literature review, <i>International Journal of Technology Assessment in Health Care</i> Int J Technol Assess Health Care, 25, 427-54, 2009	Literature review on cost effectiveness studies based on physical exercise for various diseases and population groups - none of which are for complex psychosis.
Rosenheck, R A, Evaluating the cost-effectiveness of reduced tardive dyskinesia with second-generation antipsychotics (Structured abstract), <i>British Journal of Psychiatry</i> Br J Psychiatry, 191, 238-245, 2007	Structured abstract. Does not match any review question considered in this guideline.
Rund, B. R., Moe, L., Sollien, T., Fjell, A., Borchgrevink, T., Hallert, M., Naess, P. O., The Psychosis Project: outcome and cost-effectiveness of a psychoeducational treatment programme for schizophrenic adolescents, <i>Acta Psychiatrica Scandinavica</i> Acta Psychiatr Scand, 89, 211-8, 1994	Not an economic evaluation. Cost effectiveness discussed in narrative only, with a few short sentences.
Sacristan, J A, Gomez, J C, Salvador-Carulla, L, Cost effectiveness analysis of olanzapine versus haloperidol in the treatment of schizophrenia in Spain (Structured abstract), <i>Actas Luso-espanolas de Neurologia, Psiquiatria y Ciencias Afines</i> , 25, 225-234, 1997	Available as abstract only.
Torres-Carbajo, A, Olivares, J M, Merino, H, Vazquez, H, Diaz, A, Cruz, E, Efficacy and effectiveness of an exercise program as community support for schizophrenic patients (Structured abstract), <i>American Journal of Recreation Therapy</i> , 4, 41-47, 2005	Available as abstract only
Wang, P S, Ganz, D A, Benner, J S, Glynn, R J, Avorn, J, Should clozapine continue to be restricted to third-line status for schizophrenia: a decision-analytic model (Structured abstract), <i>Journal of Mental Health Policy and Economics</i> , 7, 77-85, 2004	Available as abstract only.
Yang, Y K, Tarn, Y H, Wang, T Y, Liu, C Y, Laio, Y C, Chou, Y H, Lee, S M, Chen, C C, Pharmacoeconomic evaluation of schizophrenia in Taiwan: model comparison of long-acting risperidone versus olanzapine versus depot haloperidol based on estimated costs (Structured abstract), <i>Psychiatry and Clinical Neurosciences</i> , 59, 385-394, 2005	Taiwan is not an OECD country.
Zhu, B., Ascher-Svanum, H., Faries, D. E., Peng, X., Salkever, D., Slade, E. P., Costs of treating patients with schizophrenia who have illness-related crisis events, <i>BMC Psychiatry</i> , 8, 2008	USA costing analysis. The structure of the US health system means that costs do not translate well into a UK context.

1
2

1 **Appendix L – Research recommendations**

2 **Research recommendations for review question: 4.1 What is the best way of**
3 **involving people with complex psychosis and related severe mental health**
4 **conditions, and their families and carers, in planning their care collaboratively**
5 **with practitioners and providers?**

6 The committee did not make any research recommendations.

7

1 Appendix M – Evidence behind the reference recommendations

2 Supporting evidence and rationale/impact for adopted & adapted recommendations for review question 4.1: What is the best way of
 3 involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their
 4 care collaboratively with practitioners and providers?

5 Table 2: Evidence behind the reference recommendations

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
1.6.3 Ensure staff in rehabilitation services follow recommendations in the NICE guideline on decision-making and mental capacity.	Refers to NG108 (Decision-making and mental capacity) as a whole.	NG108: Decision-making and mental capacity (October 2018) Evidence came from 5 evidence reviews, using qualitative and quantitative research, about 'people who may lack mental capacity, now or in the future, to make a specific decision' as well as professionals and carers who work with them.	The committee felt it was highly relevant to include a recommendation on decision making and mental capacity in this guideline. They were aware this topic is already well covered in a comprehensive existing guideline and so referred readers to this guideline as a whole. They felt strongly that the existing guidance applied directly to the current population, and was highly relevant in its entirety.
1.6.4 Provide support to people, if they need it, to express their views, preferences and aspirations in relation to their care and support in line with recommendations in the NICE guideline on people's experience in	Refers to - NG86 1.1.5 Provide support to people, if they need it, to express their views, preferences and aspirations in relation to their care and support. Identify and record how the person wishes to	NG86: People's experience in adult social care services . (Feb 2018) Evidence came from four statements within this report: LD1: This evidence statement is based on some evidence of overall medium quality which found that staff shortages, and lack of support for staff results in no one being available to listen to resident complaints, or to provide regular and continued support more generally. People give high	The committee searched through existing guidelines for recommendations about good communication with service users. They agreed that recommendation 1.1.5 from NG86 covered most of the points that they would wish to make. The research behind the existing recommendation was of a reasonable quality, but noted that it came from a different target population. Despite this the committee concluded strongly that the wording and coverage was relevant and was able to succinctly

Recommendation	Original rec	Supporting evidence	Committee’s discussion – rationale and impact
<p>adult social care services.</p>	<p>communicate and if they have any communication needs (in line with the Accessible Information Standard). This could include:</p> <ul style="list-style-type: none"> • advocacy support • an independent interpreter (that is, someone who does not have a relationship with the person or the services they are using) to enable people to communicate in a language they can readily converse in, including sign language • a carer, if that is what the person wants • communication aids (such as pictures, videos, symbols, large print, Braille, hearing loops) 	<p>priority to being listened to and supported, and value regular contact with staff. In the first of 3 studies, (Hebblethwaite et al. 2007 –) investigated the experiences of people who had Adult social care: improving people's experience (February 2018) 259 of 424 © NICE [2018]. All rights reserved. Subject to Notice of rights been homeless and were in contact with learning disability services. The second study (Miller et al. 2008 +) explored outcomes important to people with learning disabilities. The third study (Hoole and Morgan 2011 +) explored the lived experiences of people with learning disabilities as users of services. The studies found that staff shortages in supported accommodation and day care services for people with learning disabilities can lead to poor experiences of care.</p> <p>Review question: Experience of social care services.</p> <p>Population: Adults with learning disabilities or autism aged 18 or over who use social care services.</p> <p>Setting: All UK settings where care is delivered.</p> <p>LD4: People with learning disabilities and disempowerment This evidence statement is based on two studies, of overall medium quality. In the studies, some people highlighted that services should treat them equally, and give them the confidence to believe they had a legitimate right to services, which helps them feel valued and</p>	<p>state the types of requirements that they would wish to see in the current guideline.</p>

Recommendation	Original rec	Supporting evidence	Committee’s discussion – rationale and impact
	<ul style="list-style-type: none"> • evidence-based techniques for communication • additional time to understand and process information • environmental conditions that support communication, such as clear lighting, and minimal noise interference 	<p>respected.. The first study (Hoole and Morgan 2011 +) explored the lived experiences of people with learning disabilities as users of services. This study further noted that people with learning disabilities felt empowered when they were given accessible information, access to self-advocacy forums and travel training. The second study (Miller et al. 2008 +) explored outcomes important to people with intellectual disabilities. The studies found that people with learning disabilities feel disempowered and not ‘afforded the same rights’ as people without a learning disability.</p> <p>Review question: Experience of social care services.</p> <p>Population: Adults with learning disabilities or autism aged 18 or over who use social care services.</p> <p>Setting: All UK settings where care is delivered.</p> <p>RQ4.7: Advocacy interviews. This evidence statement is based on a small amount of evidence of medium quality from one mixed-methods study that time limits to advocacy interviews is a barrier to delivering person-centred care. Redley et al (2010 +) evaluated a pilot Independent Mental Capacity Advocate (IMCA) service and found the timelimited nature of the interviews allowed to a person who lacked capacity was a barrier to getting to know them and to delivering a truly person-centred approach in helping their clients express their wishes. This study found that time limits to</p>	

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
		<p>advocacy interviews is a barrier to delivering person-centred care.</p> <p>Review question: Methods of gathering people's views and experiences of social care services.</p> <p>Population: Adults aged 18 or over who use social care services.</p> <p>Setting: All UK settings where care is delivered.</p> <p>V1: Matching service users and care staff. This evidence statement is based on 1 study of medium level quality (Valdeep et al. 2014 +), which examined satisfaction with social care services among black and minority ethnic populations. The study found that matching (for example, on ethnicity, age and gender) was not perceived as essential to service users, who prioritise personalised care and being listened to.</p> <p>Review question: Experience of social care services.</p> <p>Population: Adults aged 18 or over who use social care services.</p> <p>Setting: All UK settings where care is delivered.</p>	
<p>1.6.5</p> <p>Local authorities must, in line with the Care Act 2014,</p>	<p>Adopted - <u>NG86 1.3.1</u></p> <p>Local authorities must, in line with the Care Act 2014,</p>	<p><u>NG86: People's experience in adult social care services.</u> (Feb 2018)</p>	<p>The offer of independent advocacy is a key aspect of collaborative care-planning. A recommendation was identified in guideline NG86 which worded this well. The Care Act 2014 sets the requirement for advocacy to be offered to all vulnerable groups</p>

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
<p>provide independent advocacy to enable people to participate in:</p> <ul style="list-style-type: none"> • care and support needs assessment and • care planning and • the implementation process and review <p>where they would otherwise have substantial difficulty in doing so.</p>	<p>provide independent advocacy to enable people to participate in:</p> <ul style="list-style-type: none"> • care and support needs assessment and • care planning and • the implementation process and review <p>where they would otherwise have substantial difficulty in doing so.</p>	<p>Evidence came from GC consensus plus 1 evidence statement within the report:</p> <p>RQ4.7: Advocacy interviews. This evidence statement is based on a small amount of evidence of medium quality from one mixed-methods study that time limits to advocacy interviews is a barrier to delivering person-centred care. Redley et al (2010 +) evaluated a pilot Independent Mental Capacity Advocate (IMCA) service and found the timelimited nature of the interviews allowed to a person who lacked capacity was a barrier to getting to know them and to delivering a truly person-centred approach in helping their clients express their wishes. This study found that time limits to advocacy interviews is a barrier to delivering person-centred care.</p> <p>Review question: Methods of gathering people's views and experiences of social care services. Population: Adults aged 18 or over who use social care services. Setting: All UK settings where care is delivered.</p>	<p>(including those in the current guidelines' population) and the wording of the existing recommendation was considered succinct for this requirement. As a result of the Care Act's broad application the committee did not consider it a problem that the evidence underlying the recommendation was based on a much broader population.</p>
<p>1.7.10</p> <p>Ensure that care plans are shared with the person and everyone involved in the person's care (for</p>	<p>Refers to NG53 1.5.20 and 1.5.21</p> <p>1.5.20 Send a copy of the care plan to everyone involved in providing support to</p>	<p>NG53: Transition between inpatient mental health settings and community or care home settings (August 2016)</p> <p>Evidence for 1.5.20 came from GC consensus plus 1 effectiveness evidence statement within the report:</p>	<p>The committee drafted a recommendation by consensus summarising that care plans should be up-to-date and properly distributed at the point of discharge. However the committee was aware that there were two important and highly detailed recommendations in NG53 which gave further details on a full list of considerations for a care plan</p>

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
<p>example clinicians, supported accommodation staff, and the person's family or carers, if the person agrees) at:</p> <ul style="list-style-type: none"> • each review • each transition point in the rehabilitation pathway • at discharge from the service. <p>For more on care plans and assessment before discharge, see recommendations 1.5.20 and 1.5.21 in the NICE guideline on transition between inpatient mental health settings and community or care home settings.</p>	<p>the person at discharge and afterwards. It should include:</p> <ul style="list-style-type: none"> • possible relapse signs • recovery goals • who to contact • where to go in a crisis • budgeting and benefits • handling personal budgets (if applicable) • social networks • educational, work-related and social activities • details of medication (see the recommendations on medicines-related communication systems in NICE's guideline on 	<p>DC4: There is moderately good evidence from a US RCT (Swanson et al. 1999 +/-) that 2 sessions of motivational interviewing (a technique widely used with people with problem substance misuse) pre-discharge can significantly increase the proportion of patients – a mixed population of those with psychiatric problems only, and those with psychiatric and substance misuse problems – who attend their first outpatient appointment. The difference between those with the additional intervention and the controls was particularly evident for subjects with a dual diagnosis.</p> <p>Review question: Identify the effectiveness of specific services, interventions or approaches through which people are supported through safe and timely transfers of care from inpatient mental health settings to community or care home settings?</p> <p>Population: All children, young people and adults in transition from community or care homes to inpatient mental settings.</p> <p>Setting: Service users' own homes, including temporary accommodation; supported housing; sheltered housing; care (residential and nursing) homes, care homes for children, and all inpatient mental health settings for adults, older people, children and young people and specialist units for people with mental health problems and additional needs.</p>	<p>at discharge. Rather than list all the points again, the committee agreed to refer the reader to this guidance.</p> <p>The evidence supporting the two recommendations that are referred to was of good quality, intended to be applied to all people using mental health services at a transitional time. The committee were satisfied that the service users in the current guideline applies to fall under the remit of these broader guidelines. They also agreed that the wording used in these two existing recommendations was suitable and fully applicable to the population in the current guideline.</p>

Recommendation	Original rec	Supporting evidence	Committee’s discussion – rationale and impact
	<p>medicines optimisation)</p> <ul style="list-style-type: none"> • details of treatment and support plan • physical health needs including health promotion and information about contraception • date of review of the care plan. <p>1.5.21 Mental health practitioners should carry out a thorough assessment of the person's personal, social, safety and practical needs to support discharge. The assessment should include risk of suicide (see recommendations 1.6.6–1.6.8). It should:</p> <ul style="list-style-type: none"> • relate directly to the setting the person is being discharged to 	<p>Evidence for 1.5.21 came from GC consensus plus 4 evidence statements within the report, and reference to CG136 (service users experiences of mental health care):</p> <p>CYP7: There is moderately good evidence from 2 qualitative studies – 1 UK (Offord 2006 +) and 1 non-UK (Turrell, 2005 +) – that adolescents treated for anorexia nervosa value planned discharges which allow advance warning, and which are structured to give back control in small increments (e.g., allowing them to make their own meals and encouraging them to make their own decisions) in the run-up to discharge. Hospital discharge which adopts a gradual and collaborative approach helps to moderate the stark contrast between the high levels of structure in the unit and the lack of structure in the outside world – the sudden availability of freedom being perceived by some as overwhelming and potentially problematic.</p> <p>Review question: What is the effectiveness or impact of specific interventions to support children and young people during transition between inpatient mental health settings and community or care home settings?</p> <p>Population: Children and young people who are in transition between inpatient mental health settings and community or care home settings</p> <p>Setting: Service users’ own homes, including temporary accommodation; supported housing; sheltered housing; foster care and care homes for</p>	

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
	<ul style="list-style-type: none"> • fully involve the person • be shared with carers (if the person agrees) • explore the possibility of using a personal health or social care budget and ensure the person understands about charges for social care • cover aftercare support, in line with section 117 of the Mental Health Act 1983 • cover aspects of the person's life including: <ul style="list-style-type: none"> - daytime activities such as employment, education and leisure - food, transport, budgeting and benefits 	<p>children.</p> <p>DC14: There is moderately good evidence from a qualitative study (Offord et al. 2006 +) that people discharged from a general adolescent unit after treatment for anorexia nervosa experience are concerned and dismayed about the huge differences in everyday life and activities, sense of control and self-efficacy and available support between the hospital and the home environment. They may also feel they have lost touch with their peer group and fallen behind in education. Respondents suggested that discharge should be graduated and personalised according to individual need, and that introducing more 'normal' activities on the ward, and handing back 'control' gradually during discharge, would be helpful. These findings may be generalisable to other adolescents, and other inpatients, who are facing discharge.</p> <p>DC15: There is good evidence from a relatively large assessment by interview study conducted 6 weeks after discharge (Simons and Petch 2006 +/+) that people discharged from a psychiatric unit have unmet needs (ranked) for help with psychological distress (including psychotic symptoms); daytime activities and company; information about condition and treatment; food and transport; budgeting and benefits. People with a non-psychotic illness expressed higher unmet need than those with a psychotic illness. Staff ranked the most common unmet need among</p>	

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
	<ul style="list-style-type: none"> - pre-existing family and social issues and stressors that may have triggered the person's admission - ways in which the person can manage their own condition - suitability of accommodation. 	<p>patients as need for daytime activities; help with psychological distress; company; psychotic symptoms and obtaining and preparing food. Staff considered that 97% of need for information about condition and treatment had been met. for people with mental health problems and additional needs.</p> <p>DC16: There is good evidence from a qualitative study (Owen-Smith et al. 2014 ++) that the challenges faced by people leaving hospital after a psychiatric admission are concerning, and that the high incidence of suicide after discharge could be explained in those terms. Four of the 10 interviewed did not agree with the decision to discharge, and had had thoughts of self-harming. Most of the sample cited the need to return to problems which had existed prior to admission – social isolation, financial difficulties, challenging familial relationships, childcare responsibilities and dealing with everyday household responsibilities. They felt that social networks and families had disintegrated, and the sudden absence of care and support would be particularly difficult to deal with. Although 9 of the 10 had support plans, there was some cynicism about whether support would materialise or be adequate.</p> <p>Review question: Identify the effectiveness of specific services, interventions or approaches through which people are supported through safe and timely transfers of care from inpatient mental health settings to community or care home</p>	

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
		<p>settings? Population: All children, young people and adults in transition from community or care homes to inpatient mental settings. Setting: Service users' own homes, including temporary accommodation; supported housing; sheltered housing; care (residential and nursing) homes, care homes for children, and all inpatient mental health settings for adults, older people, children and young people and specialist units for people with mental health problems and additional needs.</p>	
<p>1.6.13</p> <p>Discuss with the person whether, and how, they want their family or carers to be involved in their care. Such discussions should take place at intervals to take account of any changes in circumstances, and should not happen only once. As the involvement of families and carers</p>	<p>Adapted from - CG136 1.1.14</p> <p>Discuss with the person using mental health services if and how they want their family or carers to be involved in their care. Such discussions should take place at intervals to take account of any changes in circumstances, and should not happen only once. As the</p>	<p>Evidence basis of this guideline is a 2011 review of qualitative evidence found within eight previous NICE clinical guidelines plus several UK mental health surveys.</p> <p>The review intended to cover any “people who use adult NHS mental health services”. The review was updated in 2016 with no changes.</p> <p>The identified evidence was reviewed and summarised in a table of ‘key requirements’ (qualitative statements based on the GDG’s expert opinion) for the provision of high quality service user experience for community care, shown in Table 15, pg 88.</p>	<p>Recommendation 1.1.14 in CG136 outlines good practice on considerations for how to include families and carers in care-planning. The recommendation applies to all people who use adult NHS mental health services. The inclusion of families and carers in care planning can be precarious for the current population because in some circumstances their inclusion may be greatly beneficial, but in other cases there may be historical distress or some history of people taking advantage. The committee reflected on the wording in the existing recommendation agreeing that it was highly relevant to this area, applying readily to the current guideline.</p>

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
can be quite complex, staff should receive training in the skills needed to negotiate and work with families and carers, and also in managing issues relating to information sharing and confidentiality.	involvement of families and carers can be quite complex, staff should receive training in the skills needed to negotiate and work with families and carers, and also in managing issues relating to information sharing and confidentiality.	From this the GDG developed recommendation 7.5.2.6, which has become recommendation CG136 1.1.14.	
<p>1.6.14</p> <p>Respect the rights and needs of carers alongside the person's right to confidentiality. Review the person's consent to share information with family members, carers and other services during their rehabilitation. Follow recommendations on involving families and carers in NICE's guideline on service user experience in</p>	<p>Adapted - <u>NG53 1.4.5</u></p> <p>Respect the rights and needs of carers alongside the person's right to confidentiality. Review the person's consent to share information with family members, carers and other services during the inpatient stay. For more information, see the subsection on involving families and carers in NICE's guideline on service user experience in</p>	<p><u>NG53: Transition between inpatient mental health settings and community or care home settings</u> (August 2016)</p> <p>Evidence came from 2 evidence statements within the report:</p> <p>C5: There is evidence from a small Canadian qualitative interview study (Clarke & Winsor 2010 +), a small US qualitative study (Gerson 2012 +) and a very small UK qualitative study (Wilkinson 2008) that carers' feelings and anxieties were not acknowledged by inpatient staff, and that they were excluded from any discussion of the patient's treatment or progress – often requests were declined with reference to 'patient confidentiality' (a point also flagged in Jankovic 2011, see below). Family carers often had little notice of discharge, and no idea how to support the patient, or find</p>	<p>Respect for confidentiality should be a standard part of a person's care, including care planning that might involve family members or carers. Recommendation 1.4.5 in guideline NG53 outlined the key considerations around confidentiality and was based on evidence outlining potential problems amongst a population of people with mental health problems and their families/carers generally. The committee believed that these key considerations are directly applicable to the current population and their family/carers. Based upon the committee's experience they agreed through consensus that it was appropriate to take the existing recommendation apply it to the current population, with a minor change made to the wording to make it more relevant to the rehabilitation setting.</p>

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
adult mental health services.	adult mental health services.	<p>support for themselves, after discharge. Family carers wanted greater involvement and information, and a sense of sharing care with professionals.</p> <p>C6: There is evidence from a UK qualitative interview study – (Jankovic 2011 +) that family carers of people formally admitted felt unable to get help until the person's illness lead to sectioning, which was an undesirable outcome. More than a quarter of caregivers felt that, although they were not involved by staff in decision-making or treatment review, they were unfairly expected Transition between inpatient mental health settings and community or care home settings: NICE guideline full version (August 2016) 292 of 345 to take full responsibility for the person after discharge.</p> <p>Review question: What is effective in supporting carers of people in transition between inpatient mental health settings and community or care home settings?</p> <p>Population: Families, partners and unpaid carers of children, young people and adults during admission to inpatient mental health settings.</p> <p>Setting: Service users' own homes, including temporary accommodation; supported housing; sheltered housing; care (residential and nursing) homes, care homes for children, and all inpatient mental health settings for adults, older people, children and young people and specialist units for</p>	

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
		people with mental health problems and additional needs.	
<p>1.6.15</p> <p>Give families, parents and carers information about support services in their area that can address emotional, practical and other needs (this is particularly important if the person is accessing rehabilitation services for the first time).</p>	<p>Adopted - <u>NG53 1.4.7</u></p> <p>Give families, parents and carers information about support services in their area that can address emotional, practical and other needs (this is particularly important if this is the person's first admission)</p>	<p><u>NG53: Transition between inpatient mental health settings and community or care home settings</u> (August 2016)</p> <p>Evidence came from 2 evidence statements within the report:</p> <p>C1: There is moderate evidence from 3 studies using control groups – Cassidy et al. (2001), Macdonald et al. (2014) and Pitschel-Walz et al. (2006), all rated (+/+) – that carers are willing to participate in, and do derive knowledge from, psychoeducational groups which enable them to find out more about the meaning and management of the illness of the person they care for, whether schizophrenia or anorexia, and to learn coping strategies.</p> <p>C7: There is evidence from a small US qualitative study (Gerson et al. 2012 +) and from a very small UK qualitative study (Wilkinson and McAndrew 2008, rated - for its small sample), that family carers want the following at first and subsequent admissions:</p> <ul style="list-style-type: none"> • less traumatic ways of seeking treatment (i.e. before the first onset of psychosis accelerated into a crisis), bearing in mind that the person might not want to attend a psychiatric clinic • greater recognition from staff on inpatient wards 	<p>Where families and carers are to be included in care-planning and care-giving the committee wanted to adopt a recommendation which emphasised the need for them to have support of their own. There was reasonable quality evidence that underlined recommendation 1.4.7 in NG53 about the importance of support for the families and carers of people who use adult inpatient mental health services. The committee felt this evidence was relevant and fully applicable to the current guideline's population.</p>

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
		<p>that they were under great stress, and needed both support and reassurance as well as information and involvement in assessment, treatment and discharge planning</p> <ul style="list-style-type: none"> • greater recognition from staff that they had valuable knowledge of the person to offer • information, education and dialogue about the mental health condition, and how to manage and support the person after discharge • partnership with professionals • support to find providers for ongoing care that insurance would cover (from the US paper) • less negativity and more encouragement to contemplate a positive future for their child.. <p>Review question: What is effective in supporting carers of people in transition between inpatient mental health settings and community or care home settings?</p> <p>Population: Families, partners and unpaid carers of children, young people and adults during admission to inpatient mental health settings.</p> <p>Setting: Service users' own homes, including temporary accommodation; supported housing; sheltered housing; care (residential and nursing) homes, care homes for children, and all inpatient mental health settings for adults, older people, children and young people and specialist units for people with mental health problems and additional needs.</p>	

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
<p>1.6.16</p> <p>Advise carers about their right to the following and how to get them:</p> <ul style="list-style-type: none"> • a formal assessment of their own needs (known as a 'Carer's Assessment'), including their physical and mental health • an assessment of their need for short breaks and other respite care 	<p>Adopted - NG97 1.11.4</p> <p>Advise carers about their right to the following and how to get them:</p> <ul style="list-style-type: none"> • a formal assessment of their own needs (known as a 'Carer's Assessment'), including their physical and mental health • an assessment of their need for short breaks and other respite care 	<p>NG97: Assessment, management and support for people living with dementia and their carers (June 2018)</p> <p>An intervention review was conducted, but did not produce any findings related to carers assessment. Instead it is reported that the recommendations related to assessments were based on a presentation on the legal requirements of the Care Act.</p> <p>Review question: How effective are carers' assessments in identifying the needs of informal carers of people living with dementia? Population: Carers of people (aged 40 years and over) living with dementia. Setting: Unclear – not UK only.</p> <p>15.1.2.4.1 Carers' assessments: No evidence was identified evaluating the effectiveness of carers' assessments. Many of the multicomponent interventions identified did include a structured assessment, but it was not possible to isolate the effect of one particular component of the interventions.</p> <p>15.1.5.2 Carers' assessments: The committee noted the lack of evidence from research in this area but received a contextual presentation placing carers' assessments within the framework of the Care Act 2014, delivered by one of the Local Authority Commissioners on the committee. This covered both the legal rights people have and the</p>	<p>Families or other carers may be an important feature in a service user's care plans, and so these carer's own needs are highly relevant. The Care Act 2014 specifies that all carers should be offered a needs assessment, including those caring for people with psychosis in rehabilitation. A recommendation was identified in guideline NG97 stating the important considerations of this requirement succinctly. The Care Act is law and applies to all carers equally, and resultantly the committee agreed it is not a problem that the evidence behind the recommendation was based on a different carer population.</p>

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
		<p>extent to which the legislation has been fully implemented in practice.</p>	
<p>1.6.17</p> <p>Enable the person to maintain links with their home community by:</p> <ul style="list-style-type: none"> • supporting them to maintain relationships with family and friends, for example, by finding ways to help with transport • helping them to stay in touch with social and recreational contacts • helping them to keep links with employment, education and their local community. <p>This is particularly important if people are in an out-of-area placement.</p>	<p>Adapted - <u>NG53 1.1.6</u></p> <p>Enable the person to maintain links with their home community by:</p> <ul style="list-style-type: none"> • supporting them to maintain relationships with family and friends, for example, by finding ways to help with transport • helping them to stay in touch with social and recreational contacts • helping them to keep links with employment, education and their local community. <p>This is particularly important if people are admitted to mental health units outside</p>	<p><u>NG53: Transition between inpatient mental health settings and community or care home settings</u> (August 2016)</p> <p>Evidence came from GC consensus plus 1 evidence statement within the report:</p> <p>HA10 There is evidence from 1 small qualitative study (Chinn et al. 2011 +) that people placed in specialist units for people with intellectual disabilities (IDs) with mental health problems were probably more likely than those without IDs to be placed at a distance from their homes. This made contact with families, community resources and minority language speakers more difficult, and increased dependency on staff. People detained might experience the detention as punishment, and some residents felt belittled and intimidated by staff.</p> <p>Review question: What are the views and experiences of people using services in relation to their admission to inpatient mental health settings from community or care home settings?</p> <p>Population: All children, young people and adults in transition from community or care homes to inpatient mental settings.</p> <p>Setting: Service users' own homes, including temporary accommodation; supported housing; sheltered housing; care (residential and nursing)</p>	<p>The committee wanted a recommendation that highlighted the importance of trying to maintain community links when forming a care plan. They identified recommendation 1.1.6 from NG53 as a relevant recommendation that already applies to any adult NHS mental health service users at times of transition.</p> <p>In particular the committee discussed previously presented evidence that the use of OATs is high amongst the UK rehabilitation population and this can cause disruption to people's social networks. The evidence for the existing recommendation is low quality and from an indirect population, however the committee reflected on the wording in the existing recommendation and agreed that evidence and their experience suggested it was highly relevant to the current guideline.</p>

Recommendation	Original rec	Supporting evidence	Committee's discussion – rationale and impact
	the area in which they live.	homes, care homes for children, and all inpatient mental health settings for adults, older people, children and young people and specialist units for people with mental health problems and additional needs.	

1