

Review: Transition from children's to adult services: a review of guidelines and protocols for young people with attention deficit hyperactivity disorder in England

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Background: In recent years, the difficulty for young people with mental health issues who require a transition to adult services has been highlighted by several studies. In March 2018 the National Institute of Health and Care Excellence (NICE) produced detailed guidelines for the diagnosis and management of attention deficit hyperactivity disorder (ADHD), updated from previous versions in 2008 and 2016, which included general recommendations for transition to an adult service. Yet, there is limited research on transition specifically for those with ADHD. This review aims to systematically identify, review and compare guidelines, specifically focussed on transition for young adults with ADHD within England. **Methods:** Following the general principles for systematic reviewing as published by the University of York, 10 electronic databases were searched. Further documents were identified through searches of grey literature and additional sources. **Results:** Sixteen documents were included. Results indicate very limited publically accessible guidelines in England for transition of young people with ADHD. Nearly all identified documents based their recommendations for transition on the existing NICE guidelines. Neurodevelopmental conditions such as ADHD are often encompassed within one overarching health policy rather than an individual policy for each condition. **Conclusions:** Guidelines should be available and accessible to the public in order to inform those experiencing transition; adjusting the guidelines to local service context could also be beneficial and would adhere to the NICE recommendations. Further review could examine transition guideline policies for mental health in general to help identify and improve current practice.

Key Practitioner Message

- Transition for young people with ADHD who require continued support in adulthood is a current challenge for young people, their families and clinicians.
- This systematic review of guidelines on transition for young adults with ADHD focussed on England only, to mirror the remit of NICE. NICE Clinical Guideline for ADHD (NG87) was found to be the only transition guideline publically available.
- Linking the NICE clinical guidance for ADHD (NG87) to those on transition of care between child and adult services (NG43) would provide more comprehensive guidelines for clinicians to ensure smooth and successful transition for young people with ADHD.

Keywords: attention deficit hyperactivity disorder; adolescence; mental health; National Institute of Health and Care Excellence; guidelines

Introduction

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by impairing levels of inattentive, hyperactive and impulsive behaviours (Jick, Kaye, & Black, 2004), that can impact on academic achievement, relationships and self-care (Kendall, Taylor, Perez, & Taylor, 2008). It is one of the most common neurodevelopmental disorders managed by child mental health and paediatric services (Ford, Hamilton, Meltzer, & Goodman, 2007) with prevalence rates in the United Kingdom (UK) of around 5% in children and adolescents (Faraone et al., 2015). Despite this, services and policies are often not set up to consider ADHD in isolation but as general mental health.

ADHD has traditionally been viewed as a childhood disorder but analysis showed that 15% of those with childhood ADHD met the full diagnostic criteria for the disorder at age 25. If those who partially meet the full criteria, or are considered to be in partial remission, are included this figure rises to 65% at 25 years (Faraone, Biederman, & Mick, 2006). This has led to the increasing recognition that ADHD is a life span disorder (Tatlow-Golden et al., 2017) which raises the issue of transition from child to adult services. Several studies, government documents and policy guidelines highlight the difficulty for young people who require a transition between children's services (usually Child and Adolescent Mental Health Services (CAMHS) or Paediatrics) and adult services (Singh, Paul, Ford, Kramer, & Weaver, 2008).

Transition should support a young person towards and onto a new life stage, extending beyond the simple transfer of clinical responsibility (Beresford, 2004); a successful transition has been described as being coordinated, purposeful, planned and patient centred (Singh & Tuomainen, 2015).

A report for commissioners highlights the vulnerability of young people aged 16 to 18, in a period of physiological, emotional and social change, who are at higher risk of transition problems. It is recommended that clinical support remains consistent and uninterrupted (Joint Commissioning Panel for Mental Health, 2013), and local policies for transition are important to enable that support.

In order to support young people in transition in the United Kingdom, the National Institute of Health and Care Excellence (NICE) and the CAMHS Review (Hall et al., 2013) recommend that adequate transition for adolescents who still require mental health services should include comprehensive planning, focus on *need* rather than *age*, and be coordinated by a lead person (NICE, 2016). With recognition of ADHD as a long-term condition, and increased prescription rates for ADHD in childhood, the number of graduates of ADHD from children's services has increased rapidly (Timimi & Radcliffe, 2005) which makes optimal transition particularly important. Potential barriers to an optimal transition include poor communication and collaboration, different funding structures, a lack of understanding across services and time and resource constraints, and it is reported that as few as 15% of the ADHD patients that require continued support and treatment make the transition successfully (Singh & Tuomainen, 2015). Additionally, research has shown that there is a lack of specialist services for ADHD in adulthood, and a lack of ways to access them (Coghill, 2016; Hall et al., 2013; Young, Murphy, & Coghill, 2011).

The association between childhood ADHD and criminality in adulthood has previously been highlighted (Fletcher & Wolfe, 2009; Mordre, Groholt, Kjelsberg, Sandstad, & Myhre, 2011) and a study of ADHD and criminality in Sweden has demonstrated how medication use can reduce criminal rates (Lichtenstein et al., 2012). Therefore, it is important to manage the period of transition to adulthood well, as failure to do so can lead to unmet needs, disengagement from services and poor life outcomes (Singh & Tuomainen, 2015).

Two recent systematic reviews highlight a lack of services and guidelines for young adults with ADHD. The first, a systematic review of mental health care systems, found that neither the UK's National Health Service (NHS) nor US mental health system provided sufficient support or access to adult services for young people (Embrett, Randall, Longo, Nguyen, & Mulvale, 2016). The second, an international systematic review of guidelines for ADHD (Seixas, Weiss, & Muller, 2012), suggests there is limited data or studies about ADHD and transition.

The review of guidelines by Seixas et al. (2012) discussed 10 different international guidelines and included recommendations for management of ADHD. Since publication, two included guidelines have been updated. The NICE guideline for the United Kingdom, and the Canadian Attention Deficit Hyperactivity

Disorder Resource Alliance (CADDRA) (Canadian ADHD Resource Alliance, 2018; NICE, 2018) were both updated in 2018. All included guidelines provide recommendations for clinical diagnosis and management of ADHD, however, only two of the included guidelines referred to any recommendations for transition from child to adult services; the British Association of Psychopharmacology (BAP) (Bolea-Alamanac et al., 2014) and the NICE guidelines for England (NICE, 2008). The BAP guidelines were the first guidelines to be produced on ADHD in adolescents and adults with ADHD in transition to adult services (Seixas et al., 2012), however, they describe considerations and uncertainties in the diagnosis and management of ADHD for clinicians, and do not explicitly list recommendations for a smooth transition process between services. The NICE guidelines (NICE, 2008) which were published after the BAP guidelines, provided a full review of diagnosis and management for ADHD across the life span, and were significant in developing improved service provision in the United Kingdom.

NICE was established in order to improve health and social care by reducing variation in the availability and quality of NHS treatments and care, and the organisation has been established in primary legislation since 2013. All NICE clinical or national guidelines are therefore applicable to England only (NICE, 2017). In March 2018 (previously published in 2008, with an update in 2016) NICE published an updated clinical guideline for the diagnosis and management of ADHD (originally CG72, now NG87) which explicitly lists a short detailed section with the following recommendations for transition to an adult service (section 1.1.4, 1.1.5 and 1.1.6 of NG87):

- Young person should be reassessed at school-leaving age to establish need for transition
- Transition should be complete by age 18
- Plan for smooth transition should be made with details of anticipated treatment and service young person requires
- Formal meeting between child and adult service should be considered
- Information should be provided to young person about adult service
- Care Programme Approach (CPA) should be used
- The young person and parent/carer should be involved in planning
- After transition, young person should be reassessed at adult service – to include personal, educational, occupational and social functioning

(NICE, 2018)

The guideline NG87 published in 2018 has made no changes to the content of the transition recommendations that were listed in the 2008 and 2016 (CG72) versions. It does, however, now refer the reader to guideline NG43, the general guidelines for health and social care transitions that is not condition specific, published in 2016 (NICE, 2016).

Although there has been an increased interest in transition and guidelines for the management of ADHD, there is still a scarcity of services and a lack of successful transitions (Bolea-Alamanac et al., 2014; Singh

et al., 2009). This current review therefore aims to understand what transition guidelines and protocols exist for ADHD services in England specifically, and to potentially identify any gaps in service protocols. NICE guidelines include local NHS services in their consultation and review current evidence, however, it is not mandatory that health services implement them locally. NICE guidelines have also not had the evidence base for transition reviewed or the recommendations updated since 2008. Focussing on England and ADHD transition specifically, we aim to identify local ADHD service policies, if these are in line with the NICE guidance, and what variations exist. To our knowledge, there are no existing reviews to date looking specifically at ADHD transition guidelines.

Methods

This review followed the general principles for systematic reviewing published by the University of York (CRD, 2009). It consists of two parts; an overview of existing ADHD transition guidelines and recommendations in England, and a comparison of these guidelines against NG87 for the diagnosis and management of ADHD (NICE, 2018). These two components are brought together with a narrative synthesis, which was chosen to summarise the findings primarily using text due to the qualitative nature of the data (Popay et al., 2006).

Data sources and search strategy

Four sources of data were used. First, 10 bibliographic databases were searched from the earliest date of the database to the present day (15/06/2018): EMBASE, MEDLINE, PsycINFO, Social Policy and Practice, Health Management Information Consortium (all accessed via OvidSP); CINAHL, ERIC (accessed via EBSCO); ASSIA (accessed via ProQuest); NICE Evidence Search and TRIP database (hand searching only). Databases were searched using three groups of terms or synonyms (combined by the Boolean 'AND' operator) to describe 'Attention Deficit Hyperactivity Disorder', 'Transition' and 'Guideline or Protocol', identified from the title, abstract, key words or medical subject heading (MeSH) terms. An illustration of the search strategy used in EMBASE can be found in additional files as Appendix S1. The search terms were adapted for individual databases as required.

Second, an online search was completed using the search engine Google for protocols, guidelines or documents regarding ADHD and transition within NHS sites (using the syntax 'site:nhs.uk'). The first 10 pages of results were screened (approximately 200 results) and relevant documents identified and exported.

Third, corresponding websites of professional and charitable organisations in the field (Appendix S2 in additional files) were searched for protocols, guidelines, policy documents or patient leaflets providing transition recommendations for patients with ADHD.

Finally, backwards citation chasing (one generation) was completed using references from all included documents in the review.

Inclusion/exclusion criteria

Table 1 summarises the inclusion and exclusion criteria used for the review. These were chosen to identify guidelines specific to the condition ADHD, specific to transition, and also to reflect the application of the NICE guidelines being specific to England only.

Study selection

Records identified through the bibliographic databases were exported into Endnote X8 reference management software, and duplicate papers were identified and excluded. The abstracts

and titles of all identified records were screened for relevance by one reviewer (HE) using the specified inclusion and exclusion criteria. Twenty-five per cent of records were independently screened by a second reviewer (BL and TR). Discrepancies were discussed and resolved. Full text copies were obtained for the selected studies and screened against the same inclusion and exclusion criteria.

Documents obtained via the online search and citation chasing were saved and uploaded in the same Endnote file; these were screened and reviewed following the same procedure.

Data extraction and synthesis

For the first part of the review, the relevant data from each included document was extracted and summarised descriptively. For the second part of the review, the key points for transition specified in sections 1.1.4, 1.1.5 and 1.1.6 of NG87 were used as a framework to organise the data and allowed extracted data from all documents to be compared and contrasted to the NICE guidance. The relevant data was extracted in to a spreadsheet specifically created for this review and then discussed in a narrative manner.

Results

Search and screen of results

The PRISMA diagram (Moher, Liberati, Tetzlaff, & Altman, 2009) in Figure 1 illustrates the sources from which references were identified, screened and selected.

The electronic search and title and abstract screen of the TRIP database ($n = 326$) identified 13 records for inclusion in the full text screen. When checked against the search results of the other nine databases, the 13 records were identified as duplicates. Therefore, the numbers in the PRISMA diagram reflect the results in nine databases excluding the TRIP results.

Table 1. Inclusion and Exclusion criteria

Inclusion	Exclusion
<ul style="list-style-type: none"> • Age range 0–25 years • Transition guidelines or protocols specific to a clinical diagnosis of ADHD from; <ul style="list-style-type: none"> ○ nationally recognised sources ○ local NHS services • Existing reviews of ADHD transition guidelines and protocols; <ul style="list-style-type: none"> ○ includes recommendations for ideal practice • Any type of study/review design; <ul style="list-style-type: none"> ○ editorial ○ evaluation ○ short report ○ discussion papers • From earliest date of database to present • Specific to England only • English language only 	<ul style="list-style-type: none"> • ADHD transition guidelines and protocols for age groups outside of 0–25 years • General mental health transition guidelines or protocols • Transition guidelines or protocols relating to other diagnoses • No 'working documents', unpublished or draft guidelines • ADHD transition guidelines and protocols/reviews not specific to England • ADHD transition guidelines and protocols/reviews not in English language

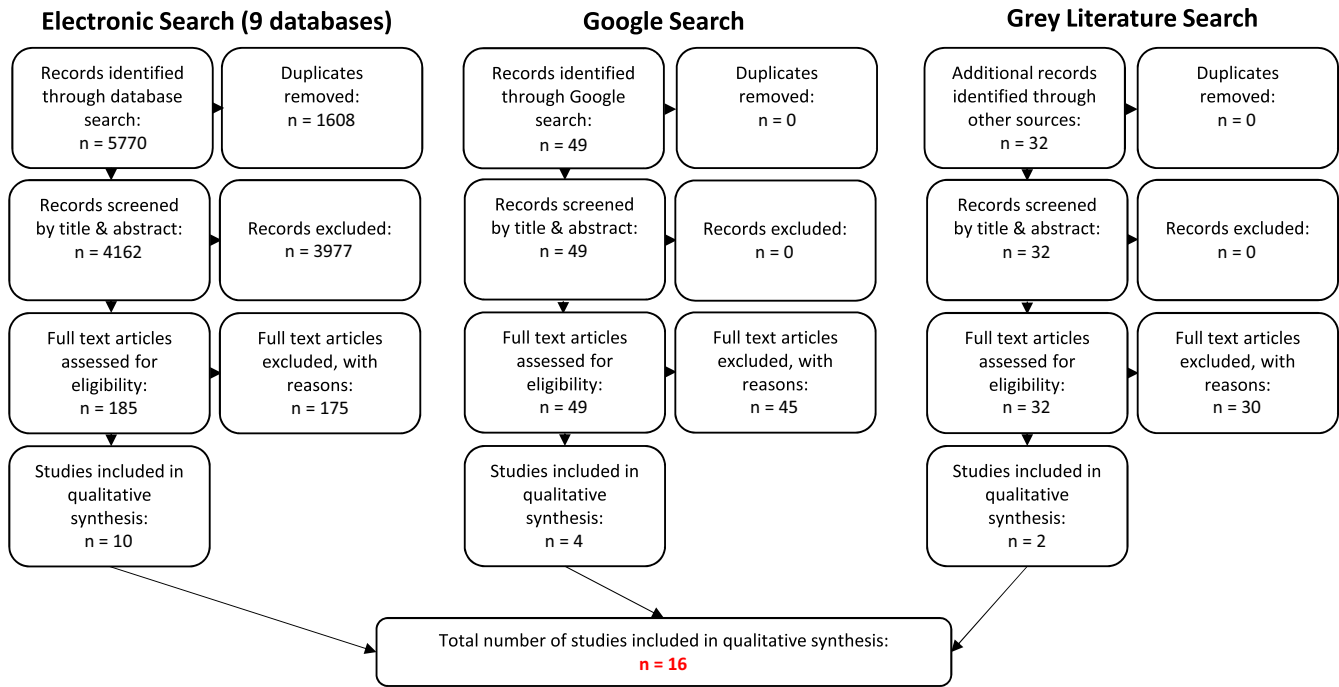


Figure 1. PRISMA showing screened and included records

At full text screen stage, records were excluded for the following reasons:

- Not specific to: England, ADHD, Transition (n = 210)
- Book chapter or review (n = 3)
- Conference abstract or presentation (n = 18)
- Clinical trial (n = 1)
- Dissertation (n = 1)
- Newsletter article (n = 7)

Three were also identified as duplicates and excluded at this stage, and one was excluded for being a case study example of patients in transition which did not include recommendations for transition. Full text was unobtainable for five documents.

Description of included studies

Sixteen documents were included for review; seven peer reviewed papers, three NICE guidelines, four local NHS Service guidelines and two professional organisation guidance documents. One peer reviewed paper (Hall, Newell, Taylor, Sayal, & Hollis, 2015) does not present recommendations for transition, however, reports on a survey of ADHD services in Mental Health Trusts in England that identified data in line with NICE guidance; for example, transition protocols and information sharing. It was therefore included.

All documents were published between 2009 and 2018, and all provide guidance for ADHD transition in England in varying detail. Table 2 summarises the content of each of the included documents.

The documents published by NICE are the full clinical guideline for diagnosis and management of ADHD NG87, the previous NICE clinical guideline CG72 and an overview of the ADHD NICE pathway, which summarises NG87 (NICE, 2008, 2017, 2018). Ten documents

(excludes Pennine Care, South West Yorkshire and Berkshire Healthcare NHS documents, and the paper by Fogler et al.) refer to the NICE guidelines and base any guidance for ADHD transition on the recommendations in NG87; mostly quoting the NICE guidance verbatim. Four documents were identified through the online google search; these were documents by Stockport CAMHS (2015), Wirral NHS (Fellick, 2014), Berkshire NHS (Tahir & Sims, 2014), and South West Yorkshire NHS (2018). All records identified via electronic databases reference the NICE guidelines. Two documents were identified via the online search of professional and charity organisations; the Royal College of Psychiatrist’s guidance on transition in ADHD (Boilson, Forbes, Quilter, & Sutherland, 2013) and an expert policy paper from Asherson et al. (2017).

Compare/contrast of guidelines

As NG87 was one of the 16 documents identified in this review, the main points of the recommended transition process were identified and the remaining 15 documents were compared against them. An example of the spreadsheet used can be found in additional files as Appendix S3. Any recommendations for transition that were additional to or outside of the NICE guidelines were clearly highlighted using this process. Table 3 provides an overview of the comparison.

Age/reason for transition. NICE guidelines recommend that transition should occur if the young person continues to have significant symptoms of ADHD, and this should be assessed when approaching the service age boundary. Ten of the documents stated the reason for transition should be significant symptoms of ADHD that require ongoing treatment or support. Four documents did not specify a reason for transition, while one specified continuation of medication. An age for transition is

Table 2. Summary of included studies

Author/Year	Title	Description
Asherson et al. (2017)	Bridging the gap: Optimising transition from child to adult mental healthcare.	Professional guidance document. Expert policy paper. Reviews challenges associated with transition for general mental health, using ADHD as an example. Chapter 3 refers to recommendations for managing and planning transition for ADHD – very detailed.
Atkinson and Hollis (2010)	NICE guideline: attention deficit hyperactivity disorder	Peer reviewed paper. Reviews NICE guidelines with summary of key points related to transition. Details of transition are replica of NICE guideline.
Boilson et al. (2013)	Royal College of Psychiatrists. Attention Deficit Hyperactivity Disorder (ADHD) Guidance for Transition from Child & Adolescent Services to Adult Services.	Professional guidance document. Clinician focused. Details transition process (replicated from NICE) and provides recommended key points of pathway and what details should be included in a case summary provided at transition.
Coghill (2017)	Organisation of services for managing ADHD.	Peer reviewed paper. Updated version of paper published in 2016. Mainly focuses on barriers to transition. Refers to transition details from NICE guidance and UK Adult ADHD network; referral if significant symptoms require treatment, transfer by 18, and planning in advance from both child and adult service.
Fellick (2014)	Attention Deficit Hyperactivity Disorder (ADHD) Guideline for the treatment and care of children and young people with ADHD. Wirral University Teaching Hospital NHS Foundation Trust.	Local NHS Trust document. Regarding treatment and care of ADHD. Details transition process used in trust. Details of transition are replica of NICE guideline.
Fogler et al. (2017)	Topical Review: Transitional services for teens and young adults with attention-deficit hyperactivity disorder: a process map and proposed model to overcoming barriers to care.	Peer reviewed paper. Provides a unique model of care to support transition. Includes; emphasising trust, respect and open communication, supporting patient independence, helping young person to navigate education and investing time to ensure young person is involved in care.
Hall et al. (2015)	Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: a national survey of mental health trusts in England.	Peer reviewed paper. No clear detailed transition process, but links NICE guidance to data collected in their survey of transition. Data collected on transition and shared care protocols and transition pathways, information sharing and joint working.
NICE (2016)	Attention deficit hyperactivity disorder: diagnosis and management: CG72.	Full clinical guidance from NICE. Diagnosis and management of ADHD. Section 1.6 details transition to adult services.
NICE (2017)	NICE Pathways: Attention deficit hyperactivity disorder overview.	Overview of NICE guidance and quality standards. Details transition process as laid out in NICE NG87.
NICE (2018)	Attention deficit hyperactivity disorder: diagnosis and management. NG87	Full clinical guidance from NICE. Diagnosis and management of ADHD. Updated from 2016. Section 1.1.4, 1.1.5 and 1.1.6 details transition to adult services.
Ogundele (2013)	Transitional care to adult ADHD services in a North West England district.	Peer reviewed paper. Summarises literature around transition, and details ideal practice. Refers to NICE and Royal College of Nursing. Main points are early planning, young person and carer involvement, inter agency, comprehensive, holistic and developmentally appropriate.
South West Yorkshire Partnership NHS Foundation Trust (2018)	Attention deficit hyperactivity disorder (ADHD) service: Assessment process.	Local NHS Trust document. Regarding transition from children's services for patient use. Details transition process used in trust. Details are in line with NICE guideline; assessed at 18, joint planning meeting, young person and carer involvement, information, reassessment at adult service.

(continued)

Table 2. (continued)

Author/Year	Title	Description
Stockport ADHD Team (2015)	ADHD Care Bundle: Stockport CAMHS (Pennine Care NHS Trust).	Local NHS Trust document. Limited detail of transition processes. States referrals should be made to adult ADHD team if patient required continued medication after 16th birthday.
Tahir and Sims (2014)	Prescribing arrangements for the use of methylphenidate, dexamfetamine and atomoxetine in children with ADHD (attention deficit hyperactivity disorder) with transition to adult services in Berkshire. Berkshire Healthcare NHS Foundation Trust.	Local NHS Trust document. Regarding treatment and care of ADHD. Details transition process used in trust. Includes: transition at 18 commencing 3 months before, comorbidities to be transitioned to community mental health, drug-free trial prior to transition, to remain with CAMHS if remaining on medication, GP to continue care post 18, reassessment at adult service.
Young et al. (2016)	Recommendations for the transition of patients with ADHD from child to adult healthcare services: a consensus statement from the UK adult ADHD network.	Peer reviewed paper. Details NICE guidelines, and provides their own general recommendations for transition, and more specific recommendations for ADHD. Follows NICE guidance with more specific detail.
Young et al. (2011)	Avoiding the 'twilight zone': recommendations for the transition of services from adolescence to adulthood for young people with ADHD.	Peer reviewed paper. Summarises NICE guidance; then further expands and develops the NICE guidelines – very comprehensive guidance which follows NICE guidance with more detail. Very similar to 2016 paper by Young et al.

not specified by NICE, but it is suggested to be complete by age 18. Nine documents also specified completing transition by age 18, while six documents did not specify an age. Six documents specified reassessment at school-leaving age to address transition need, three stated age 17 or 18, five did not specify, and one recommended starting at age 13/14.

Planning. NICE guidelines recommend planning the transition with staff from both the child and adult services, via a joint meeting and the Care Programme Approach (CPA), and involving parent/carers and the young person. Seven documents did not specify details on planning, whilst the other eight agreed that planning in advance from services at both ends of the transition should occur. Nine documents did not specify staff involved, while Stockport ADHD team (2015) specified an ADHD nurse should coordinate the transition, and Young et al. (2016) recommend a lead clinician coordinates the transition once the referral to an adult service has been accepted.

Echoing the NICE guidelines, six of the documents suggest using CPA in planning for transition; two highlighted the need for the transition process and planning to be developmentally appropriate, although the latter was not explicitly defined. Only two documents suggest a timescale for the preparation of the young person for transition, one suggesting a minimum of a 6 months (Young et al., 2011), and one suggesting commencing 3 months prior to the 18th birthday (Tahir & Sims, 2014).

Ten documents specified that the parent and young person should be included in the planning, while one also recommended that healthcare teams should be mindful of comorbidities and parental ADHD, something not considered by NICE. Another recommendation was for commissioners to take local resources into account when designing and planning transition services. This is

not mentioned by NICE under transition, however, it is added as an addendum in NG87 that it is the responsibility of commissioners to implement the guidelines.

Information. NICE guidelines recommend that information sharing between services should include details about treatment and services required, while information should also be provided to the young person about transition and adult services. Half of the documents recommended providing information to the young person, but only three documents specified information sharing between services. One document listed the information that should be shared between services, including clinical evidence, current intervention, degree of engagement and context of the young person. Five documents recommend shared care and information sharing with the General Practitioner (GP), something that was not specified by NICE.

Protocols to guide transition are not specified as a requirement in NG87 but were highlighted by two documents in this review. It is suggested that protocols should be developed locally, and created jointly between services, taking in to account available resources, and enabling support for those who disengage with services prior to transition, those who are not accepted by adult services, and those who present in adulthood for the first time. The general health and social care transition guidelines (NG43) describe this process as a care plan (NICE, 2016).

Young et al. (2011) recommend continued professional development for clinicians to stay up to date with ADHD as a condition and the services available to support it, which is not mentioned in the NICE guidance.

Post transition. NICE recommend a comprehensive assessment is undertaken once the young person reaches the adult service, which is echoed in half of the identified documents. Two documents suggest

Table 3. Overview of compare/contrast of documents to NICE guidelines

	Asherson et al. (2017)	Atkinson and Hollis (2010)	Boilson et al. (2013)	Coghill (2017)	Fellick (2014)	Fogler et al. (2017)	Hall et al. (2015)	NICE pathway (2017)	NICE CG72 (2016)	Ogundele (2013)	Stockport CAMHS (2015)	SW Yorkshire NHS (2018)	Tahir and Sims (2014)	Young et al. (2016)	Young et al. (2011)
NICE guidelines NG87 (2018)															
Reassessed at school-leaving age		✓			✓			✓	✓			✓			✓
If ongoing treatment required – arrange for smooth transition with details of anticipated treatment		✓	✓		✓			✓	✓			✓			✓
Should be complete by age 18		✓	✓	✓	✓			✓	✓			✓			✓
Formal meeting involving CAMHS and AMHS		✓	✓		✓			✓	✓			✓			✓
For age 16 + Care Programme Approach (CPA) should be used		✓			✓			✓	✓			✓			✓
Young person and parent carer involvement		✓			✓			✓	✓			✓			✓
Comprehensive assessment at AMHS		✓			✓			✓	✓			✓			✓
Refers reader to NICE guideline NG43 on transition in health and social care services															

psychological therapies should be considered by adult services, a recommendation not specified by NICE. One document also specifies that the adult service should acknowledge the referral, and the young person should not be discharged from the child service until they have attended the adult service.

Discussion

This review has systematically searched for existing guidelines or protocols, or reviews of guidelines, in England specifically outlining the preferred process to transition a young person with ADHD between child and adult services. NICE guidelines have highlighted the need for transitional services for ADHD, but most health authorities have yet to establish clear protocols for transition (Bolea-Alamanac et al., 2014). This review was limited to transition guidelines specifically for ADHD transition in England, excluding any generic transition policies for general mental health. The searches were all conducted online; due to the variability in websites it is possible that services may have such documents, but they are not available or published online for public use. Direct contact with NHS services would be required to establish exactly what procedures, guidelines or protocols clinicians are using locally.

Results indicate that literature in this area is very strongly based on the NICE guidance for the management of ADHD NG87 (first published 2008, and updated 2016 and 2018) with a small number of authors expanding it. The systematic review by Seixas et al. (2012) identified 13 guidelines, from 10 different medical associations, however, only two were relevant to England and ADHD transition; NICE CG72, and the ADHD guidelines from the British Association of Pharmacology (BAP) (Bolea-Alamanac et al., 2014). The BAP paper was excluded from this review as it did not outline explicit recommendations for transition.

There were a number of points from the NICE guidance that were echoed in the majority of the reviewed documents; these included the reason and age for transition, information sharing, patient and family involvement and prior planning. Additional recommendations highlighted in some of the included documents but not mentioned in NG87 (or CG72 previously) include that transition should be developmentally appropriate, consider comorbidities and parental ADHD, the use of psychological therapies and continued professional development of clinicians. Two documents provide recommendations that are completely unique from NICE which include improving the education of healthcare professionals, increasing public awareness of ADHD, emphasis of trust and respect between patient and doctor, and supporting patient independence (Asherson et al., 2017; Fogler, Burke, Lynch, Barbaresi, & Chan, 2017).

The reviewed documents suggest transition should be completed by age 18, but consensus is growing that transition at 18 is not in the best interest of the young person (Dunn, 2017). Further research has also emphasised the need to start transition planning early (Suris & Akre, 2015) to provide young people time to progress through transition once they feel ready (Dunn, 2017). Patients and carers also often do not anticipate the

change and therefore commencing planning from the early teens can prevent transition failing (Coghill, 2016).

Others have argued that transition planning should incorporate a developmental perspective (Singh, Anderson, Liabo, & Ganeshamoorthy, 2016) which may be particularly important for young people with ADHD, who by definition have poor executive functioning and self-management (Fogler et al., 2017); the recommendations from the expert policy paper (Asherson et al., 2017) also emphasise that the transition should be planned as developmentally appropriate for the patient which is not mentioned by NICE. The transition to an adult service also often occurs at a critical time when young people are also encountering changes in education, employment and independence from parents (Tatlow-Golden et al., 2017). Boilson et al. (2013) suggests that information regarding the patient's employment, social circumstances and quality of life is important to support effective transition, which is highlighted in the general NICE guidance (NG43), but overlooked in the more specific recommendations for ADHD (NG87).

Information is key for transition; Hall et al. (2015) highlight the lack of local transition protocols and inadequate information sharing between child and adult services. Others have also underlined information sharing as a barrier to transition with clinicians citing insufficient information, poor communication and a lack of understanding between services (Dunn, 2017). Both papers by Young et al. (2011, 2016) recommend that clear transition protocols between services are best developed locally, which outline timelines and responsibilities for transition, and describe pathways for those not accepted by adult mental health services, those who do not transition and those that reenter services as an adult with ADHD (Young et al., 2016). Coghill (2016) also recommends that local detailed clinical pathways be developed. None of the other included documents refer to how to support young people who do not transition; particularly important when only 15% of cases make the transition (Singh & Tuomainen, 2015). One of the recommendations by Asherson et al. (2017) is to develop protocols for those patients that do not meet the criteria for adult services but still require ongoing support. Research suggests that there is huge variation in local practice and a lack of clear policies for transition (Muñoz-Solomando, Townley, & Williams, 2010). As many fail to transition, the lack of information or protocols is surprising; following the guidance in NG87, providing information and comprehensive early planning may support more patients to transition successfully.

Despite the highlighted need for clear transition protocols and responsibilities to be developed locally (Young et al., 2016) and systematic methods of searching, only four relevant NHS documents were found. It may be that ADHD is encompassed within general mental health policies and there are few local protocols specifically for ADHD transition; it was indicated by Hall et al. (2015) that services had care pathways but the majority were not specific to ADHD. Or perhaps it is a reflection on the availability and accessibility of the policies, despite the recommendation from NICE is that full information is provided to the young person. Protocols or policies for transition should be readily available to guide young

people and their parents/carers through the transition process. In the modern digital generation, young people would primarily use electronic media to gain information (Ford, Mitrofan, & Wolpert, 2013) and it is significant that this review was unable to identify more than four documents online.

The results of the survey by Hall et al. (2015) also emphasised a lack of staff training and knowledge in ADHD as a barrier to successful transition. Atkinson and Hollis (2010) emphasise the challenges that NICE guidelines present for clinicians or those organising and planning services, and suggest that increasing numbers of young people requiring a transition to adult services will have implications for training and service delivery. Indeed the expert policy document identified by this review (Asherson et al., 2017) recommended improving the ADHD education, knowledge and experience of healthcare professionals. Furthermore, other studies have emphasised the lack of expertise, training and capacity of clinicians as a barrier to continuing care through transition (Montano & Young, 2012). A study of college and university health centres in the United Kingdom highlighted that 87% of clinicians had not attended any recent training for ADHD and many providing an adult service lacked resources to facilitate transition (Baverstock & Finlay, 2003). Efforts should be made to educate and inform professionals about ADHD (Young et al., 2016) and there is a clear need to upskill clinicians to practically manage ADHD and treatment (Coghill, 2015). Without training, capacity and knowledge of ADHD and services, it could be argued that clinicians are lacking the ability to implement the guidelines appropriately to support patients with ADHD through transition.

NICE states that professionals are expected to take clinical guidelines fully into account, but that the recommendations are not mandatory, while commissioners and service providers have a responsibility to enable the implementation of the guideline (NICE, 2008). This is conflicting, and presents a challenge for clinicians and local services to ensure that adequate ADHD services are provided, particularly for patients in transition.

Conclusion

This systematic review aimed to identify and describe guidelines and protocols for transition from child to adult services for patients with ADHD in England. The review identified 16 documents that were mostly based around the NICE guidelines for ADHD diagnosis and management (NG87). Few independent guidelines were found although some documents provided additional or more detailed recommendations to the NICE guidelines, and many were peer reviewed papers which discussed the recommendations made by NICE. While this review used reliable systematic methods of searching, and followed the recommended steps for data screening and extraction, it is limited by specifically focussing on transition and England only.

The nature of health services and the changing needs of service users means that service changes occur, and guidelines are also amended or updated to meet the required need. However, the NICE guidelines for management of ADHD updated and published in March 2018 (NG87) do not provide any new or updated recommendations for transition from the 2008 version apart

from referring the reader to the general NICE guidelines on transition in health and social care services (NG43). These provide more comprehensive recommendations for transition generally, however, these are not condition specific. It would be beneficial for NG87 to incorporate these recommendations and develop them to be specific for ADHD.

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Ethical Information

Ethical approval was not required for this article.

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Supporting information

Additional Supporting Information may be found in the online version of this article:

- Appendix S1.** List of search terms and strings.
- Appendix S2.** Professional and charity organisations included in searches.
- Appendix S3.** Spreadsheet for comparing/contrasting guidelines.

References

- AADD-UK. (2017). Clinical guideline (CG72) ADHD: Diagnosis & management update. Available from: <https://aadduk.org/2017/09/08/clinical-guideline-cg72-adhd-diagnosis-management-update/> [accessed 18 September 2017].
- Asherson, P., Bilbow, A., Carr-Fanning, K., Destrebecq, F., Dom, G., Galderisi, S., ... & Zorbas, S. (2017). Bridging the gap: Optimising transition from child to adult mental health-care. Available from: <https://www.adhdfoundation.org.uk/wpcontent/uploads/2017/11/Bridging-the-gap-Optimising-Transition.pdf> [last accessed 28 August 2018].
- Atkinson, M., & Hollis, C. (2010). NICE guideline: Attention deficit hyperactivity disorder. *Archives Disease Childhood Education Practice Edition*, 95, 24–27.
- Baverstock, A.C., & Finlay, F. (2003). Who manages the care of students with Attention Deficit Hyperactivity Disorder (ADHD) in higher education? *Child Care Health and Development*, 29, 163–166.
- Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child: Care, Health and Development*, 30, 581–587.
- Boilson, M., Forbes, F., Quilter, M., & Sutherland, C. (2013). *Attention Deficit Hyperactivity Disorder (ADHD) guidance for transition from child & adolescent services to adult services*. London: Royal College of Psychiatrists.
- Bolea-Alamanac, B., Nutt, D.J., Adamou, M., Asherson, P., Bazire, S., Coghill, D., ... & Young, S.J. (2014). Evidence-based guidelines for the pharmacological management of attention deficit hyperactivity disorder: Update on recommendations from the British Association for Psychopharmacology. *Journal of Psychopharmacology*, 28, 179–203.
- Canadian ADHD Resource Alliance. (2018). *Canadian ADHD practice guidelines*. Toronto, ON: Author.
- Coghill, D. (2015). Services for adults with ADHD: Work in progress: Commentary on... Specialist adult ADHD clinics in East Anglia. *BJPsych Bulletin*, 39, 140–143.
- Coghill, D. (2016). Organisation of services for managing ADHD. *Epidemiology and Psychiatric Sciences*, 26, 453–458.
- Coghill, D.R. (2017). Organisation of services for managing ADHD. *Epidemiology Psychiatric Sciences*, 26, 453–458.
- CRD. (2009). Systematic reviews: Centre for reviews and dissemination's guidance for undertaking reviews in healthcare. Available from: https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf [last accessed 22 November 2017].
- Dunn, V. (2017). Young people, mental health practitioners and researchers co-produce a Transition Preparation Programme to improve outcomes and experience for young people leaving Child and Adolescent Mental Health Services (CAMHS). *BMC Health Services Research*, 17, 293.
- Embrett, M.G., Randall, G.E., Longo, C.J., Nguyen, T., & Mulvale, G. (2016). Effectiveness of health system services and programs for youth to adult transitions in mental health care: A systematic review of academic literature. *Administration and Policy in Mental Health*, 43, 259–269.
- Faraone, S.V., Asherson, P., Banaschewski, T., Biederman, J., Buitelaar, J.K., Ramos-Quiroga, J.A., ... & Franke, B. (2015). ADHD. *Nature Reviews Disease Primers*, 1, 15027.
- Faraone, S.V., Biederman, J., & Mick, E. (2006). The age-dependent decline of attention deficit hyperactivity disorder: A meta-analysis of follow-up studies. *Psychological Medicine*, 36, 159–165.
- Fellick, J. (2014). *Attention Deficit Hyperactivity Disorder (ADHD) Guideline for the treatment and care of children and young people with ADHD*. Wirral, UK: Wirral University Teaching Hospital NHS Foundation Trust.
- Fletcher, J., & Wolfe, B. (2009). Long-term consequences of childhood ADHD on criminal activities. *Journal of Mental Health Policy and Economics*, 12, 119–138.
- Fogler, J.M., Burke, D., Lynch, J., Barbaresi, W.J., & Chan, E. (2017). Topical review: Transitional services for teens and young adults with attention-deficit hyperactivity disorder: A process map and proposed model to overcoming barriers to care. *Journal of Pediatric Psychology*, 42, 1108–1113.
- Ford, T., Hamilton, H., Meltzer, H., & Goodman, R. (2007). Child mental health is everybody's business: The prevalence of contact with public sector services by type of disorder among British school children in a three-year period. *Child and Adolescent Mental Health*, 12, 13–20.
- Ford, T., Janssens, A., Asherson, P., Beresford, B., Paul, M., Ani, C., ... & Logan, S. (2015). CATCH-uS: Children with ADHD in transition from children's services to adult services. Available from: <https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/142152/#/> [last accessed 28 August 2018].
- Ford, T., Mitrofan, O., & Wolpert, M. (2013). Life course: children and young people's mental health. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/413196/CMO_web_doc.pdf [last accessed 27 November 2017].
- Hall, C.L., Newell, K., Taylor, J., Sayal, K., & Hollis, C. (2015). Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: A national survey of mental health trusts in England. *Journal of Psychopharmacology*, 29, 39–42.
- Hall, C.L., Newell, K., Taylor, J., Sayal, K., Swift, K.D., & Hollis, C. (2013). 'Mind the gap'-mapping services for young people with ADHD transitioning from child to adult mental health services. *BMC Psychiatry*, 13, 186.
- Jick, H., Kaye, J., & Black, C. (2004). Incidence and prevalence of drug-treated attention deficit disorder among boys in the UK. *British Journal of General Practice*, 54, 345–347.
- Joint Commissioning Panel for Mental Health. (2013). *Guidance for commissioners of mental health services for young people making the transition from child and adolescent to adult*

- services. Available from: <http://www.jcpmh.info/good-services/young-people-in-transition/> [last accessed 20 September 2017].
- Kendall, T., Taylor, E., Perez, A., & Taylor, C. (2008). Diagnosis and management of attention-deficit/hyperactivity disorder in children, young people, and adults: Summary of NICE guidance. *BMJ*, 337, a1239.
- Lichtenstein, P., Halldner, L., Zetterqvist, J., Sjolander, A., Serlachius, E., Fazel, S., ... & Larsson, H. (2012). Medication for attention deficit-hyperactivity disorder and criminality. *New England Journal of Medicine*, 367, 2006–2014.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., & PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine*, 15, 264–269.
- Montano, C.B., & Young, J. (2012). Discontinuity in the transition from pediatric to adult health care for patients with attention-deficit/hyperactivity disorder. *Postgraduate Medicine*, 124, 23–32.
- Mordre, M., Groholt, B., Kjelsberg, E., Sandstad, B., & Myhre, A. (2011). The impact of ADHD and conduct disorder in childhood on adult delinquency: A 30 years follow-up study using official crime records. *MBMC Psychiatry*, 11, 57.
- Muñoz-Solomando, A., Townley, M., & Williams, R. (2010). Improving transitions for young people who move from child and adolescent mental health services to mental health services for adults: Lessons from research and young people's and practitioners' experiences. *Current Opinion in Psychiatry*, 23, 311–317.
- NICE. (2008). Attention Deficit Hyperactivity Disorder: Diagnosis and management of ADHD in children, young people and adults (CG72). Available from: <http://publications.nice.org.uk/attention-deficit-hyperactivity-disorder-cg72> [last accessed 07 April 2017].
- NICE. (2016). *Transition from children's to adults' services for young people using health or social care services*. London: Author.
- NICE. (2017). *Attention deficit hyperactivity disorder overview: NICE Pathway*. London: Author.
- NICE. (2018). Attention deficit hyperactivity disorder: diagnosis and management. Available from: <https://www.nice.org.uk/guidance/ng87/resources/attention-deficit-hyperactivity-disorder-diagnosis-and-management-pdf-1837699732933> [last accessed 2 August 2018].
- Ogundele, M.O. (2013). Transitional care to adult ADHD services in a North West England district. *Clinical Governance: An International Journal*, 18, 210–219.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews*. Lancaster, UK: Lancaster University.
- Seixas, M., Weiss, M., & Muller, U. (2012). Systematic review of national and international guidelines on attention-deficit hyperactivity disorder. *Journal of Psychopharmacology*, 26, 753–765.
- Singh, S.P., Anderson, B., Liabo, K., & Ganeshamoorthy, T. (2016). Supporting young people in their transition to adults' services: Summary of NICE guidance. *BMJ*, 353, i2225.
- Singh, S.P., Paul, M., Ford, T., Kramer, T., & Weaver, T. (2008). Transitions of care from child and adolescent mental health services to Adult Mental Health Services (TRACK Study): A study of protocols in Greater London. *BMC Health Services Research*, 8, 135.
- Singh, S.P., Paul, M., Islam, Z., Weaver, T., Kramer, T., McLaren, S., ... & Harley, K. (2009). *Transition from CAMHS to adult mental health services: A study of service organisation, policies, process, user and carer perspectives*. London: NETSCC.
- Singh, S.P., & Tuomainen, H. (2015). Transition from child to adult mental health services needs barriers experiences and new models of care. *World Psychiatry*, 14.
- Suris, J.-C., & Akre, C. (2015). Key elements for, and indicators of, a successful transition: An International Delphi Study. *Journal of Adolescent Health*, 56, 612–618.
- Tahir, O., & Sims, K. (2014). *Prescribing arrangements for the use of methylphenidate, dexamfetamine and atomoxetine in children with ADHD (attention deficit hyperactivity disorder) with transition to adult services in Berkshire*. Bracknell, UK: Berkshire Healthcare NHS Foundation Trust. Retrieved from <https://www.eastberkshireccg.nhs.uk/wp-content/uploads/2018/03/ADHD-child-prescribing-arrangement-v1Oct-2013FinalDraft.pdf> [last accessed 10 July 2018]
- Tatlow-Golden, M., Gavin, B., McNamara, N., Singh, S., Ford, T., Paul, M., ... & McNicholas, F. (2017). Transitioning from child and adolescent mental health services with attention-deficit hyperactivity disorder in Ireland: Case note review. *Early Intervention Psychiatry*, 12, 505–512.
- Timimi, S., & Radcliffe, N. (2005). The rise and rise of attention deficit hyperactivity disorder. *Journal of Public Mental Health*, 4, 9–13.
- Young, S., Adamou, M., Asherson, P., Coghill, D., Colley, B., Gudjonsson, G., ... & Arif, M. (2016). Recommendations for the transition of patients with ADHD from child to adult healthcare services: A consensus statement from the UK adult ADHD network. *BMC Psychiatry*, 16, 301.
- Young, S., Murphy, C.M., & Coghill, D. (2011). Avoiding the 'twilight zone': Recommendations for the transition of services from adolescence to adulthood for young people with ADHD. *BMC Psychiatry*, 11, 174.

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