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Multidisciplinary consensus for the development of ADHD services: the way forward

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Abstract

Purpose – Attention deficit hyperactivity disorder (ADHD) is the most commonly studied and diagnosed psychiatric disorder in children. There is a need to engage service development, commissioning and service managers to address primary care involvement and define service models that will enable effective management of people with ADHD. The purpose of this project is to define recommendations through consensus that can be implemented to improve ADHD management in the UK.

Design/methodology/approach – A set of 40 consensus statements has been developed by a multidisciplinary group of ADHD professionals in the UK. These statements cover ten topics, ranging from commissioning of ADHD services to optimisation of the care pathway. The aim of the project was to define a set of standards that could be tested across a wider clinical population.

Findings – A total of 122 respondents scored each statement on a questionnaire and levels of agreement were summated and analysed. Of 40 statements, only four scored less than 90 per cent agreement, with all statements achieving greater than 74.9 per cent agreement.

Originality/value – Recommendations support the wider integration of ADHD services and the closer involvement of commissioners within the new GP consortia to ensure that the potentially negative societal and personal impacts of ADHD are managed effectively and with appropriate use of resources.

Keywords Attention deficit hyperactivity disorder, Health care quality, Consensus statement, Integration, Recommendation, Health care, United Kingdom

Paper type Research paper

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Background

Attention deficit hyperactivity disorder (ADHD) is estimated to affect 3-9 per cent of school-aged children and young people in the UK and 2 per cent of adults worldwide (National Institute for Health and Clinical Excellence, 2008). ADHD is a neurobehavioural (National Institute of Neurological Disorders and Stroke, 2007) and developmental disorder (Zwi *et al.*, 2000), primarily characterised by the co-existence of attention problems and hyperactivity and symptoms starting before seven years of age (Biederman, 1998). ADHD is the most commonly studied and diagnosed psychiatric disorder in children (Nair *et al.*, 2006). It is a chronic disorder (Van Cleave and Leslie, 2008). Follow-up studies of children with ADHD find that 15 per cent still have the full diagnosis at 25 years, and a further 50 per cent are in partial remission, with some symptoms persisting associated with clinical and psychosocial impairments (Faraone *et al.*, 2006). Adolescents and adults with ADHD tend to develop coping mechanisms to compensate for some or all of their impairments (Gentile, 2004). The National Institute for Clinical Excellence (NICE) was set up as a special health authority for England and Wales in 1999 (Raftery, 2001) to "provide guidance to the National Health Service (NHS) on the use of selected new and established technologies". NICE was first announced in the previous government's white paper *The New NHS* in 1997 (Department of Health, 1997). NICE synthesises evidence on the effectiveness and cost of treatments and reaches a judgment as to whether, on balance, the intervention can be recommended as a cost-effective use of NHS resources (Sculpher *et al.*, 2001). Guidance from NICE applies to the NHS in the same way as guidance from other branches of the Department of Health. While local health economies are required by statute to take account of – but not necessarily follow – guidance, general practitioners (GPs) have greater clinical discretion. NICE clinical guidelines have shown how the condition should be treated in the UK (Newdick, 2001), but this guidance is not followed universally or consistently. This multidisciplinary consensus addresses some key challenges in the implementation of NICE guidelines and seeks to ascertain levels of agreement amongst ADHD professionals. There is a need to engage ADHD service development, mental health commissioning and NHS managers to address primary care involvement and define the optimal service model. The objective of this project is to define practical and achievable recommendations through consensus that can be implemented to improve ADHD management in the UK.

Method

A multidisciplinary group of professionals met in August 2010 with the objective of defining themes for future ADHD service development and the implementation of NICE clinical guidelines. Through a day of discussion, the steering group agreed the following ten themes that required further consensus:

(1) role of a care coordinator;
(2) commissioning ADHD Services in the NHS;
(3) engaging primary care in the management of ADHD;
(4) nursing resources required to manage ADHD;
(5) optimising the model patient journey in ADHD;
(6) delivering patient-centred care in ADHD;

(7) managing children with learning disability (LD);
(8) addressing co-morbidities of ADHD;
(9) improving diagnosis of ADHD; and
(10) engagement with other agencies to support care.

In total, the steering group agreed 40 consensus statements across the ten themes. The statements are listed in the Appendix.

In order to establish wider consensus, a Delphi methodology was used. The statements were collated into a questionnaire and circulated to other professionals working in the field of ADHD. The level of individual agreement with each statement is measured using a four-point Likert scale, which allows respondents to record levels of agreement with each statement and suggest changes. Each statement was scored "strongly disagree", "disagree", "agree", or "strongly agree".

Questionnaires were completed by a mixed group of clinical professionals involving 122 respondents (Table I), at ADHD health professional meetings held in various locations throughout the UK.

The Delphi method is a systematic and proven consensus method that relies on a steering group of experts. These experts are involved in one or more rounds. After each round, a facilitator provides an anonymous summary of the questionnaire feedback and the reasons they provided for their judgments. Thus, the initial steering group is encouraged to revise earlier answers in light of the questionnaire replies from the wider multidisciplinary audience. It is believed that during this process the range of the answers will decrease and the group will converge towards the "correct" answer (consensus). The process is stopped after a pre-defined stop criterion (e.g. number of rounds, achievement of consensus or stability of results) and the mean or median scores of the final rounds determine the results.

The following key characteristics of the Delphi method help the participants to focus on the issues at hand and separate Delphi from other methodologies:

- structuring of information flow;
- regular feedback;
- anonymity of the participants; and
- role of the facilitator.

Responses were collated and analysed statistically. Levels of agreement with the original statements were unusually high from the outset of the project, so no further amendment was made to the original statements.

Consultant child and adolescent psychiatrists	30
Consultant paediatricians	38
ADHD nurses	21
Trainee doctors	6
Other ADHD workers	27
Total	122

Table I. Summary of the respondents

Results

All 40 statements achieved agreement in excess of 74.9 per cent, indicating a strong consensus across the respondent group. There was minimal variation between sub-groups, indicating strong alignment across professions. Of the 40 statements initially produced by the consensus group, 36 scored over 90 per cent agreement through the questionnaires. The lowest score was 75 per cent, suggesting that wider consensus was strong for all of the statements.

Between consultant child and adolescent psychiatrists, 34 of the statements scored over 90 per cent agreement. Six statements scored lower, between 75.9 per cent and 88.5 per cent agreement.

In the paediatricians group, 37 of the statements scored over 90 per cent agreement. Three statements scored lower, between 71.4 per cent and 86.1 per cent agreement.

Among the nurses, 33 of the statements scored over 90 per cent agreement. Seven statements scored lower, between 75 per cent and 88.9 per cent agreement.

In the trainee group, 32 of the statements scored over 90 per cent agreement. Eight statements scored lower, between 66.7 per cent and 88.3 per cent agreement.

Discussion

The consensus steering group consisted of a multi-disciplinary group of ADHD professionals in the UK. Over half the contributors during the questionnaire stage were doctors and the level of consensus was over two-thirds for all statements. The variation in scoring across each of the subgroups of respondents may prove useful in understanding the different perspectives offered by each sub-group.

Managing ADHD requires a multi-disciplinary approach. It is therefore important that appropriate mechanisms are put in place for timely referral between the agencies involved. The group found a high level of agreement concerning the importance of a care coordinator. The care coordinator could be anyone within the multi-disciplinary team (MDT), providing a central point of contact for the patient, family and carer. A key focus of this role would be the provision of appropriate access to necessary support services. The components listed in the ADHD coordinator statement are all important in defining the ideal skill requirements. Some respondents noted that the care coordinator should be involved in patient assessment and triage, but not diagnosis of ADHD. A holistic approach to patient care is important and the care coordinator must be appropriately informed to identify needs and refer appropriately. Changes in structure across the NHS are rapid and far-reaching. The care coordinator may therefore require a detailed understanding of the local health economy to ensure that ADHD is understood and resourced appropriately.

A second key finding of the consensus group was the need to raise awareness in primary care regarding ADHD, especially with GPs. Commissioning may be developed collaboratively across multiple GP consortia. Failure to treat ADHD effectively has significant social and economic impact. ADHD is associated with impaired academic and social performance and causes emotional distress for both patient and family. The impacts of ADHD persist over many years and continue into adulthood in up to 50 per cent of patients.

The consensus process found the roles of health visitors, schools and teachers to be important in ensuring that children are referred quickly and appropriately for assessment. The provision of appropriate support should include education, training,

communication tools, clinical guidelines and care pathways. Shared care pathways between primary and secondary care may be useful in ensuring appropriate patient assessment and prescribing of medication. Some nurses felt that the role of the care coordinator was already covered within their activity; however, the consensus group considered that the care coordinator should be a separate role alongside the nursing role, but may be covered by the same person if appropriate. The sub-groups that were least supportive were the consultant paediatricians and psychologists.

The steering group considered that the integration of services across the MDT required the close involvement of ADHD nurses in both the primary and secondary care settings. There was consensus that the role of nurses in appropriate supplementary prescribing was a potential opportunity. Supplementary prescribing is increasingly widespread by nurses and pharmacists in the UK. Treatment initiation should always be agreed across the wider clinical team. There was strong support for the adoption of care pathways in the effective management of ADHD.

Some NHS Trusts have plans in place for patients with ADHD to transition their care from secondary to primary care, but others lack them because of the absence of an adult ADHD service. Prevalence of ADHD in adults is 2.5 per cent; hence, young people currently treated for ADHD by Child and Adolescent Mental Health Services (CAMHS) and paediatricians are likely to require treatment beyond the age of 16 (Verity and Coates, 2007). It is important that the needs of adolescent and adult patients are addressed by local service design. There is a broad need to address ADHD in order to improve the quality of life of patients, parents and carers. Appropriate treatment of ADHD is needed to avoid potentially severe difficulties (Harpin, 2005). Clinicians working with ADHD children should be familiar with the evidence base. Information and parenting support can best be provided within the primary care setting. The literature on ADHD in girls is scant and inconsistent (Sharp *et al.*, 1999). Compared with boys, girls with ADHD are under-recognised (Groenewald *et al.*, 2009). More girls may remain undiagnosed than boys, as they tend to be less disruptive. Identification of girls with ADHD is hampered by parental and teacher bias. Girls are more likely to be inattentive without being hyperactive or impulsive, compared with boys (Staller and Faraone, 2006). They may still be failing at school, however, and experiencing other problems due to their ADHD. ADHD in girls may be associated with more severe cognitive and language problems and greater social problems (Staller and Faraone, 2006). In order to recognise ADHD in girls, education for teachers, Special Education Need Coordinators (SENCOs) and school nurses is important.

Recent changes in the pattern of health and social care delivery across the UK (Department of Health, 2010) provide the context for an increased alignment between social services and the NHS in the treatment of ADHD. Local authorities have Health and Well Being Boards (HWBB) responsible for the integration of public health and social care services. ADHD has a significant negative impact on quality of life when not diagnosed and managed effectively (Harpin, 2005). Integrated care pathways (ICPs) have been shown to improve outcomes and produce efficiency savings in the delivery of care.

ADHD professionals are strongly supportive of the statements defined in this consensus project. The need for integration of ADHD services across care settings and with the involvement of commissioning teams is clear in order for ADHD services to develop in the UK. Currently many children are undiagnosed and develop into adulthood with significant deficit. The impact of this is profound and should be

addressed with urgency. There is strong consensus that the involvement of wider agencies is critical in understanding the impacts of ADHD and developing effective services. Whilst small variations in response between sub groups were observed, none of the statements scored less than 75 per cent agreement either by sub-group or in total suggesting that both clinical alignment between roles and knowledge of the current service provision is strong amongst ADHD professionals.

The strong levels of agreement between different professionals indicate the strength of feeling amongst ADHD professionals working in the NHS.

Recommendations

The following recommendations are intended to provide a stimulus to the further development of ADHD services across the UK:

- A care coordinator should be nominated for each patient in order to ensure that access to services and local agencies is optimised.
- ADHD professionals should seek to engage with other services, including education, primary care, specialist care, support services, commissioners, social care and public health.
- Wider education is needed to ensure that policy makers at national and local level are fully aware of the impacts of untreated ADHD and the course of treatment over many years.
- Adult services across the UK should be developed as a matter of urgency to avoid patients dropping out of treatment during the transitional period after paediatric care stops at age 16 (or 18 if in full time education).
- Primary care clinicians need to be educated to recognise the diagnostic signs of ADHD.
- Specialist ADHD nurses should be recognised a key resource in effective patient management.
- Integrated care pathways (ICPs) for ADHD should be implemented to ensure appropriate assessment diagnosis and management of each case. ICPs will also offer the chance of improved outcome and resource optimisation.
- Patient-centred care is paramount to successful management of ADHD and requires that the patient, family and carer be educated regarding the condition and their choices.
- Particular attention should be paid to the diagnosis and management of ADHD in children with learning difficulties.
- Early diagnosis and effective management contribute significantly to outcome in patients with ADHD. Care must be taken to recognise the differing presentations of girls and boys and to avoid under-diagnosis of ADHD in girls.
- Local authorities should be increasingly involved in the development of effective services for the management of ADHD.

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Appendix

No	Topic	Statement	Level of Agreement			
			Strongly disagree	Tend to disagree	Tend to agree	Strongly agree
1	**Care Coordinator**	A Care Coordinator should be available to assess the clinical and non-clinical needs of each patient	o	o	o	o
2		The Care Coordinator should be able to develop partnership between primary care, specialist care, support services and other agencies	o	o	o	o
3		The Skill set for care coordinator should include specialist ADHD knowledge, clinical background, ability to work independently, ability to assess patients, understanding of treatments and their side effects.	o	o	o	o
4		The care coordinator should support patient access to the local health economy	o	o	o	o
5	**Commissioning ADHD Services**	The health economy must recognise that successful treatment of ADHD will have long lasting positive impact on social and economic productivity	o	o	o	o
6		ADHD should be recognised as a long term condition requiring input over many years	o	o	o	o
7		In each health economy, one expert single commissioner should be nominated with responsibility for all aspects of ADHD service provision. Ensuring that the service meets defined standards and outcomes	o	o	o	o
8		Commissioning of services for ADHD should include seamless transition between young person, adolescent and adult services	o	o	o	o
9	**Engaging primary care in the management of ADHD**	Shared care protocols should be implemented for post diagnosis follow up and treatment	o	o	o	o
10		The primary care team should ensure that children with possible ADHD are referred for diagnosis quickly	o	o	o	o
11		Support should be provided locally to assist GPs in appropriate management of the ADHD patient journey	o	o	o	o
12		Local consortia should consider the development of a patient service for ADHD	o	o	o	o
13	**Nursing resources**	ADHD nurses are an invaluable resource in providing the role of the care coordinator	o	o	o	o
14		ADHD nurses should take a pivotal role in clinical case management of co-morbid and complex issues	o	o	o	o
15		The ADHD nurse should liaise between clinical and community agencies and family to ensure defined clinical outcomes	o	o	o	o
16		Specialist ADHD nurses should support allied professionals in diagnosis and addressing the holistic needs	o	o	o	o
17		Where possible, specialist ADHD nurses should be able to prescribe appropriate medical treatment	o	o	o	o
18	**Optimising model patient journey**	The patient journey should include the process of assessment, diagnosis and each subsequent stage of care and management including transition across services	o	o	o	o

(*Continued*)

Figure A1.
Consensus questionnaire

19		Where a diagnosis is not possible at assessment, a patient plan should still be initiated	o	o	o	o
20		It is important to integrate care across all appropriate agencies according to best practice and current guidelines	o	o	o	o
21		Evidence-based Integrated Care pathways (ICP) are available as models for the management of ADHD and may be used to facilitate the implementation locally	o	o	o	o
22		Care pathways should be developed with mental health services for the management of transition in the future	o	o	o	o
23	**Patient centered care**	The views of the young person should be central	o	o	o	o
24		Patients should be encouraged to make contact with support groups in ADHD	o	o	o	o
25		Time should be allocated to explaining therapy to the young person so that they can be involved in treatment decisions	o	o	o	o
26	**Children with Learning disability (LD)**	Children with learning disabilities (LD) have high rates of ADHD, which are under-recognised and under-treated.	o	o	o	o
27		Treatment of ADHD in children with LD will help to maximize their learning capability and quality of life	o	o	o	o
28		All professionals working with children with LD and ADHD should have appropriate knowledge to diagnose ADHD in children with LD	o	o	o	o
29		Clinicians managing children with LD should have training to manage behavioural issues arising from ADHD and possible side effects of treatment	o	o	o	o
30	**Addressing co-morbidities of ADHD**	Children with ADHD often have co-morbidities of Learning Disability (LD), Autism Spectrum Disorder (ASD), tic disorders, epilepsy, Developmental Coordination Disorder (DCD), anxiety / depression and/or Conduct Disorder (CD)	o	o	o	o
31		Treatment of co-morbid conditions is often necessary	o	o	o	o
32	**Diagnosis of ADHD**	Early access to diagnosis is important to improve outcome	o	o	o	o
33		The role of primary care is key to assessment and diagnosis	o	o	o	o
34		All clinicians in primary care need to be aware of the prevalence of ADHD and the current under-diagnosis	o	o	o	o
35		ADHD in girls often presents differently and is under-diagnosed	o	o	o	o
36	**Engagement with other agencies**	Schools may be the first to become aware of potential ADHD and should be supported to make recommendations for referral	o	o	o	o
37		Social services should recognise the impact on families of un-diagnosed ADHD	o	o	o	o
38		Social care is an integral part of holistic management	o	o	o	o
39		Integrated multidisciplinary care pathways offer the opportunity for joint working	o	o	o	o
40		Services need to be aligned with the Justice System and Youth Offending Teams (YOTs)	o	o	o	o

Figure A1.