Healthcare Improvement Scotland is committed to equality. We have assessed the performance assessment function for likely impact on equality protected characteristics as defined by age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation (Equality Act 2010). You can request a copy of the equality impact assessment report from the Healthcare Improvement Scotland Equality and Diversity Officer on 0141 225 6999 or email contactpublicinvolvement.his@nhs.net
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Background

About the Attention Deficit and Hyperkinetic Disorders – Services over Scotland (ADHD-SOS) follow-up review

The aim of the Attention Deficit and Hyperkinetic Disorders – Services over Scotland (ADHD-SOS) follow-up review was to determine to what extent recommendations made in 2008 have improved services in Scotland for children and young people with ADHD. The 12 key recommendations made in the Attention Deficit and Hyperkinetic Disorders – Services over Scotland (2008) report have been grouped under one of the following headings:

- awareness raising and recognition
- non-pharmacological interventions
- outcomes
- transition, and
- systems, processes and skills.

A summary of the findings from the review, including strengths and barriers to implementation, is shown in this report.
NHS Ayrshire & Arran

Local service provision

In 2007, NHS Ayrshire & Arran provided services for children and young people with ADHD through a number of generic teams. Three community-based children and mental health services (CAMHS) teams provided services for children up to the age of 16 years, covering north, south and east Ayrshire. A fourth generic CAMHS team provided board-wide services for young people aged 15–18 years, including those with ADHD. In addition to CAMHS, the NHS board had paediatric-led ADHD review clinics in north, south and east Ayrshire.

In response to the *Attention Deficit and Hyperkinetic Disorders – Services over Scotland* (2008) report, NHS Ayrshire & Arran commissioned a review of its ADHD services. This was undertaken in 2009. The review led to the development of a multi-agency steering group with representatives from child health, children’s mental health, school nursing and adult mental health services.

The group developed a multi-agency pathway for children and young people who are suspected of, or have, ADHD. In June 2011, NHS Ayrshire & Arran implemented the new multi-agency pathway. The pathway uses the Getting it Right for Every Child (GIRFEC) processes for all children aged 0–18 years.

There is now a single point of entry into specialist CAMHS. Pre-school services for children who may have a diagnosis of ADHD are delivered within paediatric services. Within CAMHS, NHS Ayrshire & Arran has also developed nurse-led clinics for behavioural management and parent training. Since 2009, CAMHS has delivered ADHD services within three locality teams. These are aligned with local authority and community health partnership boundaries.

NHS Ayrshire & Arran reported an ongoing challenge in 2007 to recruit consultant psychiatrists. At the time of the 2012 review, the NHS board had 3.6 whole time equivalent child and adolescent psychiatrists in post. While the recruitment challenge has been overcome, the service has grown considerably since 2007, and staff reported a new challenge concerning accommodation and training.

Summary of findings

**Strengths**

The NHS board has:

- a multi-agency pathway
- a range of parenting programmes
- a comprehensive parent information booklet
- an information gathering form completed by schools at the pre-diagnosis stage to help inform a diagnosis of ADHD, and
- nurses trained in the physical care and monitoring of children with ADHD.
Barriers to implementation

The NHS board reported:

- capacity issues in reaching across a substantial workforce in health, education and local authority
- challenges in working across three local authorities
- restricted communication, particularly by email, due to the NHS system security, and
- that due to the NHS board’s rural nature, which includes island communities, there can be issues with accessing services that are mainly delivered in the three clinic bases.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Ayrshire & Arran prevalence rate comparison

In NHS Ayrshire & Arran, the number of children receiving treatment for ADHD has increased since the previous data collection exercise in 2007. However, the reported prevalence is still lower than we would expect to see.

<table>
<thead>
<tr>
<th>2007 data</th>
<th>2011 data</th>
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<tbody>
<tr>
<td>253 reported cases</td>
<td>296 reported cases</td>
</tr>
<tr>
<td>(0.3% of under 18 population)</td>
<td>(0.4% of under 18 population)</td>
</tr>
<tr>
<td>Boys 83% Girls 17% (of caseload) Ratio 5:1</td>
<td>Boys 90% Girls 10% (of caseload) Ratio 9:1</td>
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</table>

The ratio of boys to girls appears to have changed with the proportion of boys increasing. Fewer girls are now being diagnosed and staff reported concerns about this. One staff member had attended a national conference where this issue had been highlighted and discussed. Since then staff have been more aware of the different behaviours to look out for in girls which could be a presentation of ADHD. A requirement for staff training in this area has been identified to ensure they recognise the differences in presentation of symptoms between the genders.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child’s/young person’s difficulties.

Since 2008, NHS Ayrshire & Arran has taken a number of steps to raise awareness and recognition of ADHD within health, education and social services. NHS Ayrshire & Arran provided no evidence of engagement with third sector organisations.

- In 2009, a review of ADHD services was undertaken. This led to development of a multi-agency steering group which developed the current multi-agency pathway. The group included representatives from child health, children’s mental health, school nursing and adult mental health services. CAMHS staff provided training where required.

- An information booklet has been developed as part of the multi-agency pathway and was led by education, with input from health and carer representatives.

- CAMHS staff provide advice for teachers on a case-by-case basis. The acting clinical nurse specialist is currently working with head teachers to deliver ADHD training to educational staff.

- An education event was undertaken in East Ayrshire with all head teachers.

- There are now representatives from educational psychology on the multi-agency pathway group from all three local areas.

- Social services are also represented on the multi-agency pathway group.

- There is ongoing training, supervision and liaison for social services staff, including those with responsibility for looked after and accommodated children.

The multi-agency pathway is relatively new and the service is in the early stages of rolling out training to schools and raising awareness among GPs. The NHS board recognises that this will be ongoing work for the next few years due the number of schools and GPs across Ayrshire & Arran. Staff reported that the pathway has improved access for referrals.

- NHS Ayrshire & Arran reported a challenge with capacity to cover a substantial workforce in health, education and local authority. At the time of the review, NHS Ayrshire & Arran had one acting clinical nurse specialist for ADHD. The nurse specialist was supporting teams and developing links with other services and agencies across the NHS board area.

- CAMHS are working to develop staff awareness, skills and knowledge in the recognition, assessment and management of ADHD. There is also ongoing training and liaison with the wider services and agencies across Ayrshire & Arran to support the ADHD service.
1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

NHS Ayrshire & Arran has developed and implemented an information gathering tool, which is sent to schools to complete at the pre-diagnosis stage. Schools from across the three Ayrshire & Arran local authorities were involved in the design of the form. The school returns the information to CAMHS to help inform a diagnosis of ADHD and the necessary support required within the child or young person’s school and home. The service highlighted this as a very positive initiative and an example of good practice.

NHS Ayrshire & Arran discusses and agrees all treatment options with the school once an ADHD diagnosis has been made, and develops an agreed single plan in line with GIRFEC principles.

At the time of the review, NHS Ayrshire & Arran did not have an agreed protocol for the implementation of behavioural and academic interventions. Interventions are agreed on a case-by-case basis as part of the young person’s single plan.

Staff reported that communication between CAMHS and schools could be improved. In most cases, the service does not inform the school of an ADHD diagnosis, although teachers could find out this information if they phone the healthcare professional. Diagnoses are made using GIRFEC processes and there are differences across the three local authority areas. Email contact can also be difficult due to the NHS system security. Staff within the service are unable to send emails to the school unless the school emails them first. It was noted that email contact could be made in the future through the school nurse who would be on the same email system as NHS staff. Child health also has the relevant information about a child, which they could pass onto the school on behalf of the service.

1.3 Key recommendation

Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

The multi-agency pathway group produced an information booklet on ADHD based on the North Ayrshire Council booklet. The pathway group involved parents of young people diagnosed with ADHD in the design of the booklet.

NHS Ayrshire & Arran provides the booklet to parents of children who are diagnosed with ADHD. The booklet is available in other formats or languages on request.

The booklet includes information on the range of treatment options available and how medication is used to treat moderate to severe cases. At the time of the review, NHS Ayrshire & Arran was agreeing information to include on potential side effects with the area drug and therapeutics committee.
2: Non-pharmacological interventions

2.1 Key recommendation

Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

NHS Ayrshire & Arran has the following formal parenting programmes available to parents of children with ADHD.

Parents INC. This programme is focused on empowering parents and giving them a greater understanding of ADHD. It also develops parents’ skills to manage difficult issues and behaviours. At the time of the review, the programme was being rolled out across all three areas. The aim is to deliver a 6-week rolling programme in all three areas at least once a year. The programme includes an evaluation to get feedback from parents.

Incredible Years Parenting Programme. This is a group for parents and carers who are concerned about their child’s behaviour. The aim of the group is to increase children’s social skills, self-esteem and confidence; promote positive behaviour in children; and improve the parent/child relationship. This programme runs up to twice a year in the east and north area and covers 14 weekly sessions. It includes an evaluation process. At the time of the review, NHS Ayrshire & Arran was considering the delivery of the programme within the south area. The programme is not ADHD-specific.

ADHD nurse-led clinics. An ADHD nurse specialist runs a parent support – behaviour management clinic for families who are difficult to reach in more remote and rural areas. The clinic includes reference to information used in the Parents INC group.

The parenting groups are delivered by nursing, psychology and occupational therapy staff. Parents need a referral from a CAMHS clinician to access parenting groups run specifically within CAMHS. Other parenting programmes can be accessed through education and social work in each area.

The parenting groups are delivered geographically across north, south and east Ayrshire to help provide equity of access for parents. NHS Ayrshire & Arran reported that some parts of the rural community have difficulty in accessing services based in centralised clinics due to poor public transport links.

3: Outcomes

3.1 Key recommendation

Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

At the time of the review, NHS Ayrshire & Arran did not have a formal process to routinely evaluate the outcomes for children and young people with ADHD.

The NHS Ayrshire & Arran care record includes professionally rated tools which can be used to monitor outcomes. The NHS board reported that the views of the child or young person and their parents/carers are recorded when reviewing planned outcomes.
There are systems in place to record:

- what has improved in the child or young person’s circumstances
- what if anything has got worse
- if the planned outcomes have been achieved
- if any aspects of the plan need to be changed, and
- if the plan can continue to be managed within the current environment.

A variety of tools are also available to measure outcomes:

- Conners’ rating scale
- Eyberg child behaviour inventory
- parenting daily hassles scale
- patient experience questionnaires, and
- strengths and difficulties questionnaire.

NHS Ayrshire & Arran reported that outcome results are recorded and action planned. This ensures that results are acted upon and re-audited to support improvements in patient care and experience. Reports on the progress of action plans are provided through the CAMHS clinical governance group.

However, at the time of the review, staff reported that while they know the outcomes for children and young people with ADHD on an individual case basis, there is currently no formal system for identifying and routinely evaluating outcomes across the service. The development of the user involvement strategy may help with this. Staff reported that discussion was currently taking place concerning the possible introduction of focus groups to help evaluate outcomes.

4: Transition

4.1 Key recommendation

**In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.**

NHS Ayrshire & Arran has developed draft board-wide guidelines for the transition of young people with ADHD from child and adolescent services to adult mental health services. The guidelines were due to be approved in March 2012.
4.2 Key recommendation
In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

At the time of the review, NHS Ayrshire & Arran had no dedicated adult ADHD service. Patients with adult ADHD are referred to generic adult community health teams’ single point of access.

NHS Ayrshire & Arran is not fully implementing the NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults. The NHS board reported a lack of a specialist diagnosis service. The NICE guidelines are implemented in terms of treatment of existing cases. However, there is no robust evidence of this and practice is not compared with the guidelines.

Staff reported a potential lack of skills and confidence about ADHD care among adult services clinicians. However, CAMHS can provide assistance with joint working and training to help address this issue.

5: Systems, processes and skills

5.1 Key recommendation
Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

NHS Ayrshire & Arran has an electronic system for capturing information on the number of children and young people receiving treatment for ADHD. However, the system is not yet robust enough to provide accurate data. Data on reported cases are gathered from individual clinicians and through a review of FACE, the electronic record-keeping system.

Staff are now using FACE to record diagnosis and referral to treatment times. New cases have been added to the system, but retrospective data has yet to be fully entered. The service plans to record more information on the electronic system in the future as part of the multi-agency work.

5.2 Key recommendation
Implement a standardised proforma for assessment to improve clinical record-keeping.

NHS Ayrshire & Arran has a variety of proformas to support clinical record-keeping. These include:

- the FACE generic assessment tool
- generic care standards audit tool, and
- CAMHS record-keeping matrix.

The NHS board reported that audit results are reviewed and analysed. Individual staff results are reviewed through supervision and performance reviews with the line manager.
The pathway allows a child to come back into the service for specific treatment or to deal with specific issues through the nurse-led clinics. A care co-ordinator is identified within CAMHS for each child.

NHS Ayrshire & Arran has a multidisciplinary team meeting in each area, some of which focus on complex cases. The NHS board also has an internal referral system, such as psychiatry, which can refer into the team if specific issues need to be addressed.

5.3 Key recommendation

NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

NHS Ayrshire & Arran reported that the input of the child or young person in the assessment process is documented on the FACE recording system following discussion and agreement with them. Staff review and analyse the results.

5.4 Key recommendation

Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (e.g., epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

The service has training packages in ADHD assessment and medication. NHS Ayrshire & Arran has plans to develop a package on the management of ADHD. The nurse-led clinics, facilitated by the clinical nurse specialist for ADHD, support new to service or newly qualified staff to develop their skills and knowledge of ADHD and its management through direct work.

The NHS board has undertaken a training needs analysis to identify the training needs of mental health staff to assess the child or young person’s requirement to access mental health services. If paediatric staff consider there is a mental health concern, they can either refer to CAMHS or to the clinical psychologists working in child health as appropriate.

Nurses are now trained in the physical care and monitoring of children with ADHD. Previously, the monitoring role was split between the nurse and the consultant at separate appointments. Joint appointments are now offered which reduces duplication and also the duration of appointments. Nurses reported that they can now talk to the child while the parent(s) talks to the consultant psychiatrist. Parents have fed back that they prefer the new format.

NHS Ayrshire & Arran aims to ensure the child’s physical health needs are met as part of their overall health needs in CAMHS-led clinics.
5.5 Key recommendation

*Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.*

NHS Ayrshire & Arran has a standard form for requesting further information from the school for children or young people who may have ADHD. CAMHS staff follow up with the school for further information if required.

All children referred to the ADHD pathway are observed in class. Not all will have been diagnosed at the time of the observation. It is not possible to progress down the pathway without first undertaking an observation. NHS Ayrshire & Arran has a proforma which staff reported provides a good structure for undertaking the observation, and facilitates consistency in reporting. The observation includes playtime and an interview with the class teacher(s). The completed standard form is usually received from the school before the observation is done.

Staff reported that it can be more challenging to undertake classroom observations for secondary school children due to the multiple classes attended, and also for children attending alternative schools, as these often have much smaller class sizes.

5.6 Key recommendation

*Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.*

At the time of the review, there was no local titration protocol in place. However, NHS Ayrshire & Arran was at the stage of developing a protocol with consultant psychiatrists.

Staff reported a challenge in prescribing medication for pre-school children. Medications for pre-school children should be prescribed by paediatricians rather than CAMHS staff. It was reported that the interface between these two groups of staff can be challenging, although there are opportunities for joint working.

Agreement has been reached to roll out non-medical prescriber titration clinics in the form of a pilot in the south locality team. It is hoped that the clinics could be rolled out across the north and east regions in the future, and modelled appropriately to these areas, depending on the evidence collated from the pilot.
NHS Borders

Local service provision

In 2007, a dedicated ADHD team provided services for children and young people with ADHD, along with the generic child and adolescent mental health services (CAMHS) team. Since then, NHS Borders has redesigned the service to provide a pathway for the referral, assessment and treatment of neurological disorders, including ADHD. This service is provided by the generic CAMHS team working across five localities with support and input from community paediatricians. NHS Borders reported that this change was implemented in 2010 as there was increasing recognition that many children have comorbid neurodevelopmental disorders, such as ADHD, learning disabilities and autism spectrum disorders.

Neurodevelopmental services are highlighted in the NHS board’s Children and Young People’s Service Plan 2009–2012. This document outlines NHS Borders’ vision for the service and how it is based on the principles of Getting it Right for Every Child (GIRFEC).

Summary of findings

Strengths

The NHS board has:

- an information system to provide accurate information on the number of cases of children and young adults with ADHD, and
- a range of proformas to improve clinical record-keeping.

Barriers to implementation

The NHS board reported:

- some communities experience difficulty accessing services in centralised locations, due to the geography of the area, and
- challenges remain surrounding the engagement of education staff and educational psychologists.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the NHS board area in 2007 and 2011 with this prevalence data.

**Figure 1: NHS Borders prevalence rate comparison**

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<thead>
<tr>
<th></th>
<th>2007 data</th>
<th>2011 data</th>
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<tbody>
<tr>
<td>Reported prevalence 2007</td>
<td>1.1%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Reported prevalence 2011</td>
<td>1.2%</td>
<td>1.5%</td>
</tr>
<tr>
<td>HKD UK prevalence</td>
<td>1.50</td>
<td>5.00</td>
</tr>
<tr>
<td>ADHD UK prevalence</td>
<td>5.00</td>
<td>1.2%</td>
</tr>
<tr>
<td>NHS Borders</td>
<td>HKD UK</td>
<td>ADHD UK</td>
</tr>
<tr>
<td></td>
<td>reported</td>
<td>prevalence</td>
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<tr>
<td></td>
<td>prevalence</td>
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</table>

In NHS Borders, the number of children receiving treatment for ADHD has increased since the previous data collection exercise in 2007. However, the reported prevalence is still lower than we would expect to see.

<table>
<thead>
<tr>
<th>2007 data</th>
<th>2011 data</th>
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<tbody>
<tr>
<td>260 reported cases (1.1% of under 18 population)</td>
<td>280 reported cases (1.2% of under 18 population)</td>
</tr>
<tr>
<td>Boys 88%, Girls 12% (of caseload) Ratio 7:1</td>
<td>Boys 83%, Girls 17% (of caseload) Ratio 5:1</td>
</tr>
</tbody>
</table>

The ratio of boys to girls appears to have changed with the proportion of girls increasing. Staff reported that the condition is under-diagnosed in girls due to the differences in presentation of symptoms between the genders.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child’s/young person’s difficulties.

NHS Borders has undertaken work to raise awareness and recognition of ADHD within health, education, social services and third sector organisations. This has been through continuous professional development sessions for health staff, ADHD-specific training for teaching staff and the development of information booklets.

In 2005, the NHS board created the leaflet, ‘Putting the Pieces Together: A Guide to Understanding ADHD’, with input from health, education and social services staff. Updated in 2009, this is the main guide for parents and carers, young people, and adults working with young people to increase understanding of ADHD.

This booklet is part of a series of resources, which also includes:

- tips for managing ADHD for parents and carers
- strategies for managing ADHD for teachers and education staff
- NHS Borders ADHD Family Support Group information leaflet, and
- medication information leaflets.

1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

NHS Borders links with colleagues in education on a case by case basis. The NHS board reported that clinicians have good communication processes with school teachers for individual cases. Clinicians attend meetings where possible. These meetings are minuted through the Meeting Around the Child review and details recorded in the patient notes.

However, at the time of the review, staff reported that challenges remain in the links and engagement of teaching staff and educational psychologists with health staff. It was noted that during classroom assessments for particular cases, other children have been observed displaying ADHD behaviours. Further work is also needed to strengthen the transition of children from primary to secondary school.
1.3 Key recommendation

Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

A standard information pack is available which explains about ADHD, the range of treatment available, medication and potential side effects. The NHS board created this information pack in 2005. Clinicians with a special interest in ADHD reviewed it in 2009 to ensure it was fit for purpose. The pack is available in hard copy and electronically, and can be produced in an easy read version where necessary.

The NHS board consulted with the Borders ADHD Family Support Group when developing the information pack to ensure the views of children, young people and parents/carers were incorporated.

2: Non-pharmacological interventions

2.1 Key recommendation

Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

NHS Borders offers generic parenting programmes for parents of children with mental health problems. This includes the Incredible Years programme for children between the ages of 4–10 years and parenting groups run by local CAMHS staff. The majority of parents attending these sessions have a child with ADHD. The NHS board reported that they hold these courses in three centralised locations across the NHS board area. However, the rural nature of NHS Borders means that some communities can experience difficulties accessing these services.

In addition, NHS Borders has developed an ADHD-specific programme for children of all ages, called Moving Forward with ADHD.

The Incredible Years programme is evaluated through weekly evaluation forms to allow the NHS board to consider parents’ views and opinions. The NHS board has not formally evaluated Moving Forward with ADHD. However, the NHS board has developed questionnaires and distributed these to attendees to ask for their views.

3: Outcomes

3.1 Key recommendation

Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

NHS Borders uses the Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA) tool on admission and discharge to ensure that the outcomes for children and young people with ADHD are evaluated. HoNOSCA is a routine outcome measurement tool that assesses the behaviours, impairments, symptoms, and social functioning of children and adolescents with mental health problems.

The CAMHS service also conducts a follow-up of all children on medication every 6 months. Service satisfaction questionnaires are also used to measure outcomes. Clinical
outcomes and questionnaire results are reviewed annually at the CAMHS operational management meeting.

4: Transition

4.1 Key recommendation
In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

NHS Borders has a generic protocol in place for managing the transition from child and adolescent to adult services. Young people are referred to adult services before their 17th birthday and a joint appointment is set up to manage the transition. This protocol is not specific to mental health services. However, the NHS board reported that there are good working relationships between colleagues in CAMHS and adult mental health services.

4.2 Key recommendation
In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

At the time of the review, staff reported that there are no dedicated adult ADHD services in NHS Borders and there are no plans in place to develop this service. Generic mental health services offer multidisciplinary assessment and management for adults with ADHD. The NHS board reported that adult services follow the same guidelines as CAMHS. This is the Scottish Intercollegiate Guidelines Network (SIGN) guideline 112: management of attention deficit and hyperkinetic disorders in children and young people. Staff noted that a separate pathway for adult ADHD services would be beneficial. Staff also reported that further work is needed for 18–25 year olds as engagement with health services tends to decline in this age group.

5: Systems, processes and skills

5.1 Key recommendation
Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

At the time of the review, staff reported that the NHS board has an electronic information system that provides accurate information on the number of children and young people in the NHS board area with ADHD. This includes a diagnosis tracking component and includes referrals from schools services and community paediatrics. The NHS board reported that administrative systems are in place to verify the information generated.
5.2 Key recommendation

Implement a standardised proforma for assessment to improve clinical record-keeping.

NHS Borders CAMHS teams use a range of proformas to improve clinical record-keeping. These include:

- a family interview form
- an adolescent interview form
- a child interview form, and
- a teacher interview form.

Use of these proformas is monitored through ongoing audit of the ADHD assessment and core pathway. Audit results are fed back to the team in continuous professional development sessions, where any changes are agreed and implemented.

5.3 Key recommendation

NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

The views of children and young people are recorded on the child interview form and these are kept in the child’s case notes. This is monitored through ongoing audit of the ADHD assessment and core pathway.

5.4 Key recommendation

Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (e.g. epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

The NHS board reported that mental health staff in NHS Borders work as a multidisciplinary team. There is input from dedicated paediatricians and close communication with other paediatric colleagues. A regular planned continuous professional development timetable is in place for all CAMHS and dedicated paediatric staff. All clinical staff have an annual appraisal and any additional training needs are identified as part of this process.

5.5 Key recommendation

Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

NHS Borders has a specialised neurodevelopmental teacher interview proforma to ensure that education is involved in the assessment process. This includes a section to record information on the child or young person’s level of educational attainment in each subject. This is used in conjunction with a separate schools assessment form.
The NHS reported that these forms are used in addition to the Conners’ scale assessment tool and discussions with education staff.

5.6 Key recommendation
Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

The NHS board has a protocol that provides guidelines for the above. However, there does not appear to be a standard document where this information is recorded.

NHS Borders submitted evidence of its titration protocol for initiating the drug, methylphenidate. This is designed to be used by parents together with the relevant information sheet.
NHS Dumfries & Galloway

Local service provision

In 2007, NHS Dumfries & Galloway had one generic child and adolescent mental health service (CAMHS) team that was part of the larger combined child health service. The structure for CAMHS has not changed since this time. The catchment area for this service is NHS board-wide and the service sees children and young people from 0–18 years old.

The integrated children’s service plan 2010–2014 follows the Getting it Right for Every Child (GIRFEC) process. This plan does not specifically mention ADHD, but the NHS board reported that it is implicit in several priority areas throughout the report. This includes:

- priority 2 – early intervention
- priority 3 – early years
- priority 5 – health, and
- priority 6 – managing risk and crisis.

The NHS board reported that a number of changes have been made in the development of services for children and young people with ADHD. This includes robust monitoring of patient health, systematic recording of information and the introduction of a joint psychology/psychiatry clinic for complex cases.

Summary of findings

Strengths

The NHS board has:

- a well-defined and established primary mental health worker service who provides support for services for children and young people with mental health problems
- active engagement to help achieve multi-agency involvement, including the implementation of a CAMHS steering group, and
- a wide range of information and resources for children, young people and their parents/carers.

Barriers to implementation

The NHS board reported:

- links between social care and ADHD services remain a challenge
- some colleagues in adult services do not recognise ADHD as a diagnosis, and
- there are workload challenges for consultant psychiatrists due to current service organisation.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form- equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Dumfries & Galloway prevalence rate comparison

In NHS Dumfries & Galloway, the number of children receiving treatment for ADHD has increased since the previous data collection exercise in 2007. However, the reported prevalence is still lower than we would expect to see.

<table>
<thead>
<tr>
<th>2007 data</th>
<th>2011 data</th>
</tr>
</thead>
<tbody>
<tr>
<td>160 reported cases (0.5% of under 18 population)</td>
<td>239 reported cases (0.9% of under 18 population)</td>
</tr>
<tr>
<td>Boys 88%, Girls 12% (of caseload) Ratio 7:1</td>
<td>Boys 85%, Girls 15% (of caseload) Ratio 6:1</td>
</tr>
</tbody>
</table>

The ratio of boys to girls appears to have shifted slightly; the proportion of girls has increased. The NHS board reported that colleagues in education are generally less aware of the different behaviours to look out for in girls which could be a presentation of ADHD. A requirement for staff training in this area has been identified to ensure the differences in presentation of symptoms between the genders are recognised.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child's/young person’s difficulties.

NHS Dumfries & Galloway reported that investment in a primary mental health worker service has meant that the NHS board is well placed to work with local partners to raise awareness and recognition of ADHD within health, education, social services and third sector organisations.

The NHS board introduced a primary mental health worker pilot in 2005 and this role has continued to grow and develop over the last 7 years. There is a lead primary mental health worker and locality-based primary mental health workers across the region. The remit of these posts is to provide specialist CAMHS knowledge, skills and leadership to improve the range, appropriateness, effectiveness and responsiveness of services for children and young people with mental health problems. This involves joint work, consultations and training for allied health professionals including health visitors, school nurses, and speech and language therapists.

Primary mental health workers act as mental health link workers to all schools in the NHS board area through geographic clusters. The NHS board offers ADHD awareness raising, training and consultations to education staff and other agencies. For example, the teams have worked closely with independent nurseries, providers of accommodation for looked after children, and third sector organisations such as Lesbian Gay Bisexual Transgender Scotland, Befrienders, Young Carers and Shelter.

The primary mental health workers also have regular consultations and deliver training to social work colleagues. The NHS board also reported that the CAMHS psychologist has regular input into the fostering and adoption team. At the time of the review, staff reported that challenges remain in the links between social work and ADHD services. Social work does not prioritise ADHD and is primarily involved in prioritising child protection cases.

Community paediatricians are not generally involved in ADHD cases unless there are other associated health problems. GPs and paediatricians refer cases to CAMHS for assessment, diagnosis and ongoing management.

The NHS board has established a multidisciplinary and multi-agency CAMHS steering group to improve joint working and identify areas for consultation and training.
1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

NHS Dumfries & Galloway has a care pathway in place for the management of children and young people with ADHD. CAMHS and educational psychology colleagues developed this pathway. It includes school observations and meetings to discuss the diagnosis and review process.

The service provides information on ADHD and management strategies in education for school staff throughout the NHS board area. The NHS board reported that this information is often tailored to the needs of the individual child. At the time of the review, staff reported that challenges remain in co-ordinating multi-agency work. Primary mental health workers, mental health workers and consultants consult with a child’s school and undertake classroom assessments. This process is very labour intensive for the service.

1.3 Key recommendation

Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

A standard information pack is available which explains about ADHD, the range of treatments available, medication and potential side effects. The consultant psychiatrist reviews this information pack annually and a translation service is available if required. The NHS board reported that, at the time of the review, the pack was only available in hard copy. However, there is a potential to include this on the NHS Dumfries & Galloway CAMHS website.

When developing the information pack, NHS Dumfries & Galloway consulted with the Parent Inclusion Network. This is a third sector support organisation for parents and carers. The NHS board did not seek the views of children and young people when developing the information pack. However, children routinely receive the Full of Beans leaflet, which is discussed as part of the assessment process. Feedback is also encouraged from individual families.

2: Non-pharmacological interventions

2.1 Key recommendation

Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

The NHS board delivers generic programmes for parents of children with mental health problems. This approach centres around the Incredible Years programme, which aims to reduce challenging behaviours in children and increase their social and self-control skills. Primary mental health workers with advanced training in cognitive behavioural therapy methods, or child and adolescent psychology staff deliver this course to groups of parents. The NHS board reported that CAMHS staff will begin training for Triple P in April 2012 and Incredible Years in August 2012. However, these generic programmes are not
exclusively for parents of children with ADHD. The Parent Inclusion Network also provides generic training courses as does the youth justice team, which currently provides the only service to parents of adolescents.

NHS Dumfries & Galloway employs a parent co-ordinator. However, there are still no plans to develop ADHD-specific parenting programmes within the NHS board area.

3: Outcomes

3.1 Key recommendation
Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

NHS Dumfries & Galloway has a system in place to ensure the outcomes of children and young people with ADHD are routinely evaluated. The NHS board reported that clinical staff regularly review patients either within CAMHS clinical governance meetings or within their regular 6-monthly appointments. A formal assessment tool to measure patient outcomes is not routinely used. However, the NHS board noted that, on occasion, the Conners’ rating scale is re-administered.

The NHS board further reported that there will be an audit of ADHD record-keeping in 2012.

4: Transition

4.1 Key recommendation
In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

NHS Dumfries & Galloway has a standard transition protocol for managing the transition from child and adolescent services to adult services. However, at the time of the review, staff reported that challenges remain in linking the two services. NHS Dumfries & Galloway does not have a specific adult ADHD service and staff reported that many adult psychiatrists do not accept ADHD as a diagnosis. This can mean that young adult cases are passed back to GPs for medication or stay within the CAMHS service past 18 years of age.

4.2 Key recommendation
In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

There are no adult ADHD-specific services or pathways for the management of adult patients in NHS Dumfries & Galloway. The NHS board reported that adult cases are seen by general psychiatry services. Depending on the patient’s needs, this may involve input from the community mental health team, psychology services or third sector organisations. The learning disability service manages all patients with learning disabilities and a comorbid diagnosis of ADHD.
5: Systems, processes and skills

5.1 Key recommendation
Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

At the time of the review, staff reported that NHS Dumfries & Galloway does not have a computerised system to record the numbers of children and young people diagnosed with ADHD. However, the figures submitted as part of this review are thought to be accurate as community diagnosis is rare and all suspected cases are referred to CAMHS for diagnosis.

The NHS board reported that its current IT system records the waiting times between referral and diagnosis. There is an intention to move to the Topaz IT system to enable recording of cases by diagnosis.

5.2 Key recommendation
Implement a standardised proforma for assessment to improve clinical record-keeping.

NHS Dumfries & Galloway has not implemented a standardised assessment proforma. However, the NHS board has a medication monitoring proforma and an appointment prompt sheet for clinicians to complete.

5.3 Key recommendation
NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

A CAMHS care plan is in place in NHS Dumfries & Galloway. The NHS board reported that this is often signed by the child and parent/carer. Consent is documented within the notes section. Compliance with completing the CAMHS care plan is scheduled for audit in 2012.

5.4 Key recommendation
Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (eg epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

Consultant psychiatrists are always involved in ADHD assessments in NHS Dumfries & Galloway and their skills are kept up to date through continuous professional development. This is monitored through regular appraisal and Royal College of Psychiatrists’ accreditation.

The primary mental health work service provides regular training for school nurses and child health staff. School nurses carrying out mental health assessments have been trained
to assess a child’s needs to access mental health services in accordance with the
requirements for looked after children.

The training needs of medical staff are recorded as part of the personal development
review process. The NHS board reported that the clinical co-ordinator holds an overview
of training needs and training opportunities offered in line with this.

5.5 Key recommendation

Put in place systems to ensure that education is involved in the
assessment process and that information on the child’s/young person’s
level of attainment is always requested and obtained from school.

NHS Dumfries & Galloway has a system in place to involve education in the assessment
process for children and young adults. This is demonstrated in its care pathway, which
forms part of the information pack.

The NHS board reported that clinicians routinely ask for information from school or
nursery staff and educational psychologists. This is usually in the form of written reports,
Conners’ rating scales or conversations. NHS Dumfries & Galloway also holds meetings in
schools to discuss a child’s needs and plan relevant support. This involves individual
education plans and co-ordinated support plans.

5.6 Key recommendation

Develop a protocol for the titration of medication and the monitoring and
recording of positive and negative effects.

NHS Dumfries & Galloway does not have a fixed protocol for the titration of medication.
The NHS board uses a standardised medication monitoring proforma and an appointment
prompt sheet to record these data. In 2010, an ADHD case note audit recommended
redesign of the medication monitoring proforma to improve its use. A follow-up audit was
scheduled for 2011. However, no evidence was submitted to suggest this had been
undertaken as planned. NHS Dumfries & Galloway reported improved monitoring of
physical health and more systematic recording of side effects.

Scottish Intercollegiate Guidelines Network (SIGN) guideline: 112 is also available in the
NHS board.
NHS Fife

Local service provision

In 2007, NHS Fife delivered services for children and young people with ADHD through a number of teams. The ADHD specialist team, which was part of the acute services paediatric department, saw the majority of ADHD cases. The community paediatrics team, the child and adolescent clinical psychology service and generic children and mental health services (CAMHS) saw a smaller number of cases.

Since 2007, NHS Fife has moved to a community-based model. This involved the implementation of a tiered care pathway for assessment and intervention of ADHD. The pathway was developed as a multi-agency approach. There are three tiers in the pathway. Tier 1 is with the GP, Tier 2 is with community paediatrics and Tier 3 is either with CAMHS or the acute multidisciplinary ADHD team. Most children and young people will have their assessment and treatment at Tier 2.

The new model has joined-up acute and community-based services and provides multidisciplinary input for patients requiring complex care. The outcome of this development is that the ADHD service will be entirely community based, with only a very small number of children being referred to the acute sector for specialist services.

Summary of findings

Strengths

The NHS board has:

- an multi-agency ADHD pathway which has improved service delivery across Fife
- multidisciplinary input for patients requiring complex care
- a range of information packs for families, referrers and teachers
- a variety of tools to measure clinical outcomes
- weekly evening clinics for young people from 14 years of age, to aid transition to adult services, and
- introduced a rolling programme of the ADHD-specific parent training course, Parents INC.

Barriers to implementation

The NHS board reported:

- differences in professional approach to ADHD across the various agencies involved
- a lack of specialist staff in adult services and insufficient protected sessions to allow for jointly run transition clinics
- difficulties in accessing suitable accommodation for running parent groups, and
- lack of adequate resources for parent packs, audit, evaluation and data analysis.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Fife prevalence rate comparison

In NHS Fife, the number of children receiving treatment for ADHD has decreased since the previous data collection exercise in 2007, and the reported prevalence is still lower than we would expect to see. The NHS board reported that following service reorganisation, 128 patients were recently discharged from the Tier 3 ADHD caseload.

<table>
<thead>
<tr>
<th>2007 data</th>
<th>2011 data</th>
</tr>
</thead>
<tbody>
<tr>
<td>938 reported cases</td>
<td>760 reported cases</td>
</tr>
<tr>
<td>(1.2% of under 18 population)</td>
<td>(1.0% of under 18 population)</td>
</tr>
<tr>
<td>Boys 80%, Girls 20% (of caseload)</td>
<td>Boys 86%, Girls 14% (of caseload)*</td>
</tr>
<tr>
<td>Ratio 4:1</td>
<td>Ratio 6:1</td>
</tr>
</tbody>
</table>

* NHS Fife was unable to provide gender data for children and young people accessing Tier 3 services. The data above are for the 482 patients accessing Tier 2 community services. The NHS board plans to capture all ADHD records electronically by the end of 2012.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child’s/young person’s difficulties.

Since 2007, NHS Fife has taken a number of steps to raise awareness and recognition of ADHD within health, education, the third sector and social services. These include:

- information packs on ADHD for families of newly diagnosed cases
- ADHD pathway and parent group information provided on the noticeboard at the clinic
- information on the pathway circulated to referrers and GPs, including the offer of education sessions
- a 1-day multidisciplinary event held for frontline staff
- teaching for clinical psychologists on ADHD
- regular pathway liaison meetings with education partners
- Fife Council education department circulating ADHD guidance in November 2011 to all schools as part of its policy manual
- NHS Fife meetings with Attention Fife, a support and information network for children and families affected by ADHD, to discuss the pathway and to involve them in other ADHD developments, and
- in 2010, a launch event for the ADHD pathway involving representatives from health, education, social services and the third sector.

1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

NHS Fife reported it has ongoing communication with education staff about the ADHD pathway and its ADHD pathway booklet for teachers. The NHS board also involves colleagues in education in the holistic assessment of children and young people diagnosed with ADHD in line with Getting it Right for Every Child (GIRFEC) principles.

A multi-agency strategy group meets regularly to support multi-agency working and the implementation of the ADHD pathway. Staff reported that implementing the pathway has improved service delivery across Fife.

NHS Fife reported that it offers training and consultation to education staff.
1.3 Key recommendation

**Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.**

NHS Fife developed a standard ADHD information pack with Fife Council. The pack explains ADHD and the range of treatment options available including medication and its potential side effects. The draft pack was discussed with a number of families and young people involved with the service to gain their input. The packs were rolled out in 2011 and will be reviewed annually by the ADHD management group.

The information pack can be made available in other formats or languages if required.

2: Non-pharmacological interventions

2.1 Key recommendation

**Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.**

There are a variety of programmes available to parents of children or young people with ADHD in Fife.

- Parents INC, a 6-week programme delivered by clinical psychology for parents of children with ADHD. It includes workshops for parents and carers to help them understand and manage ADHD. There are two separate programmes: one for parents of children aged 6–12 years and another for parents of young people aged 13 years and over.

- Additional intervention programmes and tools used by occupational therapists.

The Parents INC programmes are only available to parents of children and young people who have had a formal ADHD diagnosis. The clinician making the diagnosis or managing the child's care can refer the parents onto the programme. The referral is done through the child psychology service which co-ordinates the programmes.

Clinical psychology, specialist nursing and specialist occupational therapy deliver the programmes 5–7 times each year across five different venues in Fife, depending on demand.

Staff evaluate the programmes using tools such as the Eyberg Child Behaviour Inventory and Parenting Daily Hassles Scale. An evaluation form is also circulated at the end of each programme.

NHS Fife has a parent support group, although it is not currently being used. Some volunteer groups also provide ADHD-specific parent support in Fife. One of the parents has set up a network account and Facebook page which are proving popular among parents.
3: Outcomes

3.1 Key recommendation
Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

NHS Fife reported that staff use a variety of tools to measure quality of life and clinical outcomes for children and young people with ADHD. The tools include:

- ADHD rating scales
- clinical global impression improvement scales (CGI-I)
- child health and illness profile, child edition (CHIP-CE)
- Weiss functional impairment scale
- Parents INC audit measures
- Eyberg Child Behaviour Inventory, and
- Parenting Daily Hassles Scale.

Staff monitor outcomes at review meetings and evaluate them at least once a year. Staff present the findings to clinical teams at joint meetings. At the time of the review, NHS Fife was planning to audit the young people’s clinics to help inform clinical practice.

4: Transition

4.1 Key recommendation
In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

NHS Fife does not have a formal protocol to manage the transition of young people with ADHD from child and adolescent services to adult services. Services for adults with ADHD are currently delivered by generic adult community mental health teams on a GP catchment basis. However, a weekly evening clinic is provided for young people from 14 years of age, to aid transition to adult services.

NHS Fife provides information to adult services and one of the consultant psychiatrists provides a specialist adult ADHD clinic in Levenmouth. This clinician leads on the promotion of ADHD within adult services and is in regular contact with colleagues in children and young people’s services regarding transition.
4.2 Key recommendation
In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

At the time of the review, NHS Fife was partially implementing NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults.

There is currently no pathway for adults with ADHD across the NHS board area. In February 2012, a multidisciplinary meeting was held between paediatric and adult services to discuss a board-wide approach to manage transitions. At the time of the review, NHS Fife reported that further meetings were scheduled with adult services. A training event is also scheduled for June 2012 for adult services staff.

5: Systems, processes and skills

5.1 Key recommendation
Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

At the time of the review, NHS Fife was undertaking a review of ADHD case notes to assess which should be captured as Tier 2 or Tier 3 data. The NHS board has started recording Tier 2 data on a database. NHS Fife plans to have all ADHD records on the database by the end of 2012. The new pathway should lead to more accurate recording of ADHD cases.

5.2 Key recommendation
Implement a standardised proforma for assessment to improve clinical record-keeping.

NHS Fife has a standard pathway assessment protocol for ADHD. At the time of the review, the NHS board was not yet auditing use of the protocol.

For complex cases, where a child is not responding to standard treatment approaches, the child would be looked at through triage and referred to CAMHS, and ideally treated in a joint consultation.

5.3 Key recommendation
NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

The recording of the child or young person’s input into the assessment process is embedded in the ADHD pathway and assessment protocol.
5.4 Key recommendation

Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (e.g., epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

NHS Fife reported that training needs of mental health staff to assess a child or young person’s need to access non-psychiatric services, is embedded within the ADHD assessment protocol. There is ongoing continuing professional development for staff working within ADHD.

The training needs of paediatric staff are reviewed through consultation and joint working.

NHS Fife has provided training to frontline and community paediatric staff and delivered updates to CAMHS and psychology staff. Education sessions are provided to staff working with Tier 2 and Tier 3 patients. Training has also been offered to GPs and education staff.

5.5 Key recommendation

Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

The multi-agency strategy group involved education in the development of the ADHD pathway and the pathway launch event.

Education has also included information on the pathways and education staff roles in supporting assessment in their policy manual. The manual is distributed to all schools across Fife.

NHS Fife has a standard proforma, as part of the ADHD pathway, for collecting information on the child or young person’s level of attainment. Administrative staff ensure this is forwarded to education colleagues. NHS Fife reported that while information is requested from schools, it is not always received. At the time of the review, it was unclear if classroom observations are routinely undertaken as part of the assessment process.

5.6 Key recommendation

Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

NHS Fife has developed a protocol for the titration of medication for ADHD. At the time of the review, the protocol was not fully implemented. The protocol does not include reference to the monitoring and recording of positive and negative effects of medication. The NHS board considers monitoring of medication as a key component of routine patient care and record-keeping using case notes. Therefore, it does not consider a protocol as essential within the acute service.

Guidance on titration of medication is provided to staff through clinical meetings or service reviews. Where problems arise in individual cases, senior members of the ADHD team would advise less experienced clinicians.
NHS Forth Valley

Local service provision

At the time of the 2007 review, NHS Forth Valley had a dedicated ADHD service, Changing Lanes, which formed part of the generic child and adolescent mental health services (CAMHS). The age range covered by the service was 0–19 years. Although the main catchment area for the ADHD service was limited to Falkirk, the NHS board had started to extend the service to Stirling and Clackmannanshire. The catchment area for the generic CAMHS team and paediatric service was NHS board-wide. The NHS board reported that challenges still lie with co-ordinating care across three local authority areas. Since the review, ADHD assessment and case holding has been rolled out to the whole CAMHS team and a number of refinements have been made. These include:

- criteria for assessment in CAMHS have been more clearly defined
- an ADHD pathway has been introduced in CAMHS
- a medication proforma has been introduced, and
- ADHD clinicians meet regularly to discuss practice and development across the NHS board area.

Paediatric services have a very heavy workload and are limited with what additional ADHD services they can provide. In 2012, the NHS board reported that it is undertaking work to further involve paediatric services in ADHD services. NHS Forth Valley is also considering a specialised ADHD integrated care pathway.

The age range covered by the service has been reduced to 0–18 years old. Young people with ADHD are transferred on a case-by-case basis to adult mental health services.

Summary of findings

Strengths

The NHS board has:

- a range of training courses to raise awareness of the mental health needs of children and young people
- ADHD-specific programmes for parents of children with ADHD, and
- a range of ADHD assessment proformas for use in schools and in clinics.

Barriers to implementation

The NHS board reported:

- each local authority has different approaches and protocols for management of children and young people with ADHD
- limited funding for service development of non-pharmacological interventions, and
- there is no standard ADHD information pack available.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Forth Valley prevalence rate comparison

In NHS Forth Valley, the number of children receiving treatment for ADHD has increased since the previous data collection exercise in 2007. However, the reported prevalence is still lower than we would expect to see.

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The ratio of boys to girls appears to have shifted; the proportion of boys has increased. Staff reported that they are working to raise awareness about the differences in presentation of symptoms between the genders.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child’s/young person’s difficulties.

NHS Forth Valley reported that it has taken a number of steps to raise awareness and recognition of ADHD within health, education, social services and third sector organisations.

The NHS board has an advice line in place for health professionals to access information about ADHD. Also, the primary mental health services provide consultations for health visitors. NHS Forth Valley reported that the demand for CAMHS consultations has increased and this has been met by the NHS board. Further referral information is also available on the Service Information Directory, NHS Forth Valley’s guide for referrers.

Between 2009–2011, the primary mental health team facilitated 18 training sessions to raise awareness of the mental health needs of children and young people. ADHD-specific training has been undertaken with foster parents and education additional support needs staff. There is also an ongoing programme of training for foster carers. The NHS board reported that all training is evaluated, reviewed and delivered jointly through inter-agency collaboration.

Specific training has been made available for third sector organisations, where requested. Local initiatives include:

- an ADHD-specific parenting programme in Falkirk initiated by Barnardo’s, and
- PLUS facilitated an ADHD group in Stirling and produced a DVD by young people.

Falkirk Council has funded a teaching post to link services between schools and CAMHS. The council has also employed a psychologist with responsibility for looked after children, who may provide advice around issues related to ADHD. CAMHS manages the psychologist.

1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

NHS Forth Valley highlighted that progress has been made to strengthen links with colleagues in education to raise awareness of ADHD and that interventions are implemented in schools where required. The appointment of a teaching post with a remit for ADHD in Falkirk provides a link between schools and CAMHS. Similar posts in Clackmannanshire and Stirling have been proposed, but as yet these have not been commissioned. At the time of the review, the NHS board noted that classroom
assessments were not undertaken in all three areas and they would welcome these appointments.

CAMHS have developed a referral criteria document, which includes the Additional Support for Learning Act and Getting it Right for Every Child (GIRFEC) principles, to ensure that children have a staged intervention before assessment. However, challenges remain over the definition of roles between CAMHS and education. The NHS board reported that each local authority has different staged intervention protocols. The local authorities offer a range of behavioural and academic interventions for children and young people with ADHD.

### 1.3 Key recommendation

**Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.**

NHS Forth Valley reported that, at the time of the review, the service did not have a standard ADHD information pack in place. The NHS board holds a range of resources centrally at each location and individual clinicians choose which of these to use on a case-by-case basis. The NHS board reported that these resources contain information on the range of treatment options available, medication and potential side effects.

The NHS board reported that local information is reviewed and updated in line with local governance arrangements and is available in a variety of formats.

NHS Forth Valley is in the process of developing integrated care pathways and has noted that it will review ADHD information as part of this process, in conjunction with user feedback. The CAMHS senior management group will discuss the development of standardised documentation and agree an action plan. At the time of the review, staff reported that they would welcome the introduction of Scotland-wide ADHD information booklets to highlight good practice.

### 2: Non-pharmacological interventions

#### 2.1 Key recommendation

**Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.**

CAMHS in NHS Forth Valley have developed Parents INC throughout the region. This is an ADHD-specific parent/carer training programme that helps parents to develop a better understanding of ADHD, helps their children with ADHD symptoms, and helps them develop effective strategies and approaches.

Mental health practitioners run this programme three times a year for parents with children between the ages of 5–18 years who have a confirmed ADHD diagnosis. In response to demand, groups have been held in Falkirk and Stirling.

At the time of the review, staff reported that the NHS board also offers a generic programme: Incredible Years, a programme delivered by the NHS board for children and young people from 3–18 years of age. Additionally, The Parent Factor, an ADHD specific programme, is delivered by Barnardo’s in the Falkirk area.
3: Outcomes

3.1 Key recommendation
Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

NHS Forth Valley uses the Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) to ensure that the outcomes for children and young people with ADHD are routinely evaluated. HoNOSCA is a routine outcome measurement tool that assesses the behaviours, impairments, symptoms, and social functioning of children and adolescents with mental health problems. The NHS board further reported that the following tools are used to measure these outcomes:

- the Conners’ tool
- Swanson Nolan and Pelham (SNAP) IV, and
- the ADHD rating scale.

Clinicians evaluate outcomes of their patients at each review appointment. However, these outcomes are not formally audited. The NHS board reported that CAMHS are developing integrated care pathways to address this.

4: Transition

4.1 Key recommendation
In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

NHS Forth Valley reported that there is no written protocol in place to manage the transition from CAMHS to adult mental health services. This process is managed on a case-by-case basis with discussion between clinical teams when a young person reaches 18 years of age. Generic adult community mental health teams deliver services for adults with ADHD.

At the time of the review, staff reported that there are no plans to develop dedicated adult ADHD services in NHS Forth Valley. However, the following could help the transition:

- development of a generic template transfer letter to ensure effective dialogue, and
- staff exchange programmes so staff can gain experience in CAMHS.

4.2 Key recommendation
In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

Generic adult community mental health teams deliver services for adults with ADHD. At the time of the review, staff reported that there are no plans to develop dedicated adult ADHD services in NHS Forth Valley. The NHS board does not currently use NICE guideline CG72 on diagnosis and management of ADHD in children, young people and
adults. However, NHS Forth Valley reported that this is now on the adult mental health clinical governance agenda for discussion.

5: Systems, processes and skills

5.1 Key recommendation

Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

NHS Forth Valley does not have a formal system to record ADHD data. At the time of the review, staff reported that there is a database to record newly assessed patients. However, pre-existing patients or those transferring into the service are not yet included on this database. The NHS board was able to provide a breakdown by gender of children and young people who were receiving treatment, through consultation with individual clinicians. As such, the data submitted could be under-representative.

At the time of the review, staff highlighted the need for a patient information management system to effectively record all children and young adults who are diagnosed and receiving treatment.

5.2 Key recommendation

Implement a standardised proforma for assessment to improve clinical record-keeping.

Staff complete a proforma at the initial assessment. The assessing clinician then reviews this information during patient appointments. At the time of the review, NHS Forth Valley reported that no formal monitoring of this proforma had been undertaken.

5.3 Key recommendation

NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

The proforma includes a section for the clinician to routinely record and monitor the child or young person’s views of the assessment process and the recorded outcomes. The NHS board reported that this will be reviewed annually as part of the records audit undertaken in team meetings.

5.4 Key recommendation

Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (eg epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

NHS Forth Valley reported that staff training needs are discussed on an individual basis during the personal development plan process. The NHS board also has individual supervision, peer mentoring and ‘New to CAMHS’ packs to address training needs.
The CAMHS team has access to a health psychologist who advises on paediatric referrals. The NHS board also reported that joint neurodevelopmental work, including ADHD, is undertaken in partnership with paediatrics.

5.5 Key recommendation
Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

NHS Forth Valley has systems in place to ensure that education is involved in the assessment process for children and young adults. A school assessment proforma is sent to each child’s school. Teachers are asked to provide any additional relevant information including details of staged interventions and co-ordinated support plans, if these are in place.

5.6 Key recommendation
Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

NHS Forth Valley does not have a fixed protocol for the titration of medication. NHS board staff refer to Scottish Intercollegiate Guidelines Network (SIGN) guideline 112: management of attention deficit and hyperkinetic disorders in children and young people for this information. However, the NHS board does have an ‘active behaviour clinic checklist’, a proforma for recording a range of information, including medication reviews and common side effects.

The NHS board reported that it is developing integrated care pathways and these will form the basis of the NHS Forth Valley protocol.
NHS Grampian

Local service provision

In 2007, NHS Grampian had four child and adolescent mental health service (CAMHS) teams which managed children and young people with ADHD, in addition to community paediatrics. The four CAMHS teams were the child and family mental health department, the Rowan Centre in Elgin, the young people’s department in Aberdeen and the learning disability team in Aberdeen.

At the time of the review, NHS Grampian provided services for children or young people diagnosed with ADHD across four clinical areas; child and family mental health services, the young people’s department, the Rowan Centre and seven consultant-led community child development teams. Child and family mental health services provide care for children and young people from birth to their 18th birthday. The young people’s department provides outpatient services for young people from 13 years old to their 18th birthday. The Rowan CAMHS team provides services for the Moray area and Banff.

NHS Grampian is responsible for the provision of mental health services to: Aberdeen City, Aberdeenshire and Moray. A service level agreement is in place for NHS Grampian to provide CAMHS consultant psychiatry and clinical psychology services for NHS Orkney. The NHS board also provides CAMHS consultant psychiatry services for NHS Shetland.

Since 2007, NHS Grampian has strengthened its links with partner agencies by undertaking collaborative approaches to support the delivery of ADHD services. The NHS board views these services as an integral part of CAMHS, which now has closer links with community child health services.

Summary of findings

Strengths

The NHS board has:

- adopted a collaborative, multi-agency approach to ADHD strategy
- created a nurse prescriber post, and
- improved joint planning of services between community child health and CAMHS.

Barriers to implementation

The NHS board reported:

- the structure within the three local authorities can make it difficult to link with appropriate people
- resource constraints within NHS Grampian and partner agencies for the provision of non-pharmacological interventions, and
- clinical and administrative resource constraints to routinely evaluate outcomes.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

**Figure 1** below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

**Figure 1: NHS Grampian prevalence rate comparison**

<table>
<thead>
<tr>
<th></th>
<th>2007 data</th>
<th>2011 data</th>
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</thead>
<tbody>
<tr>
<td>971 reported cases (0.8% of under 19 population*)</td>
<td>1093 reported cases (0.9% of under 18 population)</td>
<td></td>
</tr>
<tr>
<td>Boys 87%, Girls 13% (of caseload) Ratio 7:1</td>
<td>Boys 83%, Girls 17% (of caseload) Ratio 5:1</td>
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</tbody>
</table>

* In 2007, NHS Grampian provided figures for under 19s.

The ratio of boys to girls appears to have shifted slightly; the proportion of girls has increased.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child’s/young person’s difficulties.

Since 2008, the NHS board has taken a number of steps to raise awareness and recognition of ADHD within health, education, the third sector and social services. Steps taken to raise awareness and recognition include the following.

- Discussion at multi-agency strategy groups in the three local authority areas across the NHS board area. The groups include representatives from health, education, the third sector and social services.
- Regular continuing professional development sessions within Royal Aberdeen Children’s Hospital.
- Promotion of ADHD training within schools.
- Development of a leadership project aimed at engaging with health promotion staff.
- Information leaflets for teaching staff.

At the time of the review, NHS Grampian reported that it was organising a north of Scotland ADHD learning event to be held in April 2012. Representatives from health, educational psychology services, third sector and social services were invited to attend.

There is currently no board-wide multi-agency pathway in place for ADHD. Local teams implement local pathways within their catchment areas.

1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

Education colleagues are represented on the multi-agency strategy groups and primary mental health workers are rolling out a nine-session teaching programme to all school networks across Aberdeen City and Aberdeenshire. This will include an ADHD component. NHS Grampian is also introducing a ‘healthy minds’ session to associated school groups in Moray.

Health staff raise awareness of ADHD through attending school planning meetings and by direct communication and correspondence with education. NHS Grampian reported that education and health colleagues work jointly to ensure that the required strategies are in place to support a young person in an educational and health setting. The joint work is co-ordinated through the multi-agency meetings.
Behavioural and academic interventions in schools are implemented in line with the Integrated Children’s Services Plans in the three local authority areas.

### 1.3 Key recommendation
Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

NHS Grampian provides the following information leaflets:
- an ADHD information pack for parents and carers, and
- an ADHD guide for young people.

The leaflets include the range of treatment and medication options and the potential side effects of medication. The leaflets can be made available in alternative formats and languages to meet the needs of the local population.

A parent from one of the local support groups was involved in the production of the parent information leaflet. NHS Grampian intends to involve the patient focus and public involvement team when the leaflets are next updated. Local CAMHS teams review the leaflets.

### 2: Non-pharmacological interventions

#### 2.1 Key recommendation
Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

At the time of the review, NHS Grampian had just started the Parents INC, ADHD-specific parenting programme. The programme is currently offered to parents with children aged 0–13 years with ADHD and is available across Aberdeen City and Aberdeenshire. In Moray, parenting programmes are available on an individual basis.

Nursing, psychology and primary mental health workers deliver the Parents INC programme and the aim is to offer the programme on an ongoing basis. Parents are offered places on the programme as part of their contact with CAMHS. The CAMHS team also undertakes individual work with parents as required.

Introduced in 2009, the ADHD DIY group is based at Royal Aberdeen Children’s Hospital. This is a drop-in support group for the parents/carers of children and young people up to 16 years. One clinical and one ADHD nurse specialist run this group and it is available on a board-wide basis.

Parents can access generic programmes offered by health, social work and third sector organisations, including health visitors and family centres. These include the Solihull, Incredible Years and Triple P programmes.

To date, parenting programmes have been evaluated using a semi-structured interview with parents. An audit was carried out in 2010 and again in 2011. Results are presented to the CAMHS clinical management group for consideration and action.
At the time of the review, NHS Grampian was working to make the parenting programmes available to parents of adolescents. The NHS board was also intending to develop a board-wide parenting strategy with partner agencies, some of which would be relevant to ADHD.

The NHS board reported a challenge in providing non-pharmacological interventions because of the time and resource constraints within the NHS and other service providers.

### 3: Outcomes

#### 3.1 Key recommendation

Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

NHS Grampian reported that specialists follow up clinical outcomes in line with the Scottish Intercollegiate Guidelines Network (SIGN) guidelines. The clinical evaluation outcomes are kept in shared case notes. Patient management systems are in place in community child health to prompt regular clinical evaluation of outcomes for individual patients.

Different tools are used to measure the outcomes of interventions with children and young people with ADHD. These include the CAMHS Outcomes Research Consortium measures, Conners’ rating scale and Vanderbilt questionnaires.

Staff undertake regular clinical reviews and complete written clinical outcome scales at least every 6 months.

At the time of the review, staff reported that the administration of outcome measures takes a significant amount of time. There is a lack of capacity among clinicians and administrative staff to undertake evaluations and to document outcomes. There are occasional evaluations of outcomes and trainees undertake audits. However, the process is not systematic or service-wide. The NHS board also reported a requirement for further workforce development.

The NHS board has a range of options available for complex cases where the child or young person is not responding to standard treatment approaches. This includes further assessment, prolonged observation and the involvement of social work, education and health colleagues.

### 4: Transition

#### 4.1 Key recommendation

In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

NHS Grampian provides a guide for young people making the transition from CAMHS to adult mental health services, but there is no protocol in place. Services for adults with ADHD are currently delivered by general adult mental health services.
Staff discuss the requirements for continuing service with the young person. If ongoing treatment is required, a clinician refers the patient to the multidisciplinary adult community mental health team. Transition takes place at age 18, or as soon after as is clinically appropriate.

4.2 Key recommendation

In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

There is currently no specific pathway for adults with ADHD within NHS Grampian. Cases are transferred to adult mental health services on an individual basis, according to agreed processes and good practice agreements. Staff reported that the adolescent service would continue to see the young person until they have settled and are known to the adult consultant.

The NHS board provided no evidence that it is implementing NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults.

5: Systems, processes and skills

5.1 Key recommendation

Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

Staff reported a challenge to obtain accurate information on the number of children and young people diagnosed with ADHD within the NHS board area. The reported data were collated from information held by community child health and CAMHS.

At the time of the review, NHS Grampian was implementing a new patient information management system to capture the required information. This will be implemented during 2012.

5.2 Key recommendation

Implement a standardised proforma for assessment to improve clinical record-keeping.

NHS Grampian does not currently have a board-wide standard proforma for the assessment of all children and young people with potential ADHD. However, the NHS board reported that the teams providing ADHD services are reviewing a pathway document that will clarify current systems and plans for future services.

The young people’s department does have an ADHD proforma for assessing young people aged 13–18 years and the department monitors its use. Community child health uses the national Support Needs System and associated proformas to record clinical data.
5.3 Key recommendation

NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

NHS Grampian reported that it uses the choice and partnership approach (CAPA) for its management of referrals. Staff record the input of children and young people in the clinical notes and routinely ask patients for their views on treatment. The young people’s department has a proforma for recording patient consent, confidential discussions and for agreeing communication with other agencies. The process is monitored through peer review of patient notes.

5.4 Key recommendation

Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (eg epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

The NHS board identifies the training needs of mental health staff through staff appraisals, objective-setting and team business planning. The training needs of paediatric staff are identified through local feedback from paediatric colleagues.

The community child health department has monthly continuing professional development sessions, which include sessions delivered by CAMHS.

5.5 Key recommendation

Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

The multi-agency strategy groups include representatives from education, who are asked to ensure that colleagues in education are involved in the assessment process. NHS Grampian requests information on the child or young person’s level of attainment through standard letters to schools and clinical contacts with school staff. Information is generally provided by the schools, although it can vary in content.

The ADHD nurse or the clinical nurse specialist usually carries out classroom observations.

5.6 Key recommendation

Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

At the time of the review, NHS Grampian was finalising its draft protocol for the prescribing and titration of ADHD medication. The protocol includes the initiation of treatment, and the ongoing monitoring and recording of positive and negative effects. The protocol is due to be implemented in spring 2012. The relevant SIGN guidelines are also available to staff.

At the time of the review, one of the nurses in the child and family mental health service was training to become a nurse prescriber.
NHS Greater Glasgow and Clyde

Local service provision

In 2007, services for children and young people in NHS Greater Glasgow and Clyde were delivered in a variety of ways across the NHS board area. In the Greater Glasgow area, ADHD services were provided through specialist child and adolescent mental health services (CAMHS) teams. In Renfrewshire, ADHD services were provided by outpatient CAMHS teams. In Lomond, there was a dedicated ADHD clinic run by a community paediatrician, with input from CAMHS. Inverclyde had a dedicated ADHD liaison nurse and ADHD teacher, with input from CAMHS.

Since 2007, NHS Greater Glasgow and Clyde has been working to incorporate the services of the Clyde region following the structure change in 2006.

CAMHS continues to provide ADHD services in Glasgow. In other localities, the service is delivered between CAMHS and community paediatrics. At the time of the 2012 review, NHS Greater Glasgow and Clyde was looking at the distribution of resources across CAMHS and paediatrics to ensure consistency across the locality teams.

The NHS board aims to implement an ADHD care pathway from April 2012.

Summary of findings

Strengths

The NHS board has:
- developed a multi-agency ADHD care pathway
- developed new protocols for record-keeping, gathering information from schools and titration of medication, and
- developed a new database which will capture information on ADHD diagnoses and outcomes.

Barriers to implementation

The NHS board reported:
- a growing number of ADHD patients which places pressure on resources
- varying practice and protocols for ADHD across the six different local authority areas, and
- a lack of staff resource to routinely evaluate outcome measures.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Greater Glasgow and Clyde prevalence rate comparison

In NHS Greater Glasgow and Clyde, the number of children receiving treatment for ADHD has increased since the previous data collection exercise in 2007. However, the reported prevalence is still lower than we would expect to see.

<table>
<thead>
<tr>
<th>2007 data</th>
<th>2011 data</th>
</tr>
</thead>
<tbody>
<tr>
<td>603 reported cases (0.2% of under 18 population)</td>
<td>703 reported cases (0.3% of under 18 population)</td>
</tr>
<tr>
<td>Boys 95%, Girls 5% (of caseload) Ratio 19:1</td>
<td>Boys 87%, Girls 13% (of caseload)* Ratio 7:1</td>
</tr>
</tbody>
</table>

* The NHS board was unable to provide gender data for West Dunbartonshire. Data were provided for 673 of the 703 reported cases.

The ratio of boys to girls appears to have shifted with the proportion of girls increasing. Staff reported an increasing recognition of ADHD symptoms in girls, such as inattention. The NHS board is working to raise awareness about the difference in presentation of symptoms between the genders.
1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child's/young person’s difficulties.

At the time of the review, a multi-agency working group had developed an ADHD care pathway for use across NHS Greater Glasgow and Clyde. The working group included representatives from health, education and social services. NHS Greater Glasgow and Clyde did not provide evidence of involvement of the third sector.

The proposed pathway includes a wide range of information including:

- referral pathways for GPs, community assessment teams and colleagues in education and social work
- parent/carer information
- proforma documents for use in schools and in clinics, and
- how to deal with complex cases where the child is not responding to standard treatment approaches.

The pathway is scheduled to be formally implemented in April 2012. Staff reported that implementation is generally in place as services were already working to the Scottish Intercollegiate Guidelines Network (SIGN) guideline 112: management of attention deficit and hyperkinetic disorders in children and young people. However, at the time of the review, there were some differences in service provision between the locality teams.

1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

NHS Greater Glasgow and Clyde has been building stronger links with education through the ADHD multi-agency working group. Joint support teams also work in Glasgow schools to raise awareness of ADHD.

The NHS board reported a challenge to raise awareness of ADHD in education given the six local authorities within the NHS board area. Local practice concerning behavioural and academic interventions in school varies for each authority.
1.3 Key recommendation

Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

The ADHD pathway includes information for parents and carers about ADHD, the range of treatment and medication options available, and the potential side effects of medication.

There was informal input from parents in the development of the pathway through discussions with clinicians and professionals.

NHS Greater Glasgow and Clyde intends to put the pathway through an equality impact assessment process. The process will determine the need for the document to be made available in alternative formats or languages according to the needs of the local population.

2: Non-pharmacological interventions

2.1 Key recommendation

Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

NHS Greater Glasgow and Clyde delivers the Parents INC, ADHD-specific parenting programme within northwest Glasgow, and parts of east and west Dunbartonshire. The programme is available to parents of children with ADHD aged 6–12 years. Parents are referred onto the programme through the CAMHS locality team. Clinicians from locality-based teams, including nursing, social work and family therapy staff deliver the programme every 3 months.

The generic programme, Triple P, is available to parents across NHS Greater Glasgow and Clyde. It is also offered to teachers in schools to encourage greater awareness. At the time of the review, the NHS board was evaluating the programme on behalf of the multi-agency parenting core group.

Staff reported challenges in:

- providing equitable access to ADHD-specific parenting programmes
- promoting the parenting programmes to parents, and
- encouraging parents to engage more in the programmes.

3: Outcomes

3.1 Key recommendation

Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

At the time of the review, NHS Greater Glasgow and Clyde was implementing the CAMHS Outcomes Research Consortium (CORC) measures for children and young
people with ADHD. The outcomes are evaluated using the following tools:

- strengths and difficulties questionnaire
- Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA)
- children’s global assessment scale, and
- patient and family questionnaires.

The NHS board reported that outcomes are evaluated at initial contact, at the start of the treatment, at 6-monthly intervals and on discharge. However, a recent lack of staff resource has made it difficult for staff to run the CORC process and to produce meaningful data.

4: Transition

4.1 Key recommendation

In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

NHS Greater Glasgow and Clyde does not have a protocol to manage the transition of young people with ADHD from child and adolescent service to adult services. However, the NHS board reported that there is a transition process in place for all young people with learning disabilities, and who are on medication for ADHD. They are accepted for ongoing care by adult learning disability psychiatry services.

The British Association for Psychopharmacology guidelines are available to staff to help them manage transitions. At the time of the review, the NHS board was considering developing a formal pathway to manage transitions.

4.2 Key recommendation

In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

NHS Greater Glasgow and Clyde does not have a dedicated adult ADHD service. Services for adults with ADHD are currently delivered by clinicians in general adult mental health services with a special interest in ADHD. Staff reported a potential training issue for adult services to recognise and treat ADHD, particularly new cases. In some cases, GPs will continue to prescribe and monitor treatment and will fast track patients to adult psychiatry if required.

At the time of the review, the NHS board was not implementing NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults.
5: Systems, processes and skills

5.1 Key recommendation
Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

The NHS board has commissioned the development of a new database to record information on the number of children and young people diagnosed with ADHD. This will include referral to treatment data gathered from each of the locality teams. The database will also be used to capture diagnostic information from psychological therapies and outcome data from the CORC tool. This will enable clinicians to check outcomes against diagnosis to improve the management of patients with ADHD.

5.2 Key recommendation
Implement a standardised proforma for assessment to improve clinical record-keeping.

NHS Greater Glasgow and Clyde has developed a specialist CAMHS ADHD protocol document to improve clinical record-keeping. The protocol is scheduled to be implemented from April 2012 as part of the ADHD care pathway.

5.3 Key recommendation
NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

At the time of the review, the NHS board was implementing the CORC tool to record the input of the child or young person into the assessment process.

5.4 Key recommendation
Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (eg epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

The training needs of mental health and paediatric staff are assessed as part of individual performance development plans or through medical staff peer reviews. Training needs are also supported through joint continuing professional development meetings, where psychiatrists and paediatricians discuss ADHD learning gaps.
5.5 Key recommendation
Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

Education was involved in the development of the ADHD care pathway as part of the multi-agency consultation.

The pathway includes a process for gathering information from the school or educational psychologist on the child or young person’s level of attainment. This includes collecting data on the level of achievement relative to age and ability, and qualitative information about classroom functioning.

Classroom observations are a standard part of the ADHD assessment process across NHS Greater Glasgow and Clyde.

5.6 Key recommendation
Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

The ADHD pathway includes a protocol for the titration of medication. The protocol includes the ongoing monitoring and recording of positive and negative effects. At the time of the review, NHS Greater Glasgow and Clyde was considering the introduction of nurse-led prescribing.
NHS Highland

Local service provision

The overall structure of ADHD services remains largely unchanged since the 2007 review. Services for children and young people with ADHD continue to be delivered through generic services, mainly through community paediatrics, and child and mental health services (CAMHS). The CAMHS service is delivered within a tiered structure with ADHD services mainly provided at Tier 3.

Following the 2006 boundary restructure, NHS Highland continues to have two separate community health partnerships (CHPs) and two local authorities, Argyll and Bute, and Highland councils. In Argyll and Bute, CAMHS and community paediatric services are provided by NHS Greater Glasgow and Clyde. All other areas within NHS Highland are covered by the Highland CHP and are within the Highland Council boundary. In 2009, NHS Highland implemented a board-wide pathway within community paediatrics.

Since December 2010, NHS Highland and Highland Council have been developing a joint commissioning and lead agency approach for children and young people’s services. This involves developing a single-system approach to improve children and young people’s experience of care and increase their level of attainment. The NHS board reported that the ADHD pathway is being revised to reflect this new approach.

As a result of service reorganisation, a number of staff previously employed by NHS Highland are now employed by Highland Council.

Summary of findings

Strengths

The NHS board has:

- plans to extend the board-wide ADHD care pathway to include CAMHS
- a nurse-led prescribing clinic, and
- plans to implement a joint commissioning and lead agency approach for children and young people’s services.

Barriers to implementation

The NHS board reported:

- lack of capacity to deliver scheduled parenting programmes at CHP level
- lack of staff resource to evaluate outcomes, and
- recruitment challenges within community settings.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Highland prevalence rate comparison

![NHS Highland Prevalence Rate Comparison](image)

* At the time of the review, NHS Highland was unable to provide complete data on the number of children and young people receiving treatment for ADHD.

<table>
<thead>
<tr>
<th>2007 Data</th>
<th>2011 Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>311 reported cases</td>
<td>Highland CHP: data not available</td>
</tr>
<tr>
<td>(0.5% of under 18 population)</td>
<td>Argyll and Bute CHP: 80 estimated cases</td>
</tr>
<tr>
<td>Boys 83%, Girls 17% (of caseload)</td>
<td>Data not available</td>
</tr>
<tr>
<td>Ratio 5:1</td>
<td></td>
</tr>
</tbody>
</table>
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation
Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child’s/young person’s difficulties.

Since 2007, NHS Highland has worked to raise awareness of ADHD. This includes:

- community paediatricians and Tier 3 CAMHS undertaking a service redesign to improve service delivery for ADHD across NHS Highland
- increased engagement with education to explore how to support and enable learning for those diagnosed with ADHD
- links with Highland’s Children’s Forum and Children in the Highlands Information Point Plus (CHIP+) websites, and
- a trauma recovery service supporting children and young people with ADHD in Argyll and Bute.

During 2012, the NHS board is planning an ADHD education session for the providers of integrated children’s services.

1.2 Key recommendation
Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

Through discussions with education, NHS Highland identified the need for a joint commissioning and lead agency approach to improve ADHD services for children and young people. NHS Highland reported that this will be a priority for next year.

Within Argyll and Bute, discussions and awareness-raising are in progress with the education service and individual schools. This supports a better understanding of the need and benefits of identifying ADHD and the impact of interventions on behaviour and learning.

NHS Highland has systems and interventions in place in schools across Highland and Argyll and Bute to support children with additional behavioural needs. Highland Council also has a positive behaviour policy to help promote positive relationships and an inclusive ethos in schools.
1.3 Key recommendation

Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

NHS Highland has an information pack for parents and carers which explains about ADHD. The pack is available on the CHIP+ website. This website provides a range of information for the parents and carers of children and young people with additional support needs. Information can be provided in hard copy, electronic or large print format and a translation service is available if required. The NHS board reviews the pack each year in consultation with relevant clinicians.

The pack does not currently include information on the range of ADHD treatment options available, medication or the potential side effects. Information on treatment options, medication and potential side effects can be provided on request. NHS Highland refers parents and carers to relevant ADHD guidance, such as the NICE website, as and when required.

2: Non-pharmacological interventions

2.1 Key recommendation

Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

Within the Highland CHP, staff in Tier 3 CAMHS are currently piloting the Parents INC, ADHD-specific parenting programme. NHS Highland proposes to hold three programmes each year for possible roll-out across the Highland CHP area.

Argyll and Bute CHP provides an ADHD-specific programme in Dunoon. The CHP is currently discussing how to extend this across the partnership area.

Parents in the NHS board area can currently access a number of generic parenting programmes including:

- Incredible Years
- Parents in Partnership - Parent Infant Network (PIPPIN)
- Positive Parenting, and
- the Solihull parenting programme.

Parents can be referred onto the parenting programmes through health professionals or by self-referral. The programmes are delivered by CAHMS, primary mental health workers, public health nurses, early years’ children’s workers, social workers, third sector workers, teachers, education psychologists and midwives.

Action for Children and Barnardo’s run their own parenting support programmes within the Highland CHP area. There is also an ADHD support group in Inverness.

The Highland CHP plans to develop a parenting framework to introduce a more systematic approach to parenting programmes and will involve parent support groups in this work. A parenting framework is already established in Argyll and Bute.
Each of the programmes includes an evaluation tool which trainers use to obtain feedback from parents. NHS Highland plans to review evaluation results across the various programmes and to introduce related quality indicators.

### 3: Outcomes

**3.1 Key recommendation**

Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

NHS Highland currently has no formal mechanism to routinely evaluate outcomes for children and young people with ADHD. Both the Highland and Argyll and Bute CHPs use the Conners’ tool to measure outcomes. Staff have undertaken occasional audits of outcomes; however the process is not formalised or routine.

A joint clinical management plan is in development between community paediatrics and CAMHS to ensure improved service delivery. At the time of the review, staff reported that a move from paediatrics services to CAMHS could involve a lengthy referral to treatment waiting time, particularly for more complex cases that do not respond to standard treatment approaches.

### 4: Transition

**4.1 Key recommendation**

In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

The Highland Council website includes general guidance on transitions as part of a multi-agency project to improve the transition process for all young people. It focuses on those with additional support needs and those at risk of not moving onto a positive post-school destination. The CHIP+ website also has a general information sheet on transitions.

Both CHPs use Getting it Right for Every Child (GIRFEC) transition processes and mapping tools. However, there is no automatic transition from Tier 3 CAMHS into adult services, unless the young person has comorbid conditions. A more formal transition protocol is required for young people with ADHD.

**4.2 Key recommendation**

In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

NHS Highland does not have a board-wide pathway for adults with ADHD.

A limited adult service is provided within the Highland CHP area. A consultant psychiatrist provides some services in the Argyll and Bute CHP which includes a consultation service for primary care.
The NHS board recognises that its adult services are under-resourced and that it does not currently have staff with a special interest in ADHD. NHS Highland is currently working to implement NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults.

5: Systems, processes and skills

5.1 Key recommendation

Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

NHS Highland does not have a board-wide electronic system to capture information on the number of children and young people diagnosed with ADHD. In 2007, the NHS board had a database which was updated by clinicians and administrators. However, data are now compiled manually or extracted from other databases. NHS Highland has plans to implement the Support Needs System (SNS) database.

5.2 Key recommendation

Implement a standardised proforma for assessment to improve clinical record-keeping.

Highland CHP does not have a standardised proforma for assessment to improve clinical record-keeping.

An ADHD assessment form is available in Argyll and Bute CHP. At the time of the review, it was unclear if this form is routinely used.

5.3 Key recommendation

NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

Neither CHP has a system to formally engage and document the child or young person’s involvement in the assessment process. NHS Highland acknowledges that it needs to develop a system to record this information and to develop systematic audit cycles.

The child or young person’s views may be captured in the child’s plan.
5.4 Key recommendation
Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (eg epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

The training needs of mental health and paediatric staff are assessed through annual appraisal, job planning and personal development plans.

5.5 Key recommendation
Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

The involvement of education in the assessment process is captured within the NHS Highland practice model. The ADHD clinic in Inverness uses a standard letter to request information from schools, while the assessment form in use in Argyll and Bute has space to record that information from the schools has been received. At the time of the review, there was no standard document in use on a board-wise basis. This is being developed along with other standardised paperwork.

CAMHS undertake classroom observations as required. Paediatric services undertake classroom observations where there is diagnostic uncertainty.

5.6 Key recommendation
Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

CAMHS currently deliver a nurse-led prescribing clinic within the Highland CHP area and there is a titration protocol for non-medical prescribing. This is used with a standard clinical management plan that includes the ongoing monitoring and recording of positive and negative effects of medication.

Argyll and Bute CHP does not have a protocol, but uses the Scottish Intercollegiate Guidelines Network (SIGN) and NICE guidelines.

NHS Highland anticipates that it will implement a board-wide titration protocol during 2012–2013.
NHS Lanarkshire

Local service provision

At the time of the 2007 review, ADHD services in NHS Lanarkshire were delivered by community paediatric services and five locality-based child and adolescent mental health services (CAMHS) teams. The age range covered by the service was 0–16 years, although young people already on the caseload often remained with the service for a further 2 years.

Within NHS Lanarkshire, there are now six locality-based CAMHS teams, a board-wide CAMHS learning disabilities team, and a board-wide CAMHS primary mental health team. The latter two teams already cover the 0–18 age range. During 2012, this age range will apply to all CAMHS teams. All referrals from multi-agency sources are directed to one of the six locality teams for assessment.

In 2011, NHS Lanarkshire established a board-wide ADHD working group with representatives from CAMHS, learning disability services, general practice and adult mental health services. This group is developing the protocols and pathways for young people as they move into adult services.

Lanarkshire is piloting the Getting it Right for Every Child (GIRFEC) process development. This involves multi-agency and multidisciplinary working to improve integrated approaches and service delivery.

Summary of findings

Strengths

The NHS board has:

- improved multidisciplinary and multi-agency working
- set up an ADHD working group
- participated in GIRFEC service development work, and
- provided ADHD training to colleagues in health, education and social services.

Barriers to implementation

The NHS board reported:

- there are no systems in place to record the number of children and young people with a diagnosis of ADHD, and
- the volume of improvement and service configuration work being undertaken places a strain on clinical and managerial resources.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Lanarkshire prevalence rate comparison

While children’s services have expanded, NHS Lanarkshire reported that since the previous data collection exercise in 2007, the number of children receiving treatment for ADHD has decreased, as has the reported prevalence. Staff reported that the data for 2007 would have included information from the community health and special needs systems. It is unclear if the data returned for 2011 includes all of the NHS board’s locality and specialist teams. It was noted that since 2007, the incidence of diagnosis of autism spectrum disorder appeared to have increased but that there had not been a corresponding increase in the presentation and diagnosis of ADHD.

<table>
<thead>
<tr>
<th>2007 data</th>
<th>2011 data</th>
</tr>
</thead>
<tbody>
<tr>
<td>336 reported cases (0.3% of under 18 population)</td>
<td>289 reported cases (0.2% of under 18 population)</td>
</tr>
<tr>
<td>Boys 88%, Girls 12% (of caseload)</td>
<td>Boys 86%, Girls 14% (of caseload)</td>
</tr>
<tr>
<td>Ratio 7:1</td>
<td>Ratio 6:1</td>
</tr>
</tbody>
</table>

The ratio of boys to girls appears to have shifted slightly; the proportion of girls has increased.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child's/young person’s difficulties.

Since 2008, the NHS board has taken a number of steps to raise awareness and recognition of ADHD within health, education and social services. NHS Lanarkshire provided no evidence of engagement with third sector organisations.

Steps taken to raise awareness and recognition include the following.

- Delivering neurodevelopmental and infant mental health training to public health nurses.
- Providing CAMHS training to new and existing adult psychiatry colleagues and special school nursing staff.
- Contributing to in-service training days for education staff.
- Joint training of CAMHS and educational psychology staff.
- Training of additional support for learning nurses by the CAMHS learning disability team in the recognition of physical and mental health problems.
- CAMHS input to multi-agency GIRFEC training.
- Participation by social work colleagues in CAMHS practice development events.
- Providing a CAMHS consultation service to social work locality staff.
- Complex cases, where the child or young person is not responding to standard treatment approaches, can be discussed at the west of Scotland child and adolescent psycho-pharmacological interest group. This group meets every 2 months.

1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

In the last 3 years, involvement with GIRFEC has resulted in significant joint development work to strengthen working practices, and improve stepped and matched intervention processes. The pilot GIRFEC sites are in school clusters and are not yet board-wide.

In secondary schools, the CAMHS primary mental health team and Lanarkshire youth counselling service provide targeted behavioural interventions through direct referral in school. The NHS board is also involved in a number of multi-agency children’s services groups, including those for additional support needs.
1.3 Key recommendation
Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

A standard ADHD information pack is available that includes all of the information required by this recommendation. An easy read version is available and a translation service is available if required. The clinical governance group reviews the information each year. The views of children and young people and/or their parents or carers were not sought in developing the information pack. However, their views are monitored through the use of regular patient satisfaction questionnaires.

2: Non-pharmacological interventions

2.1 Key recommendation
Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

NHS Lanarkshire offers a range of generic parenting programmes to the parents/carers of children aged 3–10 years. The programmes include Incredible Years, Triple P, and Mellow Parenting. All programmes are delivered by the NHS board, while Mellow Parenting is also delivered by North Lanarkshire Council. In some cases, individual programmes may be offered, dependent on the local authority area.

Access to parenting programmes is through referral from CAMHS or social work. Satisfaction questionnaires and assessment scales are used to evaluate the programmes. Results are evaluated at the end of each course and as part of the planning process for the next course. The NHS board reported that it runs parenting programmes regularly and on an ongoing basis.

As parenting programmes are held in two central locations, travel can be difficult from more rural areas. NHS Lanarkshire reported a lack of appropriate accommodation in which to run the courses.

3: Outcomes

3.1 Key recommendation
Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

At the time of the review, outcomes are reviewed at a locality level as part of the annual audit process. However, there is no formal evaluation system in place across the NHS board. During 2012–2013, NHS Lanarkshire plans to introduce a new IT system that should allow a service-wide approach to audit and review.
The tools used to measure outcomes are:

- the Children’s General Assessment Scale
- Conners’ rating scale, and
- the Strengths and Difficulties Questionnaire.

4: Transition

4.1 Key recommendation

In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

At the time of the review, the NHS board recognised that there is the potential for young people to disengage from services at this stage. A board-wide ADHD working group is developing a transition protocol from CAMHS to adult mental health services. NHS Lanarkshire plans to introduce this protocol by the end of 2012. General guidelines are in place regarding provision of services up to 18th birthday. Transition to adult services may take place before this date, if appropriate, in terms of the young person’s age and stage of development.

4.2 Key recommendation

In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

Adults with ADHD are seen within general adult mental health services. There is currently no board-wide pathway for adults with ADHD. CAMHS clinicians reported regular meetings with adult services colleagues and also provide ADHD training to them. The ADHD working group is developing a shared care protocol with GPs that will include monitoring every 6 months. This group is also considering the NICE guideline on diagnosis and management of ADHD in children, young people and adults.

5: Systems, processes and skills

5.1 Key recommendation

Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

There is currently no system in place. The NHS board reported that it is developing an electronic information system, which will be implemented during 2012. This system is being developed for use by a range of health professionals including; community nurses, allied health professionals, mental health practitioners, single shared assessment practitioners and related hospital-based staff. The second phase of this development programme will provide CAMHS with the capacity to fulfil this recommendation.
5.2 Key recommendation
Implement a standardised proforma for assessment to improve clinical record-keeping.

At the time of the review, NHS Lanarkshire reported that a single, standardised proforma for use across the NHS board area is still to be developed. Within each locality team, ADHD assessment elements are in place and are audited every year. An outcome report and action plan are produced and overseen by the clinical governance committee.

5.3 Key recommendation
NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

The recent introduction of GIRFEC systems has resulted in the wider use of the What I think questionnaire. The use of this questionnaire will be monitored through the annual audit of record-keeping standards.

The views of children and young people are recorded in their case notes as required, and their consent is always obtained before information is shared.

5.4 Key recommendation
Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (eg epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

The NHS board reported that the workforce training databases are reviewed every year to inform annual training priorities. This information is reviewed and implemented by either the clinical management team or the children’s services management team as appropriate.

Paediatric nursing staff are included in CAMHS in-house training and there is clinical supervision in place for the paediatric dietician.

5.5 Key recommendation
Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

Educational assessment is now a standardised component of the assessment pathway. The implementation of GIRFEC systems and the introduction of an information sharing protocol between agencies have contributed to improvements in this area.

Classroom observations are undertaken for ADHD, but not for every child. This would depend on how recently an observation had been completed and by whom. In some instances, a phone call to the school would replace a physical visit.

Primary mental health teams work closely with local authorities and with colleagues in education. A mental health pack, ‘positive mental attitudes’ has been developed for use in
schools. In south Lanarkshire, the primary mental health team is very active and attends parents’ evenings in schools every 6 months.

5.6 Key recommendation

**Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.**

The ADHD working group is developing a medication protocol, which will be implemented during 2012. Within NHS Lanarkshire, consultant psychiatrists are responsible for the titration and monitoring of medication.
NHS Lothian

Local service provision

In 2007, services for children and young people with ADHD were delivered in a variety of ways across NHS Lothian. Each outpatient team or service had its own catchment area. Edinburgh had two generic children and mental health services (CAHMS) teams and two dedicated ADHD teams covering particular areas of the city. East, mid and west Lothian also had generic CAMHS teams, with mid and west Lothian having some, but varying, dedicated ADHD resource. There was an additional board-wide CAMHS outpatient service for children and young people with learning disabilities including those with co-morbid ADHD.

Since 2007, NHS Lothian has redesigned its ADHD service to provide a more coordinated approach, improve efficiency and enable greater equity of access for young people with ADHD. All young people being assessed and treated for ADHD are now seen within one of four specialist ADHD teams (north Edinburgh, south Edinburgh, mid and east Lothian, and west Lothian).

In 2011, NHS Lothian introduced a board-wide ADHD pathway for the assessment and management of children and young people with ADHD. The four ADHD teams are currently implementing the pathway, which includes standardised paperwork for use across Lothian and a plan to deliver regular parenting groups in all areas. The NHS board has also developed a pathway to help young people with ADHD to access occupational therapy. This includes an occupational therapy screening questionnaire, which leads to input from paediatric or CAMHS occupational therapists where appropriate.

Staff reported that the service redesign in 2011 has slowed the implementation of some of the recommendations made in the *Attention Deficit and Hyperkinetic Disorders – Services over Scotland* (2008) report. There is a challenge to assess and follow-up the increasing number of young people requiring long term follow-up for ADHD. Closer links with education and increased awareness has resulted in more young people being assessed and diagnosed with ADHD. While this is a positive result, it has not been matched with increased resources to assess and follow-up these young people. Many of these young people are treated with medication and require long term follow-up by specialist services, often over 10–12 years. The need to meet this clinical need makes it difficult to prioritise time for service development and audit. However, in the long term, NHS Lothian considers that the redesign will lead to a better, more uniform service across Lothian and will support ongoing service audit and development.
Summary of findings

Strengths
The NHS board has:

- a specialist ADHD service
- a standardised pathway for ADHD across Lothian
- provided regular parenting groups at a variety of sites, and
- developed a matched care model for ADHD, which includes provision for young people who are in transition.

Barriers to implementation
The NHS board reported:

- needing sufficient resources to meet an increasing number of assessments and young people requiring long-term follow-up
- not having sufficient staff capacity to record ADHD data, undertake audits and evaluate outcomes, and
- needing sufficient resources to continue to offer regular ADHD parenting groups.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Lothian prevalence rate comparison

In NHS Lothian, the number of children receiving treatment for ADHD has increased since the previous data collection exercise in 2007. However, the reported prevalence is still lower than we would expect to see and the ratio of boys to girls has increased.

<table>
<thead>
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<th>20011 data</th>
</tr>
</thead>
<tbody>
<tr>
<td>834 reported cases</td>
<td>1075 reported cases</td>
</tr>
<tr>
<td>(0.5% of under 18 population)</td>
<td>(0.7% of under 18 population)</td>
</tr>
<tr>
<td>Boys 80%, Girls 20% (of caseload)</td>
<td>Boys 86%, Girls 14% (of caseload)*</td>
</tr>
<tr>
<td>Ratio: 4:1</td>
<td>Ratio: 6:1</td>
</tr>
</tbody>
</table>

* At the time of the review, NHS Lothian was unable to provide gender data for all children and young people accessing ADHD services. The data above are for the 850 patients whose information has been recorded electronically.

Staff reported a possible under-diagnosis of young females with ADHD. Symptoms demonstrated by young females with ADHD can often be missed in the classroom as in general they present fewer behavioural issues. Staff suggested the possibility of raising awareness by highlighting the gender differences in presenting symptoms during teacher training sessions.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child's/young person’s difficulties.

Since 2007, NHS Lothian has taken a number of steps to raise awareness and recognition of ADHD within health, education, the third sector and social services.

Health

- CAMHS staff provide ‘Introduction to ADHD’ training sessions every 6 months to all new trainees, new staff and community paediatric staff.
- CAMHS staff provide regular training on ADHD to other staff groups within health including community paediatrics, GP trainees, psychiatry trainees, and medical students during their paediatric placements.
- Recent ADHD workshops involved community paediatricians, adult psychiatrists, paediatric occupational therapists and GPs.
- Members of the ADHD teams meet regularly with community paediatricians.
- In 2011, a multidisciplinary training day on ADHD was held for CAMHS staff.

Education

- CAMHS offer regular half-day training sessions to teachers about ADHD, how it presents and useful strategies for its management in the classroom.
- NHS Lothian is developing an ADHD liaison teacher role, with the aim of identifying a teacher in every school who will develop specialist knowledge about ADHD. This teacher will have close links with CAMHS ADHD teams, and will be able to provide advice and support to other teachers within their school. The CAMHS teams will provide training or consultation every 6 months for these specialist teachers, as well as being available for telephone consultation.
- A member of the ADHD team carries out a classroom observation for all young people being assessed for ADHD within NHS Lothian. This provides an ideal opportunity for face to face contact with teaching staff to discuss how ADHD presents in the classroom and useful strategies for managing ADHD in the classroom.
- Once an ADHD assessment is complete, NHS Lothian writes to the young person’s school to inform them of the outcome of the assessment. If a diagnosis has been made, the NHS board will include an ADHD additional support for learning plan, an information booklet about ADHD in the classroom, as well as informing teaching staff of various training opportunities for teachers on ADHD. The letter also directs the school to web-based information for teachers.
Third sector

- Representatives from the third sector have attended workshops and interviews about ADHD in Edinburgh.
- Barnardo’s is involved in delivering parenting packages through funding made available by CAMHS. NHS Lothian considers the third sector as key to linking with young people and their families, and to the development of local services.

Social services

- Links are made between health and social services where appropriate. Families involved in social services care with a young person diagnosed with ADHD are offered the services available to all other young people.

1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

At the time of diagnosis, the service sends an ADHD booklet and an ADHD additional support for learning plan to the young person’s school.

NHS Lothian uses standardised letters to gather information from education staff on a young person’s progress within school before a review appointment. The NHS board also has standardised letters to inform education staff of any changes made to a young person’s medication.

NHS Lothian reported that it routinely informs educational psychology colleagues of the outcome of ADHD assessments. Psychologists on the ADHD teams also meet regularly with educational psychology colleagues.

The west Lothian ADHD team has a specialist teacher who is involved in teacher training as well as advising teachers on the management of individual young people in the classroom.

NHS Lothian reported that engagement from schools has improved since 2007. Teachers have become more aware of ADHD and are keen to have training on the topic. The ADHD service is now in touch with schools by email which has improved communication.
1.3 Key recommendation

Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

The ADHD service in west Lothian has a detailed information pack for parents, young people and children. The pack includes information on the range of treatment options available, medication and the potential side effects. The pack can be provided in electronic or large print format, and a translation service is available if required.

The ADHD implementation group is currently adapting the information pack resource for use across the rest of NHS Lothian. In the meantime, the rest of the service uses the Scottish Intercollegiate Guidelines Network (SIGN) information leaflet for parents and carers which is based on SIGN guideline 112: management of attention deficit and hyperkinetic disorders in children and young people.

NHS Lothian is also in the process of developing medication information leaflets about stimulants and the use of the drug atomoxetine.

2: Non-pharmacological interventions

2.1 Key recommendation

Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

Before 2012, community mental health workers and ADHD nurse specialists were delivering a regular Introduction to ADHD parents’ group over three sessions within Edinburgh, east and mid Lothian. The sessions were available at various CAMHS and community locations and were offered to parents and carers of all young people who are diagnosed with ADHD.

For parents and carers who would benefit from more intensive parenting work, there was also a regular ADHD Incredible Years parents’ group and the Barnardo’s Parents Factor ADHD parents’ group (also run by CAMHS staff in various locations).

Staff would inform parents or carers about the parents’ group at the time of diagnosis. Staff would also consider whether parents would benefit from the more intensive parenting group either at the end of the three session group, or at a later stage.

Staff collected feedback from parents at the end of each group in the form of questionnaires. The format of future parents’ groups would be amended where applicable in response to feedback. Staff reported that the parents’ groups had been very successful, particularly the Introduction to ADHD group, and that feedback had been very positive.

In 2012, following the redesign of its ADHD services, NHS Lothian suspended its parenting groups in Edinburgh, east and mid Lothian. This was to prioritise staff time to enable staff to work with the increasing number of ADHD assessments and young people requiring long term follow-up. NHS Lothian plans to clear the back log which built up during the reorganisation and to restart the parents’ programmes later in 2012. In west Lothian, the NHS board commissions Barnardo’s to deliver their ADHD parent training.
3: Outcomes

3.1 Key recommendation

Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

NHS Lothian does not have a formal system to routinely evaluate outcomes for children and young people with ADHD.

Children and young people taking medication are reviewed in clinic at least every 6 months. This frequently includes feedback received from the school. Formal feedback is also collected at the end of the parents’ groups.

NHS Lothian measures symptom reduction as an outcome measure. Other outcome measures are currently under review. The NHS board has set up an ADHD audit and evaluation group to review tools to gather more formal information on outcomes. The group has also secured access to a part-time psychology assistant who will audit the service. This should include a review of clinical outcomes.

4: Transition

4.1 Key recommendation

In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

At the time of the review, NHS Lothian was piloting a draft generic protocol for managing the transition of young people from child and adolescent services to adult services. NHS Lothian reported that the final protocol document is likely to include a specific appendix relating to young people with ADHD.

4.2 Key recommendation

In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

At the time of the review, adults with ADHD were seen within the general adult mental health service. NHS Lothian is developing a board-wide approach to provide appropriate assessment and continuing care services to adults with ADHD. The new approach is scheduled to begin in April 2012. The new service: will use a matched care model; will offer specialist input where required; and will include ongoing training and education. This should lead to a more sustainable service in the longer term for adults with ADHD.

NHS Lothian is implementing NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults.

The NHS board has taken over responsibility for the healthcare of prisoners within its area. Staff will be delivering ADHD education sessions to prison staff and discussing with them how best to identify and treat the condition.
5: Systems, processes and skills

5.1 Key recommendation
Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

NHS Lothian has an electronic system to record ADHD diagnosis, and was previously able to provide a breakdown by gender of all children and young people who were receiving treatment. Recently there has been a lack of administrative capacity within some teams to ensure that they add all ADHD patients on to the system. A plan is in place to address this.

5.2 Key recommendation
Implement a standardised proforma for assessment to improve clinical record-keeping.

Staff complete an assessment proforma at the initial assessment and review the document during formulation meetings held about young people with ADHD. NHS Lothian is currently working on an audit plan which will include monitoring the use of this proforma across teams.

5.3 Key recommendation
NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

The assessment proforma includes a section for the clinician to routinely record the child/young person’s views.

5.4 Key recommendation
Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (e.g. epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

NHS Lothian reported that all CAMHS staff are regularly supervised and their training needs are regularly reviewed. Consultant psychiatrists have annual appraisal meetings during which their training needs are reviewed. Training needs are considered in relation to the professional’s current job plan. This includes staff working within ADHD teams.

NHS Lothian does not routinely assess paediatric colleagues’ training needs. However, the NHS board offers its 6-monthly induction training programme to colleagues in community paediatrics. The programme provides lectures on most of the mental health disorders seen in children and young people, including ADHD. The programme is aimed at new staff working in CAMHS. However, it is also open to community paediatrics and any member of staff in CAMHS who would benefit from the training. The programme is frequently taken up by new trainees in community paediatrics.
5.5 Key recommendation
Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

NHS Lothian uses a rating scale questionnaire (Conners’ questionnaire), an occupational therapy questionnaire and an additional information sheet to gather information from schools.

A member of the ADHD team also undertakes a classroom observation. This enables ADHD staff to observe the young person directly in the school environment, and to have face-to-face discussion with teaching staff.

If a child or young person has been assessed by educational psychology, NHS Lothian requests a written copy of the assessment outcome.

5.6 Key recommendation
Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

NHS Lothian uses a standard proforma for initiating medication. The NHS board also has standardised monitoring sheets for following up patients on medication. This includes ongoing monitoring and the recording of positive and negative effects of medication.
NHS Orkney

Local service provision

In 2007, NHS Grampian provided services for children and young people with ADHD living on the Orkney Islands. NHS Orkney had a service level agreement with NHS Grampian for a consultant psychiatrist to travel from Aberdeen to Orkney for a 1-day clinic every 3 months, and a consultant paediatrician to travel from Aberdeen to Orkney for a 2-day clinic every 6 months.

Since 2007, NHS Orkney has introduced:

- more regular 3-monthly child and adolescent psychiatry clinics
- regular services from clinical psychology
- improved links with education, and
- a new practitioner role with special interest in paediatrics.

A consultant psychiatrist from NHS Grampian continues to deliver child and adolescent mental health services (CAMHS) clinics on Orkney every 3 months, while a paediatrician from NHS Grampian currently delivers a clinic on Orkney every 6 months. A CAMHS nurse has recently been appointed and is taking forward development of a local multidisciplinary team pathway. Non-medical prescribing is being considered.

Summary of findings

Strengths

The NHS board has:

- good links with NHS Grampian which can be built on, and
- good support for the needs of individual children, especially within schools.

Barriers to implementation

The NHS board reported:

- low numbers of children or young people with ADHD with some resident on small islands
- a challenge to raise awareness of ADHD given the small number of cases
- fragmentation of service with inconsistent management and liaison between education, CAMHS and health teams, and
- fragmented referral pathways and a lack of awareness of the types of ADHD presentation among potential referrers.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

**Figure 1** below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

**Figure 1: NHS Orkney prevalence rate comparison**

In NHS Orkney, the number of children receiving treatment for ADHD has increased since the previous data collection exercise in 2007. However, the reported prevalence is still lower than we would expect to see. It was noted that since 2007, the incidence of diagnosis of autism spectrum disorder appeared to have increased but that there had not been a corresponding increase in the presentation and diagnosis of ADHD.

<table>
<thead>
<tr>
<th>2007 data</th>
<th>2012 data</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 eligible cases (0.4% of under 18 population)</td>
<td>21 reported cases (0.5% of under 18 population)</td>
</tr>
<tr>
<td>Boys 92%, Girls 8% (of caseload) Ratio 11:1</td>
<td>Boys 81%, Girls 19% (of caseload) Ratio 4:1</td>
</tr>
</tbody>
</table>

The ratio of boys to girls has changed with the proportion of girls increasing. This may be a reflection of the higher teacher to pupil ratio within the NHS board area, and the awareness of needs of neurodevelopmentally challenged children and young people in the school setting.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation
Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child’s/young person’s difficulties.

NHS Orkney reported that the local CAMHS team has worked with GPs and schools to raise awareness of CAMHS, which includes ADHD. The NHS board provided no evidence of engagement with third sector organisations or social services.

There is currently no multi-agency pathway in place for children and young people who are suspected of, or have, ADHD. Staff reported a need to review current practice for the assessment and diagnosis of ADHD, and to develop a multi-agency pathway.

1.2 Key recommendation
Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

NHS Orkney reported that it links with colleagues in education on a case-by-case basis in line with Getting it Right for Every Child (GIRFEC) principles.

At the time of the review, NHS Orkney did not have an agreed protocol for implementing behavioural and academic interventions.

1.3 Key recommendation
Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

At the time of the review, NHS Orkney was in the early stages of developing a standard information pack with NHS Grampian consultants, the local CAMHS team and the education department.

2: Non-pharmacological interventions

2.1 Key recommendation
Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

There are no ADHD-specific parenting groups on the Orkney Islands.

A generic Stepping Stones parent programme, which includes information on ADHD, is available throughout the NHS board area. The Triple P parenting programme is also available and includes information on managing children’s behaviour and families with complex needs. The Incredible Years parent training programme has been provided in the
past. NHS Orkney reported that there are a number of practitioners who are trained in the approach, who could offer the training again.

Health visitors, school nurses, home link workers, CAMHS and school-based social workers deliver the parenting programmes. Individual practitioners evaluate courses and the local network evaluates results on a wider scale.

Parents can be referred onto a programme either through inter-agency colleagues or by self-referral.

3: Outcomes

3.1 Key recommendation
Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

NHS Orkney does not have a formal process to routinely evaluate the outcomes for children and young people with ADHD.

Clinical outcomes are discussed at GIRFEC multidisciplinary team meetings. NHS Orkney reported a challenge with the fragmentation of referral pathways and a lack of awareness of the types of ADHD presentation among potential referrers. Some ADHD cases are referred into the CAMHS or psychiatry services; others are referred through the visiting community paediatrician. Some cases are managed by clinical psychologists and some are managed within education.

4: Transition

4.1 Key recommendation
In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

Due to the very small number presenting, services for young people with ADHD making a transition to adult services are identified on an individual basis during the transition process. A joint transition planning guidance document is used by NHS Orkney, Orkney Islands Council, Skills Development Scotland and Voluntary Action Orkney.

4.2 Key recommendation
In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

At the time of the review, NHS Orkney did not have plans to develop a dedicated adult ADHD service. This was due to funding, resource restrictions and the small numbers involved.

There was no evidence that the NHS board was implementing NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults.
5: Systems, processes and skills

5.1 Key recommendation
Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

There is no formal system in place to gather information on the number of children and young people diagnosed with ADHD. To provide data for the review, NHS Orkney approached all GP surgeries and schools. However, the NHS board is not confident that the figures represent all cases.

5.2 Key recommendation
Implement a standardised proforma for assessment to improve clinical record-keeping.

NHS Orkney does not have a standard proforma for assessment of ADHD. Where there is a complex case, a case review is undertaken at the school or within a clinic.

5.3 Key recommendation
NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

There is no system in place to record and monitor the input of the child or young person in the assessment process.

5.4 Key recommendation
Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (eg epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

As there are very small numbers of children and young people with ADHD in the Orkney Islands, staff work closely together. NHS Orkney reported that it identifies the training needs of staff to assess requirements for non-psychiatric services, through direct liaison.
5.5 Key recommendation

Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

Education staff undertake routine classrooms observations, but not specifically for ADHD. NHS Orkney staff reported that children are well supported in schools and there are currently two part-time and one full-time educational psychologists in the Orkney Islands.

However, staff also reported that while the observation work is good, communication between the schools and community paediatrics or CAMHS could be improved.

NHS Orkney does not have a standard form for requesting further information from schools for children or young people who may have ADHD.

5.6 Key recommendation

Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

NHS Orkney does not have a specific protocol for the titration of medication and the monitoring and recording of positive and negative effects. Clinical decisions are currently based on the NHS Grampian prescribing protocol for ADHD and advice from the visiting NHS Grampian staff.

At the time of the review, NHS Orkney had just appointed a full-time CAMHS nurse scheduled to start in April 2012. The NHS board plans that, once in post, this nurse will have an involvement in developing local services. This additional capacity will enable local medication protocols to be developed with the multidisciplinary team, including GPs. Non-medical prescribing is being considered.
NHS Shetland

Local service provision

- The structure of ADHD services in the Shetland Islands remains largely unchanged since the 2007 review. ADHD services are provided by:
  - NHS Shetland children and mental health service (CAMHS)
  - NHS Shetland child health (a GP with special interest in ADHD and visiting paediatricians), and
  - Shetland Islands Council Children’s Services.

Within NHS Shetland, ADHD services are delivered by both CAMHS and community mental health staff. CAMHS sits within the community mental health team. CAMHS provides a specialist service with support from a visiting psychiatrist and psychologist from NHS Grampian. NHS Grampian also provides specialist advice where required. GPs are guided by CAMHS and one GP has a special interest in ADHD. Children seen by community health colleagues are also reviewed by CAMHS. This provides a useful audit to check that all cases are captured and to ensure each child receives a regular review.

A multi-agency forum has been in place for many years. Previously responsible for joint planning, it is now responsible for the integrated planning of children and young people’s services across Shetland and to agree priorities and outcomes. The forum includes representatives from NHS Shetland, Shetland Islands Council Children’s Services (social work and schools service), the third sector, housing, Northern Constabulary, sport and leisure, and child protection. In June 2011, the forum published its integrated children and young people’s services plan for 2011–2014.

Summary of findings

Strengths

The NHS board has:

- a multi-agency approach for developing plans and pathways
- good support for the needs of children, particularly within schools
- a multi-agency parenting strategy, and
- increasing awareness of ADHD across the Shetland Islands.

Barriers to implementation

The NHS board reported:

- small teams of staff and remote locations which can limit access to specialist training, and
- a small, scattered population across a remote and rural setting that is insufficient to justify a separate ADHD service.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Shetland prevalence rate comparison

In NHS Shetland, the number of children receiving treatment for ADHD has decreased since the previous data collection exercise in 2007. Administrative prevalence has also decreased slightly and remains lower than we would expect to see.

<table>
<thead>
<tr>
<th></th>
<th>2007 data</th>
<th>2011 data</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>39 reported cases</td>
<td>27 reported cases</td>
</tr>
<tr>
<td></td>
<td>(0.8% of under 18 population)</td>
<td>(0.6% of under 18 population)</td>
</tr>
<tr>
<td>Boys 90%, Girls 10% (of caseload)</td>
<td>Ratio 9:1</td>
<td>Boys 70%, Girls 30% (of caseload)</td>
</tr>
</tbody>
</table>

The ratio of boys to girls appears to have changed with the proportion of girls increasing significantly. NHS Shetland reported that awareness-raising has led to an increased proportion of girls being diagnosed with ADHD.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child's/young person’s difficulties.

Since 2008, NHS Shetland has taken a number of steps to raise awareness and recognition of ADHD within health, education, the third sector and social services. These include:

- providing CAMHS training at multi-agency monthly teaching sessions, which includes ADHD topics
- providing CAMHS training and consultation to colleagues working within the wider children's sector, where required
- signposting multi-agency staff to relevant materials within the NHS board’s health improvement resource centre and to national web-based resources, and
- a resource library based in one of the local authority schools, which can be accessed by multi-agency staff.

In the Shetland Islands, the local authority has created an integrated children’s services team which includes social services and education. Educational psychology colleagues are also developing training resources for use by parents or carers of children and young people with ADHD.

NHS Shetland’s response to a complex case where the child is not responding to standard treatment approaches would depend on the age of the individual and if the problem was presenting at home or at school. For example, NHS Grampian provides additional specialist support under supervision. Problems can also be discussed at the fortnightly Getting it Right for Every Child (GIRFEC) outreach group meetings. Staff reported that off-island placements are jointly commissioned.

1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

Referrals from schools to CAMHS follow GIRFEC principles. As mentioned above, fortnightly outreach group meetings are held to strengthen multi-agency links, and improve referral systems and access to services.

Written confirmation of the consultation outcome and plan of action is sent to the school, as part of the assessment process. This prompts education colleagues to hold a meeting with relevant professionals to agree any behavioural and educational interventions to be implemented in school. NHS Shetland reported that behavioural and academic
interventions are in place in Shetland Islands schools for all children and young people with ADHD.

### 1.3 Key recommendation

**Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.**

NHS Shetland does not have a standard information pack for ADHD. The NHS board provides parents and carers with links to relevant websites and resources, such as Hands on Scotland and Patient UK. These resources include information on the range of treatment options available, medication and its potential side effects. The NHS board would actively respond to requests for information in other formats or languages.

At the time of the review, services were still developing a multi-agency integrated care pathway for diagnosis and treatment of attention difficulties. The pathway will include a Shetland-wide policy and support pack, and will be developed in consultation with parents and children.

### 2: Non-pharmacological interventions

#### 2.1 Key recommendation

**Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.**

There are no ADHD-specific parenting programmes in Shetland.

The multi-agency group has developed a parenting strategy to offer a range of generic parenting programmes across Shetland: Parenting Strategy for Shetland 2011–2014. At the time of the review, the strategy was being implemented.

The parenting programmes include Family Support, Triple P and Mellow Parenting. Services are tailored to the individual needs of families and are delivered by a range of professionals including health visitors, social workers and third sector workers.

There was extensive parental involvement in the development of the parenting strategy, including feedback on the service and identification of local gaps and needs. The parenting strategy includes a process for undertaking evaluation and parental surveys. The multi-agency steering group monitors the evaluation results. The group reports to the multi-agency forum and integrated children and young people’s services planning group.

Access to parenting programmes is by referral from a range of professionals, including GIRFEC assessment and planning processes, or by self-referral. A range of partner agencies is used to ensure that parenting programmes are available in remote and rural areas. The parenting strategy group has links to local parent or carer support groups.
3: Outcomes

3.1 Key recommendation
Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

NHS Shetland undertakes child development initiative reviews to assess the outcomes of children and young people. The local GIRFEC process includes a focus on outcomes and regular reviews.

Within CAMHS, patients being treated for ADHD are routinely reviewed every 6 months and the results are fed back to GPs and other appropriate agencies. The child health team undertakes a general audit of patient experience every 2 years.

NHS Shetland has evaluated outcomes for individual children and families within clinical practice. However, the NHS board recognises the need for a more systematic, strategic evaluation of outcomes and to standardise GIRFEC processes across each element of the health service.

The integrated children and young people’s services plan includes a work programme. The programme contains a priority action to develop a more robust local approach to continuous service improvement.

4: Transition

4.1 Key recommendation
In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

A transitions pathway is in place to manage the transition out of secondary school for young people with additional support needs. As CAMHS sits within community mental health, the transition to mental health services is managed on a case-by-case basis at the appropriate age.

Within the GIRFEC process, children with ADHD automatically transition into the adult single-shared assessment process, using With You, For You guidelines. Adults with identified support needs are managed within the relevant generic adult service. Staff reported that some young adult cases continue to be managed by CAMHS.

4.2 Key recommendation
In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

NHS Shetland does not have a board-wide pathway for adults with ADHD. The local mental health strategy does not highlight the needs of individuals with ADHD or any other specific diagnosed condition. The strategy aims to include all aspects of mental health to support the needs of individuals requiring specialist intervention. NHS Shetland considers the small and scattered population across a remote and rural setting to be insufficient to justify a separate ADHD service and does not plan to introduce a dedicated adult ADHD
service. Instead, its generic adult service will focus on meeting the needs of each individual with ADHD.

All adults with identified support needs are assessed and supported with multi-agency support tailored to meet their requirements. This includes support from:

- adult mental health
- adult learning disability
- social work
- supported employment, and
- adult education and training services.

NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults is used in principle for adults. However, the NHS board acknowledges that further work is required to implement a diagnostic service for newly presenting adults. NHS Shetland reported plans to develop staff skills and expertise in adult mental health services to further support adults with ADHD.

5: Systems, processes and skills

5.1 Key recommendation

Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

NHS Shetland does not have an electronic system for recording the number of children and young people diagnosed with ADHD. The NHS board gathers data through a variety of sources including from GPs, CAMHS, child development and the learning disabilities database. NHS Shetland is confident it has captured accurate figures on the number of children and young people diagnosed with ADHD across the NHS board area.

5.2 Key recommendation

Implement a standardised proforma for assessment to improve clinical record-keeping.

At the time of the review, NHS Shetland was working to introduce a standardised proforma for assessment to improve clinical record-keeping. CAMHS currently uses a standardised assessment pack for ADHD and a standard assessment for neurodevelopmental vulnerability.

All areas in NHS Shetland are undertaking a record-keeping audit for completion in June 2012. The audit is designed as a rolling programme and will include use of the standardised proforma once it is implemented. NHS Shetland has allocated support from the clinical governance team to help develop improvement plans in response to gaps identified in the audits. Progress will be monitored through the clinical governance structure.
5.3 Key recommendation
NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

The child health team actively engages the child or young person during review meetings to record their views on treatment and potential side effects. Child assessment undertaken within the GIRFEC process includes formal recording of the child’s involvement.

There is no specific system within CAMHS to record the input of the child or young person. NHS Shetland reported that it is routine practice within CAMHS to provide a summary of the consultation to the young person, their family, relevant agencies and GP following the meeting. This includes notes on the child or young person’s contribution to the assessment, their opinion and consent.

5.4 Key recommendation
Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (eg epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

Within CAMHS, only the consultant psychiatrist diagnoses ADHD. The consultant has the required specialist skills and expertise to recognise psychiatric or non-psychiatric comorbidities. The paediatric consultant helps identify the training needs of paediatric staff.

Various training is in place for staff including:
- e-learning modules for GPs
- a training day in April 2012 for the GP with a special interest in ADHD, and
- junior staff attending consultation meetings to observe the consultant process.

5.5 Key recommendation
Put in place systems to ensure that education is involved in the assessment process and that information on the child's/young person’s level of attainment is always requested and obtained from school.

The CAMHS ADHD assessment pack includes a section for schools to complete and return before the child or young person’s first appointment. This information is used with the Conners’ teacher rating scale.

The NHS board reported that for referrals through the child health team, a letter is sent to the school, requesting the teacher’s observations and completion of the Vanderbilt teacher rating scale.
NHS Shetland reported that partners in education are active participants in the GIRFEC process and the majority of school-age referrals are through schools. Classroom observations are routinely undertaken and CAMHS will accept observations by educational psychology colleagues.

5.6 Key recommendation
Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

NHS Shetland does not have a protocol for the titration of medication and there are currently no plans to develop one. The NHS board reported that clinical practice is guided by the Scottish Intercollegiate Guidelines Network (SIGN) guidelines for medication.

Within CAMHS, only the consultant psychiatrist prescribes medication and ADHD patients are reviewed every 6 months. Any positive and negative effects are recorded within the consultation summary document.
NHS Tayside

Local service provision

In 2007, a multidisciplinary specialist development psychiatry team provided services for children and young people with developmental mental health conditions. The service was part of the generic child and adolescent mental health services (CAMHS) which also included a team providing dedicated ADHD services.

At the time of the review, NHS Tayside provided services through a board-wide specialist ADHD pathway within CAMHS. Since 2007, the NHS board has:

- changed its clinical pathway to fully document the child’s input into the assessment process
- trained staff to provide ADHD-specific parent training, and
- strengthened links with education.

ADHD patients are now routinely allocated to a named case holder and the NHS board has also allocated more staff resource to address patient waiting list issues. The service has moved to a model of nurse-led review clinics for continuing ADHD care. The nurse is supported by a ‘floating doctor’ who provides advice and support on complex issues.

NHS Tayside reported that during 2012 the service would move to a choice and partnership approach (CAPA) to care. In future, the titration of medication and continuing care for ADHD may be designated as ‘core’ work to be shared more evenly among staff within CAMHS and the ADHD pathway. However, ADHD assessment would remain as a specialist intervention. The NHS board estimates that the process of change to CAPA will take between 1–2 years.

Summary of findings

Strengths

The NHS board has:

- introduced a number of standard documents in 2007, including an assessment form, blood pressure centile charts, and a form to assess child and family quality of life
- established nurse-led clinics that include the initiation and titration of medication
- introduced formal documentation of the child or young person’s input into the assessment process, and
- continued to develop the named clinician for all patients with ADHD.

Barriers to implementation

The NHS board reported:

- high caseload and varying approach by partner agencies which limits the integration of the pathway
- challenges to provide non-pharmacological interventions due to high caseload, and
- lack of protocols and variation in the treatment and management of adults with ADHD.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

**Figure 1: NHS Tayside prevalence rate comparison**

In NHS Tayside, the number of children receiving treatment for ADHD has increased since the previous data collection exercise in 2007. However, the reported prevalence is still lower than we would expect to see.

<table>
<thead>
<tr>
<th>2007 data</th>
<th>2011 data</th>
</tr>
</thead>
<tbody>
<tr>
<td>407 reported cases</td>
<td>743 reported cases</td>
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<tr>
<td>(0.5% of under 18 population)</td>
<td>(1.0% of under 18 population)</td>
</tr>
<tr>
<td>Boys 85%, Girls 15% (of caseload)</td>
<td>Boys 80%, Girls 20% (of caseload)*</td>
</tr>
<tr>
<td>Ratio 6:1</td>
<td>Ratio 4:1</td>
</tr>
</tbody>
</table>

* These data are based on a representative sample of caseload and not on the total number of reported cases.

The ratio of boys to girls appears to have shifted slightly; the proportion of girls has increased.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation
Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child’s/young person’s difficulties.

Primary mental health workers attached to CAMHS undertake general awareness-raising activities of child mental health issues. This includes delivering training on ADHD, with the support of specialist ADHD staff where required. The training is available to all sectors and is advertised on the GLOW network, NHS Education for Scotland’s national online learning resource.

CAMHS staff work closely with Parent to Parent, a local third sector organisation that provides support to parents and carers of children and teenagers with additional needs.

The ADHD clinical pathway is delivered in partnership with local authorities, education, social work and third sector organisations. NHS Tayside reported that the high caseload and differences in approach by partner agencies has limited the integration of the pathway.

1.2 Key recommendation
Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

In 2007, NHS Tayside already had an ADHD clinical pathway in place. Since 2007, NHS Tayside has made changes to the pathway to strengthen links with colleagues in education. This includes updating outcome measures and adopting a more targeted measure of school performance using the Swanson, Kotkin, Atkins, M-Flynn, and Pelham (SKAMP) rating scale.

Primary mental health workers attend joint action team meetings in schools to provide advice on interventions. ADHD staff also work with schools as required and interventions are based on the needs of the child. Staff reported variation in the way that schools deal with the presentation and management of ADHD.
1.3 Key recommendation

Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

NHS Tayside uses the National Institute of Mental Health ADHD booklets and the Royal College of Psychiatrists factsheets. The booklets and factsheets include information on the range of treatment options available for ADHD and the potential side effects of medication. The information is available in easy read or electronic formats.

2: Non-pharmacological interventions

2.1 Key recommendation

Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

NHS Tayside delivers the New Forest parenting programme for parents of children with ADHD aged from 3–10 years. The NHS board has provided initial training on the programme to 15 staff. At the time of the review, three team members including two primary mental health workers and a consultant psychiatrist delivered the programme. Referral onto the programmes is through CAMHS. The delivery of the New Forest programme is not Tayside wide, as not all staff who undertook the initial training have delivered it to families. There is no ongoing programme for the delivery of parent training groups and all parent training programmes are currently delivered to individual families. When previously offered, the uptake by parents of parenting training delivered in group format was very limited.

CAMHS clinicians have training in a variety of generic parenting programmes that can be used in group or individual work. The local authority also delivers generic parenting programmes such as 123 magic and Incredible Years. These are available throughout the NHS board area and are also available to parents of children with ADHD.

At the time of the review, NHS Tayside was not evaluating specific outcomes from the parenting programmes. The NHS board reported that it uses standard outcome measures to measure overall improvement.

NHS Tayside also liaises with Parent to Parent, a local parent support group.

3: Outcomes

3.1 Key recommendation

Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.

Since 2007, NHS Tayside has updated its outcome measures for children and young people with ADHD and outcome data are routinely collected. These include ADHD symptoms, impairment, comorbidity, medication problems, adverse effects, vital signs, growth and weight.
The NHS board uses the following tools to measure outcomes:

- ADHD rating scale
- SKAMP rating scale
- Children’s global assessment scale
- Clinical global impressions scale
- adverse effects rating scale
- Dundee difficult times of day scale
- growth centile charts, and
- Dundee blood pressure centile charts.

At the time of the review, outcomes were measured on a 6-monthly basis using patient feedback and evaluation tools. Staff discuss outcomes at the pathway meetings and plans for improvement are put in place, where required.

Additional treatments and support are available for more complex cases and comorbidities as required. This may involve junior and senior medical staff, nursing staff, clinical psychology and family therapy.

4: Transition

4.1 Key recommendation

In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.

NHS Tayside has a generic protocol for managing the transition from CAMHS to adult services. The protocol is not specific to ADHD patients.

Adults with ADHD are managed by the individual community mental health teams and learning disability services. The NHS board reported that there are no adult ADHD assessment and management protocols. It also reported that there is considerable variation between the teams in the treatment and management of ADHD in adults.

4.2 Key recommendation

In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.

At the time of the review, there was no board-wide pathway for adults with ADHD and NHS Tayside was not implementing NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults.
CAMHS provide training to adult services to help support assessment and continuing care services for adults with ADHD. However, staff reported that the transition to adult services could be improved for patients and acknowledged that there was a risk of disengagement from services at this time.

5: Systems, processes and skills

5.1 Key recommendation
Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

NHS Tayside has a database for recording data on the number of children and young people diagnosed with ADHD. At the time of the review, the database was unable to show a breakdown of data by gender for all children and young people.

5.2 Key recommendation
Implement a standardised proforma for assessment to improve clinical record-keeping.

NHS Tayside has had a standardised assessment proforma since 2001, to improve clinical record-keeping. The initial assessment is undertaken by nursing staff. All ADHD assessments are checked by senior medical staff. Senior medical staff undertake formulation and treatment planning appointments with young people and their families.

5.3 Key recommendation
NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

The child or young person attends all parts of the assessment and is fully involved in discussions about diagnosis and treatment planning for ADHD. The input of the child or young person is routinely recorded as part of this process. Senior medical staff check that all relevant information is captured.

5.4 Key recommendation
Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (eg epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

NHS Tayside reported that training needs of mental health and paediatric staff are identified through ongoing supervision and yearly staff appraisals.

As mentioned above, initial assessment of children and young people for ADHD is undertaken by nursing staff with support from senior medical staff and clinical psychology
as required. All staff conducting ADHD assessments have received extensive training on the assessment of a broad range of mental health problems using structured assessment tools.

5.5 Key recommendation

Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

NHS Tayside routinely requests information from school on the child or young person’s level of attainment. The NHS board uses standard reports and questionnaires to gather information. If particular issues need further clarification, staff will telephone or visit the school.

5.6 Key recommendation

Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

The NHS board has a protocol for the titration of medication which includes the initiation of treatment and the ongoing monitoring and recording of positive and negative effects. The titration of medication is nurse-led.

NHS Tayside reported that when CAPA is introduced, stable cases not receiving medication may be discharged to primary care. Stable cases on medication may have follow-up appointments reduced from two to one each year, with an interim appointment for measurement of height, weight and vital signs.
NHS Western Isles

Local service provision

At the time of the 2007 review, NHS Western Isles did not have a dedicated ADHD service. Services for children and young people with ADHD were provided by a generic child and adolescent mental health services (CAMHS) team which was based locally. This team comprised a senior CAMHS nurse, a community mental health worker and a clinical psychologist, all of whom worked on a part-time basis. A consultant CAMHS psychiatrist from NHS Highland provided psychiatry input for the CAMHS team. The psychiatrist held a monthly clinic in Stornoway and a quarterly clinic in Uist, and was available via phone or video link outwith the scheduled clinic times.

In response to the *Attention Deficit and Hyperkinetic Disorders – Services over Scotland* (2008) report, NHS Western Isles launched a review into the framework for assessment and access to specialist CAMHS. An integrated process map was developed to outline the integrated care pathway for access to specialist services and the assessment process for ADHD. This formed the baseline for developing an ICP for the systems and processes for care.

In addition, the capacity and capability of the CAMHS team has also been increased. The local team is supported by a locum consultant psychiatrist and a clinical psychologist from NHS Greater Glasgow and Clyde who are available twice a month. However, due to the small numbers involved, the NHS board does not currently provide specialist ADHD services.

Summary of findings

Strengths

The NHS board has:

- introduced a multi-agency inclusion policy
- good support for the needs of individual children, especially within schools, and
- developed a CAMHS strategy that has led to the identification of a nominated ‘link person’ in each school.

Barriers to implementation

The NHS board reported:

- resource and capacity issues with reference to parental respite, and provision of training programmes outwith Triple P
- limited local supervision and expertise
- lack of resources to implement and progress ADHD-specific training initiatives, and
- recent restructuring within the local authority has restricted several areas of work.
Updated data collection and prevalence information

The prevalence rate of ADHD is considered to be approximately 5% of school-aged children; the rate of the most severe form - equivalent to hyperkinetic disorder (HKD) is approximately 1.5%. It is recognised that more boys than girls have ADHD. At the time of the last review, the proportion of girls diagnosed in Scotland was much lower than expected, with a male to female ratio of 6:1.

Figure 1 below compares the number of reported cases for the NHS board area in 2007 and 2011 with the prevalence data mentioned above.

Figure 1: NHS Western Isles prevalence rate comparison

<table>
<thead>
<tr>
<th></th>
<th>2007 data</th>
<th>2011 data</th>
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<tbody>
<tr>
<td></td>
<td>16 reported cases (0.3% of under 18 population)</td>
<td>12 reported cases (0.2% of under 18 population)</td>
</tr>
<tr>
<td>Boys 63%, Girls 37% (of caseload)</td>
<td>Ratio 2:1</td>
<td>Boys 83%, Girls 17% (of caseload)</td>
</tr>
</tbody>
</table>

In NHS Western Isles, the number of children receiving treatment for ADHD has decreased since the previous data collection exercise in 2007. The reported prevalence is still lower than we would expect to see.

The ratio of boys to girls appears to have shifted slightly; the proportion of boys has increased. Staff reported that this may be due to population changes within the NHS board area.
Detailed findings against the key recommendations

1: Awareness raising and recognition

1.1 Key recommendation

Investigate more effective ways to raise awareness and recognition of ADHD within health, education, the third sector and social services to ensure that ADHD is considered as a potential underlying cause of a child’s/young person’s difficulties.

Since 2008, the NHS board has taken a number of steps to raise awareness and recognition of ADHD within health, education, the third sector and social services.

Steps taken to raise awareness and recognition include the following.

- The generic CAMHS mental health training Introduction to CAMHS includes information on the presenting features, diagnosis and management of ADHD and references Scottish Intercollegiate Guideline Network (SIGN) guideline 112: management of ADHD in children and young people.

- The clinical psychologist provides training and awareness on the ‘unique characteristics’ of the child with ADHD diagnosis as part of an individual care package. The educational psychologist provides education and awareness-raising with the child’s teachers and inclusion staff.

- The inclusion policy outlines staged and stepped intervention approaches. Awareness-raising of ADHD is included in the document. Education and care staff also have access to this training.

- Action for Children, a national third sector organisation, provides ADHD-specific training and local staff access this resource as required.

However, the NHS board reported that the main barrier to raising awareness and recognition of ADHD is a lack of resources to implement and progress planned joint training initiatives.

1.2 Key recommendation

Strengthen links with colleagues in education to raise awareness of ADHD and to ensure that all children and young people with ADHD have behavioural and academic interventions implemented in school if required.

The development of the NHS board’s CAMHS strategy has led to the identification of a nominated ‘link person’ in each school and close working within the new learning communities.

NHS Western Isles has restored the public health nurse links with schools and each school has a named nurse. The NHS board delivers a range of awareness-raising and training to both staff and pupils:

- management of self-harm
- anxiety and depression in young people
- suicide prevention,
• sexual health.

The implementation of behavioural and academic interventions in schools has focused on shared interdisciplinary training, particularly the Triple P parent training programme. One NHS staff member has been trained in the Incredible Years programme for parents, teachers and children. Both the inclusion policy and additional support needs handbook outline a stepped and staged approach to interventions within the education system.

1.3 Key recommendation

Develop a standard information pack which explains about ADHD, the range of treatment options available including medication and its potential side effects.

A standard information pack is available which consists of the booklet ‘Talking ADHD’ from the Healthy Living Collection and SIGN guideline information leaflets for children and parents. The packs are generic and not locally designed. Families are given verbal information on options for treatments that are available locally.

Packs are reviewed on an individual basis in order to best meet the needs of the child.

2: Non-pharmacological interventions

2.1 Key recommendation

Invest in provision of more accessible ADHD-specific programmes for parents of children with ADHD.

In the Western Isles, a range of generic parenting programmes is offered to the parents/carers of children aged 0–18 years. The programmes include Mellow Babies, Incredible Years, and Triple P. The NHS board, the local authority, education, social work and third sector colleagues deliver the programmes.

Parenting programmes are delivered based on the needs of the individual family and are available throughout the NHS board area. At the time of review, a pilot programme was being considered for parenting education to be delivered to 1st–3rd year secondary school pupils as part of Curriculum for Excellence.

Screening tools are used to evaluate the programmes as well as reports and feedback from the family. Monthly community meetings, community action team meetings and school action team meetings are also used to evaluate the programmes used. In addition, there are initiatives such as co-ordinated support plans and parent and teacher learning support meetings to help evaluate and monitor the tools that are used.

The NHS board reported resource and capacity issues due to the individual nature of the programmes offered, and the challenges posed by a remote and rural setting in delivering such programmes.
3: Outcomes

3.1 Key recommendation

**Implement systems to ensure that the outcomes for children and young people with ADHD are routinely evaluated.**

At the time of the review, NHS Western Isles reported that a range of screening tools and clinical reviews are used to evaluate outcomes for children and young people.

The tools used to measure outcomes are:

- the strengths and difficulties questionnaire
- the adolescent wellbeing scale
- Conners’ ADHD rating scale
- Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA), and
- the Children’s Global Assessment Scale.

Outcomes are evaluated according to individual ability and suitability, and on an ongoing basis. Clinical reviews by the consultant psychiatrist are conducted at least twice a year. The NHS board reported that regular case conferences, school and inclusion meetings and individual education plan meetings are also used. Care plans and education support plans are modified, as required in the interest of continuous service improvement.

4: Transition

4.1 Key recommendation

**In the shorter term, protocols are needed in order to manage transition of young people with ADHD from child and adolescent services to adult services.**

NHS Western Isles submitted their protocol for managing transition from CAMHS to general adult services. This includes the need for joint planning meetings and identifying any additional support needs. The NHS board recognises that there is the potential for young people to disengage from services at this stage.

4.2 Key recommendation

**In the longer term, a strategy is required to ensure that appropriate assessment and continuing care services are developed for adults with ADHD.**

Adults with ADHD are seen within general adult mental health services with support from community and third sector organisations as appropriate. There is currently no board-wide pathway for adults with ADHD. At the time of the review, NHS Western Isles was partially implementing NICE guideline CG72: diagnosis and management of ADHD in children, young people and adults.

At the time of the review, the NHS board reported that there are very few new diagnoses of adults with ADHD; either the individual will have been known to services since childhood or will have moved to the islands with an existing diagnosis. Due to the small
number of cases within NHS Western Isles, a board-wide pathway for adults with ADHD is being developed alongside an ADHD pathway for children and young people.

5: Systems, processes and skills

5.1 Key recommendation
Ensure that systems are in place to provide accurate information on the numbers of children and young people diagnosed with ADHD in the NHS board area, and on their treatment and management, and to ensure that these systems are maintained and regularly updated.

NHS Western Isles provided a breakdown by gender of all children and young people who were receiving treatment at the time of review.

5.2 Key recommendation
Implement a standardised proforma for assessment to improve clinical record-keeping.

At the time of the review, the NHS board reported that no standardised proforma for assessment is in place. However, clinical leads carry out record-keeping audits to monitor the information that is recorded against SIGN guideline 112.

5.3 Key recommendation
NHS boards should put in place systems to ensure that the child/young person concerned is fully engaged in the assessment process and this is documented in the clinical notes.

At the time of the review, the NHS board reported that a number of systems have been put in place to record the input of the child/young person in the assessment process. This includes:

- self-assessment tools such as the strengths and difficulties questionnaire
- signed-off care plan agreements
- self-developed, agreed and consented safe plans to manage risk taking behaviours
- consent to treatment and information sharing as directed by the child/young person, and
- signed and consented individual health plans inserted into education and co-ordinated support plans.

Clinical leads monitor all of the above.
5.4 Key recommendation

Ensure that there is a consistent approach to screening for psychiatric comorbidities or associated non-psychiatric comorbidities (e.g., epilepsy) and that all staff who undertake ADHD assessments have the necessary skills to do this.

The training needs of mental health staff to assess the child/young person’s requirements to access non-psychiatric services are assessed through:

- the CAMHS competences framework (this was developed by NHS Education for Scotland)
- personal development plans and knowledge and skills framework
- supervision, and
- care plan evaluations of assigned practitioners.

Paediatric staff are assessed using case-on-case consultations with CAMHS where training needs are highlighted, including attendance at mental health training sessions. At the time of review, the NHS board anticipated that the proposed pathway developments and associated policies and protocols would also help to identify training needs.

The training courses that are available are organised year-on-year as part of a rolling programme.

5.5 Key recommendation

Put in place systems to ensure that education is involved in the assessment process and that information on the child’s/young person’s level of attainment is always requested and obtained from school.

The local authority has appointed inclusion managers who work between agencies to co-ordinate reports and observations as part of the assessment process. NHS Western Isles support this process through the community mental health worker linking with the learning community meetings where interventions and progress within the child/young person’s school or learning environment is discussed. Case conferences and a stepped and staged intervention approach encourage consistency in the process. Educational psychology colleagues carry out a classroom observation for every child who is assessed for ADHD.

Co-ordinated support plans and individual education plans can be used to obtain information regarding the child/young person’s level of attainment. The NHS board provided copies of the inclusion policy and additional support needs handbook as supporting evidence.

5.6 Key recommendation

Develop a protocol for the titration of medication and the monitoring and recording of positive and negative effects.

At the time of review, NHS Western Isles did not have a locally developed protocol for the titration of medication and the monitoring of the positive and negative effects. The NHS board reported that it follows SIGN guidelines and British National Formulary guidelines, in conjunction with a clinical management medication plan for the nurse prescriber to
follow up on. This includes the monitoring and recording of positive and negative effects of medication. However, the NHS board did not provide evidence to support this statement.

Due to limited locum supervision and local expertise, advice is also taken from pharmacy colleagues as and when required. It is anticipated that a board-wide protocol will be implemented following the development and implementation of the integrated care pathway for ADHD.
# Appendix 1: Membership of evaluation panels

<table>
<thead>
<tr>
<th>Name</th>
<th>Role and Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carol Cartwright</td>
<td>Acting Clinical Nurse Specialist (ADHD), NHS Ayrshire &amp; Arran</td>
</tr>
<tr>
<td>David Coghill</td>
<td>Reader, University of Dundee, and Honorary Consultant, NHS Tayside</td>
</tr>
<tr>
<td>Fiona Forbes</td>
<td>Child and Adolescent Mental Health Advisor, Healthcare Improvement Scotland</td>
</tr>
<tr>
<td>Sarah Glen</td>
<td>Consultant Child and Adolescent Psychiatrist, NHS Borders</td>
</tr>
<tr>
<td>Kathy Leighton</td>
<td>Consultant Child and Adolescent Psychiatrist, NHS Greater Glasgow and Clyde</td>
</tr>
<tr>
<td>Mandy Mulvanny</td>
<td>Consultant Child and Adolescent Psychiatrist, NHS Lothian</td>
</tr>
<tr>
<td>Chris Steer</td>
<td>Consultant Paediatrician, NHS Fife</td>
</tr>
<tr>
<td>Fiona Thomson</td>
<td>ADD It UP, NHS Ayrshire &amp; Arran</td>
</tr>
<tr>
<td>Ruth Thomson</td>
<td>Ecosse Adders, NHS Forth Valley</td>
</tr>
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## Healthcare Improvement Scotland team

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
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<tbody>
<tr>
<td>Hana Barvik</td>
<td>Project Administrator</td>
</tr>
<tr>
<td>Jane Byrne</td>
<td>Programme Manager</td>
</tr>
<tr>
<td>Pamela Campbell</td>
<td>Project Administrator</td>
</tr>
<tr>
<td>Sean Doherty</td>
<td>Performance Manager</td>
</tr>
<tr>
<td>Nanisa Feilden</td>
<td>Programme Manager</td>
</tr>
<tr>
<td>Joanne Hendry</td>
<td>Project Officer</td>
</tr>
<tr>
<td>Tricia Kettles</td>
<td>Personal Assistant</td>
</tr>
<tr>
<td>Susan Lowes</td>
<td>Project Officer</td>
</tr>
<tr>
<td>Catriona Macmillan</td>
<td>Project Officer</td>
</tr>
<tr>
<td>Lorraine McLafferty</td>
<td>Project Administrator</td>
</tr>
<tr>
<td>Ahsan Mustafa</td>
<td>Project Administrator</td>
</tr>
<tr>
<td>Fiona Russell</td>
<td>Programme Manager</td>
</tr>
<tr>
<td>Edel Sheridan</td>
<td>Project Officer</td>
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</tbody>
</table>
## Appendix 2: Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADHD</td>
<td>attention deficit and hyperkinetic disorders</td>
</tr>
<tr>
<td>CAMHS</td>
<td>child and adolescent mental health services</td>
</tr>
<tr>
<td>CGI</td>
<td>Clinical global impressions scale, used to measure symptoms and responses to treatment.</td>
</tr>
<tr>
<td>Conners'</td>
<td>An ADHD-rating scale.</td>
</tr>
<tr>
<td>CORC</td>
<td>CAMHS Outcomes Research Consortium</td>
</tr>
<tr>
<td>GIRFEC</td>
<td>Getting it Right for Every Child – the Scottish Government’s multi-agency initiative to improve outcomes for children and young people.</td>
</tr>
<tr>
<td>HoNOSCA</td>
<td>Health of the Nation Outcome Scale for Children and Adolescents</td>
</tr>
<tr>
<td>Incredible Years</td>
<td>Training programmes for parents, teachers and children</td>
</tr>
<tr>
<td>Mellow Parenting</td>
<td>A parent training programme.</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
</tr>
<tr>
<td>Parents INC</td>
<td>Parents In Control – an ADHD-specific parent training programme.</td>
</tr>
<tr>
<td>SIGN</td>
<td>Scottish Intercollegiate Guidelines Network</td>
</tr>
<tr>
<td>SKAMP</td>
<td>Swanson, Kotkin, Atkins, M-Flynn, and Pelham (SKAMP) rating scale.</td>
</tr>
<tr>
<td>SNAP IV</td>
<td>Swanson, Nolan and Pelham IV rating scale.</td>
</tr>
<tr>
<td>Triple P</td>
<td>A parent training programme.</td>
</tr>
<tr>
<td>Vanderbilt tool</td>
<td>A behavioural rating scale.</td>
</tr>
<tr>
<td>What I think</td>
<td>A questionnaire used as part of the GIRFEC process to promote discussion with children and young people.</td>
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</tbody>
</table>
The Healthcare Environment Inspectorate, the Scottish Health Council, the Scottish Health Technologies Group and the Scottish Intercollegiate Guidelines Network (SIGN) are part of our organisation.