Developing an ADHD Integrated Care Pathway (ICP)

Dr Susan Yarney
Consultant Community Paediatrician and ADHD Clinical lead East/North Hertfordshire NHS Trust
Susan.yarney@nhs.net

Abstract

One of the key recommendations of the National Institute for Health and Clinical Excellence (NICE) guideline on the diagnosis and management of attention deficit hyperactivity disorder (ADHD) in children, young people and adults in September 2008 (1) is that Health Trusts, in collaboration with major stakeholders, develop ADHD Specialist teams that will be instrumental in implementing integrated care pathways. An ADHD integrated care pathway (ICP) can provide a valuable structure for patient identification, referral, assessment, diagnosis, management, support and follow up. By assisting a patient through their healthcare journey, an ICP can help to facilitate effective clinical governance. An ICP should set standards for interventions that are evidence based in line with the definition of clinical governance by the Commission for Health Improvement (CHI). In this paper, the advantages of an Integrated Multiagency ADHD Care Pathway, together with the steps required in its development and implementation are considered.

Key words
Integrated care pathway, ADHD, NICE, Clinical governance, Stakeholders

Introduction

Attention deficit hyperactivity disorder (ADHD) is one of the most common neurodevelopmental conditions underlying behavioural and academic difficulties in children and young people. It is a heterogeneous behavioural syndrome characterised by symptoms of inattention, impulsivity and hyperactivity.

The report of the National group of chairs of the NHS next stage review (2) in June 2008 made the following recommendations.

1. Commissioning of pathways of care delivered by staff with the relevant skills in evidenced based interventions.

2. This will require a combination of general skills for frontline practitioners and a stepped care approach to more specialised competencies. For example, appropriate competencies in liaison psychiatry are required to back up the generalist knowledge of clinical staff working in any acute physical health care service.

3. Commissioners, providers and regulators should work together to ensure that contracts encourage high-quality staff into mental health commissioning and service provision.

4. Develop and maintain staff skills to deliver improved outcomes and reduce the stigma of mental health services by promoting the field as an important career choice for the long term emotional, social and economic wellbeing of the country.

5. Training and continuing professional development should be driven by service design based on effective care pathways to address local need, rather than existing skill sets driving service design.

The above recommendations can be achieved by the implementation of a clear and robust integrated care pathway involving all major stakeholders.
Definition

There are many definitions for an integrated care pathway.

One of the earliest formal definitions states that an integrated pathway is a tool which is determined and agreed locally; multidisciplinary; based on guidelines and evidence when available; forms part or all of the clinical record; documents care given and facilitates the evaluation of outcomes for continuous quality improvement (3).

The European Pathway association (EPA) as suggested by Vanhaecht et al in 2007 (4) defined this as: ‘A complex intervention for the mutual decision making and organization of predictable care of a well defined group of patients during a well defined period’.

Historical perspectives

Pathways were introduced in the Healthcare system in the early 1980s in the USA (5). Prior to their introduction in healthcare, certain non-health industries had already been using care pathways. The first use of clinical pathways was in Boston USA in 1985 and 1987. This was as a result of introduction of diagnosis-related groups in 1983. By the late 1990s the majority of US hospitals were using some form of clinical pathway (6).

Clinical care pathways were introduced in the 1990s in the UK. Care pathways are now used worldwide.

Aims of an Integrated Care Pathway (7).

Figure 1
Integrated patient care becomes possible when the patient remains the central focus

**Figure 2**

Patient-centred pathways occur when all major stakeholders including service users and providers work together in partnership. It is important to incorporate the views of patients during this process and there are different methods to achieve this (8).

**Vanhaecht et al, 2010 described 3 different care pathway models (5):**

Chain models are used for high predictability processes like elective surgery or chemotherapy teams. They require a high level of agreement between the members of the multidisciplinary teams.

Hub models are used for less predictable processes like psychiatry and palliative care. The key or lead worker leads the organization and planning of the care process around the patient.

Web models are also used in unpredictable care processes where it is essential to have frequent and regular meetings to enable organization and structuring of the process.

The goal of these models is to enhance multiagency and multidisciplinary team working.

**Advantages/benefits of integrated care pathways (7)**

Integrated pathways:

- Encourage multidisciplinary working and communication.
- Facilitate the introduction of local protocols, research and audit.
- Promote patient-focused care.
- Improve patient information.
• Result in a more efficient data collection and encourage changes in practice.
• Encourage the use of evidence-based care into clinical practice.
• Provide clear and concise standard of care.
• Provide the framework for the management and reduction of clinical risk.
• Are cost effective by reducing hospital stays.
• Enhance communication between different care sectors.
• Support education and training.
• Provide a baseline for future initiatives.
• Provide a standardised system for progress and monitoring of care.

Campbell et al. (7) further described concerns about integrated pathways as being:

• Investment of time that could be spent in other clinical activities.
• Discouragement of appropriate clinical judgement in certain individual cases.
• The stifling of innovation and progress.
• Being difficult to develop in situations with multiple pathologies or variable clinical management.

Developing an Integrated ADHD Care Pathway - Key considerations

• Identify a specific area for further development
• Recognise that an ADHD ICP is needed to enhance patient experience and produce better outcomes for all.
• Identify bench-marks e.g. NICE guidelines which can be used to support your rationale for an ICP development.
• Identify a project facilitator or lead.
• Solicit the support/ involvement of team members and educate them about the ICP.
• Identify, involve and manage key stakeholders.
• Map out ICP process and timelines for development.
• Agree ICP with all major stakeholders.
• Implement pathway.
• Review and audit pathway regularly.

Identifying a specific area for further development

- The Rationale for ICP development

Audits, surveys and research can help to identify and strengthen the value of an ADHD ICP. It is important to obtain feedback from service users and also to review and audit existing patient data. Regularly updated ADHD patient databases make the process of data collection for audit or research purposes easier.

Information can be obtained from service users by issuing survey cards, conducting short interviews, organising focus groups or arranging workshops. Service users may also be accessed via voluntary organizations or multiagency meetings.

National and local clinical standards and guidelines can provide a rationale for developing an ADHD ICP. The ICP should have a strong evidence base. The evidence base should contain the relevant clinical standards/benchmarks and best practice.
Some of the key documents that should support an ADHD ICP include:

• NICE guidance 2008 (1).
• SIGN guidance 2006 (9).
• Every child matters integrated working (10).
• Every child matters Lead Professional (11).
• Department of Health 2010 New Horizons (12).

Identify a project lead or facilitator

A designated facilitator or lead should manage the ICP process. The facilitator should have the relevant skills to manage all the major stakeholders effectively. He or she will provide leadership, ongoing support and education, acting as a link between different professional groups.

Gaining support of Team members and colleagues is vital to the success of the ICP. The project lead or facilitator may be the clinical ADHD lead or a specialist working with children and young people with ADHD.

Colleagues, managers and commissioners should be made aware of the need and rationale for an integrated pathway. Colleagues may have very little knowledge about the condition particularly if they do not assess and manage ADHD regularly.

Team member involvement and education will involve providing information about the role, aims, objectives and benefits of an ADHD ICP. It will also involve explanation of how the ICP may affect practice, cost effectiveness and the role of the team in contributing to the overall process. Team members may feel sidelined if their views are not solicited and represented in the process. It is very important that the project lead or facilitator communicate effectively with the team.

Once interested team members are identified, a steering or working group can be formed and roles delegated to key members.

It is essential to widen membership to members of other multidisciplinary/multiagency teams. This should include all providers of ADHD care and support, including representatives from parent support groups, voluntary organizations, social care and education. Service users, including families and young people, should also be included in this process.

Hussein (13) makes the following points about the importance of the inter/multidisciplinary nature of pathways.

Team members should reflect all the disciplines involved in delivery of care. Communication at all levels is essential. Exchanging resources across different agencies and disciplines is cost effective. Availability of various sources of data is integral to decision making. Every discipline is important, regardless of the degree of involvement.

The importance of incorporating the views of service users (patients/carers) into the process has been stressed by the Irish society for quality and safety in Health Care (14). They state that the benefits of involving patients and their carers include:

Better quality of services for patients resulting in improved outcomes. Patient-focused planning and decisions. Enhanced communication between organizations and the communities they serve. Elimination of waste by identifying well in advance services required for specific purposes.
Examples of key stakeholders forming part of an ADHD ICP working group are:

**Preschool**
- Preschool teachers/advisory teachers.
- Nursery nurses.
- Health visitor.
- Family liaison worker.
- Community nurse.
- Pre School SENCO.
- GP.
- Paediatrician.
- Clinical psychologist.
- Psychiatrist.
- Voluntary organizations.
- Parent/carers.
- Social Care.
- Commissioners.

**School Age**
- Educational psychologist.
- SENCO.
- Teacher/teaching assistant.
- Clinical psychologist.
- Behaviour support team.
- Youth offending team (YOT).
- Social Services.
- Voluntary Organizations.
- Paediatrician.
- Psychiatrist.
- Commissioners.

**Designing an ADHD ICP**

Brainstorming sessions chaired by the project lead/facilitator will identify the rationale for the ICP, aims/objectives and how the pathway should be designed. The design should be simple and easy to understand.

The pathway should include evidence-based standards of practice, allow for regular analysis, should form a single record of use by the whole multidisciplinary/multiagency team and should be easily accessible (15). It is essential for the ICP to be incorporated into organizational strategy thus empowering service users.

The ideal ADHD ICP maps a framework for identification, diagnosis, management, follow up and progress at each step of the patient’s journey. It has the potential to shorten the patient’s journey from
time of identified concerns, referral, management and support. An ADHD ICP will also raise the profile of ADHD within a certain geographical area. Services are more visible, clear, robust and streamlined. Communication is enhanced between primary and specialist care providers. Lack of a clear pathway can lead to a ‘pot luck’ system of referral from primary care or universal services into specialist services further lengthening the patient journey. An ADHD ICP will ensure the provision of a uniform service in a wider geographical area thus eliminating a possible ‘postcode lottery’. Standardizing the whole process should result in a more efficient and cost-effective service.

Mapping the patient journey by the method of process mapping captures the delivery of care at each stage of the patient’s journey, providing a detailed view of the process and outcome. Process mapping identifies the strengths and weaknesses in delivery of care whilst providing robust evidence to support the need to review and develop solutions for change. It also identifies delays, duplication of care, gaps in the patient’s journey, deviations from best practice and quality/safety issues.

Process mapping involves a number of stages. These are:

- Identifying what occurs along a patient’s journey from their experience.
- Analyzing the map to identify waste, duplication, errors, blockages and unnecessary steps to the flow of health delivery.
- Developing solutions to any identified issues.
- Testing possible solutions and their impact on care delivery.
- Implementing necessary changes to improve the patient’s journey.
- Evaluating impact of change on the care continuum.
- Reviewing regularly to ensure continuous quality improvement.

Launching and implementing the pathway should involve all the members of the working group. This entails education and training of all major stakeholders in the proper use of the ICP, together with audit and review of the ICP periodically to ensure updated standards are continually incorporated. An effective ADHD ICP supports the audit process and assists in maintaining clinical governance standards. Members of the working group should identify and agree on outcome measures at the start of the pathway development process.

**Conclusion**

A well developed ADHD ICP should shorten the patient’s care journey, empower patients and carers, make services more visible and uniform, and support both providers and commissioners in providing a more accessible service appropriate for the needs of service users.

**GP Comment**

What have I learned from this paper?

1. An integrated care pathway may be of particular benefit in the management of ADHD because this is a condition that affects the individual in many different settings, is often associated with comorbidity and generally involves a large number of professionals.

2. An integrated pathway can facilitate referral, management, audit and measurement of outcome; by incorporating NICE and other relevant guidelines, regularly updated with the best available clinical evidence, it can help to maintain high standards in managing complex conditions such as ADHD. This is very much in keeping with the concept of Clinical Governance.

3. Because shared-care arrangements with general practice are an essential aspect of the integrated care pathway, it is very relevant to the GP in managing patients with ADHD.
4. In this paper, the lists of professionals and others who should be involved in the care of the individual with ADHD at different ages provide a valuable aide-memoire to assist us in ensuring that appropriate comprehensive management is being provided.

**Dr Vinita Manjure, GP, Milton Keynes.**

**References**


*This article was sponsored by an educational grant from Janssen. Janssen had no editorial control in the writing of this article.*