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Information Provision in ADHD
Evaluation of internet resources and the needs of school teachers

By
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‘This thesis is the result of the author’s original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.’

Signed:
Date:

The roots of education are bitter but the fruit is sweet

– Aristotle

This thesis is dedicated to my father

Mohammed Akram Khan

(1934 – 1997)

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Glossary

Abbreviation	Text in full
ADHD	Attention Deficit Hyperactivity Disorder
CAMHS	Child and Adolescent Mental Health Services
CAP	Child and Adolescent Psychiatrist
CF	Cystic fibrosis
CYP	Cytochrome P450 enzyme system
CPD	Continuous Professional Development
DEX	Dexamfetamine
DSM	Diagnostic and Statistical Manual of Mental Disorders
DVD	Digital Video Disk
FRES	Flesch Reading Ease Score
GTC	General Teaching Council
5HT	5-Hydroxytryptamine (serotonin)
ICD	International Classification of Diseases
ITE	Initial Teacher Education
MPH	Methylphenidate
MPharm	Master of Pharmacy undergraduate degree
NHS	National Health Service
NIH	National Institutes for Health (USA)
NICE	National Institute for Clinical Excellence
QTc	Heart rate interval (corrected)
RCPsych	Royal College of Psychiatrists
RCPCH	Royal College of Paediatricians and Child Health
SIGN	Scottish Intercollegiate Guidelines Network
SD	Standard deviation
SPSS	Statistical Package for the Social Sciences
SWEF	Strathclyde Website Evaluation Form
$T_{1/2}$	Elimination half life of a drug *in vivo*
UoS	University of Strathclyde
WHO	World Health Organisation
X^2	Chi square

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ABSTRACT

Attention Deficit Hyperactivity Disorder (ADHD) is a developmental disorder largely diagnosed in children. A multi-method approach was used to explore internet and printed sources of ADHD information and to establish school teachers' knowledge of the disorder. An assessment tool (called the SWEF) was developed and through its application it was found that ADHD websites hosted by government/professional bodies were the most informative. However, details of medication are basic on most sites regardless of the host organisation. The lack of medication specific information was also seen on UK schizophrenia and cystic fibrosis websites.

A postal survey of clinicians (n = 47) found that the majority provided printed information in leaflet form. Most leaflets were produced by the Pharmaceutical Industry and whilst medication was routinely mentioned (94%), details of side effects, particularly the less common but more severe effects, were only discussed in a few. Clinicians also exhibited a lack of faith in school teachers' abilities towards recognising the symptoms of ADHD or understanding the role of medication.

This was investigated further amongst a sample of 43 qualified and 25 student teachers. 77% of qualified teachers had taught a child with ADHD, yet only 26% had received information or training about it. Knowledge of ADHD was determined by a self administered questionnaire and was generally poor; the mean (SD) number of correct responses (out of 15) was 5.1 (2.3) and 5.4 (2.5) for qualified and student teachers respectively. Student teachers were found to be more knowledgeable about medication specific issues. Following delivery and partial evaluation of a training programme to student teachers, the mean (SD) number of correct responses significantly improved from 9.1 (6.3) to 22.5 (3.4), $p = 0.00$. A more comprehensive training package with input from various members of the ADHD multidisciplinary team was ultimately designed and recorded onto a DVD.

Chapter 1

Attention Deficit Hyperactivity Disorder

1.1 INTRODUCTION

This thesis is primarily concerned with the identification and evaluation of internet and printed sources of information on Attention Deficit Hyperactivity Disorder (ADHD). It also identifies gaps in school teachers' knowledge about the disorder, and reports on the development and evaluation of a training package that teachers can use to support their educational needs in this area.

The thesis consists of seven chapters. Following a generalised introduction to ADHD in chapter 1, chapter 2 describes the characterisation and evaluation of internet sources of information on ADHD. The internet sources, otherwise known as ADHD websites, were evaluated using a bespoke assessment tool called the Strathclyde Website Evaluation Form (SWEF). Chapter 3 reports on a national survey (within NHS Scotland) of psychiatrists and paediatricians. The aim was to investigate their provision of written information on ADHD and its treatment to their patients, their parents or school teachers. In chapter 4, the knowledge and attitudes of student teachers and qualified school teachers towards ADHD and its medical treatment are investigated and compared. The findings from this chapter inform the design of a training session for school teachers with the aim of improving their knowledge about the disorder and its treatment. Chapter 5 describes the effect this training has on student teacher's knowledge and also reports on the development of a more comprehensive ADHD training package for school teachers. Recommendations relating to further evaluation and improvement of the training package are also proposed. Chapter 6 reports on studies in which cystic fibrosis and schizophrenia websites were evaluated using modified versions of the SWEF. These studies were performed to confirm the reliability and adaptability of the SWEF as an instrument for the evaluation of medicines information on the internet. The final chapter (chapter 7) draws together the main findings and conclusions of the thesis and presents some recommendations for future work.

1.2 GENERAL INTRODUCTION AND BACKGROUND TO ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a psychiatric disorder that is commonly diagnosed in childhood and is characterised by abnormalities in attention, impulsivity and / or hyperactivity. This chapter is intended to provide generalised background information about the disorder and is primarily concerned with its clinical properties such as the symptomology, aetiology and treatment.

1.2.1 History behind the diagnosis of ADHD

ADHD is a complex and controversial diagnosis, which is often portrayed as a bogus condition contrived by the pharmaceutical industry (Timini, 2005). Proponents of this belief see the diagnosis and its medical treatment as a quick fix for what are basically normal childhood behaviours (Mayor, 1996) or as a means for "*adults to exonerate themselves from responsibility for their children's behaviour"* (Breggin, 2001). Such attitudes fuel the debate that *"ADHD has become a scapegoat for many individual and societal dysfunctions"* (Sava, 2000). There is, however, reliable historical evidence within the medical literature of individuals displaying impulsive behaviours and having problems sustaining attention. Sir George Still, in his seminal lecture at the Royal College of Physicians (Still, 1902), described *"restless, overactive, often aggressive children who had morbid deficits in moral control of behaviour"*. Case studies continued to report children with impairments in attention, impulsivity and memory who were deemed to be suffering from a 'post encephalitic behaviour disorder' (Stryker, 1925). It was thought that the symptoms were a result of brain damage; however, no real evidence of such damage was ever presented. By the 1950s the condition became known as 'minimal brain dysfunction' (MBD). However, MBD gradually fell out of favour for being an over inclusive term of little prescriptive value which was based upon scant neurological evidence (Herbert, 1964). MBD was replaced by specific labels such as dyslexia, language disorders and hyperactivity. The concept of a hyperactivity syndrome was thus born. By the 1970s, professionals became aware that these 'hyperactive' children also had short attention spans, poor concentration and an inability to delay gratification. Other

common features included a low frustration tolerance, lack of planning or forethought, disorganisation and recklessness.

In North America, poor impulse control and inattention were considered of greater significance than hyperactivity, especially since hyperactivity is not specific to any one disorder (it is also a feature in anxiety and mania) and the distinction between 'normal' and 'abnormal' levels of activity is unclear. Nevertheless, the prevailing view in Europe was that it was primarily a disorder of over-activity with some association with brain damage. By the 1980s, the condition officially became known as Attention Deficit Disorder [ADD] (with or without hyperactivity) and a detailed list of symptoms with numerical 'cut-off' scores was developed by the American Psychiatric Association (APA, 1980). Guidelines for age of onset and duration of symptoms and (exclusion) criteria detailing differential diagnosis also become available and by the end of that decade, an international symposium of experts drew up a list of criteria to define what is now known as Attention Deficit Hyperactivity Disorder (ADHD).

The criteria are:

1. The core symptoms of inattention, hyperactivity and impulsivity must be developmentally inappropriate.
2. Symptoms should be apparent before the age of 7 years and must be present for longer than 6 months.
3. Symptoms must be pervasive and evident in more than one setting (e.g. at home and at school).
4. Symptoms cannot be explained or caused by another mental health disorder (e.g. autism, psychosis).

The core problems of ADHD are thought to persist over time, throughout adolescence and into adulthood (Farone *et al*., 2000), although the actual behaviours may present in different, age appropriate ways, i.e, hyperactivity in later life may present as extreme fidgetiness or an inner sense of restlessness, whereas inattention remains as such.

1.2.2 Core features and subtypes of ADHD

The main features of the disorder tend to appear around the ages of 3 to 4 years and consist of: extreme and persistent restlessness; sustained and prolonged motor activity; difficulty in maintaining attention; impulsiveness; and difficulty in withholding responses (Voeller, 2006). The Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association, characterises three definitive types of ADHD: the inattentive type; the hyperactive / impulsive type; and the combined type. The inattentive type is particularly affected by poor concentration, disorganisation and forgetfulness. The hyperactive-impulsive type is more likely to be over active, impulsive and noisy, whilst the combined type will have a mixture of symptoms. All are likely to suffer from poor memory, lack of motivation, and general clumsiness. The diagnosis also depends on the pervasiveness of the symptoms, the age of onset, and the degree of impairment and disability caused. The World Health Organisation International Classification of Disease (ICD-10) classifies the condition slightly differently in that all three symptoms of inattention, hyperactivity and impulsivity must be present (See Table 1.1). ICD-10 hyperkinetic disorder describes a severe subgroup of the DSM combined subtype of ADHD and is therefore more restrictive and impairing. Generally, within the literature and indeed this thesis, the phrase ADHD is used as an umbrella term for all disorders associated with impairments in attention and activity.

Table 1.1 Criteria for Hyperkinetic Disorder (ICD-10)

- Onset of disorder before age 7
- Pervasive across settings: Diagnostic evidence dependent on information from > 1 source; parental reports about classroom behaviour unlikely to be sufficient.
- Clinically significant impairment in social, academic or occupational functioning.
- Symptoms have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level.

Inattention (6 of the following)

1. fails to give close attention to details, (careless errors in school, work or other activities).
2. fails to sustain attention in tasks or play activities.
3. often appears not to listen to what is being said.
4. often fails to follow through instructions or finish school work, chores or duties (not because of oppositional behaviour or failure to understand instructions).
5. is often impaired in organising tasks and activities.
6. often avoids or dislikes tasks, such as homework that require sustained mental effort.
7. often loses things necessary for certain tasks, such as pencils, books, toys or tools.
8. is often easily distracted by external stimuli.
9. is often forgetful in the course of daily activities.

Overactivity (3 of the following)

1. often fidgets with hands or feet or squirms on seat.
2. leaves seat in classroom or in other situations in which remaining seated is expected.
3. often runs about or climbs excessively in situations where it is inappropriate (in adolescence or adults, only feelings or restlessness may be present).
4. is often unduly noisy in playing or has difficulty in engaging quietly in leisure activities.
5. exhibits a persistent pattern of motor activity that is not substantially modified by social context or demands.

Impulsivity (1 of the following)

1. often blurts out answers before questions have been completed.
2. often fails to wait in line or await turn in games or group situations.
3. often interrupts or intrudes on others (butts into others conversations or games).
4. often talks excessively without appropriate response to social constraints.

Item list in DSM-IV is essentially the same but split into two sub-lists (inattention & hyperactivity-impulsivity) with only minor word differences. Inattention list is, for practical purposes, identical. List of hyperactivity-impulsivity items in DSM-IV combine the ICD-10 overactivity and impulsivity lists but has a threshold of 6/9 rather than 3/5 and 1/4

1.2.3 Prevalence of ADHD

Prevalence rates vary across countries but generally range from 2% to 29% of the school aged population (Barkley, 2006). A recent systematic review of prevalence estimates concluded that the variability was due to differences in the sampling methods and on the diagnostic criteria used for identification (Polanczyk *et al.,* 2007). For example, studies using DSM criteria tended to report higher rates. The authors did, however, conclude that there were relatively minor differences among different parts of the world and the best estimate of the rate was 5%. In the UK, historically, the identification and treatment of ADHD has lagged behind that in the USA. A survey in the UK of over 10 000 children between the ages of 5 and 15 years found that 3.6% of boys and 0.8% of girls had the disorder (Ford *et al.,* 2003). In Scotland, 0.6% of school children are known to services as having a diagnosis of ADHD (NHS QIS, 2007). Both surveys suggest significant under diagnosis of ADHD within the UK.

ADHD was previously thought to be gender related, with boys more likely to be affected than girls. This now does not appear to be the case (Biederman *et al.*, 2005). A possible explanation as to why more boys are diagnosed with ADHD than girls could be due to the referral and treatment process. Boys tend to have higher rates of conduct disorder and oppositional defiant disorder and so may come to the attention of mental health services (from where prevalence studies are often conducted) more readily than girls. In the classroom, teachers may be more inclined to notice the disruption caused by boys than girls. However, girls are more likely to have higher rates of depression, anxiety, poor self esteem and problems related to social interaction (Gershon, 2002).

1.2.4 Aetiology of ADHD

The exact aetiology of ADHD is poorly understood but is thought to be multi-factorial and influenced by biological, psychosocial and environmental factors. There is a strong genetic component to the disorder, with monozygotic twins found to be 92% concordant (Goodman and Stevenson, 1989). Family studies also show that at least one of the parents of a child with ADHD is 2 to 8 times more likely than

control parents to also meet the diagnostic criteria for ADHD (Biederman *et al.,* 1992). Premature birth is also found to increase the risk for ADHD (Bhutta *et al.,* 2002). A possible reason for this may be that premature infants are at a higher risk of recurrent apnoeic attacks. This makes the cerebral dopaminergic system in those babies vulnerable to damage caused by the lack of oxygen (Decker and Rye, 2002). Since the dopaminergic pathways are involved in sleep, wakefulness, locomotion and executive function, hypoxia at this perinatal stage may be the cause for subsequent neurotransmitter dysfunction later on. Another explanation may be the inability of premature babies to conjugate bilirubin (leading to hyperbilirubinemia), which is why some premature babies are born jaundiced. Unconjugated bilirubin can also have a toxic effect on neurons in the basal ganglia, causing damage in the brain pathways associated with attention and other ADHD symptoms (Soorani-Lunsing *et al.,* 2001).

Exposure to environmental toxins is also associated with ADHD, perhaps due to chemical or structural damage to the brain. Several studies have found an association between ADHD and maternal cigarette smoking during pregnancy (Thapar *et al.*, 2003). Lead and mercury ingestion, both in-utero and in early childhood, can cause subtle impairments in executive function (Gittleman and Eskinazi, 1983). Exposure to psychosocial adversity from an early age is another risk factor for ADHD. Children who grow up in conditions of deprivation and poverty, maternal psychopathology, and parental discord are at much higher risk of developing ADHD (Roy *et al*., 2000).

Structural and functional brain imaging studies show that children with ADHD have a smaller prefrontal cortex and reduced brain blood flow and glucose metabolism compared to normal controls (Castellanos and Swanson, 2002). The prefrontal cortex area is critical for inhibitory functions, i.e. behavioural inhibition, and is also concerned with learning, memory, alertness and attention i.e Executive Functioning. Transmission of neural impulses is mediated by monoaminergic neurotransmitters, notably dopaminergic and noradrenergic neurons. Both types of neurons are prominent in the prefrontal cortex area and recent research would suggest that at the

synaptic level, dopamine receptors D_1 and D_4 and the dopamine presynaptic transporter, (the 'reuptake pump') are all implicated in the pathogenesis of ADHD (Langley *et al*., 2004; Waldman *et al*., 1998). The reuptake pump regulates the amount of dopamine which is transported back into the neurone, and hence controls the amount of dopamine in the synapse. A malfunction in the reuptake pump, as observed in ADHD, means that too much dopamine is reabsorbed with a concomitant decrease in synaptic dopamine, thereby compromising the brain's 'arousal system'. Noradrenaline antagonists also produce hyperactive behaviours whilst noradrenaline agonists are known to improve mental function. The symptoms of ADHD are thought to arise because of a defective inhibitory response in a neuro-developmentally compromised pre-frontal cortex. At its simplest, ADHD is caused by a dys-regulation of brain neurotransmitters: some areas are insensitive to sensory input and others too receptive. In other words, the brain's 'filter and braking system' is functioning at a suboptimal level (Castellanos and Swanson, 2002).

1.2.5 Co-morbidities

The majority of individuals with ADHD (up to 65% of all cases) also tend to have another co-occurring psychiatric disorder. Common co-morbidities include anxiety disorders such as obsessive compulsive disorder, bipolar affective disorder, conduct disorder, depression, and learning disabilities (Newcorn *et al.*, 2001). Conduct disorder and oppositional defiant disorder occur in at least 30% of children with ADHD, and tics (sudden, coordinated repetitive movements or sounds) or Tourette's Syndrome can occur in up to 60% of ADHD cases (Sheppard *et al.,* 1999). The extent and nature of co-morbidities in ADHD is unsurprising since most psychiatric disorders have a shared pathology due to complications within the brain's neuronal pathways, including the monoaminergic neurotransmitters.

1.3 DIAGNOSIS AND TREATMENT OF ADHD

1.3.1 Diagnosis of ADHD

These days, ADHD is less likely to be viewed as a "*trivial and vaguely amusing problem of childhood"* (Popper, 1997) but as a developmentally disabling condition with a strong biological or hereditary predisposition and a chronic course. As in other mental health disorders, there is no definitive biological test or marker for ADHD. Diagnosis is therefore dependent on a clinical interview, a medical examination and direct observation, where behaviours are scored against validated population norms using standardised rating scales. Cognitive, neuropsychological, developmental and literacy skills assessments are also sometimes used.

Parents concerned about their child's behaviour will most probably consult their General Practitioner (GP) who is likely to refer the child to specialist psychiatric or paediatric services. Referral pathways are subject to variation depending on the availability of services. In formulating a diagnosis, the specialist is likely to seek advice from the child's school teacher or other relevant personnel (including the local educational psychologist). Depending on the severity and complexity of the symptoms, some children may only need careful manipulation of their classroom and home environment to contain their behaviour; others will require medication. It is usually the specialist who assumes management of the treatment regimen, although the GP is often responsible for its prescription and the routine monitoring of physical health parameters, such as blood pressure.

1.3.2 Treatment of ADHD

A multimodal approach consisting of psychosocial and behavioural interventions, educational supports and pharmacotherapy is thought to be the most effective treatment for ADHD (MTA, 1999). In the UK, it is recommended that for mild to moderate ADHD, parents are referred to group parent-training / education programmes (NICE, 2009). These programmes equip the parents with techniques to help them manage their child's behaviour and tailor their parenting style to meet the child's needs. This can lead to changes in the emotional quality of the child-parent

relationship as the child becomes less exposed to criticism and correction and so feels less like a failure and more likely to engage with the therapeutic process (Barkley, 1997). The child is also encouraged to develop strategies or skills to compensate for their difficulties using a variety of cognitive behavioural techniques. School teachers are expected to adapt the classroom environment so that it is most conducive to the child's needs. This includes emphasis on clarity and precision in the presentation of learning tasks; care in the sequencing and structuring of learning tasks; and frequent and prompt feedback to the student on performance (Cooper and Bilton, 2002). Reactive strategies characterised by positive reinforcement or reward when behaviours are desirable are helpful but negative reinforcement, such as 'time out' or ignoring strategies when behaviours are undesirable, are also used (DuPaul and Stoner, 2003).

1.3.3 Medication used in the treatment of ADHD

1.3.3.1 Introduction

In the UK, methylphenidate [MPH] and dexamfetamine [DEX] (types of stimulant medication) and a non stimulant, called atomoxetine, are the only licensed treatments available for ADHD. The choice of medication depends on a number of factors, including the presence of co-morbidities, side effects profile, compliance issues, potential for drug abuse, cost and child and parent preferences (NICE, 2006).

1.3.3.2 Stimulant medication

The number of NHS prescriptions dispensed in Scotland for MPH and DEX have increased from 5,000 items in 1996 to just under 66, 756 in 2008 (SHS, 2009). Their efficacy in reducing the core symptoms of ADHD is well documented, although long term effectiveness when compared with psychological treatment modalities is inconclusive (MTA 1999; MTA, 2007). Whilst there is considerable debate concerning the results of the MTA study, both MPH and DEX are consistently recommended as first line therapy by various government funded health organisations (NICE, 2006; SIGN, 2001; RACP, 2008).

Both DEX and MPH are similar in chemical structure and physical properties, but act differently in the brain neurons, particularly at the synapse. Amfetamines (including DEX) are thought to facilitate the release of dopamine from presynaptic cytoplasmic storage vesicles (hence increasing the total amount of dopamine in the synapse) and also by blocking the dopamine reuptake pump, thereby inhibiting the reuptake process. MPH however, is thought to act primarily on the reuptake pump and to have little, if any, effect on dopamine vesicular synaptic release. Stimulant side effects are predominately a class effect arising from the increase in sympathetic tone and are similar for DEX and MPH. These include elevations in blood pressure and heart rate, headache and insomnia. Weight loss caused by a fall in appetite is also common. Cardiovascular adverse effects, although small in number, have attracted much attention, so much so that in February 2006, the American Food and Drug Administration (FDA) issued advice that "*all stimulant medication packaging carry increased warning labels to highlight to parents the increased (potential) cardiovascular risk of these drugs*".

The duration of the therapeutic action of both DEX and MPH is limited due to their rapid metabolism and clearance (elimination $t_{1/2}$ = 3 - 6 hours), which means that several doses must be taken throughout the day to maintain a flat steady state concentration-time profile. This frequent dosing is likely to cause problems amongst children, parents and the school since doses need to be 'topped up' during the day. Similarly, if a dose is taken too late in the day it may be too stimulating, which may lead to sleep disturbances. Stimulant medication is however, available in a variety of formats, including intricately designed oral dosage forms and transdermal patches. In the UK, however, only oral forms of sustained / modified release preparations exist. These deliver a constant input of the drug throughout the school day, therefore avoiding issues associated with administration at school, such as storage and security of the medication and potential problems of illicit diversion. In the UK, there are several oral immediate release MPH formulations, e.g. Ritalin®, Equasym®, generic brands and three modified (sustained) release preparations: Concerta® XL; Equasym XL®; and Medikinet XL®. There is only one DEX immediate release preparation;

this is called Dexedrine®. [The Summary of Product Characteristics for each product, is available at http://emc.medicines.org.uk]

The stimulants are categorised as 'Controlled Drugs' according to The Misuse of Drugs Act (1971) and are subject to strict controls with regards to their manufacture, supply and possession.

1.3.3.3 Atomoxetine

Most children with ADHD respond favourably to stimulant medication but a sizable minority (30%) either suffer from side effects, are unable to take them because of specific contra-indications or are simply non responsive. In these cases, atomoxetine, a selective presynaptic inhibitor of noradrenaline may be used. By blocking the re-uptake of noradrenaline at the synaptic level, it means that the extracellular levels of noradrenaline, most notably in the prefrontal cortex, are increased. This is thought to be the mechanism of action of atomoxetine in ADHD.

Atomoxetine is also metabolised by the CYP2D6 pathway and needs to be used cautiously in individuals who are poor metabolisers. The elimination half-life of atomoxetine is 5 hours, but it is still effective in providing 24 hour symptom relief when given as a once daily dose. The reasons for this anomaly are unclear but may be due to differences in brain and plasma pharmacokinetics or to the sustained effect of the drug at the cellular level in the brain at the synaptic junction, or more specifically on the noradrenaline transporter. Unlike the stimulants, the effects of atomoxetine are not seen immediately. The maximum effect builds up gradually and can take up to 6 to 8 weeks. Side effects are few and mostly mild, the most common of which are gastrointestinal in nature. Somnolence is also sometimes reported and when it occurs it is often helpful to administer the dose in the evening, especially since at least 20% of children with ADHD also report significant sleep disturbances (Gillberg *et al*., 2004). Since its launch in 2004, post-marketing surveillance programs have highlighted other problems, notably idiosyncratic, dose dependent liver problems and suicide related behaviours. Further cautions regarding its use in patients with a history of seizures or cardiac abnormalities, including prolongation of

the QTc interval, have only recently been added to its Summary of Product Characteristics (Lilly, 2008). [The QT interval is the time taken to complete the depolarisation and repolarisation cycle of the ventricles in the heart i.e. the start of the Q wave and the end of the T wave and can be read from an electrocardiogram (ECG)].

Since atomoxetine has no effect on the limbic system in the brain, especially the nucleus accumbens (where the 'reward and reinforcing' system is located), it is particularly suitable for patients for whom illicit diversion or misuse of stimulant medication is a concern. Atomoxetine is available in several strengths as an oral capsule and is exempt from prescription medicine controlled drugs legislation.

1.3.3.4 Unlicensed medicines used in ADHD

In the UK, licensed medicines are those that have received a 'marketing authorisation' from the Medicines and Healthcare products Regulatory Agency (MHRA). A marketing authorisation allows the manufacturer to market their product according to the terms of its licence, which details its indications, cautions, side effects and doses. As there are only three licensed drugs for ADHD in the UK, this means that any other medicine used for ADHD is unlicensed for that indication. Unsurprisingly, many of these are reserved as 2nd line therapy. A variety of drugs may be used, such as atypical antipsychotics, antidepressants, modafinil and nicotine, but the most common and widely used are clonidine and the tricyclic antidepressant imipramine. Clonidine is an antihypertensive agent which also shows positive effects on ADHD symptoms. It can be used on its own or in combination with MPH. Sedation and dizziness are its common side effects. The side effect profile and overall cardiac toxicity of the tricyclic antidepressants tend to limit the use of imipramine in clinical practice, particularly in children.

1.4 KNOWLEDGE ABOUT ADHD

1.4.1 Role of the school teacher

School teachers are ideally placed to provide the necessary feedback to both clinicians and parents about the child's behaviour and functioning in the classroom. In doing so, they may be involved in evaluating the effects of medication that may have been prescribed to control ADHD symptoms. The evaluation may consist of scoring behaviours against ADHD specific checklists or rating scales and measuring the degree to which certain behaviours are evident or causing impairment. There are several rating scales that can be used, such as the ADHD Rating Scale IV and the SNAP-IV questionnaire, but the earliest and most widely used are the Connors ADHD Rating Scales (CRS) (Connors, 1997). CRS are self administered and reported from the perspective of the parent [Conner's Parent Rating Scale-Revised (CPRS-R)], the teacher [Conner's Teacher rating Scale-Revised (CTRS-R)] and, in the case of adolescents, by themselves [Conners-Wells' Adolescent Self-Report Scale (CASS)]. All the questionnaires are available in long (80 items) or short forms (27 items) and have been translated into several languages. By involving teachers in this way, there is a tacit assumption by the clinician that the teacher is suitably knowledgeable about the disorder or the effects of medication. However, recent UK government reports show that current systems in place for the training of teachers are inadequate to meeting the needs of children who have learning difficulties, which include ADHD (OFSTED, 2008).

School teachers in other countries, including the United States of America, have also been found to lack basic knowledge of the disorder, its treatment and even classroom management techniques (Arcia *et al.,* 2000). Where a teacher lacks knowledge of the disorder, implementing behavioural management techniques in the classroom tends to have little impact. If, however, the teacher is knowledgeable, early implementation of interventions can be successful in reducing behavioural problems and negative outcomes (Farrington, 1994; Pfiffner *et al.,* 2006). Teachers themselves report that their lack of training in this area is a barrier towards them implementing effective strategies. They welcome further training, mainly in the form of in-service

days. In the meantime, they consult the specialist literature or their colleagues for information about ADHD, as well as other lesser quality resources, including the media, 'friends' and 'parents of children with the disorder' (Brook *et al.,* 2000; Snider *et al*., 2003).

1.4.2 Role of the parent / carer

Current trends in health care delivery and government policy are geared towards making individuals take greater responsibility for their own health and well-being (DoH, 2001). Whereas previously patients were expected to comply blindly with their treatment regimen (implying passive acceptance), nowadays patients are invited to engage in a 'therapeutic alliance' with the health care team, a concept known as concordance (Weiss and Britten, 2003). This alliance is dependent on the patient's understanding and appreciation of the issues concerning their condition or treatment. The literature investigating this subject matter is drawn from a range of disciplines and out with the scope of this chapter, but hinges on theories and concepts related to the Health Belief Model (HBM) (Becker 1974; Becker and Maiman, 1975) and the Health Locus of Control theory (HLoC) (Rotter, 1966). According to the HBM, before adopting any health behaviours, the individual will weigh the cost of the treatment against its benefits. This rationale is further dependent on the extent of one's locus of control (LofC). Individuals who attribute their health outcomes to their own actions have an Internal LofC; those who attribute their outcome to the actions of others, have a Powerful Other LofC; and those who attribute their health/treatment outcomes to chance or fate, are considered as having an External LofC. Those with an Internal LofC are more likely to actively seek information and increase their knowledge base than those with External LofCs. The ILofC, informed patient has been found to be less anxious during doctor-patient consultations but also to have improved compliance with treatment regimens and better treatment outcomes (Stewart, 1995; Haynes *et al.,* 2002).

In the paediatric setting, education of the parents (or carers) so that they become better informed has been found to have a positive impact on the child's treatment outcomes (Bellew *et al.,* 2002). Educating or the imparting of information is

commonly provided in written form, usually as leaflets. These 'patient information leaflets' (PILs) serve a variety of functions, including the reinforcement of verbal instructions, which may ultimately aid compliance with treatment. Printed materials have been found to be the most cost effective and time efficient means of communicating heath messages (Dixon-Woods, 2001; Kenny *et al.*, 1998). The extent of an individual person's 'health literacy' is therefore dependent on access to accurate, reliable and intelligible information. Nowadays, information is increasingly being sought via the internet. However, the quality of online health information cannot be guaranteed, yet access to unbiased, timely, factual information for parents and school teachers would seem to be an appropriate goal for the management of ADHD.

1.5 BACKGROUND TO THESIS

The author is also employed as a Senior Clinical Pharmacist in the Department of Child and Family Psychiatry at the Royal Hospital for Sick Children in Glasgow, Scotland. The stimulus for this thesis came from a conversation the author had with one of the school teachers working at the hospital as part of the hospital education service. The teacher had commented that one of her pupils had recently been diagnosed with ADHD and was also prescribed methylphenidate. She described some behaviour the child was demonstrating that she attributed to the medicine but which the author did not think was connected. The teacher also claimed to have searched the internet for information about the medication but was overwhelmed with what she found. She ended the conversation by asking the author if "*she [the author] was aware of any good ADHD websites that could help with her understanding of the condition and its treatment?"*

This encounter highlighted two issues that appeared to be neglected within the wider realm of ADHD treatment. This research programme was undertaken to attempt to evaluate internet sources of information on ADHD and school teachers understanding of ADHD medication.

Chapter 2

Identification and evaluation of internet sources of information on ADHD

2.1 INTRODUCTION

Information about health is accessible from many sources in a multitude of formats. Printed literature on specific conditions and treatments is often produced by government bodies, charitable organisations or the pharmaceutical industry. Another source of health information is the Internet. Its popularity is likely to be enhanced by its convenience and anonymity and the sheer volume of information that can be accessed through it. Individuals seeking information about ADHD are likely to consult the internet as well as other traditional sources.

2.1.1 The Internet

2.1.1.1 Conception and background

The internet is a global electronic communications network which was developed by the American military during the 1950s for research, education and government purposes. By the mid 1970s, most universities and public sector institutions in the USA were connected to 'APRANET', as it was known. The US government was still funding the operation but commercial organisations, increasingly aware of its potential, began to offer services whereby internet traffic could pass through their commercial networks and not the government funded structure (Hewson *et al*., 2003). A new computer language known as hypertext was used to connect the whole internet structure through 'links' that were embedded in the actual text. This gave the internet the appearance of huge spider's web, hence the term 'World Wide Web'. In 1995, the US government ended its sponsorship of the internet and transferred management to the private sector. When Microsoft integrated the 'Internet Explorer' browser into their Windows 98 package, worldwide appeal and usage was practically guaranteed.

2.1.1.2 Searching the internet

Search tools were soon developed to allow effective searching and identification of information within the internet structure. The first of these tools was called "archie" (archive without the 'v'). The archive tools soon became known as 'search engines' because they identified relevant material by searching and locating strategic

keywords within sites. Search engines are essentially data retrieval systems and have become synonymous with the internet. Search engines operate at three levels; crawling, indexing and searching. Pages are originally retrieved by a crawler, or spider, that visits a page, reads it and then follows links to other pages from that site. The contents of these pages are analysed ('spidered') and the pages stored in an index database for use in later queries (indexed / catalogued). When a query is entered into the search engine, usually based on key words, the engine looks up the index and provides a list of best matching web pages. The results are usually reported according to their overall relevance to the original search term (Muller, 2003; Search Engine Watch, 2007).

All search engines operate (crawl) to different criteria, which explains why the same search on different engines produces different results. The size and nature of the internet makes it impossible for one engine to search the whole structure, so Meta Search Engines have been developed. Meta Search Engines operate by simultaneously searching multiple search engines, collating the information and then displaying it in a new form. They do not search or crawl the internet themselves but rely on the findings of other engines. The results from a Meta search are therefore only as good as the search engines covered by the original Meta engine.

An alternative to search engines are directories. Directories are also a referencing system but their search results are displayed within the context of specific categories. This categorisation is based upon the complete contents of the website, rather than a page or some keywords. The websites are therefore listed in only one or two categories. The different categories a site can be catalogued under depend on the description that the site owners submit to the editors of the directory site. Subsequent searches are limited to a search of the description submitted in the directory. Most directories are organised either by subjects or themes and direct or signpost to other relevant web pages or sites (Muller, 2003).

Gateways, also known as portals, are intrinsically gatekeepers to direct individuals to sites that are connected by a common theme. Gateways are usually a good starting

point when looking for information in a particular topic. Health Gateways in the UK include NHS Direct Online and the National Electronic Library for Health (NeLH).

2.1.2 The Internet and health information

2.1.2.1 Types of E-health

In 2002, there were an estimated 70,000 health related websites on the internet, representing approximately 2% of all sites (Benigeri and Pluye, 2003). More recent figures for the number of health websites are generally unknown as the field is expanding almost exponentially. The E-healthcare market place is extremely diverse. Websites advertising products and services as cures or treatments for a variety of conditions appear to dominate. Some websites allow individuals to self diagnose using algorithms based upon symptom descriptions; others provide facilities for online discussions with clinicians or other patients which are set up as 'virtual support groups' (Cline and Haynes, 2001)

2.1.2.2 E-health consumers

The majority of literature on consumer online behaviour is American. A series of longitudinal surveys known as The Pew Internet and America Life Project (PIALP) found that in 2002, 46 million Americans were online searching for health information; by 2004 this number had risen to 96 million (PIALP, 2005). According to the Pew Surveys, the average 'online health seeker' is female, younger than 65 years and online for approximately 30 minutes; visiting between two to five sites in an average sitting. She rarely uses a defined search strategy and searches generally start at non medical sites. The typical online health seeker is reassured by advice that matches what they already know (believe) and by statements that are repeated at more than one site. Sites selling products, or where the source of information is not clearly identified, tend to be avoided (Rice, 2006).

Most 'online health seeking behaviour' is concerned with searching for disease specific information. It is usually triggered by a diagnosis and is referred to as 'event-sparked searching' (Adams *et al.,* 2006). Not surprisingly, given their high morbidity and mortality, heart disease and cancer attract the greatest number of

searches, followed by children's health. For medication specific information, an Australian study found that searches were often initiated by entering the medicine's name directly into a generic search engine (Peterson-Clark *et al*., 2004). It is also found that few individuals go beyond the first page of the search results and sites where the key words appear on the site description or URL are generally preferred and hence visited more often. The same study reported on respondent's awareness of the limitations of any information they found citing bias, commercialism and lack of regulation as factors to consider when deciphering internet based health information. These findings were mirrored in a study of Dutch internet users (Adams *et al.*, 2006) who also carried out most searches on general search engines and based their decisions to access the site on the presence of keywords in the URL.

2.1.3 Quality of online health information

The lack of boundaries or regulations makes it possible for anyone to develop and maintain a website, regardless of its content or appropriateness. Web pages / sites can be made to look professional and authoritative, especially when they are not. There is no guarantee that the products offered for sale are authentic or have been subjected to rigorous scientific study. The credentials of the site's author are not always supplied or can be easily falsified. Anxiety around the quality and nature of e-healthcare websites has prompted the medical fraternity and various governments to develop systems of accreditation and issue good 'e-practice' guidelines (Eysenbach and Diepgen, 1998; Risk and Dzenowagis, 2001). One such accreditation body is the Health on the Net (HoN) Foundation, which was developed by the United Nations in 1995 (HoN, 1997). The HoN Code of Conduct is based on eight principles concerned with authorship, transparency, reliability, attribution, justifiability, privacy, disclosure and sponsorship. Health related websites that satisfy HoN criteria are able to display the HoN logo on their pages. Unfortunately, the fluid nature of the internet and logistics in policing its contents limit the capacity and authority that organisations such as HoN are able to exert (Nater *et al*., 2002).

2.1.4 Evaluation of online health information

2.1.4.1 Evaluation tools

Most of the tools or instruments used in the evaluation of online material are based upon a checklist of desired attributes. The website is scored according to how well it (or its contents) conforms to designated attributes or criteria (Gagliardi and Jadad, 2002; Bernstam *et al.,* 2005). For example, website accountability can be measured using the 'JAMA benchmark' [Journal of the American Medical Association](Silberg *et al*., 1997) and is based upon the principles behind peer-reviewed publication, i.e accountability of authorship, disclosure and currency. The criterion measuring site authorship would be judged according to whether an author was named; if their credentials and contact details were supplied, etc. The greater transparency afforded to the information, the higher the score assigned. Websites offering information about medical conditions or treatments are expected to base their comments on recognised policy, guidelines or current evidence. When information on the site concurs with current practice or expert opinion, it receives a higher score than a site displaying material that does not. The physical characteristics of the site such as its design, layout and readability are also part of the evaluation process. Criteria rating the physical components of a site can often be standardised across disease states. Evaluation of the physical parameters should not be considered a wasteful process because a poorly designed website is of little use, regardless of the quality and detail of information that it contains.

2.1.4.2 The DISCERN instrument

A variety of tools and instruments are used in the evaluation of printed health information (Oxman *et al.*, 1993). One of these is the DISCERN Scale which was developed in 1998 using an expert panel peer consensus approach (Charnock *et al*., 1999). The instrument is a self administered questionnaire consisting of three sections measuring a series of attributes. The first section measures the reliability of the information (questions 1-8), the second section measures the quality of the information (questions 9-15) and the final section (question 16) elicits an overall rating for the publication. Scoring is largely subjective and for each question ranges from a score of 1 (indicating a no answer) to 5 (a yes answer). Scores in-between

depend on the extent to which the attribute under investigation is fulfilled, so that a value of 3 indicates partial fulfilment. Although DISCERN was primarily conceived to measure the quality of written information, it has been used for evaluating online treatment information (Charnock and Sheppard, 2004) in a range of clinical areas including colorectal cancer (Al-Bahrani and Plusa, 2004) and depression (Griffiths and Christensen, 2002). However, DISCERN is primarily aimed at the consumer to allow them to judge for themselves the quality of the (online) information. As a generic tool it can be used at a superficial level to rate if the information is unbiased, objective and fair. It cannot be used by experts for matters of quality assurance in relation to the accuracy and coverage of the information.

2.1.5 Evaluation findings

Differences in methodology, quality criteria and topics pose difficulties in generalising about the quality of online health information but it does appear that the quality of clinical information on the majority of websites is poor (Eysenbach, 2000; Eysenbach *et al.,* 2002). In a review of 79 studies, in which 5941 websites were evaluated, Eysenbach found that 70% of the studies had concluded that quality was a problem, with only seven studies reporting positive findings. Reed and Anderson (2002) found that information about medication side effects was largely biased i.e from the perspective of the site provider and incomplete, with many sites lacking authorship and currency, a finding duplicated in an evaluation of websites on the management of stroke (Griffin *et al.,* 2004). Most health websites also require a high reading ability (Berland *et al*., 2001). Readability of site material is often measured and reported as the Flesch Reading Ease Score (FRES) or the Flesch-Kincaid Grade Level Score (FGLS). Both scores are dependent upon the number of syllables per word and the number of words per sentence. The Flesch Reading Ease Score provides a value between 0-100. The higher the score, the easier the material is to read and subsequently understand. A FRES of 60 or higher is considered acceptable for consumer orientated information (Clement *et al*., 2002) whereas text with FRES between 0-30 usually requires a graduate level education in order to be understood. The Flesch-Kincaid Grade Level score is based upon US school years. A score of 8

(equable to US 8 grade schooling), is the recommended reading level for standard documents. The main findings from these studies are illustrated in Table 2.1.

Table 2.1 Summary table of main findings of studies identified in review.

Author/ Year/ Disease/ Condition	Methodology including search engines	Sample (sites)	Evaluation/ Outcome Measures	Results
Reed *et al.*, 2002 Menopause and hormone replacement therapy	Top 50 sites from Yahoo™, Lycos™, Google™, Looksmart™, HotBot™, Ask Jeeves™, Excite™ & AltaVista™ search engines	25	Factual content, quality, appearance & credibility.	Biased, incomplete information on side effects & contraindications. Poor evidence of currency & authorship
Aslam *et al.,* 2005 Clubfoot (orthopaedics)	Top 30 from '*5 most commonly used search engines'* (specific details not provided)	150	Authorship, content, information value, aetiology, disease summary, surgical treatment	Majority of sites have unidentified authorship (14 from academic sources). 54 sites provide conventional information. Average score 26 out of 100.
Griffin *et al*., 2004 Stroke	First 200 sites from Google™ & top 60 sites from MetaCrawler	30	Authorship, currency, authority, accessibility/links/ ease of use, attribution / documentation, user support, design, aesthetics, content	Poor referencing, user support & currency. Little information on long-term management & rehabilitation. Readability:10th grade
Seidman *et al*., 2003 Diabetes	Direct Hit	90	'Diabetes QII' tool based on American Diabetes Association's Clinical Practice Recommendations	Variable quality in all categories, mean scores 50%.
Al-Bahrani & Plusa 2004. Bowel, colon & rectal cancer	Google™ & Hotbot™ 400 sites visited	118	DISCERN Instrument	55% sites rated as good, very good or excellent. Poor information about side effects.

Author/ Year/ Disease/ Condition	Methodology including search engines	Sample (sites)	Evaluation/ Outcome Measures	Results
Griffiths & Christensen 2000 Depression	Direct Hit & MetaCrawler	20	Content: 43 item scale developed from evidence based guidelines and practice. Accountability: Silberg's criteria of authorship, attribution, disclosure and currency.	Content: 5 / 43 Accountability: 5 / 9 Poor accuracy & coverage. Quality found to be better if website has editorial board.
Kisley, Ong & Takyar 2003 Schizophrenia, Attention Deficit Hyperactivity Disorder	20 highest ranked sites from MSN™, AOL™, Yahoo™, Lycos™ & Excite™	Not quoted	Accountability: aesthetics, compliance with evidence based practice and guidelines. Readability via Flesch scores	Accountability 3 out of 9. Aesthetics 2 out of 4. ADHD sites comply better with evidence base. High reading level. (Flesch-Kincaid reading grade 11.5).
Griffiths & Christensen 2002 Australian Depression websites	17 Australian, 6 international and one Meta search engine	15	DISCERN & other parameters based on evidence based guidelines /treatments. Site accessibility	Mean score 3 / 5. Shortcomings in medication specific information e.g duration of treatment, side effects.
Ilic *et al.,* 2003 Androgen Deficiency in the aging male	Top 50 from Alta Vista™, Excite™, Google™, Yahoo™, Health Institute, Health on the Net, NHS Direct, National Library of Medicine	52	DISCERN Instrument	Mean score 1.7 / 5 General search engine more efficient than medical search engines; no difference in quality of information.

2.1.6 Limitations of evaluation findings

Most of the online health evaluation literature reports on websites identified by generalised (global) searches, and so the findings are not always relevant to a UK audience. Consequently, there is little information on the nature and quality of UK websites and how these compare with other (international) sites. Differences in clinical practice and the availability of treatments can render information on non UK websites inappropriate or not applicable to a UK audience. This is particularly relevant when evaluating ADHD website material as there is considerable variation in the diagnosis and treatment of the condition throughout the global community. Therefore, the review of ADHD websites by Kisley *et al.,* in 2003 has limited applicability in the UK as their Top Ten sites all originate from outside the UK. Kisley *et al.,* (2003) also reported that accountability, presentation and readability (measured by the FGLS) was poor. Clinical information was assessed depending on its agreement with various evidence based practices and recommendations e.g SIGN, NIH and NICE). Information on the sites agreed with guideline practice in only 12 to 54% of sites evaluated. No comparable information on the nature and quality of UK ADHD websites is available. It is therefore desirable to revisit this area but with emphasis on sites with a UK origin aimed at a UK audience.

2.2 AIMS

To characterise and evaluate UK internet sources of information on ADHD.

2.2.1 Objectives

1. To design and validate a tool for the evaluation of UK based ADHD websites.
2. To characterise identified websites according to their host organisation.
3. To evaluate the contents of the websites in relation to the information presented on the webpage and the physical properties of the actual site.
4. To produce a list of the Top Ten highest scoring websites based upon their total SWEF score.

2.3 METHODS

2.3.1 Development of evaluation tool

The principles behind this website evaluation study were similar to those described by Sidhu, (2006); Kisley, (2003) and Reed, (2002). It therefore seemed reasonable to base the design and structure of the new ADHD tool upon the format of evaluation tools used in those studies. Since information on drug therapy was a major feature of this evaluation, many of the attributes or criteria under investigation were related to medication specific issues. The new tool once developed was called the Strathclyde Website Evaluation Form (SWEF).

2.3.1.1 Content of tool

The SWEF measured 23 characteristics of the site and was split into two sections. Section 1 (questions 1-14) was largely concerned with evaluation of the websites clinical attributes (i. e the contents) and to what extent the information on the site agreed with evidence based practice or consensus recommendations (including current NICE and SIGN ADHD guidelines). Section 2 (questions 15-23) set out to evaluate the physical components of the site. This was achieved using Silberg's accountability criteria and other criteria related to readability and site navigation. Each criterion was scored on a 3 point scale (0, 1 or 2). A score of 0 was awarded if the criterion under investigation was unfulfilled. A score of 1 was awarded if it was partially fulfilled and 2 points when it was completely fulfilled (satisfied). The final total score for each site was the sum of the individual attributes (criterion). The maximum possible score was 46. A copy of the SWEF can be found in Appendix 1.

2.3.1.2 Validation of the SWEF using DISCERN

The DISCERN instrument was used to provide partial validation of the SWEF by comparing the scores from both scales on a sample of Australian ADHD websites. The sites were identified by entering the terms 'adhd' and 'Australia' into Google™ search engine. The first three sites listed on the first page of the search results were evaluated by the author and four MPharm undergraduate students. The scores from

each site from each individual were compared using Pearson's Correlation Coefficient (r).

2.3.1.3 SWEF inter-rater reliability

Inter-rater reliability was determined using the same sample of Australian websites and the same individuals as before. The total or final SWEF score per site per individual were compared and reliability was measured by the Fleiss' (kappa) statistic. Kappa scores between (0.60-0.80) indicate substantial agreement amongst different raters.

2.3.1.4 Pilot study with the SWEF tool

The SWEF was piloted on six sites identified by Google™ search engine by entering the phrase 'adhd' and 'USA and New Zealand'. Searching specifically for American and New Zealand based websites was intended to avoid contamination of the main UK data set and avoid potential bias from the individual raters, who may have become familiar with the Australian sites.

2.3.2 Identification of websites for evaluation

The term ADHD was entered into the following search engines on the 8th of January 2007: Google™ (www.google.com), Yahoo™ (www.yahoo.com), Ask™ (www.ask.co.uk/), Look Smart™ (//search.looksmart.com/) and MSN™ (//live.com/?searchonly=true&mkt=en-gb). Where searching restrictions could be employed, engines were compelled to search only UK sites. The first 20 pages, (containing details of 200 links or URLs (Uniform Resource Locators) from each search engine) were identified. The first five pages (containing links to 50 websites) were accessed and stored. The links were all re-visited and scrutinised for eligibility which was defined as 'sites whose focus is educational and informative about the disorder or its treatment. URLs linking to news articles on ADHD, ADHD books and other inappropriate sites were excluded.

2.3.3 Data analysis

Data were analysed using SPSS (Statistical Package for the Social Sciences, V13. Chicago). Differences in mean scores between host categories were compared by analysis of variance (ANOVA) using (post hoc) Bonferroni correction for multiple tests. SWEF inter-rater reliability was determined by Fleiss' Kappa statistic and validity by correlation [Pearson's correlation coefficient (r) and Kendal's tau_b] with the significance level set at $p<0.05$.

2.4 RESULTS

2.4.1 SWEF reliability and validation

2.4.1.1 Evaluation of Australian websites using SWEF and DISCERN

1,280,000 URLs were identified and the first 3 URLs were copied and accessed. Two sites were from government sources (www.adhd.com.au and www.healthinsite.gov.au/topics/Attention_Deficit_Disorder__ADD_or_ADHD) and the other was by the pharmaceutical company Janssen Cilag (www.psychiatry24X7.com/homes/adhd). Scores assigned by each rater for each site and the subsequent correlation (r) and Kappa values are given in Table 2.2.

Table 2.2 SWEF and DISCERN scores for each evaluator per website.

	SWEF score / 40			Kappa score	DISCERN score / 60			Average r (n=1 6)
	Site 1	Site 2	Site 3		Site 1	Site 2	Site 3	
GA	26	18	21		52	31	45	
S 1	25	18	20	0.74	46	25	54	0.69
S 2	27	18	27	0.72	47	31	50	0.81
S 3	27	18	27	0.80	55	28	53	0.75
S 4	22	18	24	0.78	48	27	54	0.65

Some variability in scores measuring individual criteria was seen even though final scores are similar. For SWEF, kappa scores ranged between (0.72-0.80) which suggests the SWEF is a reliable tool. The DISCERN scores and the subsequent correlation values (ranging from 0.65-0.81) also indicate substantial inter-rater agreement despite the unstructured and subjective nature of the task.

2.4.2 SWEF pilot study

Six websites belonging to governmental or professional bodies were evaluated in the pilot study. These were:

Site 1: US National Institute for Mental Health: www.nimh.nih.gov/publicat/adhd.cfm

Site 2: US Child Development Institute: //childdevelopmentinfo.com/disorders/adhd.

Site 3: US Mayo Clinic: www.mayoclinic.com/health/adhd/DS00275

Site 4: NZ Voluntary non profit organisation: www.adhd.co.nz

Site 5: US Centres for Disease Control and Prevention: www.cdc.gov/ncbddd/adhd

Site 6: American Academy of Family Physicians: //familydoctor.org/118.xml

Issues raised by the pilot study were largely concerned with clarification of wording such as what constituted an 'image' and how to define the difference between a 'page' and a 'link'. DISCERN was not included in the pilot as it was an established, previously validated tool

2.4.3 Results of ADHD website study

2.4.3.1 Identification of websites

Each search engine initially identified several hundred thousand websites. There appeared to be considerable overlap and duplication in sites identified by each search engine. Forty eight websites were ultimately chosen for evaluation. The majority (77%) of websites had been identified by Google™ and Ask™ search engines. Table 2.3 illustrates how the sites were chosen.

Table 2.3 Number and characteristics of ADHD websites identified by each search engine

Factor	Google™	Yahoo™	Ask™	MSN™	LookSmart
Number of total hits/URLs	805,000	816, 000	165,000	111,049	Not given
ADHD exclusive websites in 1st 50 URLs	40	36	42	44	50
Website inaccessible or irrelevant	2	2	5	4	0
Non UK website	0	4	4	6	43
ADHD news article or similar	6	7	1	1	3
Books about ADHD	1	0	3	1	0
ADHD Hospital/Academic department*	3	1	0	1	0
ADHD Directories	2	3	0	4	1
Potential sites per engine	26	19	29	27	3
Sites per engine after cross reference & elimination of duplicates	**26**	**4**	**11**	**7**	**0**

* Psychiatry/Child Health University/hospital based research unit

Websites were categorised according to their host organisations. The largest category (n = 22, 46%) consisted of sites by charities and support groups, including generic mental health charities and ADHD specific support groups. Eight of the 22 sites belonged to local or regional support groups and were aimed mainly at parents of children with ADHD. The second largest category (n = 12, 25%) was made up of sites with commercial undertones and included services by educationalists or psychologists who were offering bespoke treatment programmes using behaviour modification techniques. The next category contained nine sites (19%) which were from government or professional bodies such as the NHS and the Royal College of Psychiatrists. Five sites were categorised as miscellaneous, 2 of which were the health pages from the BBC and Channel 4 websites. The names and URLs of the forty eight websites evaluated are available in Appendix 1.

2.4.3.2 Evaluation details

Individual websites scores measured by SWEF and DISCERN are presented in Appendix 1.

2.4.4 Quality of websites

The mean (SD) total SWEF score for the whole sample was 20.4 (5.5) out of 46. The mean total SWEF score for the governmental/professional category was significantly higher than the total SWEF scores for the commercial category, $F_{(3,44)} = 3.5$, $p = 0.02$ and the category containing the charities and support groups $F_{(3,44)} = 4.3$, $p = 0.009$. The mean scores per category using SWEF and DISCERN are summarised in Table 2.4.

Table 2.4 Mean (SD) SWEF and DISCERN scores according to website category.

	SWEF Mean (SD) Total score (max 46)	SWEF Mean (SD) Content score (max 28)	SWEF Mean (SD) Physical score (max 18)	DISCERN Mean (SD) Total score (max 80)	DISCERN Mean (SD) Overall rating (1-5)
Charities/ support groups (n = 22)	18.9** (4.3)	4.1(3.7)	14.8 (2.6)	40.5 (9.5)	2.5 (0.8)
Commercial organisations (n = 12)	18.8* (5.9)	5.2 (3.9)	13.5 (3.7)	41.2 (12.8)	2.2 (1.0)
Government/ Professional (n = 9)	25.7 (4.5)	9.1 (2.8)	16.6 (2.3)	51.9 (10.9)	3.1 (1.0)
Miscellaneous (n = 5)	21.0 (6.5)	6.4 (6.3)	14.6 (3.5)	41 (11.6)	2.6 (1.1)

* $p<0.05$, ** $p<0.01$ compared with government/professional category

2.4.4.1 SWEF clinical attributes

The total mean (SD) SWEF score for clinical attributes (content) was 5.5 (4.2) out of 28. Most sites described the symptoms of ADHD with 15 sites detailing the different (DSM IV) subtypes and their corresponding symptoms. The majority of sites were devoid of ADHD prevalence details; however three sites did give details of UK prevalence and gender distribution. Sites performed particularly poorly against the six attributes specifically concerned with medication. Most sites made some reference to stimulants, but a large proportion (n = 30) failed to describe how the medicine actually controlled symptoms. Eight sites mentioned an alternative to stimulants, namely atomoxetine. None of the sites acknowledged that the safety data on long term stimulant use is limited to 2 years, although a few sites commented about limitations of trial data in general. Just over half (56%) of the sites failed to mention any side effects, and only ten sites reported more than four separate side effects and their expected rate of occurrence. The majority of sites (87%) either did not mention the different stimulant formulations or only described them in passing. Further details, such as the need for different formulations, or individual brand names, were found on six sites. Nine sites commented that stimulant medication is not always appropriate and can be contraindicated but only one site provided an explanation for this. Co-morbidity with ADHD was also poorly discussed, with most

sites failing to mention it at all or making the briefest of comments. Although some sites acknowledged the need for second line treatment options, none of them commented on the unlicensed nature of this kind of therapy.

2.4.4.2 SWEF physical attributes

The total mean (SD) SWEF score for physical attributes was 14.8 (3.0) out of 18. There was little difference in scores among host categories, although the government/professional sites had the highest mean score. Authorship details were scarce across the sample with more than half of sites failing to provide any details of the author. A quarter of sites provided not only the author's name and professional credentials but also their contact details. Currency was also good with most sites; (73%) found to be updated or created within the previous 3 years. The target audience of the sites could be deduced fairly easily although two sites did not mention it at all and it could not be easily identified. Almost all the sites were easy to navigate. Half of the sites had search/help facilities on their main page. Most sites also had links to either other external ADHD related sites or provided links to other pages within their own organisation. Advertising was generally absent or subtle and appeared intrusive on three occasions. Graphic images were largely absent, although some sites did display cartoon type characters. A disclaimer and advice to consult a health professional was visible in 13 sites, with just under half of the sample failing to mention it. No association was found between the clinical score of a site and the score for its physical attributes, $r = 0.09$, $p = 0.5$.

The criteria used to asses the websites and the number of sites per SWEF score are presented in Table 2.5.

Table 2.5 Websites numbers and scores for criteria examining site contents and physical properties *(n = 48)*.

Criterion	Scores 0	1	2
Criteria measuring clinical attributes (content)			
Distinction of subtypes & > 3 corresponding core symptoms described	16	17	15
UK prevalence & gender distribution stated	28	17	3
2 or more theories about the aetiology described	27	15	6
Advice on behaviour management for home, school & one other setting	27	15	6
Stimulants & atomoxetine mentioned & mechanism of action described	30	10	8
Explanation that long term safety data of stimulants is limited to 2 yrs	42	6	0
At least 4 side effects listed with indication of expected occurrence	27	11	10
Distinction & explanation of different stimulant formulations, their properties & uses	32	10	6
Explanation provided as to why & when stimulants are contraindicated	39	8	1
2nd line therapy mentioned including its unlicensed status	34	14	0
At least one co-morbid disorder mentioned & a description of its symptomology	26	14	8
Terminology is appropriate (i.e absence of jargon) or glossary provided	2	13	33
Disclaimer & reference to consult health professional clearly visible	22	13	13
Comprehensive list of support/resources including contact details	6	18	24
Criteria measuring physical attributes			
Author named, professional credentials & contact details supplied	27	9	12
Site developed or updated < 3yrs ago	9	4	35
Target audience clearly specified	2	26	20
Site easy to navigate & search facility provided	1	23	24
Advertising absent or subtle with no interference with text	3	10	35
Good layout of text, easy to read & follow	1	9	38
Appropriate, useful, relevant images present	44	3	1
Links to relevant sites with appropriate deposition	8	11	29
Readability Statistics			
FRES <30	18		
FRES 30-60		26	
FRES >60			4

2.4.5 Validity of SWEF measurements

SWEF total scores were strongly correlated with DISCERN total scores, r = 0.82, p = 0.0. SWEF clinical scores were also strongly correlated with the scores for DISCERN Section 2 (which was used as a proxy measure for clinical attributes), r = 0.79, p = 0.0.

The mean score for the overall rating of the site measured by DISCERN Section 3 was 2.5 out of 5 implying a moderate level of quality. A significant correlation was found between the total SWEF score and the DISCERN overall rating score, r = 0.84, p = 0.0.

2.4.6 Website readability

Four sites had Flesch Reading Ease Scores above 60. One of these sites was specifically aimed at young people (www.youngminds.org.uk), and another belonged to a support group for parents of children with ADHD (www. liverpooladhd.org.uk). The other two sites were from the miscellaneous category: www.rasingkids.co.uk and www.educational-psychologist.co.uk/adhdcklist.htm.

2.4.7 Top ten UK ADHD websites

The Top Ten sites according to their total SWEF scores are presented in Table 2.6.

Table 2.6 Top ten highest scoring ADHD sites according to SWEF.

Website Host	Site URL	SWEF Score
BMJ Publishing Group Best Treatments webpage	www.besttreatments.co.uk/btuk/conditions/10235.jsp	34
NHS Direct Health Encyclopaedia ADHD webpage	www.nhsdirect.nhs.uk/articles/article.aspx?articleId=40 &sectionId=27010	29
Pharmaceutical company Janssen-Cilag Products homepage	www.janssen-cilag.co.uk/bgdisplay.jhtml?itemname=parents_background_adhd&_requestid=1343815&s=1	29
Online Health portal	http://premium.netdoktor.com/uk/adhd/index	29
NICE Technology Appraisal No 98 document webpage	www.nice.org.uk/guidance/TA98/guidance/pdf/English/download.dspx	29
BMJ Publishing Group Clinical Evidence ADHD page	www.clinicalevidence.com/ceweb/conditions/chd/0312/0312.jsp	27
ADHD Support Group based in Milton Keynes	www.mkadhd.org.uk/home.html	27
Mental Health Charity MIND ADHD information page	www.mind.org.uk/Information/Booklets/Understanding/ Understanding+ADHD.htm	26
Pharmaceutical company Janssen-Cilag Disease information page	www.psychiatry24x7.com/homes/adhd.jhtml;jsessionid=Q04US1CWYPKBQCUCERDBXCQ	26
ADHD Support Group based in Lincoln	http://beehive.thisislincolnshire.co.uk/default.asp?WCI=SiteHome&ID=3499	26

2.5 DISCUSSION

Forty eight UK based websites on ADHD were identified. The majority were hosted by support groups or charities and largely aimed at parents. The quality of information on the sites was generally poor but this was mainly due to a deficiency in information rather than the information being incorrect.

2.5.1 Validation of findings

The high degree of inter-rater reliability between users of the SWEF implies it is a relatively easy tool for individuals to use, even when knowledge about the condition is variable. The high correlation between SWEF and DISCERN scores further validates the SWEF as a tool for website evaluation. The SWEF could be considered an improvement on previous evaluation tools as it measures a greater range of evidence based attributes, particularly those related to medication, and can be customised according to condition or speciality with relative ease.

2.5.2 Evaluation of websites

The highest rated site was www.besttreatments.co.uk which is produced by the BMJ Publishing Group. Since previous studies have also shown that consumers are more receptive to health information websites that have been developed by governments or professionals (Peterson *et al.*, 2003), this site, and others in its category, should be recommended by clinicians as useful and reliable sources of information about ADHD and its treatment. Sites offering herbal, psychological or alternative treatments automatically scored lower because the quality criteria were biased towards evidence based pharmacological treatments. There was also lack of accountability or disclosure on many commercial sites. Eysenbach (2002) reported a similar experience but commented that individual authors may be reluctant to disclose details on sites aimed at a non professional audience.

2.5.2.1 Clinical properties of websites

Information about the clinical aspects of the disorder was lacking with actual descriptions of the disorder mostly incomplete. Few sites explained the different

subtypes of ADHD (inattentive, hyperactive and combined) and how these are characterised. Previous studies have shown that individuals may use the internet before visiting a health professional, in some cases arriving at a diagnosis (Peterson *et al.,* 2003). If parents and carers in the UK also behave in this manner, it is debateable whether the sites identified in this sample would help or hinder them in doing so. Similarly, information detailing the causes and prevalence was largely absent. This is unfortunate as an awareness of the different factors implicated in the disorder can address the anxiety and frustration often expressed by parents by helping them to put things into perspective. Wider dissemination of such basic information may help to provide a deeper understanding of ADHD among the general public.

Whilst the treatment of ADHD is multimodal, very few sites, with the exception of the life coaching organisations, mentioned educational and behavioural interventions or how these are implemented. In an Australian study of online health seeking behaviour, the internet was used to identify alternative treatments, especially in chronic or uncontrolled conditions (Peterson-Clark *et al.,* 2004). If UK residents were to behave in the same manner, then the results of the present study suggest that they are unlikely to find much information. Furthermore, it is concerning that less than half of the sample did not display a disclaimer or recommendation to consult a health professional. In agreement with the observations of Kisley (2003), such details were often in small print and difficult to find.

Information about the role and nature of medication in ADHD was particularly scarce. In the UK, only MPH and DEX are licensed for use in ADHD. Both are similar in structure and effect to known drugs of abuse (cocaine and amfetamine), so considerable time can be spent by health professionals in reassuring individuals, especially parents, about their exact function and associated problems. However, more than half of the sites in the sample failed to mention how stimulant medication controls symptoms or made any attempt in reinforcing its non-addictive nature. The lack of information about atomoxetine is also concerning and may compromise treatment. For example, some parents may be wary about its role and assume they

are being offered medication that is in some way experimental or out of the ordinary. One explanation for the lack of atomoxetine information may be that it hadn't quite penetrated the ADHD armamentarium. However, the majority of sites were less than 3 years old (atomoxetine was licensed in 2005) and it is specifically mentioned by NICE in their technology appraisal for ADHD (NICE, 2006) so it is difficult to explain why it was omitted. A sizable minority (30%) of individuals are unable to take stimulant medication for reasons previously mentioned in Chapter 1. Therefore information about alternatives (other than atomoxetine) is needed and likely to be sought after. Alternative drugs, such as clonidine tend to be used in an unlicensed manner. Although some sites did allude to the need for alternative or second line treatment, none mentioned its unlicensed nature or the lack of accompanying trial data. Prescribing off-license can often be difficult to negotiate with parents so information detailing the main issues would be extremely welcome.

There was also little information about medication side effects, such as what problems might be expected or how frequently, even though this is often a main reason for searching for information (Griffiths and Christensen, 2000). Information about cardiovascular adverse effects, such as heart attacks and stroke, although relatively uncommon, would probably still benefit from being included, since these side effects have been the ones targeted by the US regulatory authorities (US FDA, 2005). It is possible that UK individuals accessing American websites come across these warnings or other websites, such as 'ritalinkills.com', and could become worried or confused as to why UK sites do not appear to reflect the same degree of concern.

Information about the different stimulant formulations and their role in treatment outcomes was wholly inadequate. Many patients and parents fail to appreciate that the success or failure of stimulant therapy is often dependent on the careful manipulation of the timing of doses or the correct combination of different formulations. The various formulations play an important role in the management of ADHD and it is disconcerting that so few sites made any reference to them. The Janssen-Cilag site was the most detailed, which is perhaps not unexpected since

Janssen manufacture the osmotic release methylphenidate preparation, Concerta™. Sites by local support groups were generally lacking in information about clinical issues, perhaps because the authors of many of these sites feel unqualified to comment on such matters. However, some parents searching for information on ADHD might prefer to receive information from other parents instead of sites that could be seen as having a vested interest.

2.5.2.2 Physical properties of websites

The physical properties of the sites were generally of a higher quality although accountability with respect to authorship scored poorly. Precise details including affiliations and contact details were largely missing. If an author was named, it was usually impossible to deduce if this was a (medical) specialist or someone with relevant clinical experience, possibly affecting the credibility and utility of information on the sites. Overall, sites were easy to use and navigate. Keyword searching was available on sites hosted by large parent organisations, such as the mental health charity MIND and NHS Direct. Pictorial images and animated features were largely absent, as were diagrams and illustrations. This is unfortunate considering that only four sites were written in a language deemed appropriate for consumer directed information and a third of sites had a reading level consistent with graduate education. These results indicate that site authors need to place more emphasis on diagrams and images to make the content more accessible to the general public.

Identification of a high level of reading ability is a consistent problem encountered within other website evaluation studies (Eysenbach and Jadad, 2001). This finding raises uncertainty about the extent to which consumers actually understand the material they find. Some sites may have performed badly because readability was calculated on the medication section where scientific language or polysyllabic words were more prominent. However, the treatment section is likely to attract considerable interest, so should be written in a clear comprehensible manner, regardless of the content. The children's charity "Young Minds" was particularly

innovative in using cartoon imagery making it suitable for young people and non English speakers as well as adults with a limited education.

Advertising on websites can be a contentious issue with pop-up adverts identified as the most troublesome (Peterson *et al*., 2003). In the present study, no pop-up adverts were identified, although some sites did have advertising along the side of their page or across the top. Sites by support groups and web based health organisations carried the most adverts, perhaps due to their dependence on advertising revenue. Most of the advertising was not too intrusive, but could still prejudice or unduly influence visitors to the site. This is an area which requires further investigation. Where advertising was present it appeared to be largely for US based companies selling 'cures' for ADHD.

Most sites, especially those by charities and support groups, provided links to other sites; most commonly to the national parent support organisation Attention Deficit Disorder Information and Support Service (ADDISS). Links to government/professional sites, such as NHS Direct or the Royal Colleges, were largely absent which seems to be a wasted opportunity.

Previous reviews of mental health websites (Kisley *et al.,* 2003, Griffiths and Christenson, 2000) have found that the site's physical presentation has little to do with the quality of its contents. This may be a property unique to mental health websites so any further use of the SWEF should preferably be on a physical condition. Such an evaluation would also show if government/academic professional sites still out perform sites in other categories.

2.5.3 Study limitations

The major limitation of this study is the currency of the information. Although these findings are a true representation of the situation in January 2007, the fluid and virtual nature of the internet means that the findings cannot be guaranteed if the study was repeated. Nonetheless, this snapshot of UK ADHD websites provides professionals working in the area some guidance to the nature of the sites available.

Another limitation arises from the methodology, since only one search term was used to identify the websites. The phrase 'adhd' was used instead of the official diagnostic definition 'attention deficit hyperactivity disorder' or other abbreviations 'attention deficit' or 'hyperactivity' so that the search would mimic one conducted by a lay person such as a parent, or school teacher. If different phrases and Boolean searching techniques had been applied, it is possible that a greater number, or different sites, would have been identified. Although possible, it is unlikely since the sample was taken from the first 50 sites from the top 5 search engines as recognised by the UK IT industry. Google™ is generally acknowledged as the most superior in terms of coverage and efficiency, followed by Yahoo™ and Ask™. The results from these three engines combined with results from Look Smart™ and MSN.com would be expected to give maximum coverage and identify the majority of UK based internet traffic (Search Engine Watch, 2007).

2.6 CONCLUSIONS

The main findings of this chapter are:

- There are a small number of UK based ADHD websites that clinicians can confidently recommend.
- The information on these websites is basic with some serious omissions, most notably details of the different stimulant formulations and descriptions of side effects. Information about atomoxetine and other unlicensed medication is also minimal.
- The quality of information is generally poor, but there do not appear to be any instances of wrong or misleading information.
- Sites by governmental and other professional bodies tend to score the highest.

Chapter 3

Clinician knowledge and provision of information resources and views on school teachers' understanding of ADHD

3.1 INTRODUCTION

3.1.1 ADHD services in Scotland

NHS services in Scotland are delivered at a regional level. In total there are 14 regions named after the geographical area that they cover e.g. NHS Lothian, NHS Grampian etc. Each region or area is responsible for the local delivery of services. Service provision is mainly dependent on the needs of the local population, funding by the Scottish Government and the availability of appropriate personnel. NHS services for ADHD tend to be delivered through the Community Paediatric Service or Child and Adolescent Mental Health Services (CAMHS). However, there are differences in education and training within the psychiatric and paediatric specialities, for example community paediatricians receive negligible training in child mental health and child and adolescent psychiatrists (CAPs) have little training in clinical child health. Such discrepancies may affect the knowledge and attitudes of clinicians towards ADHD, which may influence the delivery or make up of services. Such differences in practice could also affect the nature and quality of care an individual with ADHD can expect to receive, which may ultimately affect clinical outcomes.

This chapter is concerned with establishing the extent of written ADHD information provided by clinicians, their knowledge of internet sources of information on ADHD and their views towards the role of schoolteachers in the management of the disorder. A separate study detailing the provision of information by local ADHD services was also conducted to allow comparison with the clinician's responses.

3.1.2 Knowledge and attitudes of ADHD amongst different professional groups

Studies conducted amongst various professionals, including educational psychologists, child care social workers and General Practitioners (GPs) in different locations across the world provide some information about how different professionals understand the disorder. Frankenberger *et al.*, (2001) surveyed 258 American educational psychologists and found them to have appropriate knowledge

and reasonable attitudes towards the disorder. A survey of UK social workers found that the amount of post qualification experience of ADHD influenced both knowledge and preference for particular interventions (Pentecost and Wood, 2002). Amongst GPs, it appears that understanding and knowledge of the disorder is generally lacking, although many report experiences of seeing patients with the disorder. For example, in a postal survey of GPs in South Wales, of the 150 who responded, 85% had a child or children with a diagnosis of ADHD, yet only 9% had received any formal training about the disorder (Ball, 2001). Just under a third received their information about the disorder from journal articles, with 21% getting it from the media. No reference was made to internet sources of information, although this was probably because the study was conducted when internet use was not so widespread. The majority of GPs (89%) were prescribing methylphenidate; however most (98%) were doing it under the supervision of a psychiatrist (69%) or a paediatrician (19%). Eighty four percent of the sample said they wanted further training in ADHD, with 88% wanting this to be specifically related to drug treatment. Another study (Shaw *et al.*, 2003) amongst Australian GPs found levels of interest in becoming more involved in ADHD management to be generally low. Concern over the complexity of cases, time constraints and insufficient education and training on the disorder were cited as the main reasons. This 'lack of ownership' of the disorder and the fact that few GPs and nurses have received formal training, has been identified by various sources as potential hindrances to the delivery of ADHD services (Rasch, 1994; Thapar, 2002).

3.1.1.1 Knowledge, attitudes and practice amongst non UK paediatricians and psychiatrists

Most of the research into this topic is biased towards American clinicians. Early postal surveys (Copeland *et al*., 1987; Wolraich *et al*., 1990) set out to determine clinician case loads and their identification of cases and treatment strategies. Both of these surveys were fairly limited in scope and did not investigate the attitudes of clinicians towards treating ADHD patients or their interactions with parents / carers. These issues were studied much later in a large postal survey of 1000 members of the American Paediatric Association (Kwasman *et al*., 1995). Respondents were given a

48 item questionnaire that included some items from the Copeland *et al*., (1987) survey, and which required responses based upon a 10 point Likert index for agreement. Three hundred and eighty (38%) paediatricians responded. Improvements in school teacher education, increased availability of resources for parent education (15%) and more interdisciplinary contact (12%) were identified as areas that could help improve the care of ADHD patients. Regarding information provision to patients, it is unclear whether this was provided verbally or in writing. Nevertheless, paediatricians reported that they did describe what the medication was for and how it worked: 31% told their patients/parents that it helped concentration; 22% that it helped attention; 24% with school work; and 7% said it helped with 'everything'. Twelve per cent of paediatricians used generalised language implying that it had a calming effect. They also reported that they used more technical language (phrases like neurological networking) when talking to parents.

Kwasman *et al*., (1995) also reported on the perceived misconceptions held by parents about the disorder and its medication. A fifth of the 380 paediatricians reported that parents often think ADHD is caused by poor diet, that drugs can cure ADHD (11%) and that children 'grow out of it' (11%). The lack of medication specific information was further highlighted by the paediatricians who reported that common parental misconceptions are that the medication is addictive (49%) or damaging to the body (26%). This and a previous study conducted amongst parents of children with ADHD (Bowen *et al.,* 1991) highlight the need and importance of parental education.

Differences in training, consultative styles and delivery of services may result in psychiatrists holding different opinions and attitudes from paediatricians towards the management of children with ADHD. To date, three studies [Salmon and Kemp, (2002); Venter *et al.,* (2004); Kirby *et al.,* (2007)] have appeared in the UK literature which specifically investigate and compare psychiatrist and paediatrician attitudes, knowledge or practice regarding ADHD and its treatment. The most informative of these studies, by Venter *et al.,* (2004), was conducted in South Africa. Three hundred and eighty eight registered psychiatrists and 546 paediatricians were

surveyed using a questionnaire similar in content to that used by Kwasman *et al*., (1995), although more in-depth questions regarding knowledge and perceptions of MPH were also included. Responses were higher from paediatricians (61%) than psychiatrists (51%). Findings from this study mirrored those by Kwasman *et al*., (1995) in many areas, such as the need for improved teacher (96% psychiatrist and 97% paediatrician) and parental education (97% both professions). A higher proportion of psychiatrists (60%) compared to paediatricians (50%) reported difficulty liaising with the school. Both groups found schools to be cooperative in making a diagnosis, offering remedial teaching, dispensing medication, giving feedback and supervising behavioural modification programs, although psychiatrists were generally less convinced than paediatricians about the abilities of schoolteachers.

Differences in attitudes towards the management of ADHD were also evident between the two professions. Paediatricians were significantly more likely to consider remedial and speech therapy as important whereas psychiatrists were more likely to consider psychotherapy. Both professions responded in similar proportions that they always or often used MPH (92% psychiatrists, 96% paediatricians). However, more psychiatrists (63%) used antidepressants as second line therapy compared to paediatricians (17%). The reasons for such a large difference are unknown and maybe reflect psychiatrists having a greater familiarity with psychotropic medication. A higher proportion of psychiatrists also indicated that the aetiology of ADHD was related to abnormal cerebral function. Surprisingly, more psychiatrists (53%) than paediatricians (32%) indicated that MPH had a paradoxical effect. This paradox, that a stimulant drug can cause a calming effect, is an outdated concept which was generally refuted by the early 1990s (Whalen and Henker, 1991). It is disappointing to note that so many psychiatrists still held that view in 2004 and suggests that clinicians themselves may warrant further education about stimulant medication. Clinician knowledge of side effects was also examined. The majority correctly identified anorexia and insomnia as the most common side effects of MPH. A significantly higher proportion of psychiatrists were more likely to name other side effects, such as convulsions, drug abuse, dysphoria, rebound effects and weight loss.

Although not all of these are recognised as side effects of stimulant medication, psychiatrists were generally found to be more knowledgeable, perhaps indicative of their training. Paediatricians, however, were found to have a more inter disciplinary approach towards ADHD treatment.

3.1.1.2 Knowledge, attitudes and practice amongst UK paediatricians and psychiatrists

These studies are fairly recent and based upon a UK sample. The largest study in terms of sample size, Kirby *et al.,* (2007), surveyed the knowledge of psychiatrists and paediatricians regarding developmental disorders that co-occur with disorders of attention, motor control and perception and whether they routinely assessed children for these. Four hundred self-administered questionnaires were hand distributed to delegates attending three different educational meetings in the UK. Delegates included consultants in child and adolescent psychiatry and paediatrics and other CAMHS professionals. Two hundred and forty six (Response Rate = 61.5%) questionnaires were returned of which one hundred and seven were from CAPs and fifty one from paediatricians. Even though a reasonable response rate was achieved and respondents were more likely to be biased towards 'good practice', evidenced by their attendance at the meetings, the survey found that psychiatrists were generally less knowledgeable about motor coordination difficulties compared to their paediatric counterparts. A higher proportion of psychiatrists (67%) rated their knowledge as poor or very poor compared to 14% of paediatricians. Nearly half (49%) of the psychiatrists did not know what the abbreviation DCD stood for (Developmental Coordination Disorders), compared to 14% of paediatricians. The study highlighted the discrepancies in education and training about developmental disorders and the differences in knowledge between the two professions. No studies were identified that specifically surveyed psychiatrists as a professional group.

Salmon and Kemp (2002) surveyed Welsh registered CAPs and hospital and community paediatricians, to identify differences between the two groups in the assessment and management of ADHD. The studied yielded a high response rate (88%) but only included 29 respondents. Nevertheless they found that paediatricians

were more likely to conduct physical assessments, including neuro-developmental examinations and sight/hearing tests, in the assessment phase, whilst CAPs were more likely to offer other treatment approaches, such as parent training and behaviour modification programmes instead of medication. The authors concluded that the different styles in training probably account for the differences. They also proposed that triage of patients at the point of referral should channel patients with co-morbid mental health problems to CAMHS and those with developmental disorders to the paediatricians. These proposals are, however, subject to the availability of both services.

3.1.3 Provision of written information to patients and their parents / carers.

The provision of written information to patients and their carers is generally accepted as good practice. The literature concerning its use, requirements and quality is adequately covered elsewhere (Nair *et al*., 2002; Dickenson and Raynor, 2003) Nevertheless, details regarding the provision of written information resources by UK health personnel are generally scarce. One study, with a 42% response rate, surveyed 775 Scottish GP Practice Nurses on their use of written information in asthma (Jaffray *et al*., 2001). Nearly three quarters of respondents worked to a protocol that included the provision of written information. The most common information resource used was in the form of leaflets produced by either the pharmaceutical industry or asthma charities, such as National Asthma Campaign (now Asthma UK). However, 22% used resources that they had written and developed themselves. The majority (n = 170) indicated that the pharmaceutical industry produced information was better in terms of attractiveness and ease of access. The overall perception was that there was an abundance of asthma information available and it was generally satisfactory in quality. Some nurses did state that they felt overwhelmed by the sheer amount of information available and some voiced discomfort in using industry literature as it may be perceived as 'product pushing'.

No studies were found which investigated the nature of information supplied to patients or their parents/carers in the diagnosis of ADHD. It is assumed that written

information would be provided at some point during the consultation. However, the physical nature and contents of any information resource are unlikely to be standardised and practice is likely to vary across the different NHS regions and indeed between professionals and specialities.

3.1.4 Clinician use of information technology for information provision

Use of the internet as a source of health based information has been discussed in Chapter 2. Increasingly, clinicians are also taking on the role of internet consultant and becoming 'net-friendly clinicians' (Ferguson, 2000). This type of clinician is also more likely to offer help and advise patients on how to navigate the internet for health care information. In essence, clinicians are increasingly expected to provide an 'internet prescription' of recommended sites (Gerber and Eiser, 2001). Such expectations also imply that clinicians are comfortable and competent with using the internet.

Wilson (1999) in his study of GPs and Practice Nurses in Greater Glasgow found that 160 GPs (54%) and 96 (74%) Practice Nurses had come across patients who had obtained health care information from the internet. They were further questioned as to whether they would refer patients to the internet for further information and, if so, which particular websites they would recommend. Even though the study was conducted in 1999, when internet use less widespread, almost half of the GPs compared to 29% of Practice Nurses, said they would consider referring a patent to the internet for further information.

In general, the attitudes and awareness of clinicians regarding information sources, including appropriate websites suitable for patients and carers, is a poorly researched area. To date, there are no published studies which investigate information provision by UK paediatricians and psychiatrists or their knowledge and recommendation of websites as sources of information for patients with ADHD and their parents/carers.

A national survey of paediatricians and psychiatrists and of locally delivered ADHD services was therefore designed to address some of these concerns.

3.2 AIMS

Study 1: To determine the nature of written information on ADHD that is provided by psychiatrists and paediatricians in NHS Scotland and their views on the role of school teachers in its management. Clinicians' knowledge and use of internet sources of information on ADHD was also investigated.

Study 2: To determine the extent and nature of printed information resources provided by ADHD services in NHS Scotland to the parents or carers of children diagnosed with ADHD.

3.2.1 Objectives

1. To determine the prevalence of information provision to parents of children with ADHD by psychiatrists and paediatricians within NHS Scotland.
2. To characterise the nature of the information resources provided by psychiatrists and paediatricians within NHS Scotland.
3. To determine the views of both professional groups regarding the usefulness of the resources they provide.
4. To determine the views of both professional groups towards school teachers' understanding of ADHD.
5. To determine each professional groups knowledge and use of UK based ADHD websites.
6. To characterise the various types of printed information resources provided to parents (carers) by local ADHD services in each region of NHS Scotland.
7. To evaluate some of the locally provided printed information resources using the SWEF.

3.3 METHODS

3.3.1 Study 1: Questionnaire development

3.3.1.1 Questionnaire content

A bespoke 17 item self administered online questionnaire was developed to record the nature of information provided by paediatricians and psychiatrists in Scotland to the parents/carers of children diagnosed with ADHD. Section 1 of the questionnaire, questions 1 – 9, were concerned with establishing the format, content and suitability of individual clinician's most commonly used and hence, supplied printed information resource on ADHD. Resource content was assessed by the number and nature of information topics that were mentioned. It was expected that any information resource on ADHD should include details of (i) disease symptomatology, (ii) the diagnostic process, (iii) behavioural / educational interventions and (iv) medication. Medication specific information was judged against the following criteria: (i) that an explanation of how the medication worked and its limitations was provided; (ii) that generic drug names were used; (iii) that information about different formulations and doses was given; (iv) that common and rare side effects were both discussed; and (v) that explanations for contraindications to medication were given. Questions 10 – 13 solicited opinions from clinicians on the knowledge they expected schoolteachers to have about medication and whether they believed that schoolteachers could benefit from additional training in this area.

The subjective aspects of the questionnaire were recorded using a five point Likert index for agreement (i.e. strongly agree; agree; undecided; disagree; strongly disagree). The final section, questions 14 – 17, determined respondent familiarity with internet sources of ADHD information. Respondents had to indicate by yes/no responses if they had ever visited any of the websites listed in the questionnaire. The URLs of the two highest scoring sites from each of the four categories identified in the evaluation study (Chapter 2), i.e. commercial, academic/professional, charities and miscellaneous, were provided. Two versions of the questionnaire were developed, with the words psychiatrist and paediatrician used interchangeably. Respondent sex and the number of years they had been working as a consultant

psychiatrist/paediatrician was also recorded. The questionnaire was formatted and hosted on a secure site within the University of Strathclyde's SPIDER (Strathclyde Personal Interactive Development and Educational Resource) network. The location and web address of the questionnaire was http://spider.science.strath.ac.uk/gasurvey/questionnaire. The paper version of the questionnaire can be found in Appendix 2.

3.3.1.2 Questionnaire validity

A common method of establishing content or face validity is to have an expert in the field judge whether the questionnaire items are an accurate reflection of the subject under investigation, i.e. the questionnaire measures what it is designed to measure, in this case, the provision of information and clinician views. Face validity was confirmed by an eminent UK psychiatrist specialising in ADHD. He commented on a paper version of the questionnaire and was satisfied with the content.

3.3.1.3 Pilot study

Three psychiatrists from the Republic of Ireland piloted the online questionnaire. They were asked to log onto the website and complete the questionnaire, preferably in one sitting, so that time for completion could be determined accurately. No problems in relation to layout or content were identified and it took on average 10 minutes to complete.

3.3.2 Establishing ethics approval

Advice concerning NHS ethics approval was sought from the Research and Development department at the Royal Hospital for Sick Children, Glasgow (the author's clinical base). The advice given was that the study comprised an audit of existing practice and therefore NHS ethics approval would not be required. The study was, however, lodged with the hospital audit team.

The Strathclyde Institute of Pharmacy and Biomedical Sciences, University of Strathclyde Departmental Ethics Committee requested confirmation of the audit nature of the study, preferably from the NHS Central Office for Research Ethics

Committees (COREC). COREC advice was similar to that given locally and stated that *"Based on the information provided, our advice is that the study may be classified as service evaluation"* (Jo Downing, Information Officer, Queries Line, COREC, National Patient Safety Agency (Ref 041/01)). A copy of the response as an email can be found in Appendix 2.

3.3.3 Respondent recruitment

The initial plan was to send all psychiatrists and paediatricians in NHS Scotland an email to their place of work advising them of the study and inviting them to participate. A web link directing respondents to the survey was to be incorporated into the email message. A request for access to the relevant email addresses was therefore made to the Scottish divisions of the respective professional bodies; the Royal College of Psychiatrists (RCPsych) and the Royal College of Paediatricians and Child Health (RCPCH). The request was accompanied by the relevant paperwork, including the study protocol and a paper version of the questionnaire. Both organisations agreed in principle to support the research study and to permit contact with their membership.

3.3.3.1 Recruitment of psychiatrists

The RCPsych denied access to the e-mail addresses of the CAPs because it was concerned that confidentiality might be compromised. The RCPsych also refused access to member's postal addresses or other contact details as it would contravene standard policy. However, the RCPsych agreed to forward any correspondence about the study to their CAP membership. Letters of invitation, in which the aims of the study and details (including passwords) of how to access the online questionnaire, were sent to the offices of the Scottish Division of the RCPsych in Edinburgh. These were then forwarded by administrators at the RCPsych to all CAPs registered in Scotland. College records stated that there were 176 CAPs in Scotland but this figure included individuals who had retired or were no longer practising in child psychiatry. Informal discussions with psychiatric colleagues and RCPsych administrators revealed the number of practising CAPs to be 62. Details of the study were also posted on the News section of the RCPsych's Scottish Division's

website. A web-link to the university SPIDER site was incorporated so that the study questionnaire could be accessed from the RCPsych site. This was intended to make it more convenient and easier for individuals to participate.

3.3.3.2 Recruitment of paediatricians

The RCPCH voiced no objection to contacting its members but was unable to provide e-mail addresses. It was, however, willing to supply computer generated address labels of its members even though the labels did not distinguish or characterise the medical speciality. Furthermore, the College was unable to quantify the number of paediatricians who actually worked in mental health. The convenor of the British Paediatric Mental Health Group was contacted and, although unable to provide specific details, thought there to be fewer than 100 eligible paediatricians in Scotland. Informal discussions with paediatricians working in NHS Scotland suggested that approximately 80 paediatricians were currently prescribing medication for ADHD in Scotland. In total, 361 labels were provided to account for all the paediatricians registered with the Scottish arm of the RCPCH. This included retirees and individuals from various specialties. Letters of invitation containing the relevant passwords were sent to the membership. A copy of the invitation letters can be found in Appendix 2.

3.3.4 Study 2: Provision of ADHD information by NHS region

Details of all CAMHS and Community Paediatric services in NHS Scotland were accessed from the relevant pages of the Scotland's Health On the Web (SHOW) website: http://www.show.scot.nhs.uk/. Further enquiries, by telephone and personal contact, provided details of the exact make up of ADHD services within each of the 14 NHS regions in Scotland and how these are delivered. The relevant personnel for ADHD service provision in each NHS region were contacted by telephone, e-mail and letter and a request made for them to provide samples of any printed information resources on ADHD that they routinely supplied. A stamped address envelope was enclosed with every letter or provided as requested.

3.3.5 Data collection

Study 1: Data were collected between June and October 2007. Two reminder letters were sent at 3 weekly intervals after the first letter. Included with the final batch of reminder letters was a paper version of the online questionnaire and a return stamped addressed envelope. The paper version of the questionnaire for psychiatrists can be found in Appendix 2.

Study 2: Data were collected between October 2008 and February 2009. A reminder letter or e-mail was sent to non responders on 8th January 2009.

3.3.6 Data analysis

Study 1: Data were analysed for frequencies and distribution. Differences in responses between professions, sex and time qualified were evaluated using Pearson's chi-squared (χ^2) test. Differences were considered statistically significant if p values were <0.05. Correlations between the length of time qualified and the provision of written information were determined using Spearman's correlation coefficient (for ordinal data) with the significance level set at $p<0.05$.

Study 2: Different types of printed resources used within NHS Scotland were evaluated using

(i) the criteria outlined in questions 4 and 5 of the clinicians study questionnaire.

(ii) the SWEF. Some questions in the SWEF relating to websites' physical attributes were not applicable in this instance, e.g. number of links, ease of use, and so were omitted in the final analysis.

3.4 RESULTS

3.4.1 Study 1: Survey of paediatricians and psychiatrists in NHS Scotland

3.4.1.1 Response rates

From the 361 labels provided by the RCPCH, 92 were addressed to individuals working in hospital nephrology, cardiology or respiratory departments thereby making them ineligible. The remaining 269 letters of invitation were posted out to the membership. Forty seven questionnaires were completed, of which 13 were submitted online and 34 were returned by post. An additional 46 questionnaires were returned unanswered from 16 psychiatrists and 30 paediatricians because they had either retired (9 psychiatrists and 12 paediatricians) or did not practice in child psychiatry (7 psychiatrists and 18 paediatricians). Based upon the number of invitation letters sent, the response rates were: 20% (19+16/176) for psychiatrists and 22% (28+30/269) for paediatricians. However, based upon eligibility, as described earlier, the overall response rates were: 31% (19/62) for psychiatrists and 35% (28/80) for paediatricians.

3.4.1.2 Respondent demographics

Of the 47 respondents; 12 were male and 33 were female. Two respondents (1 psychiatrist and 1 paediatrician) did not answer this question. Further respondent characteristics are summarised in Table 3.1.

Table 3.1 Characteristics of survey respondents *(n = 47)*

		Psychiatrist	Paediatrician
Online questionnaire		3 F	2 M, 8 F
Postal questionnaire		5 M, 9 F, 1 UK	5 M, 13 F, 1 UK
Years Qualified	<5	8	2
	6-15	4	13
	16-24	1	8
	>25	5	5
	unknown	1	
Total number		19	28

M = males. F= females. UK unknown

3.4.1.3 Provision of information

Thirty-one of responding clinicians (66%) provided written information. Twenty-five of these (14 psychiatrists) 'always' provided it or provided it 'on most occasions'. Six (5 paediatricians) provided written information 'sometimes'. Twelve paediatricians and four psychiatrists never or rarely provided written information. Information about ADHD was most commonly provided as a factsheet or leaflet (n = 26). Five paediatricians reported to mostly providing a booklet or book. There was no significant difference between the professions regarding the provision of a written information resource, $\chi^2 = 5.50$, $p = 0.06$. The length of time qualified was found to have no effect as to whether information was provided, Spearman's Correlation = 0.009, $p = 0.95$.

3.4.1.4 Properties of the information resource

The majority of clinicians (n = 12) used leaflets produced by the pharmaceutical industry as their main information resource for parents. Eight clinicians used resources produced by governmental or other professional bodies, whilst six used resources by charitable organisations. Five clinicians used a resource they had written and produced themselves.

All the resources were reported as describing the symptoms of the disorder. Details of behavioural / educational interventions were listed in all except six resources. Eleven of the printed resources mentioned the diagnostic process and what that involved, whilst 19 resources also included four or more medication related topics. All the resources produced 'in house' by the clinicians themselves mentioned four or more of the desired topics. Further details of these findings are in Table 3.2.

Table 3.2 Nature and frequency of desired topics in printed information resources distributed by clinicians.

	Mentioned in number (%) of resources
General topics	
Disease symptomatology	31 (100%)
Medication	29 (94%)
Non drug therapy management	25 (81%)
Description of diagnostic process	11 (36%)
Medication specific topics	
Generic drug names	24 (83%)
Limitations of medication	23 (79%)
Common side effects	22 (76%)
Explanation of how medication works	21 (72%)
Details about drug doses/administration	19 (65%)
Less common side effects	10 (34%)

The majority of clinicians who provided written information (n = 19/31) acknowledged that their primary resource had some deficiencies or gaps in it. These were identified as: '*the need for more details of non drug interventions, especially parenting techniques/skills and how to implement these'; 'more about the prognosis of the disorder; and better descriptions of how to recognise symptoms'*.

Gaps in medication-specific issues were also identified and included details of the expected duration of treatment and a wider description of side effects. A few clinicians indicated a need for age appropriate literature that also made reference to drug and alcohol use.

3.4.1.5 Usefulness of the resource

Twenty-eight of the 31 clinicians who provided written information resources agreed with the statement that their chosen resource was useful to parents. Thirteen clinicians agreed with the statement that it was appropriate for children but seven clinicians disagreed or strongly disagreed with this statement. Twenty clinicians agreed or strongly agreed that their resource was appropriate for schoolteachers. Ten

clinicians (five from each profession) were undecided. One psychiatrist disagreed with the statement.

3.4.1.6 School teacher's knowledge

Twenty-four clinicians (51% of respondents) either disagreed or disagreed strongly with the statement, "schoolteachers are trained to recognise the symptoms of ADHD". Sixteen clinicians were undecided and seven agreed with the statement. Responses to this question were not significantly affected by professional background ($\chi^2 = 0.87$, $p = 0.65$), length of time qualified ($\chi^2 = 5.3$, $p = 0.81$) or sex ($\chi^2 = 4.0$, $p = 0.26$). Forty-one clinicians, roughly equal proportions of each profession, either disagreed or were undecided with the statement that schoolteachers have sufficient understanding of the purpose of stimulant medication. Five female clinicians (3 paediatricians and 2 psychiatrists) agreed with the statement.

Forty clinicians, including all 19 psychiatrists, answered yes when asked if schoolteachers could benefit from more information. Suggestions for potential teacher training topics included: *'equipping teachers with the skills to recognise and manage ADHD symptoms in the classroom'*; '*information about the purpose and limitations of medication (including side effects)*'; and '*information on how to recognise the symptoms of other disorders (differential and co-morbid diagnosis)'*.

Fourteen clinicians indicated that printed leaflets or booklets would be the best medium for imparting information to schoolteachers. This was followed by audio-visual materials such CDs or DVDs (n = 11), and the internet (n = 11). Nine clinicians opted for 'other' and suggested verbal contact, lectures/presentations or other interactive training models. Printed media resources were favoured by psychiatrists (39%) whereas the internet was most popular among paediatricians (30%).

3.4.1.7 Knowledge of websites

From the list of websites in the questionnaire, all had been visited at some point by at least one clinician. The most popular site was the ADDISS website (ADHD National

Information & Support Service), which had been visited by 21 clinicians. The ADDsucess Consultancy site was the least popular having only been visited by one paediatian. A breakdown of knowledge and visitation of website by profession is given in Table 3.3.

No differences were found between the professions with respect to their knowledge of the different websites. The mean number of websites visited by each profession was 1.8 for the paediatricians and 2 for the psychiatrists.

Table 3.3 Number (%) of clinicians who have knowledge of specific websites.

Website	Total number	Site visited by Paediatrician *(n = 28)*	Site visited by Psychiatrist *(n = 19)*
ADDISS	21	10 (36%)	11 (56%)
BMJ Best Treatments ADHD page	19	13 (46%)	6 (47%)
MIND ADHD page	15	8 (29%)	7 (37%)
Jansen-Cilag ADHD	13	7 (25%)	6 (47%)
NHS Direct ADHD page	9	7 (25%)	2 (10%)
Raising kids ADHD page	4	2 (7%)	2 (10%)
Netdoktor ADHD page	4	2 (7%)	2 (10%)
ADDsuccess Consultancy	1	1 (4%)	0

Nine clinicians reported that they had visited other ADHD websites in the past year. Details were provided for 3 of these sites:

1. *http://www.chadd.org.* CHADD: Children and Adults with Attention Deficit Hyperactivity Disorder (An American site aimed at parents, patients and professionals).

2. *http://www.sign.ac.uk/guidelines/fulltext/52/index.html*. SIGN Guideline 52: (Attention Deficit and Hyperkinetic Disorders in Children and Young People).

3. *http://www.medscape.com/home.* Medscape (An American medicines information and education site for health care professionals).

Twelve clinicians stated that they routinely recommend other ADHD/mental health websites. Details of these sites are given in Table 3.4.

Table 3.4 Details of other websites recommended by clinicians *(n=9)**

Site details/URL	Number of clinicians
Australian mental health resources. *http://www.shrinkrap.com.au/fullofbeans.*	1
BBC health (ADHD) page *www.bbc.co.uk/health/conditions/adhd2.*	2
National Project for Young Peoples Mental Health (Scotland) *http://www.headsupscotland.com/*	2
UK Children's Mental Health charity *www.youngminds.org.uk/adhd/p2.php*	2
Royal College of Psychiatrists patient information page *www.rcpsych.ac.uk/mentalhealthinformation/mentalhealthandgrowingup/5adhdhyperkineticdisorder.aspx.*	2

*Not all 12 respondents provided details of other websites

3.4.2 Study 2. Survey of resources provided by ADHD Services in NHS Scotland

3.4.2.1 Provision of information by NHS region

Thirteen of the 14 NHS regions in Scotland responded to the request for information giving a response rate of 93%. Two regions; NHS Lanarkshire and NHS Ayrshire & Arran reported that they did not routinely provide any information resources or materials as part of their delivery of ADHD services. Both stated that if and when resources were provided to patients or their families, it was the decision of the individual clinician and it was not known from where the clinician would access the resource. Table 3.5 provides a summary of the resources supplied by each region within NHS Scotland.

Table 3.5 Provision of ADHD information in each NHS region within Scotland.

Health Board	Service Provision	Nature of Resource
NHS Ayrshire & Arran Population = 67,010 86,148 < 18yrs old No with ADHD=340	4 CAMHS teams	Lack of standardised approach within service. In process of developing materials.
NHS Borders Population=109,730 24,700 < 19yrs old No with ADHD=197	1 dedicated ADHD team (partnership of CAMHS & community paediatrics)	Three leaflets/booklets as one resource/pack. • Leaflet entitled 'All about ADHD' by Scottish Borders ADHD Service. • Leaflet entitled 'Supporting families and Carers of children with ADHD' by Borders ADHD family Support Group. • 14 page A4 booklet entitled 'Putting the pieces together: A guide to understanding ADHD' by Scottish Borders Council
NHS Dumfries & Galloway Population=148,340 29,722 <18yrs old No with ADHD=153	1 generic CAMHS team (part of Child Health)	Four leaflets/booklets as one resource/pack. • pdf copy of NHS Direct Health Encyclopaedia ADHD page. • pdf copy of ADDISS ADHD factsheet. • pdf copy of mental health charity MIND factsheet 'Drugs for ADHD' • 24 page booklet by Mental Health Foundation entitled 'All about ADHD'.
NHS Forth Valley Pop=284,379 68,767 <18yrs old No with ADHD=300	1 ADHD team & 1 CAMHS team	Choice of three different resources • Changing Lanes ADHD Guide consisting of 2 X 10 page A4 booklets aimed at young person/child and parents. The parent booklet includes details of local support groups. • Pack designed and distributed by Lilly containing five separate booklets on various aspects of ADHD and treatment. 20 page A5 glossy booklet by NHS Health Scotland entitled 'Talking about ADHD'
NHS Fife Pop=356,664 80,561<18yrs old No with ADHD=576	1 dedicated ADHD clinic	Two leaflets • pdf copy of NHS Choices ADHD webpage. • Young Minds children's charity double sided A3 size leaflet entitled 'What is ADHD'
NHS Grampian Pop=525,930 525,930 <19yrs old No with ADHD=670	2 CAMHS teams & 1 generic Child Health team & 1 generic team in Young People's Department, Royal Cornhill Hospital	• 20 page A5 glossy booklet by ADHD Aberdeen & North East Family Support Group entitled 'All About ADHD'

Health Board	Service Provision	Nature of resource
NHS Greater Glasgow & Clyde Pop= 1,191,551 145,482 < 18yrs old No with ADHD=563	10 CAMHS teams (city wide) & 2 dedicated ADHD teams (Clyde)	Responses from two CAMHS teams. • A4 black and white leaflet produced 'in house' entitled ADHD Family information on stimulant medication. • Paper copy of RCPsych pdf factsheet No5 entitled ADHD and hyperkinetic disorder • pdf copy of RCPsych Factsheet No 6 entitled stimulant Medication. • Product specific PILs from product manufacturers e.g Janssen, UCB Pharma
NHS Highlands Pop= 302, 530 44,900 <18yrs old No with ADHD=245	1 CAMHS & 1 community paediatrics team	No response
NHS Lanarkshire Pop=557,088 122,654 <18yrs old No with ADHD=200	4 CAMHS & 1 generic paediatric clinic at Wishaw General Hospital & 1 generic Community Paediatrics team	No materials routinely provided.
NHS Lothian Pop=792, 593 168,000<18yrs old No with ADHD=880	4 CAMHS & 2 dedicated ADHD teams in city & 1 CAMHS/ Community Paediatric team in West Lothian	Five leaflets/booklets received from three CAMHS teams. • paper copy of 10 page pdf A5 booklet by ADDISS. • 12 page A5 sized booklet entitled 'Understanding ADHD' by MIND. • 10 photocopied pages from a book entitled Help4ADD@HighSchool which is aimed at teens with ADHD. • Eight A4 size photocopied pages taken from an unknown resource stapled together entitled 'coping with an ADHD child' • NHS Health Scotland ADHD booklet entitled 'Talking about ADHD' West Lothian provides a pack containing seven different pieces of information in a variety of formats. • Three A4 double sided leaflets describing the role of the Assessment Clinic, the ADHD Nurse and the Outreach Teacher • 3 X A4 size documents each between 4-10 pages long. • 2 A4 pages on general information using a Q&A format, specifically aimed at the young person and their parents. • Leaflet about diet and which foods to avoid. Workbook specifically for child summarising information contained in the other booklets.

Health Board	Service Provision	Nature of resource
NHS Orkney Pop=19,590 4,000<18yrs old. No with ADHD=14	SLA with NHS Grampian. (Psychiatrist & paediatrician 1-day clinic every 3 months)	• NHS Health Scotland ADHD booklet.
NHS Shetland Pop= 22,000 5151 <18yrs old. No with ADHD=39	SLA with NHS Grampian (Psychiatrist clinic every 6 weeks) 1GP led Child Health team; 1 Health Visiting Team & 1 Children & Families social work team.	2 leaflets • pdf copy of RCPsych Factsheet No5 entitled ADHD and hyperkinetic disorder • pdf copy of RCPsych Factsheet No 6 entitled Stimulant Medication.
NHS Tayside Pop=389,707 79,104<18yrs old No with ADHD=400	1 Developmental Psychiatry Team based at Centre for Child Health, Dundee. (psychiatrist & paediatrician input)	• Glossy booklet by Janssen-Cilag entitled 'ADHD: a compact guide for parents'. Areas covered include diagnosis, treatment, medication (not just Concerta) and details of other resources. Booklet contents written by child psychiatrists.
NHS Western Isles Pop=26,370 5,462<18yrs old No with ADHD=12	1 generic CAMHS & SLA with NHS Highland (monthly psychiatric clinic)	• Glossy booklet produced by Janssen-Cilag entitled ADHD- A compact guide for parents. (as above) • pdf copy of factsheet produced by local Occupational Therapy service

Population data and numbers of children with ADHD are based upon a national survey conducted in 2003 (NHS QIS, 2008. Services over Scotland)

3.4.4.2 Evaluation of information resource using questionnaire (basic criteria)

Six of the printed resources used within NHS Scotland were further evaluated. These were:

A Changing Lanes: A guide for parents/carers & children & young people with ADHD. No date

B ADHD Aberdeen & North East Family Support Group: All about ADD/ADHD. 2000

C Janssen-Cilag: ADHD-A compact Guide for Parents. 2006

D Lilly Strattera-Information pack. 2008

E West Lothian Community Health & Care Partnership: ADHD. 2005

F NHS Health Scotland: Talking About ADHD. 2005

The resources were produced by a variety of agencies including the NHS, pharmaceutical industry and ADHD support groups. Their details and results of their 'suitability analysis' are provided in Table 3.6.

Table 3.6 Properties of printed resources used within NHS Scotland.

	A	**B**	**C**	**D**	**E**	**F**
Type of publication						
• Single sheet						
• Leaflet <10 pages					✓	
Booklet >10 pages	✓	✓	✓	✓		✓
Topics mentioned:						
• ADHD symptoms	✓	✓	✓	✓	✓	✓
• Diagnostic process	X	✓	X	✓	✓	✓
• Non pharmacological interventions	✓	✓	✓	✓	✓	✓
• Medication	✓	✓	✓	✓	✓	✓
Medication specific topics:						
• Generic names used	X	✓	✓	✓	✓	✓
• Administration & dosing details	X	✓	✓	✓	✓	X
• Explanation of how medication works	✓	X	✓	✓	✓	✓
• Common side effects listed	✓	✓	✓	✓	✓	✓
• Limitations of drug treatment explained	X	X	✓	✓	✓	✓
Suitable for						
• parents	✓	✓	✓	✓	✓	✓
• Child/young person	✓	X	X	X	✓	X
• School teacher	✓	✓	✓	✓	✓	✓

3.4.4.3 Evaluation of information resource using the SWEF

The total, clinical content and physical appearance scores for each of the six printed resources are given in Table 3.7.

Table 3.7 SWEF scores for printed information resources per host category

	SWEF Total score (max 40)	**SWEF Content score** (max 28)	**SWEF Physical score** (max 12)
Charities/support groups			
A Changing Lanes	21 (52.5%)	11 (39%)	10 (83%)
B All about ADD	17 (42.5%)	10 (36%)	7 (58%)
Commercial organisations			
C Janssen Cilag ADHD guide	30 (75%)	19 (68%)	11 (92%)
D Lilly Strattera pack	29 (72.5%)	18 (64%)	11 (92%)
Government/professional			
E West Lothian ADHD pack	31 (77.5%)	22 (79%)	9 (75%)
F NHS Scotland booklet	25 (62.5%)	17 (61%)	8 (67%)

The government/professional category only contained NHS produced resources, one of which (West Lothian ADHD pack) scored the highest for the total and clinical content scores. Industry based literature (from Janssen Cilag and Lilly) scored the highest when measured against attributes concerned with physical appearance. The charities / support groups scored the lowest in all three categories.

In depth analysis of individual resources and their scores per SWEF attribute show that some attributes are better addressed than others. For example, all the resources scored the maximum 2 points for their descriptions of the core symptoms and the different ADHD subtypes and all, except those by the support groups, scored maximum points for prevalence details. Only one resource (NHS West Lothian pack) provided a detailed description of ADHD aetiology and prognosis of the disorder. All the resources except the one by Changing Lanes scored maximum points for their descriptions of (non drug) treatment including details of educational and behavioural interventions. All the resources mentioned medication but none commented on the limitations of the long term safety of the psychostimulants. All the resources mentioned side effects but only three (Resource B, C & E) provided details of four or more specific adverse effects. Two resources (Janssen & the West Lothian pack) provided detailed descriptions about the different stimulant formulations. The publications by the support groups did not mention this aspect at all. The two NHS publications briefly mentioned other possible drug treatments,

such as clonidine and antidepressants. All the resources mentioned co-morbidity. Three resources (including the two NHS publications) displayed a disclaimer or made reference to consulting a health professional. All the resources provided detailed information for additional support and hence scored the maximum two points. Telephone numbers for various support groups and charities were provided in all the resources. Most resources also provided web site addresses for various organisations, including ADDISS. Six resources had details of books written by parents and other self help publications.

All the resources except one (by the Aberdeen group) listed an author and their contact details and all had a date of publication, however, only the two industry resources were less than 3 years old. The majority scored maximum points for their layout except the Aberdeen group and the West Lothian pack which both scored 1. Two publications had the desired FRES of above 60. One of these was the West Lothian pack and the other was written by the Changing Lanes support group. Both organisations had separate leaflets within their larger packs that were specifically written for a younger audience.

3.5 DISCUSSION

This study has uncovered several issues in relation to the provision of written information by clinicians and by locally delivered ADHD services. It has also allowed comparisons to be made between the two professions most closely involved in the treatment of ADHD with regards to their practice, attitudes and knowledge of certain ADHD issues.

3.5.1 Findings from the clinician online and postal survey

3.5.1.1 Provision of printed information resource by clinicians

The majority of clinicians who responded to the study admitted to providing some form of written information to the parents or carers of children receiving treatment for ADHD. However, about a third of respondents indicated that they never or only rarely provide written material. Reasons for non-supply require further investigation if only to determine what barriers, if any, exist in providing information. It could be that the clinician expects, or there are systems in place by which, other members of the multidisciplinary team actually provide the information. This lack of clear responsibility amongst team members as to who should provide what information has also been noted in other chronic illness research and was identified as an issue as far back as the 1970s (Pleiss *et al.*, 1978).

Since details of where and in which NHS region the clinicians practised were not collected, it is difficult to say if non provision of information by clinicians correlates with the findings of the second study. Whilst collecting data from the various services, it transpired that many of the ADHD teams in the country are actually nurse led and information is provided, albeit not personally by the clinician. Most of the resources identified by the clinician (in study 1) and by the teams (in study 2) tend to consist of printed leaflets or factsheets, probably because of their size and ease of use. None of the clinicians provided hard copies of the resources they used, so the content and readability was only assessed for the resources provided by the individual teams (identified in study 2). The clinicians and local teams appear to use resources produced by a variety of organisations, namely the pharmaceutical

industry, charities and other professional bodies, including the NHS and the Royal College of Psychiatrists. Industry produced literature is often of a high standard and can be extremely informative and useful (Jaffray, 2001). However, commercial undertones and product placement can raise ethical issues which may compromise its utility. It also appears that well-established, and presumably well-equipped, services tend to use and distribute information leaflets that have been produced in-house, e.g. NHS West Lothian. Further work may be needed to identify why clinicians do not make greater use of literature produced by their own professional bodies or mental health charities or even share in-house resources.

3.5.1.2 Content of primary information resource provided by clinician.

The content of the resource was used as a proxy measure to determine how useful it would be to a potential reader. Hummelinck and Pollock (2006) reported that parents of chronically ill children find information about the diagnosis of the disease, its management and prognosis the most pertinent. Most of the clinicians in this study appear to use resources that mention the above issues. All resources detailed information about the symptoms, and nearly all mentioned medication. Considering the multimodal nature of ADHD treatment, it is unfortunate that behavioural / educational interventions did not feature to the same extent as drug therapy. One explanation for this anomaly may be that some resources, especially those produced by the pharmaceutical industry, may be biased or selective in the treatment options they present. Only a third of clinicians use resources that mentioned the actual diagnostic process. This issue was also neglected in the resources provided by some of the local groups, namely those by Changing Lanes and the Aberdeen support group. Whilst it may not be possible to provide specific details of the diagnostic process, which is often dependent on local service provision, one would have expected the more locality based resources to be able to do this.

Almost all the resources referred to the medication by its generic name; although literature produced by the pharmaceutical industry used both branded and generic names. The media often refer to Ritalin® as 'the' treatment for ADHD, so it is important that in literature aimed at the public, a distinction is made between brand

and trade names and parents are made aware that not all stimulant medication is 'Ritalin®'. Brand names should ideally be reserved for distinguishing between formulations, in particular those of MPH.

Side effects are often reported as the main concern individuals have about their medication (Nair *et al*., 2004; Dickenson and Raynor, 2003). Three quarters of the resources used by the clinicians and all the resources distributed by the local ADHD services listed information about common side effects. The more serious and rarer side effects of stimulant medication, which often attract the most publicity, were not mentioned to any great extent in any of the resources. Given that the successful treatment of ADHD is often dependent on the careful manipulation of different doses and formulations, it was reassuring to find that the majority of resources did provide information about dosages and frequency of administration.

3.5.1.3 Information gaps identified in printed resource

Some gaps in information were identified by the clinicians in areas relating to behavioural and educational interventions to manage symptoms and age appropriate information about illicit drugs and alcohol. With regards to the latter, it may be that industry produced literature is bound by certain professional or ethical guidelines, such as those by the Association of the British Pharmaceutical Industry (ABPI), which make it inappropriate or unlikely that they would mention risky and illegal behaviours. However, some agencies, particularly those in the voluntary sector, such as Lifeline and Drugscope, tend to adopt a harm reduction approach to substance misuse and so may have age appropriate literature on drug and alcohol misuse that clinicians might find useful.

3.5.1.4 Usefulness of resources

The majority of clinicians reported their resource as not being appropriate for children. However, some local teams, most notably those in Forth Valley and West Lothian, provide resources especially written for children and the young person. Perhaps these particular resources could be made more freely available and used throughout NHS Scotland. The majority of resources were mainly written from a

parental viewpoint but are still likely to contain information that any adult with responsibility for a child with ADHD would find useful. This may explain why clinicians considered their resource to be appropriate for schoolteachers. Further investigation is required to find out where schoolteachers get information about ADHD and if they ever directly consult the clinician or any of the information resources supplied by them. A study among Australian primary schoolteachers found that over three quarters rarely or never contacted the child's doctor for information (O'Keefe and McDowell, 2004).

3.5.2 Knowledge of internet sources of information on ADHD (ADHD websites)

The most popular websites, identified as those that had been visited by the majority of clinicians, were: ADDISS (A National ADHD charity offering information and support); BMJ Best Treatments ADHD page; and MIND (a mental health charity). The least popular websites were those hosted by a psychology consultancy service and internet based health websites.

It is perhaps not that surprising that the ADDISS website was so popular. The ADDISS URL often appears in the list of top five sites whenever the term ADHD is entered into the Google search engine. The ADDISS charity is very active with regard to fundraising and is a stakeholder in many ADHD / NHS initiatives. It would be pertinent to investigate how useful the clinicians found these sites as sources of information for their patients and their families, particularly as two NHS regions have teams where pdf factsheets from the ADDISS website are used as sources of ADHD information.

The psychiatrists generally had a better knowledge of ADHD websites than the paediatricians. There were also some characteristic trends. For example, almost half of the psychiatrists had visited the Janssen-Cilag site compared to only a quarter of the paediatricians. Janssen-Cilag is a major supplier of psychiatric pharmacotherapy and most psychiatrics would be familiar with their products and services. Consequently, a psychiatrist may have other reasons for visiting the Janssen site and

could easily find themselves at the Janssen ADHD page. A higher proportion of psychiatrists indicated knowledge of the MIND website. This may be a reflection of their overall increased awareness of the mental health charity. It may also explain why a greater proportion of paediatricians indicated knowledge of the NHS Direct site, which by definition is a more generalist medical site. Some clinicians indicated knowledge and recommendation of other sites; a few of which were not of UK origin: CHADD (USA) and Shrinkrap (Australian). The usefulness of these sites is questionable, for reasons discussed in Chapter 2. However, it would be helpful to determine why clinicians recommend non-UK sites and if they have ever encountered any problems by doing so.

Overall, the findings confirm that clinicians are generally aware of ADHD websites and also, perhaps inadvertently, have knowledge of sites that have been found to perform the best when measured using a systematic evaluation approach.

3.5.3 Clinician attitudes towards school teachers

3.5.3.1 Clinician perception of school teacher's knowledge

The majority of clinicians lacked faith in the ability of school teachers to recognise the symptoms of ADHD and in their knowledge about the purpose of medication. Some clinicians perceived a need for better education and training for schoolteachers. Similar opinions were expressed by Venter *et al*., (2004) who found that 96% of paediatricians and 97% of psychiatrists reported that management of children with ADHD could be improved through teacher education. Venter *et al*., (2004) also found that professional status and gender of the clinicians had an effect on their expectations with respect to schoolteachers. No such differences were found in the present study but this may be due to the small sample size. However, this study did find paediatricians to be more receptive to the abilities of schoolteachers than psychiatrists. One reason for this may be that paediatricians, especially community (child health) paediatricians, probably have more experience and contact with teachers because they tend to treat a wider portfolio of childhood conditions, including physical health problems. This may make them more familiar with the school environment and appreciate its role in the management of a condition. In

contrast, psychiatrists may be less familiar with the teaching profession; in fact, very few mental health multidisciplinary teams, including CAMHS have a designated schoolteacher as part of their service.

It is interesting to find such little faith in school teachers' abilities, even though they are often asked to report on the progress of the child before and during medication trials. Eighty percent of Venter's respondents (2004) often or always obtained information from the school as part of their assessment and 77% of Kwasman's (1995) sample reported obtaining a written report from the schools of children they treated, while some (39%) reported telephoning the school for information. The lack of faith in the knowledge and abilities of schoolteachers that was identified in the present study does not bode well as most cases of ADHD are dealt with on an outpatient basis, where the role school reports and assessments is paramount. Further work should investigate the extent to which schoolteachers contribute to assessment and feedback to the clinical team.

3.5.3.2 Addressing shortfalls in school teacher's knowledge

Clinicians were able to identify topics of education or training that they felt would benefit schoolteachers. The suggested topics appear to be rather basic and one would expect them to be covered in most teaching training curriculums. Clinicians expressed a desire for teachers to have better understanding about the role and limitations of medication as well as some appreciation of its side effects, especially those that may affect the child's presentation in the classroom.

Most clinicians indicated that printed media would be best for imparting information about ADHD to schoolteachers, even though more sophisticated options were given, such as CDs, DVDs and the Internet. Ambivalence towards new technology from these respondents may be expected to some degree considering the poor response to the online survey. Some respondents indicated that lectures or other face to face formats should be used. One respondent commented that they had been told by some schoolteachers that they considered lectures to be the most effective medium for them. This coincides with findings from another study, which found that

schoolteachers preferred written material accompanied by in-service training about the disorder and its treatment (O'Keefe and McDowell, 2004).

3.5.4 Limitations of findings from Study 1

3.5.4.1 Design limitations

The low response rate from clinicians imposes limitations on the generalisability of the findings and threatens the validity of the study because of potential non-response bias. The non-responders may be clinicians who provide completely different formats and types of information to their patients or they might not provide any at all. Therefore, a degree of caution is required when interpreting the findings of this study.

The online method was chosen for data collection because it is more cost effective than a postal survey and data can be collected much quicker. It was also assumed that most clinicians working in the NHS are familiar with information technology and would prefer to complete a questionnaire online. It is unclear why there was such a poor response to the initial online survey. The design and format of the survey was relatively simple but did require at least ten minutes for completion. This may have been too much of an intrusion into busy clinical time, although no questionnaires were returned partially completed.

It is possible that the actual recruitment process was itself too laborious since it depended on the clinician receiving the letter of invitation and then accessing the webpage, which required additional effort. Some clinicians may have doubted security assurances and might be concerned about confidentiality, especially as online surveys can never be truly anonymous. Some degree of identifiable information can be visible to administrators because of user names, which are allocated by the Internet Service Provider. This may also explain why no questionnaires were completed via the RCPsych 'what's on' page. One respondent commented on their returned postal questionnaire that they had been unable to access the university SPIDER site from their NHS homepage. This may also have been a problem for other clinicians. Furthermore, some clinicians may not have had

computer access at the address to which the letter was posted. If access for these individuals was only possible from a different location, it required a certain degree of tenacity on their part to participate in the survey.

Previous studies have shown that clinician response rates to surveys, especially postal surveys, tend to be low, averaging at 61% (Cummings *et al.*, 2001). Differences have been identified among clinical specialities and according to the methods used for recruitment. The response rates in the present study were lower than those reported in postal survey of paediatricians and psychiatrists (61% and 52% respectively) conducted by Venter *et al.,* (2004). However, at 35%, the paediatrician response rates were similar to the 38% reported by Kwasman *et al.,* (1995) in their postal survey of American paediatricians' knowledge and attitudes about ADHD.

3.5.4.2 Methods used to increase response rates

a) Reminder letters

Two reminder letters were sent to respondents; however as the need to access the website may have been the limiting factor, it was decided to include a paper version of the questionnaire with the final letter of invitation. The paper version was redesigned so that it fitted onto one double-sided A4 sheet and mostly required tick box responses for completion. It was considered not to be too time consuming and a stamped addressed envelope was included, which might explain why so many questionnaires, both completed and uncompleted, were returned. A mixed method approach of web and mail survey has been shown to increase response rates (Beebe *et al.*, 2007) particularly if respondents can be directly contacted via their email address.

b) Incentives

Offering incentives, especially in the health care setting, can raise ethical issues. Those offered 'up front', and not necessarily of a financial nature, produce better response rates than promised incentives (Delnevo *et al.*, 2004). On the whole, evidence for incentives is not conclusive and they do not appear to influence

response rates of health professionals for work related surveys, which is why an incentive was not offered in this particular study.

c) Survey design

Short questionnaire length, personalised letters, coloured ink, stamped address envelopes, especially 1st class, University headed paper and saliency of topic have shown to have a positive effect on clinician response rates to surveys (Edwards *et al.*, 2002). Several of the strategies discussed in this review were utilised in the data collection of this study. Saliency of topic became especially apparent from the large number of questionnaires returned from ineligible individuals offering their support and by the amount of detailed information provided in response to some of the questions.

3.5.5 Study 2: Evaluation of printed information resources using the SWEF

Printed information resources supplied in those areas with the largest number of ADHD patients were evaluated using the SWEF. Differences in format between online and printed resources meant that some of the desired (physical) attributes were not applicable. This resulted in the SWEF total scores and physical scores for the printed and online resources not being directly comparable. Nevertheless, the government/professional category scored the highest followed by the commercial organisations category. In this study, the commercial category only contained literature produced by the pharmaceutical industry. The SWEF evaluation also found that most resources adopted an 'all or nothing' approach with their provision of information. In other words, if a topic is mentioned it tends to be fairly detailed. A typical example is the SWEF attribute which measures how well the disorder and its symptoms are described. In this case, all the publications scored the maximum 2 points. The opposite occurred for the attribute detailing stimulant safety. All the publications scored zero points in that regard. Similarly, none of the publications scored the maximum two points for information about contraindications to stimulant therapy. When measuring the physical characteristics, fewer extremes were seen. Only a few scored zero points for any of their physical attributes. It is interesting to find that Janssen-Cilag performed so well in the evaluation of both its printed and

online resources. A further detailed analysis would be appropriate to uncover the similarities and differences between these resources. One obvious similarity is the authorship of the material as it seems it is the same person who writes the printed material as well as its online counterpart.

The government/professional category contained the highest scoring material which is similar to the online evaluation findings which also scored NHS websites as very high. This suggests that the resources produced by clinicians and those actively involved in the delivery of ADHD services appear to be the best at producing the most meaningful and useful information (either online or in print format) to members of the public.

3.6 CONCLUSIONS

The main findings of this chapter are:

- The majority of clinicians who responded to the survey provide some degree of written information about ADHD to the parents and carers of their patients.
- Much of this information is presented in leaflet format.
- Most of the leaflets contain basic information about the disorder but are more detailed when discussing the medication.
- The quality and nature of written information varies considerably between clinicians and in services operating within the same NHS region.
- Most of the clinicians surveyed are unconvinced that schoolteachers have adequate knowledge and understanding of ADHD issues.

Chapter 4

Knowledge and attitudes of qualified and student teachers regarding ADHD and its pharmacological treatment

4.1 INTRODUCTION

4.1.1 ADHD in the school

A child with ADHD is likely to find that their symptoms are most problematic within the classroom, compared to other environments, such as the home. School teacher's involvement in the management of the disorder is well recognised and documented elsewhere (Cooper and Bilton, 2002). One would therefore expect school teachers to be familiar not only with the physical presentation of ADHD but also to be knowledgeable about the expected effects of medication, including side effects, which can also affect the child's behaviour or functioning. In the UK, there is an expectation that teachers become more closely involved in the diagnostic and treatment phases of ADHD and that there is close liaison between health and education services (SIGN, 2001; NHS QIS, 2008). For these developments to be effective, it would suggest that teachers have a sound knowledge of both the disorder and its treatment.

4.1.2 School teachers and ADHD

4.1.2.1 School teacher's knowledge of ADHD and stimulant medication.

Much of the literature in this area relates to American and Australian school teachers who teach in 'elementary' or 'middle' schools and are the equivalent of primary school teachers in the UK. Most of these studies use a similar methodology (self administered questionnaires) and comparable questionnaire items. The results tend to be reported either as a comparison between different types of teachers, for example, regular and Special Needs, or between teachers in different geographical areas, for example, New York and Florida. The studies show that knowledge of the aetiology, symptomatology and educational implications of the disorder amongst teachers is highly variable. One study averaged 77% for correct answers (Jerome *et al.,* 1994) in relation to ADHD and school teachers' knowledge whereas another averaged less than 50% (Sciutto *et al.,* 2000). The large disparity in scores seen in these studies may be a true indication of knowledge but could also be due to the format of the survey instruments used to collect the data. Studies reporting higher scores used questionnaires with fewer items and a format which relies on true or

false answers, whereas those with lower scores tended to be longer in length and collated true, false and don't know responses. The inclusion of a 3rd 'don't know' option may have reduced the likelihood of respondents guessing and hence produced a lower proportion of correct answers.

The American studies found that teachers lacked not only factual clinical knowledge about the disorder but also appeared to believe or endorse some of the associated myths, for example the association between E numbers or diet and hyperactivity (Jerome *et al.,* 1994). Knowledge of ADHD medication was found to be particularly poor. In the study by Kasten *et al*., (1992), half the sample of regular teachers was unaware of the behavioural and physical effects of stimulant medication. Elementary and middle school teachers were found to be more positive about the usefulness of stimulants than their high school counterparts. Whilst some teachers are likely to have misconceptions towards the acceptability and use of medication, perhaps this is amplified amongst high school teachers who may perceive stimulants as inappropriate or dangerous because of the older group of children that they teach. They might think that 'risk taking behaviour' and peer pressure make the use of any kind of psychoactive drug inappropriate or unsuitable in this age group. Snider *et al.,* (2003) found that whilst teachers had basic understanding of the effects of medication, they had little knowledge of the side effects. This is despite findings from the Kasten *et al*., (1992) survey (which was conducted 10 years previously) where it was found that the majority of respondents (70%) agreed with the statement that "teachers should take greater responsibility for reporting side effects to parents and clinicians". If teachers do not know what the side effects are or what to look out for, then the utility of any feedback that they provide is likely to be limited.

More recently, Australian researchers compared knowledge and attitudes between student teachers and qualified teachers (Bekle, 2004) and between primary and secondary school teachers (West *et al.*, 2005). Both studies used self administered questionnaires similar in content to those used by Jerome (1994) and Sciutto (2000). Bekle (2004) found qualified teachers to be better informed than student teachers about the causes of ADHD and associated myths, however any differences were

small and the overall knowledge base of both samples was generally poor. Knowledge scores amongst Australian primary school teachers were found to be higher than secondary school teachers (West *et al.*, 2005). Both groups were, however, most knowledgeable about the causes of the disorder, followed by its characteristics and least knowledgeable about its treatment

Relatively little is known about the knowledge and understanding that British school teachers have of ADHD. One study of primary school teachers compared their beliefs about the disorder with their Canadian counterparts (Couture *et al.*, 2003). Since the UK sample was taken from those attending a CPD course (unrelated to ADHD), it is perhaps not surprising that the majority regarded ADHD as a true biological problem, however, both British and Canadian teachers felt that medication was overused. In another study investigating the prevalence of ADHD in three school districts within the UK (Holowenko and Pashute, 2000), the need for information about medication, particularly administration details, its effects and side effects was ranked as the second most frequent comment when respondents were asked for any additional issues they wanted to highlight to the survey team.

A breakdown of the methodology and main findings of all the studies discussed in this chapter are provided in Table 4.1.

Table 4. 1 Summary of literature investigating school teacher's knowledge about ADHD and/or stimulant medication.

Author & year	Study Details	Aims & objectives	Parameters investigated	Results	Methodological Issues
Kasten *et al.* 1992	**Location** Ohio, USA **Population** Elementary, middle & high school teachers **Method** 27 item self-administered postal questionnaire. **Sample size** N = 201 (RR 65%)	1. Determine teachers' knowledge about effects & side effects of stimulants. 2. Compare knowledge between Special Needs & regular teachers.	Demographics including years of experience, current & past teaching roles & level of PG training. Factual knowledge, attitudes & beliefs about stimulants.	80% elementary, 66% middle school and 40% of high school teachers believe stimulants are useful. 50% of regular and 19% of Special Needs teachers unaware of behavioural or physical side effects of stimulants 96% of sample received little or no training about stimulants in their UG studies.	Study population localised so difficult to generalise. Study currency limited as conducted over 15 years ago.
Jerome *et al.* 1994.	**Location** New York & Florida, USA Ontario, Canada **Population** Elementary school teachers of various grades. **Method** 40 item self-administered questionnaire. **Sample size** N = 1289	1. To assess teachers' knowledge of essential concepts involved in the diagnosis and treatment of ADHD.	Demographics including educational background and training in ADHD. Knowledge of basic concepts assessed by 20 True/False questions.	Mean score out of 20 was 15.5. Staff lacked knowledge of long term prognosis. >90% of sample received no training about ADHD in their UG studies. >97% expressed strong interest in wanting additional training. 86% of both samples reported having no contact with the outside clinician.	The true / false format may give an inflated correct response due to guessing. Specific questions relating to medication effects not asked.

Author & year	Study Details	Aims & objectives	Parameters investigated	Results	Methodological Issues
Sciutto *et al.* 2000.	**Location** New York, USA **Population** Elementary school teachers. **Method** Postal survey using 36 item scale. **Sample Size** N = 149 (RR 37%)	1. Examine teachers' knowledge & misconceptions of ADHD.	Demographics Knowledge of symptoms, diagnosis and treatment General information about nature, causes and outcome of ADHD.	Scores on symptoms / diagnosis subscale higher than scores on treatment and general information subscales. 'Don't know' responses lower for symptoms but equal for general information and treatment. Past experience with teaching a child with ADHD gives better response.	Likely to be lower incidence of guessing the correct response as questionnaire used a True / False / Don't Know format.
Snider *et al.* 2003.	**Location** Wisconsin. USA **Population** 400 regular & Special Needs teachers of various classes. **Method** Postal self-administered questionnaire **Sample Size** N= 145 (RR 36.5%)	1. Teachers' knowledge about ADHD and its treatment. 2. Determine teachers' opinions about effect of stimulants on classroom behaviour and academic work. 3. What are teachers' experiences of ADHD students?	Demographics. Factual knowledge using 5 point Likert scale (13 items) Views of stimulant medication (23 items) Source used most frequently to obtain information about ADHD.	Modal score of 3 indicating uncertainty or ambivalence amongst respondents. Knowledge about stimulant effects on classroom behaviour generally good but poor regarding side effects. Sources of information: *In service training = 80%* *Parents of children with ADHD = 57%* *Professional journals = 48%* *Media = 45%* *Professional organisations = 40%* *CHADD (US parent support group) = 17%*	Low response rate. 5 point Likert instead of 4 point may have contributed to neutral responses. Some survey items ambiguous or misleading.

Author & year	Study Details	Aims & objectives	Parameters investigated	Results	Methodological Issues
Beckle B 2004	**Location** Perth, W Australia **Population** Qualified teachers & final year Primary Education students. **Method** Self administered questionnaire **Sample Size** N= 70	1. Investigate differences between practising teachers and UG student teachers. 2. Determine relationship between knowledge and attitudes.	Demographics including years teaching experience, training. 20 True/False questions (similar to Jerome *et al*). 7 point Likert to measure attitudes.	Means score for teachers was 16.6 and 15 for students regarding knowledge. Qualified teachers better informed regarding ADHD myths. No significant differences regarding attitudes. 95% of student teachers received some training in ADHD but still performed poorly when tested for factual knowledge.	Small convenience sample.
Kos, Richdale & Jackson 2004	**Location** Victoria, Australia **Population** 16 Primary schools and final year Education degree students **Method** Self administered questionnaire. **Sample Size** N= 165	1. Investigate relationship between teachers' characteristics and knowledge of ADHD. 2. Compare knowledge between in-service and pre-service primary school teachers.	Demographics 27 item questionnaire using True/False/Don't Know format (based upon Jerome *et al* and Sciutto questionnaires).	61% correct responses (higher than Scuitto but lower than Jerome samples). No correlation between ADHD knowledge and teaching experience. More experienced teachers perceive knowledge to be better than it actually is.	Sample restricted to one geographical area.

Author & year	Study Details	Aims & objectives	Parameters investigated	Results	Methodological Issues
West *et al*. 2005	**Location** Perth, W Australia **Population** Primary & secondary school teachers **Method** Teachers attending CPD course & random sample from schools. **Sample Size** N= 256	Determine teachers' knowledge of ADHD and its treatment.	67 item KADD-Q (Knowledge about Attention Deficit Disorders Questionnaire) modelled upon 20 item KADDS (Sciutto *et al*)	Mean knowledge scores significantly higher in primary school teachers than secondary. No correlation between years of teaching experience and total scores. Knowledge of causes is better than symptoms; even less is known about treatment.	Sample restricted to one geographical area. Use of True / False format can lead to inflated scores.
Couture *et al* 2003	**Location** Quebec Canada. Cambridge UK **Population** 1000 Canadian, 550 UK primary school teachers. **Method** Postal questionnaire **Sample Size** 331 (154 Canadian & 177 UK) RR 15% & 32%	1. Compare teachers' beliefs & knowledge about ADHD.	Self -administered questionnaire called ADHDOS (Bilton, 1996) Item agreement on 4 point Likert scale.	Beliefs patterns significantly different in both countries. Majority believe in an allopathic medical model, i.e. that ADHD is a biological problem with no conscious control by the patient. Fewer British teachers received information about ADHD in their UG training compared to Canadian teachers (7% vs 40%) Both groups of teachers believed that medication was overused.	Relatively low response rate from Canadian teachers. British teachers taken from sample who had attended post qualification course. Might have introduced bias.

4.1.2.2 School teachers training and sources of information about the disorder

One would expect to find a relationship between an individual's experience of teaching children with ADHD and their knowledge base. This is not reflected in the literature surrounding the subject. Years of teaching experience was related to knowledge of ADHD in Canadian teachers but not in American (Jerome, 1994) or in Australian teachers (Kos *et al.*, 2004). Reasons for this anomaly are unclear but it does imply that exposure to the condition is not enough to inform knowledge or understanding. Most of the teachers investigated reported to have received little or no training about the disorder in their undergraduate studies (Kasten *et al.,* 1992, Jerome *et al.,* 1994). Most teachers also reported that whilst they do consult the specialist literature or their colleagues for information about the disorder, other lesser quality resources, including the media, were also relatively popular (Snider *et al.*, 2003).

4.1.3 Pre and post qualification education for school teachers in Scotland.

In Scotland, compulsory schooling occurs at the primary level (pupils aged 5-12 yrs) followed by secondary education (13-18 yrs). Teachers can train to teach in either sector. The training programmes are known as Initial Teacher Education (ITE) and are offered by seven accredited institutions across the country. ITE is offered either as a four year undergraduate programme such as the Bachelor of Education or the one-year Professional Graduate Diploma in Education (PGDE) usually after completion of a degree in a relevant subject (TeachingInScotland, 2008).

Each institution offering the ITE must be accredited by the General Teaching Council of Scotland (GTC). The GTC of Scotland is the independent regulatory body for the teaching profession in Scotland. Only teachers registered with the GTC can teach in Scottish schools. Teachers who have passed the ITE programme must undertake a further year of probation; the Induction year. On successful completion of the Induction year the individual becomes a fully registered teacher and is free to teach without supervision.

The ITE curriculum differs among institutions. Whilst they all cover important pedagogic techniques and theories most lack content about teaching children with

emotional and behavioural disorders (EBD), of which ADHD is one of the most common. The recognition and management of EBDs in ITE is largely non existent (Florian and Rouse, 2009). When it does appear it is generally reserved for those teachers who wish to specialise in teaching children with Special Educational Needs. The term Special Educational Needs refers to children who have learning difficulties or disabilities that impinge on their ability to learn (DCSF, 2008). In Scotland the preferred term is children with 'additional support needs' (ASN). Regardless of the terminology, these children often require extra help because of difficulties in thinking or understanding; physical or sensory difficulties; emotional and behavioural difficulties or difficulties with speech and language. By law, each school must have a nominated learning support teacher. These are known as Special Educational Needs Co-ordinator in England and Wales and Learning Support Teachers in Scotland. It is their responsibility to make sure that any child with special needs has these met in an appropriate manner (Record of Need).

There are no mandatory or professional requirements that these learning support teachers be further trained or hold additional qualifications related to Special Needs education. However, many of the teachers and indeed mainstream school teachers do undertake as part of their continuous professional development, courses that cover this aspect of teaching.

Of the seven GTC accredited institutions in Scotland, only three offer postgraduate courses that are specifically aimed at Special Needs Education. The Postgraduate Certificate in Additional Support for Learning at the University of Edinburgh does not offer any specific training on ADHD. The University of Glasgow Postgraduate certificate / diploma in Support for Learning includes the topic of social, emotional and behavioural difficulties but consists of a generalised introduction to EBDs and offers very few, if any, specific details about ADHD. The University of Strathclyde Postgraduate Certificate / Postgraduate Diploma in Educational Support offers a specialist module in Social, Emotional and Behavioral Difficulties but this does not include specialist training in ADHD.

It would, therefore, be safe to assume that the majority of teachers in most mainstream schools in Scotland have not received much training concerning the management of ADHD. This would suggest that teachers' understanding and knowledge of medication used in the treatment of ADHD is likely to be poor.

4.2 AIMS

To determine the knowledge and attitudes of qualified and student school teachers towards ADHD and its treatment and explore how the teachers source information about the disorder and what their professional training needs are.

4.2.1 Objectives

1. To develop a survey instrument based upon previously validated questionnaires to identify teachers' knowledge and attitudes towards ADHD and its treatment.
2. To recruit a sample of qualified and student teachers and administer the questionnaire to both.
3. To compare the knowledge base of both cohorts and identify any gaps (if they exist) in their knowledge.
4. To identify the sources of information both cohorts use to access information about the disorder.
5. To identify the education and training needs of teachers in relation to the treatment of ADHD.

4.3 METHODS

The study was discussed with academic staff in the Faculty of Education. A Senior Lecturer in Professional Educational Studies (MM) was identified to facilitate access to potential research participants.

4.3.1 Development of study questionnaire

4.3.1.1 Questionnaire content

A self administered questionnaire was developed that was similar in format and included some items from previously validated questionnaires (Jerome *et al.,* 1994, Kasten *et al*., 1992, Kos *et al.,* 2004). Subtle changes were made to some items to reflect the Scottish education system and drug specific terminology.

The first section (A) of the four part questionnaire was largely concerned with establishing the overall experience respondents had of ADHD. Respondent demographics including gender, qualifications held, number of years and type of teaching experience were also recorded. Details of potential sources of information about the disorder, including internet sources (the URLs of websites identified in chapter 2) were also provided and respondent's familiarity with those sites determined.

Section B was concerned with respondent knowledge of the disorder and its pharmacological treatment and consisted of 33 statements which required a True / False / Don't Know response. The "Don't Know" option was included to minimise the likelihood of guessing and increase the probability that the response was a true reflection of the respondent's knowledge.

Section C consisted of 13 statements designed to uncover respondent attitudes towards the disorder. Each statement required a response based upon a 5 item Likert index for agreement where 1 = strongly disagree, 3 = undecided, 5 = strongly agree.

The final section (D) was concerned with respondent training needs related to ADHD and how they would like these needs met. Responses in this section were made by checking multiple choice items.

A copy of the questionnaire can be found in Appendix 3.

4.3.1.2 Questionnaire validity and Pilot test.

The questionnaire was checked for content and face validity by academic staff in the Faculty of Education who also conducted a pilot test. The pilot test took 20 minutes to complete and resulted in minor changes being made to some of the wording and the layout of the questionnaire.

4.3.2 Ethics approval

Ethical approval for the study was sought and granted by the Faculty of Education ethics committee. A copy of the approval letter can be found in Appendix 3.

4.3.3 Sample recruitment

The sample of qualified teachers was taken from individuals enrolled on a week long (18^{th} – 22^{nd} February 2008) course at the University of Strathclyde (UoS) as part of the Post Graduate Certificate in Educational Support (Pg Cert in Ed Support). The sample of student teachers was taken from final year students on the Bachelor of Education (BEd) degree program at the UoS.

4.3.4 Data collection

Forty nine questionnaires were distributed by hand to the qualified teachers at the beginning of the first class on the 18^{th} February 2008. Participants were encouraged to complete the questionnaire as soon as possible and to return it no later than the end of the week. Daily reminders about the study were given by teaching colleagues.

Thirty two questionnaires were distributed by hand to the student teachers present at the first class on the 8^{th} of April 2008. Participants were given the option of returning the questionnaires at the end of that class or another time during the week.

4.3.5 Data analysis

Data were stored and analysed using SPSS Version 16. Total knowledge score for each individual were summed and the mean value calculated. The mean scores (value) per cohort were compared statistically using a Students t-test, with the significance level set at $p < 0.05$. When comparing cohorts in terms of the proportions answering an individual question correctly, Pearson's χ^2 test was used. Correlations between the number of years of service and knowledge scores were examined using Pearson's Correlation Coefficient (r) with the significance level set at $p<0.05$.

Teachers' beliefs and attitudes towards ADHD and medication were assessed using a series of Likert items. To compare attitudes across cohorts, mean values (in this case the mean level of agreement with that item) were calculated and differences were evaluated using Student's t-tests as before. This approach is in line with much research showing that Likert responses show broadly interval level properties (Nunnally, 1978).

4.4 RESULTS

4.4.1 Respondent demographics

Forty three questionnaires were returned by the qualified teachers and twenty five were returned by the student teachers. This gave response rates of 92% and 78% respectively. The total sample (n = 68) consisted of 59 females and 8 males (one missing response for gender). The qualified teachers had a mean number of 11.4 years (range 2 - 30) of teaching experience. The majority of qualified teachers were educated to degree level (10 with BEd and 25 with PGCE) while the rest (n = 6) held the Diploma in Education. The bulk of qualified teachers (n = 22) had experience of primary school teaching only, 5 teachers had experience of both primary and secondary and a third (n = 14) had experience of secondary school teaching only. A third (n = 14) of qualified teachers were currently teaching in a Support Unit within a mainstream school, 11 teachers taught in a mainstream primary school, another 11 in a Special Educational Needs school, and 7 teachers taught in a mainstream secondary school. The student teachers held both honours (n = 15, 60%) and ordinary degrees (n = 10, 40%) in a variety of disciplines including Business Studies, History, English and Modern Languages.

4.4.1.1 Experience of teaching pupils with ADHD and training received

A quarter of the qualified teachers had received some information about ADHD during their Initial Teacher Education, compared to just over half of student teachers. Most of the qualified teachers had experience of teaching a child with ADHD with 4 teachers indicating experience with over 10 children (Table 4.2).

Table 4.2 Teaching experience of ADHD amongst qualified (QT) and student (ST) teachers

Variable	QT *(n = 43)*	ST *(n = 25)*
Number of females in sample	36 (84%)	23 (92%)
ADHD training received in ITE course	11 (26%)	14 (56%)
ADHD training received since qualifying	15 (35%)	0 (0)
Ever taught a child with ADHD	33 (77%)	11 (44%)

4.4.2 Sources of information about ADHD

Of the fifty nine individuals who answered this question, the majority cited teaching colleagues (87%) and the internet (86%) as sources of information about ADHD. Just over half (54%) also choose the specialised literature option, followed by support teachers (49%) and in-service training (14%). Only four teachers (7%) chose the medical personnel option.

4.4.2.1 Knowledge of specific internet sources of information

Very few individuals had visited any of the sites listed in the questionnaire. Student teachers were less knowledgeable of specific ADHD websites than the qualified teachers, although numbers for both were low. The most popular site was the NHS 24 site (www.nhs24.com: Health information and Self Care advice from NHS Scotland), visited by 11 qualified teachers (QTs) and 3 student teachers (STs). This was followed by the ADDISS site (www.addiss.co.uk: National ADHD information & support service) which was visited by 8 QTs and 3 STs. The mental health charity MIND website (www.mind.org.uk) was visited by 7 QTs and 3 STs. Four individuals (2 QTs and 2 STs) had visited the HandsOnScotland site (www.handsonscotland.co.uk:Online resource for anyone working with children). One student teacher had visited the website by Janssen-Cilag (www.janssen-cilag.co.uk) which is the pharmaceutical company that manufacturers a formulation of methylphenidate in the UK. One student had visited the BMJ Best Treatments site (www.besttreatments.co.uk) which had been identified as the most informative site in an earlier chapter. Some of the qualified teachers indicated knowledge of other sites that they visited for information including Learning & Teaching Scotland (www.ltscotland.org.uk), ContactAFamily (www.cafamily.org.uk) and the health pages of the BBC (www.bbc.co.uk/health/conditions/attention2.shtml) which had all been visited by one respondent.

4.4.3 Knowledge of ADHD and its treatment

The knowledge of teachers was assessed in two areas

1. General knowledge of the disorder and its management (including medication).

2. Specific details about medication, in particular, its expected cognitive and behavioural effects and side effects.

4.4.3.1 General Knowledge:

The 15 items investigating basic knowledge of ADHD and its management were poorly answered by both groups as shown in Table 4.3. The mean (SD) number of correct responses was 5.1 (2.3) out of 15 and 5.4 (2.5) for qualified and student teachers respectively. The difference in mean values between the two cohorts was not statistically significant, $t_{(66)}= -0.37$, $p = 0.71$.

Some questions were better answered than others, most notably those on the distribution of the disorder between the sexes and the multimodal nature of treatment for ADHD. A third of each group were aware of the classroom prevalence of ADHD and while more student teachers were unaware of the genetic nature of ADHD, qualified teachers seemed particularly unaware of the different subtypes of ADHD. The majority of participants in both samples correctly identified that medication is not the only treatment for ADHD but only a few knew that there are no medical procedures or tests used in its diagnosis. Basic knowledge of medication was also poor, as seen by the relatively low proportions of correct responses to each question. The majority of respondents were aware that medication is not a cure for ADHD but just under half of both samples also incorrectly believed that a positive response to stimulants is indicative of underlying ADHD. More qualified teachers knew about the different stimulant formulations and their controlled drug status but seemed less knowledgeable about other drugs that can be used for treatment or that almost a third of individuals do not respond to stimulants. Only one teacher correctly answered the statement 'that stimulant use in childhood does not lead to drug addiction in adult life'.

Table 4.3 Percentages of respondents who correctly answered knowledge questions

Question	Correct answer	QT *(n = 43)* (%) correct	ST *(n = 25)* (%) correct
General knowledge of ADHD			
There are a greater number of boys than girls with ADHD	True	88%	80%
If medication is prescribed, educational interventions are often unnecessary	False	63%	40%
Approximately 5% of Scottish school-aged children have ADHD	True	30%	36%
ADHD can be inherited	True	26%	12%
There are 3 main subtypes/categories of ADHD	True	7%	32%
ADHD is a medical disorder that can only be treated with medication	False	58%	76%
Medical procedures are useful in the diagnosis of ADHD	False	16%	16%
Knowledge of pharmacological treatment of ADHD			
If a child responds to stimulant medication then they probably have ADHD	False	40%	48%
When stimulants are used they improve a child academic performance	False	33%	16%
Medication is a cure for ADHD	False	84%	84%
Antidepressants can be used to treat ADHD symptoms	True	9%	12%
Prolonged use of stimulant medications leads to increased addiction in adulthood	False	2%	12%
Almost 30% of children with ADHD do not respond to stimulant medication	True	14%	16%
Availability of different stimulant formulations means doses do not have to be taken during the school day	True	44%	24%
Controlled drugs are often used to treat ADHD symptoms	True	40%	32%
Mean (SD) score out of 15		5.1 (2.3)	5.4 (2.5)

QT = qualified teachers, ST = student teachers

The mean (SD) number of correct responses for teachers (including student teachers) with experience of teaching a child with ADHD was 5.1 (2.5). This value was not

significantly different from the mean value of 5.4 (2.3) obtained by teachers with no experience of teaching a child with ADHD $t_{(66)} = 0.5$, p=0.6. No relationships were identified between an individual's total knowledge score and their number of years of service as a qualified teacher, r = -0.06, p = 0.62.

4.4.3.2 Detailed knowledge of medication (including side effects)

Both groups lacked knowledge of medication. This is evident by the low mean number of correct responses for this section, as shown in Table 4.4. Student teachers had a slightly higher number of correct responses compared to qualified teachers; mean 3.6 (SD 3.4) compared to 3.3 (SD 2.8), although the difference was not statistically significant, $t_{(66)}$= -0.47, p = 0.64. Both groups were aware that medication improves concentration (70 – 72%) and decreases impulsivity (64 – 65%) but were less able to identify 'false' expected effects. For example, 40% of student teachers and almost a quarter of qualified teachers thought that medication increases peer interactions. A few individuals in both samples also incorrectly believed that medication improved long term memory and classroom performance. Knowledge of the side effects of ADHD medication was particularly deficient. However, most items in this section were answered with a 'don't know' response, indicating ignorance rather than false knowledge. Knowledge about the effects on mood and affect were also lacking, although a greater proportion of qualified teachers knew that symptoms of anxiety could occur in pupils who were taking stimulants (19% compared to 4%). However, this difference did not reach statistical significance, χ^2=2.51, p = 0.113.

Table 4.4 Percentages of respondents who correctly answered medication questions

Question	Correct Answer	QT (N = 43) (%) correct	ST (N = 25) (%) correct
Medication for ADHD has the following effect(s)			
Improves concentration	True	70%	72%
Decreases impulsiveness	True	65%	64%
Increases peer interactions	False	23%	40%
Improves long term memory	False	16%	28%
Improves classroom performance	False	12%	20%
Stimulant medication has the following side effects			
Decreased appetite	True	19%	20%
Insomnia or trouble sleeping	True	16%	20%
Day dreaming	False	7%	12%
Headache	True	19%	24%
Drowsiness	False	2%	8%
Stomach problems	True	9%	16%
Irritability	True	7%	16%
Low mood/sadness	True	19%	20%
Anxiety	True	19%	4%
Tics/nervous movements	True	9%	4%
Dizziness	True	12%	8%
Euphoria	False	12%	12%
Addiction	False	5%	0
Mean (SD) score out of 18		3.3 (2.8)	3.6 (3.4)

QT = qualified teachers, ST = student teachers

4.4.4 Attitudes of teachers towards ADHD and medication

These were determined by responses to statements using a 5 item Likert index for agreement. Table 4.5 details how each group answered each question where SA = strongly agree; A = agree; U = undecided; D = disagree and SD = strongly disagree.

Table 4.5 Number of respondents and their associated attitudes towards ADHD

Statement		Number of Respondents				
		SA	*A*	*U*	*D*	*SD*
ADHD is a valid diagnosis	QT	10	27	3	3	0
	ST	8	14	2	0	1
School teachers are trained to recognise the symptoms of ADHD	QT	0	3	6	19	15
	ST	0	2	3	16	4
ADHD is a behavioural disorder that should not be treated with medication	QT	4	1	22	14	2
	ST	0	0	11	13	1
Medication should only be used as a last resort	QT	14	12	14	3	0
	ST	1	7	12	5	0
School teachers have sufficient understanding of the purpose of stimulant medication	QT	0	1	2	21	19
	ST	1	1	4	15	4
All children with ADHD should take medication	QT	0	0	10	23	10
	ST	0	0	4	17	4
Some ADHD medication can cause mood swings	QT	1	10	30	2	0
	ST	0	5	20	0	0
School teachers should be aware of the side effects of ADHD medication	QT	20	18	1	0	4
	ST	11	11	3	0	0
Too many children are prescribed stimulants	QT	3	13	25	2	0
	ST	0	3	21	1	0
School teachers should be able to provide feedback to parents and doctors on a child's response to medication	QT	14	21	5	2	1
	ST	2	20	3	0	0
School teachers should be more involved in monitoring a child's response to medication	QT	4	29	4	4	2
	ST	0	17	7	1	0
Drugs other than stimulants are used in the treatment of ADHD	QT	0	5	36	2	0
	ST	0	2	23	0	0
I am able to tell if one of my pupils has not taken their ADHD medication that morning/day	QT	7	15	20	0	1

QT = qualified teachers, ST = student teachers

The above data can also be presented to give the mean value response for each question as shown in Table 4.6. This allows generalised statements to be made about

each cohort's attitudes and makes it easier to make comparisons between the two cohorts.

Table 4.6 Mean (SD) values for respondent attitudes.

Statement	All respondents mean (SD)	QTs mean (SD)	STs mean (SD)
ADHD is a valid diagnosis	4.1 (0.8)	4.0 (0.8)	4.1 (0.9)
School teachers are trained to recognise the symptoms of ADHD	2.0 (0.8)	1.9 (0.9)	2.1 (0.8)
ADHD is a behavioural disorder that should not be treated with medication	2.6 (0.7)	2.7 (0.8)	2.4 (0.6)
Medication should only be used as a last resort	3.6 (0.9)	3.9 (0.9)	3.2** (0.8)
School teachers have sufficient understanding of the purpose of stimulant medication	1.8 (0.8)	1.6 (0.7)	2.2** (0.9)
All children with ADHD should take medication	2.0 (0.6)	2.0 (0.7)	2.0 (0.6)
Some ADHD medication can cause mood swings	3.2 (0.5)	3.2 (0.6)	3.2 (0.4)
School teachers should be aware of the side effects of ADHD medication	4.2 (1.0)	4.2 (1.2)	4.3 (0.7)
Too many children are prescribed stimulants	3.3 (0.6)	3.4 (0.7)	3.1*(0.4)
School teachers should be able to provide feedback to parents and doctors on a child's response to medication	4.0 (0.8)	4.0 (0.9)	3.9 (0.4)
School teachers should be more involved in monitoring a child's response to medication	3.7 (0.8)	3.7 (0.9)	3.6 (0.6)
Drugs other than stimulants are used in the treatment of ADHD	3.1 (0.4)	3.2 (0.4)	3.1 (0.3)
I am able to tell if one of my pupils has not taken their ADHD medication that morning/day	N/A	3.6 (0.8)	N/A

Statements were rated using a 5 point Likert scale (1 = strongly disagree to 5 = strongly agree). **P<0.01; *P<0.05. QT = qualified teachers, ST = student teachers

There was general agreement that ADHD was a valid diagnosis; that teachers should be aware of the side effects of medication; that teachers should be able to provide feedback about a child's response to medication to parents and doctors and that they should be more involved in monitoring a child's response to medication. There was

overall disagreement with the statement that school teachers are trained to recognise the symptoms of ADHD or that they have sufficient understanding of the purpose of medication. Qualified teachers were more likely to disagree with this later statement than student teachers ($t_{(66)}$= -2.8, p = 0.006). All respondents disagreed with the statement that all children should take medication. Qualified teachers were more likely to agree that ADHD is a behavioural disorder that should not be treated with medication ($t_{(66)}$= 1.8, p = 0.08) and that medication should only be used as a last resort ($t_{(66)}$= 3.1, p = 0.003). They were also more likely to believe that too many children are prescribed stimulants ($t_{(66)}$= 2.1, p = 0.04).

4.4.5 Teachers training needs

Sixty six respondents (42 QT and 24 ST) indicated that they would benefit from further training in ADHD. The topics and the preferred format in which they would like to receive further training are outlined in Tables 4.7 and 4.8.

Table 4.7 Potential training topics and respondent numbers

Training Topic	QT *(n = 43)*	ST *(n = 25)*
Causes and prevalence of ADHD	32	18
Assessment & Diagnosis	23	17
Symptomology	33	19
Role of Medication	23	16
Classroom Management	39	23

Table 4.8 Respondents preferred medium for receiving training

Format	QT *(n = 43)*	ST *(n = 25)*
Lecture/presentation	28	21
Written medium (booklets)	12	21
Audio Visual (CD)	19	19
As a web page	16	21

Unsurprisingly, the majority in both samples wanted more training in the classroom management of the disorder. Such training tends to consist of advice and techniques on how maintain a therapeutic learning environment for the child who has ADHD whilst also equipping them with the skills on how to minimise the disruption that can be caused by such a child. Further training related to the symptoms and presumably

their identification was identified as a 2nd priority by both groups. The role of medication was also identified as a training issue by more than half of both samples.

The student teachers did not appear to have any particular preference for how any future training should be delivered. Qualified teachers however seemed to prefer a lecture format accompanied with a presentation.

4.5 DISCUSSION

This study has demonstrated that teachers' knowledge of some basic concepts of ADHD and more in-depth issues about ADHD medication are generally lacking. This suggests that education and training of teachers lacks coverage of contemporary clinical and scientific knowledge about ADHD.

4.5.1 School teachers knowledge of ADHD and its treatment

4.5.1.1 Knowledge of the disorder

Amongst the sample studied, knowledge of the disorder was found to be quite poor as seen by the low mean number of questions answered correctly by both cohorts. Other studies which used a similar methodology and questionnaire items report much higher proportions of correct answers; ranging from 47 to 60% (Kos *et al*., 2004, Scuitto *et al.*, 2000). However, the latter study (Scuitto *et al.*, 2000) was based in the United States, where teachers are generally more proactive in the assessment and likely treatment of ADHD and this may inadvertently make them more knowledgeable. The study by Kos *et al*., (2004) was based in Australia where the education and healthcare systems are similar to the UK; therefore teachers' knowledge would be expected to be similar. However, it should be acknowledged that the present questionnaire was biased towards teachers' knowledge and understanding of medication, which has not been addressed to the same extent in previous studies.

Education policy makers may find it useful to know that teachers, some with previous teaching experience of children with ADHD, were found to have a similar degree of knowledge of ADHD to teachers currently completing the PGDE. Although Scuitto *et al* (2000) found knowledge to be related to the teacher's past experience of teaching a child with ADHD and the extent of prior exposure (the number of children taught), no such association was found in this study. However, the size of this sample may have been too small to detect any effect, if present. Nonetheless, it is concerning that the qualified teachers in this study appeared to have a similar knowledge base to student teachers, especially when one considers

these teachers to be at the 'front line' of support and teaching to children with ADHD.

It may be that some teachers do not believe in the validity or existence of the disorder, or are confused over its basic symptoms. Whilst this could be a factor amongst generalist teachers one would not expect to find it amongst individuals expressing an interest in educational support and who also have experience of teaching children with ADHD. Snider *et al* (2003) also found that Special Education teachers scored no better than general teachers when surveyed about their knowledge of the disorder. As few of the qualified teachers in this sample had attended any training courses about the disorder, either during their initial education (ITE) or since qualifying, it may be that exposure in the classroom is not enough to guide knowledge. Many of the teachers in this sample will have gained their qualifications more than 10 years ago, when knowledge of ADHD was less advanced than now. The student teachers' knowledge may have been attained in their professional/academic backgrounds before beginning the PGDE. Perhaps 'life' exposure confers knowledge and experience equal to that found in an exclusive teaching degree.

4.5.1.2 Knowledge of medication used in ADHD

Findings from this study concur with other studies (Barberesi and Olsen, 1998; Snider *et al*., 2003) that also found teachers to be misinformed about the uses and side effects of medication. Some individuals may perceive psychostimulant drugs as inappropriate or dangerous or a risk factor for substance misuse and addiction. The evidence does not support this view, in fact a recent meta analysis (Wilens *et al*., 2003), using data from 6 studies, found an almost a 2 fold reduction in risk for substance misuse in people with ADHD who had taken stimulant medication, compared to those with untreated ADHD. The exact reasons for this are unknown but several theories exist. One is that by addressing ADHD, the individual is in a better position to integrate into both school and family life and less likely to 'drop out' and indulge in truancy or other antisocial behaviour (Gordon, 1993). Furthermore, the oral ingestion of methylphenidate tends to lack the physiological

rush or high that is required to sustain the cycle of reinforcement, reward and euphoria that is associated with the classic drugs of abuse (Stahl, 2008). This lack of understanding of the pharmacology of the medication may also result in teachers having unrealistic expectations of its abilities. A number of teachers in this study also thought medication increases peer interactions and improves classroom performance. As Snider *et al* (2003) eloquently expressed, "*there is no evidence to either confirm or refute the idea that stimulant medication improves organisation, study habits, grades and interpersonal relationships, it seems optimistic to assume that a pill could undo years of poor work habits or reverse the cumulative effects of academic underachievement without other interventions occurring as well"*. It is not the medication that causes improvements in peer interactions; it is the change in their behaviour that allows them to have a better quality of interaction with their peers.

Although stimulant medication is devoid of serious side effects, decreased appetite and headache are fairly common. The fact that some individuals thought stimulant medication can cause drowsiness or day dreaming shows how little is actually known about the medication. Most of the studies in which teachers' knowledge is assessed say that teachers could benefit not only from information about the different types of drugs used for ADHD, but also their different modes of action, contraindications, side effects and limitations (Kos *et al*., 2004; Snider *et al.,* 2003).

Overall it does appear that there is a gap in teachers' knowledge and that they could benefit from additional training in this area. The teachers in this survey recognised their own limitations, and of teachers in general with regards to understanding the purpose of medication in ADHD and also acknowledged the need for greater awareness of medication side effects. This would have to be incorporated into training programmes and would probably be most effective if delivered during the ITE and also offered post qualification as a CPD module.

4.5.2 School teacher's sources of information

Addressing this need is particularly important since the majority appear to consult 'other colleagues' (who may be similarly ignorant) or the internet for information

about ADHD. As discussed in earlier chapters, the quality of internet based health information is variable. Teachers in this study were generally ignorant of the sites which had been evaluated as useful and although some individuals indicated knowledge of other sites, including sites hosted by the pharmaceutical industry; these may not contain objective or comprehensive information. Only a handful of teachers were aware of government, health or education based sites, such as NHS24 and Learning & Teaching Scotland, which suggests that more effort may be required to advertise their existence. Interestingly, the student sample had greater awareness of the internet and ADHD sites. However, this may be a reflection of the lower average age of the student teachers compared to the qualified teachers.

4.5.3 School teacher's ADHD training needs

The overwhelming response by both qualified and student teachers was that they wanted more training in a variety of issues associated with ADHD. This suggests that current provision in the undergraduate and postgraduate curricula is insufficient to meet their needs. Course organisers could offer a short training module in which the topics identified in this study are delivered using a lecture format. Student teachers however appeared to be more receptive to other mediums for receiving their training but again this might be a reflection if their younger age and familiarity with new technology.

4.5.4 Study limitations

The main limitation of the study is the relatively small (and local) sample size which means the findings may be unique to this sample or the geographical area. This makes it difficult to generalise any conclusions to the wider teaching profession. However, since the sample was drawn from one of only seven teacher training establishments in Scotland, it could be argued that it is a fair representation of Scottish school teachers.

4.6 CONCLUSIONS

The main findings of this chapter are:

- Scottish teachers receive little formal training about the disorder at pre and post qualification stages of their careers.
- The school teachers investigated lack knowledge and understanding of ADHD and the medication used in its treatment.
- The attitudes and beliefs about the disorder amongst the teachers investigated are indicative of a limited and poor understanding about the disorder.
- Most of the school teachers tend to rely on their colleagues and the internet for information on ADHD. However, their knowledge of suitable ADHD websites is poor.

Chapter 5

Development and evaluation of a Pharmacist led training session

5.1 INTRODUCTION

In common with other professional groups, the training and education of school teachers occurs along a continuum. It begins at Initial Teacher Education (ITE), followed by a probationary period and continues up to retirement in the form of Continuous Professional Development (CPD) (Livingston & Robertson, 2001).

5.1.1 Post qualification training of school teachers / Continuous Professional Development (CPD)

Since it is impractical to prepare teachers for every teaching scenario during their pre-service education, much of their training occurs 'on the job' as part of their professional and personal development, which is also known as Continuous Professional Development (CPD). Whilst there are various definitions of CPD, the concept can be defined as "*the education, training and support activities engaged in by teachers which are aimed primarily at adding to their professional knowledge, improving their professional skills and helping them to clarify their professional values so that they can educate their students more effectively*" (Bolam, 2000). The CPD framework therefore appears to be a suitable forum for the delivery of training to address the gap in school teachers' knowledge of ADHD and its treatment.

5.1.1.1 CPD in the Scottish education system

CPD was made a condition of service, and a national CPD framework was developed, after a comprehensive review of teaching provision in Scottish schools entitled, 'A Teaching Profession for the 21st Century' (Scottish Exec, 2000). It stipulated that all teachers must undertake 35 hours of CPD per annum. Although the exact nature and content of CPD were not specified, it was recommended that "*it should be all encompassing and cross curricular and include training in teaching methodologies, the use of information and communication technology, management, Special Needs Education, multicultural teaching and conflict / behaviour management*". In Scotland, CPD is usually delivered by GTC accredited institutions, the employing local council or other private agencies, including the Open University, and usually takes the form of attendance at nationally accredited courses and small

scale, school based activities. No single model of CPD is considered the most effective, but the prevailing view in Scotland is that teachers define CPD as courses, seminars and workshops (GTC Scotland, 2006). Teachers in England also appear to support this view. A study of 2500 primary, secondary and Special Needs school teachers in England found that the majority preferred to receive their CPD by attending courses or as in-service days; online learning was their least popular option (Hustler *et al.,* 2003). It is unclear why the teachers had such an aversion to online learning, particularly as education providers increasingly see the internet as a cost effective medium by which they can deliver courses and expand their client base.

5.1.1.2 Types of CPD

The CPD of school teachers should not be restricted to pedagogical issues. Since school aged children can spend up to half of their waking day in the company of their school teacher, it would be useful if teachers had some basic knowledge of medical conditions commonly found in children. The education of teachers in health matters can also come under the remit of CPD. For example, Moor *et al.,* (2000) delivered a training package to teachers designed to improve their recognition of depression in their pupils. The package was developed and presented by a Special Needs teacher and a doctor from a local adolescent psychiatric inpatient unit. The package consisted of four parts: a short informative lecture on the signs and symptoms of depression; small group workshops to identify issues working from case vignettes; a short talk presenting the depressed pupil's experience of coping with school life and an open discussion session. Since only 16 teachers undertook the training, it is difficult to draw any real conclusions about it; however, the participants did say that they had a greater awareness of the symptoms and felt significantly more confident in their knowledge.

A thorough search of the literature for similar training initiatives for ADHD found no descriptions of any British models of training and/or their impact. The only study identified is a decade old and was conducted amongst elementary school teachers from a rural area in South Western Minnesota, USA. This study (Barbaresi & Olsen, 1998) described the results of a pilot study in which 44 school teachers (including 15

Special Needs teachers) received the Children and Adults with Attention Deficit Disorder (CHADD) Educators In-service programme. The training lasted approximately 2.5 hours and was delivered by physicians specialising in ADHD. The CHADD training included basic information about ADHD (history, prevalence, diagnosis) and its classroom management. There was also a brief interactive case study of a child with ADHD. After discussing the non medical aspects, the training programme concentrated on stimulant medication and its side effects. The session finished with a question and answer session. The study compared pre and post training responses to a 27 item ADHD knowledge test and the authors concluded that the CHADD training improved teachers' knowledge of ADHD. Stress levels were also decreased when measured by the Index of Teaching Stress. It is difficult to say whether the improvement in scores was a direct result of the training but the study does highlight the potential of such a package.

Barberesi and Olsen's approach would suggest that they were only reinforcing the recommendations made previously by other researchers in this area, most notably, Jerome, who as far back as 1994 had stated that "*there is a need for closer working relationships between outside professionals and classroom teachers, which would reduce misdiagnosis and improve the efficacy of medication management. Clearly, in-service training would need to include outside professionals, particularly prescribing physicians if this problem is to be satisfactorily addressed"* (Jerome, 1994). The responses of teachers surveyed in the previous chapter complement Jerome's view since they also stated that they would prefer training to be delivered face to face and by a variety of professionals.

In this chapter, pharmacist led training is delivered to a cohort of student teachers and its impact evaluated. The feasibility of other ADHD multidisciplinary team (MDT) members also delivering CPD is investigated and the resulting format is reported.

5.2 AIMS

i) To deliver a pharmacist led training session on ADHD and its medical treatment to a group of student teachers.

ii) To develop a multi-disciplinary training package for school teachers to enhance their knowledge and understanding of ADHD.

5.2.1 Objectives

1. To develop a training session on ADHD and its medical treatment and deliver it to a cohort of student teachers.
2. To evaluate the impact of the training session on the knowledge and attitudes of student teachers regarding ADHD.
3. To recruit members of the ADHD MDT and invite them to deliver training based upon the different perspectives and issues associated with their management of the condition.
4. To make the training session available in a format that could be used by school teachers to fulfil their CPD requirements.

5.3 METHODS

5.3.1 Development of Pharmacist led training session

The most appropriate format for delivering training was identified (in Chapter 4) to be as a lecture. Even though the classroom management of ADHD was found to be the most popular of all options, training about medication issues was still considered to be worthwhile. It was also the area of expertise of the author. A training session consisting of a lecture accompanied by slides was prepared by the author with the aim of providing school teachers with basic information about the role of medication in the treatment of ADHD.

5.3.2 Evaluation of Pharmacist led training session

5.3.2.1 Evaluation by questionnaire

The author delivered a training session on the 5th of February 2009 to a sample of University of Strathclyde (UoS) post graduate Diploma in Education (PGDE) student teachers. Before the lecture, participants were asked to complete a modified version of the questionnaire used in Chapter 4. The questionnaire was similar in format but shorter as some items were removed because they were considered unnecessary. These mainly included open ended questions relating to respondents' (post qualification) experience of teaching. Section A of the questionnaire consisted of six questions relating to access and use of ADHD information resources; section B consisted of 17 knowledge based items and section C consisted of 12 items describing attitudes. After the presentation, the students were asked to complete a second questionnaire that was similar in content and format to the first one. Questionnaires were colour coded to match participant pre and post presentation responses. A copy of the questionnaire can be found in Appendix 4.

Data were stored and analysed using SPSS Version 16. Total knowledge score for each individual were summed and the mean value calculated. Differences in mean scores (for knowledge and attitudes) before and after the presentation were calculated using t-tests for dependent means with the significance level set at $p<0.05$.

The following hypothesis was also tested:

- There was no difference in the baseline mean total knowledge scores between the 2008 cohort of student teachers and the 2009 cohort.

5.3.2.2 Evaluation using focus groups

Student teachers who were willing to take part in a focus group to discuss the training session and their wider (ADHD) training needs were asked to provide a contact email address. An email was subsequently sent inviting interested students to attend one of two planned focus groups scheduled for the 8th of May 2009. The focus group discussions would be digitally recorded and analysed using a content analysis technique. A reminder email was sent two weeks later.

5.3.3 Delivery and recording of an MDT pilot training session

Since it had been identified in Chapter 4 that teachers wished to receive training in a number of ADHD topics, it was decided that a more comprehensive training package should be produced and delivered. This training package would ideally address the training needs of both qualified and student teachers and would preferably take the format of a short accredited course that teachers could use towards their CPD requirements. It was decided that any training session that required a full day would best be delivered in collaboration with the UoS Professional Development Unit (PDU). The PDU is responsible for developing, supporting and delivering CPD courses that teachers can use towards their annual CPD requirement. Key individuals involved in the care of children with ADHD; in this instance a psychiatrist, a school teacher and a parent of a child with ADHD were approached by the author. The purpose and nature of the training was explained and their co-operation requested. Each individual was asked to deliver a short presentation from their own 'professional' perspective or background that addressed the issues which had been identified by school teachers in both the literature and in Chapter 4. It was decided that each presentation should be delivered using Microsoft Office PowerPoint slides, which would allow the slides and presentations to be recorded and incorporated onto a Digital Video Disk (DVD). This DVD could then either be

distributed amongst attendees at subsequent training events or as a ‘stand alone’ short course / training session distributed by the PDU.

A pilot training session that incorporated a recording session was conducted. Each speaker was expected to deliver their presentation in front of an audience of teaching staff and undergraduate students from the Education Faculty of the UoS. After the presentations, a question and answer session was planned in which speakers would take questions from the audience members.

5.4 RESULTS

5.4.1 Development of Pharmacist led training session

A training session consisting of a lecture and presentation (composed of 16 PowerPoint slides) was developed. The session lasted approximately forty minutes and the following topics were addressed.

- An overview of the biological basis of ADHD.
- The role of medication in treating ADHD symptoms.
- A description of the different types of medication used in the treatment of ADHD.
- Details of the side effects and limitations of the medication.
- Internet sources of information on ADHD.

At the end of the session several students enquired about the possibility of receiving a copy of the slides. These were emailed to the class co-ordinator the following day who agreed to pass them onto the students.

5.4.2 Evaluation of Pharmacist led training

Thirty three pre and post presentation questionnaires were completed by 7 men and 26 women. Thirty one respondents reported that they had not received any information about ADHD in their ITE. Seventeen respondents claimed to have had contact with a child with ADHD during their ITE.

5.4.2.1 Impact of presentation upon student teachers' knowledge

Knowledge was determined by each individual's response to items in section B of the questionnaire. The proportions of correct answers before and after the presentation are presented in Table 5.1.

Table 5.1 Percentages of respondents who correctly answered knowledge questions before and after the presentation *(n = 31)*.

Question	Correct answer	Before % correct	After % correct
General knowledge of ADHD			
There are a greater number of boys than girls with ADHD	True	85%	55%
If medication is prescribed, educational interventions are often unnecessary	False	49%	33%
Approx 5% of Scottish school-aged children have ADHD	True	15%	61%
ADHD can be inherited	True	15%	12%
There are 3 main subtypes/categories of ADHD	True	15%	64%
ADHD is a medical disorder that can only be treated with medication	False	55%	39%
Medical procedures are useful in the diagnosis of ADHD	False	24%	39%
Knowledge of ADHD medication			
If a child responds to stimulant medication then they probably have ADHD	False	39%	33%
When stimulants are used they improve a child academic performance	False	33%	82%
Medication is a cure for ADHD	False	67%	100%
Antidepressants can be used to treat ADHD symptoms	True	6%	94%
Prolonged use of stimulant medications leads to increased addiction in adulthood	False	24%	97%
Almost 30% of children with ADHD do not respond to stimulant medication	True	12%	12%
Availability of different stimulant formulations means doses do not have to be taken during the school day	True	18%	76%
Controlled drugs are often used to treat ADHD symptoms	True	39%	100%
Medication for ADHD has the following effect(s)			
Improves concentration	True	52%	88%
Decreases impulsiveness	True	70%	88%
Increases peer interactions	False	27%	33%
Improves long term memory	False	30%	46%
Improves classroom performance	False	3%	27%

Question	Correct answer	Before % correct	After % correct
Stimulant medication has the following side effects			
Decreased appetite	True	18%	97%
Insomnia or trouble sleeping	True	24%	100%
Day dreaming	False	9%	27%
Headache	True	24%	97%
Drowsiness	False	6%	27%
Stomach problems	True	12%	97%
Irritability	True	30%	79%
Low mood/sadness	True	27%	94%
Anxiety	True	30%	70%
Tics/nervous movements	True	9%	85%
Dizziness	True	15%	73%
Euphoria	False	3%	58%
Addiction	False	9%	91%
Mean (SD) number of correct responses out of 33		9.1 (6.3)	22.5 (3.4)

There was an increase in the proportion of correct answers for 27 of the 32 statements and a reduction in 5. The proportion who answered the statement "Almost 30% of children with ADHD do not respond to stimulant medication" correctly did not change.

The mean (SD) number of correct responses for the whole sample before the presentation was 9.1 (6.3) out of 33. This increased to 22.5 (3.4) after the presentation. The difference in mean scores before and after the presentation was statistically significant, $t_{(32)} = -12.5$, $p = 0.00$.

5.4.2.2 Impact of presentation upon the attitudes of student teachers

Attitudes were determined by the responses of each individual to items in section C of the questionnaire. The number of student teachers and their corresponding responses before and after the presentation are given in Table 5.2.

Table 5.2 Student teachers' responses to attitudinal statements before and after the presentation *(n=33)*

Statement		Number of students				
		SA	***A***	***U***	***D***	***SD***
ADHD is a valid diagnosis	Pre	6	17	9	0	1
	Post	10	18	5	0	0
School teachers are trained to recognise the symptoms of ADHD	Pre	0	1	1	16	13
	Post	1	4	1	18	9
ADHD is a behavioural disorder that should not be treated with medication	Pre	1	2	14	14	2
	Post	0	3	7	19	4
Medication should only be used as a last resort	Pre	5	5	20	3	0
	Post	2	5	11	13	2
School teachers have sufficient understanding of the purpose of stimulant medication	Pre	0	2	4	13	14
	Post	0	1	5	16	11
All children with ADHD should take medication	Pre	0	0	11	17	5
	Post	0	6	13	10	4
Some ADHD medication can cause mood swings	Pre	0	11	21	1	0
	Post	8	24	1	0	0
School teachers should be aware of the side effects of ADHD medication	Pre	20	11	1	0	1
	Post	24	9	0	0	0
Too many children are prescribed stimulants	Pre	2	4	24	3	0
	Post	3	1	23	5	1
School teachers should be able to provide feedback to parents and doctors on a child's response to medication	Pre	7	19	6	1	0
	Post	10	20	2	1	0
School teachers should be more involved in monitoring a child's response to medication	Pre	3	17	11	2	0
	Post	7	16	9	1	0
Drugs other than stimulants are used in the treatment of ADHD	Pre	0	5	28	0	0
	Post	11	19	3	0	0

Responses are based upon a 5 item Likert index for agreement where SA = strongly agree; A = agree; U = undecided; D = disagree and SD = strongly disagree

The data in Table 5.2 can be further analysed to give the mean value of the 5 item Likert index for each statement, where 1 = SD, 2 = D, 3 = U, 4 = A and 5 = SA. The results of this analysis are shown in Table 5.3.

Table 5.3 Mean (SD) values for student teachers attitudinal statements before and after the presentation

Statement	Mean (SD) Before	Mean (SD) After
ADHD is a valid diagnosis	3.8 (0.8)	4.1 (0.7)
School teachers are trained to recognise the symptoms of ADHD	1.7 (0.8)	2.1 (1.0)
ADHD is a behavioural disorder that should not be treated with medication	2.6 (0.8)	2.3 (0.8)
Medication should only be used as a last resort	3.4 (0.9)	2.8 (1.0)
School teachers have sufficient understanding of the purpose of stimulant medication	1.8 (0.9)	1.8 (0.8)
All children with ADHD should take medication	2.2 (0.7)	2.6 (0.9)
Some ADHD medication can cause mood swings	3.3 (0.5)	4.2 (0.5)
School teachers should be aware of the side effects of ADHD medication	4.5 (0.8)	4.7 (0.4)
Too many children are prescribed stimulants	3.1 (0.7)	3.0 (0.8)
School teachers should be able to provide feedback to parents and doctors on a child's response to medication	3.9 (0.7)	4.2 (0.7)
School teachers should be more involved in monitoring a child's response to medication	3.6 (0.7)	3.9 (0.8)
Drugs other than stimulants are used in the treatment of ADHD	3.1 (0.4)	4.2 (0.6)

Statements were rated using a 5 item Likert index for agreement (1 = strongly disagree to 5 = strongly agree).

No significant differences were found between the mean values for each statement before and after the presentation. This suggests that the presentation had little effect on the attitudes of the 2009 student teacher sample.

5.4.3 Comparison of findings between different cohorts of student teachers

The mean (SD) number of correct responses for overall knowledge from the 2008 student cohort was 9.0 (5.2) whereas the corresponding number from the 2009 cohort was 8.9 (6.2). There was no significant difference between the mean values from the

two cohorts [students t-test] $t_{(56)} = 0.20$, $p = 0.98$. This suggests that there is no difference in baseline knowledge between the 2 student cohorts.

5.4.4 Evaluation of pharmacological component of training

Thirty three invitations to attend a focus group were sent by e-mail on the 13th of March 2009. Three messages were returned as 'unknown recipient'. Two individuals responded upon receipt of the reminder e-mail and agreed to take part. Since it would not be feasible to conduct a focus group with only two participants it was decided not to pursue this any further.

5.4.5 Content and nature of pilot training session

The pilot training session was delivered on the 5th of May 2009 in the Sir Henry Wood Building at the Jordanhill Campus of the UoS. The session started at 6.30 pm and finished at 9 pm. Three members of a typical ADHD MDT and a parent from a local ADHD support group each delivered a presentation which lasted approximately 25 minutes.

1st speaker Dr J Graham. Specialist Registrar in Child & Adolescent Psychiatry, NHS Tayside.

Presentation entitled: *ADHD: Actually Didn't Have Discipline*

Dr Graham's lecture was mainly about the diagnostic aspects of the disorder and the processes by which doctors arrive at a diagnosis. He also discussed the history of the disorder, its aetiology and symptoms.

2nd speaker Ms G Akram. Author and Senior Pharmacist, Department of Child Psychiatry, NHS GG & Clyde.

Presentation entitled: *Medication used in the treatment of ADHD*

The author provided a detailed account of the different types of medication used in the treatment of ADHD. The properties of each medicine including its mode of action and side effects were discussed. Issues concerning the safe storage and adminstration of the medication were also described.

3rd Speaker Mrs E Smith. School liaison teacher, NHS West Lothian ADHD Services.

Presentation entitled: *Extending teachers' understanding in the support of children with ADHD.*

Mrs Smith concentrated on the issues faced by school teachers when teaching a child with ADHD and provided helpful advice and strategies that teachers could employ in the classroom.

4th Speaker Mrs R Thomson. Co-ordinator of support group called Ecosse ADDers & the mother of a child with ADHD.

Presentation entitled: *Home, Health & Education: Joined up working*

Mrs Thomson provided a parent's perspective on raising a child with ADHD and described how the school (and teachers) can work with parents to meet parents' expectations to provide the best learning environment for the child.

A short question and answer session followed the presentations. The whole event was video recorded and then converted to a DVD format. After editing, the total running time of the DVD and hence the training time was 110 minutes. The DVD can be played on a domestic DVD player or on a PC using Microsoft Windows Media Player. A copy of the DVD can be found in Appendix 4.

5.5 DISCUSSION

5.5.1 Pharmacist led training

The author's lecture was well received by the students. Their enthusiasm and interest in the subject was particularly evident by the number and nature of questions asked at the end of the session. The student teachers acknowledged the fact that the author was a pharmacist and seemed receptive to being taught by this health care professional. This suggests that as a profession, pharmacists need not limit their expertise to the clinical medical environment but should feel confident in working in non-traditional environments and amongst a variety of audiences. In doing so, it would not only raise their profile within other disciplines but would also reinforce the message concerning the importance of the need for clear, accurate reliable information on the use and effects of medication within society.

5.5.1.1 Evaluation of pharmacist led training by questionnaire

The proportion of student teachers who correctly answered each of the knowledge questions increased after the presentation. This suggests that the student teachers were originally lacking in knowledge (about the disorder) and its medical treatment and that the training session improved their understanding of it. Since the presentation was largely about ADHD medication, it is not too surprising that most of the improvements in knowledge were in medication specific topics. For example, the section detailing stimulant side effects contained some of the largest increases in the number of correct responses. There were at least six statements in this section for which the proportion of students with correct answers rose from 9 – 27% (pre-presentation) to 90 – 100% (post presentation). The five statements for which the proportion of correct answers decreased after the presentation were largely concerned with diagnostic issues of ADHD. These were addressed in the presentation but it may be that the information 'got lost' in the more detailed medication-specific aspects of the lecture.

On the surface, a single presentation and the subsequent pre and post questionnaire based evaluation may not appear to be conducive to the learning process nor an effective means of evaluation. It is acknowledged that students may not have gained

a deep understanding of the topic, particularly when the approach is considered alongside the many theories and concepts underpinning the learning process. However, if one consults Kolb's seminal Cycle of Learning theory (Kolb, 1984), a one off training session can, in some situations, make an impact on (student) learning. Kolb describes four stages, regardless of individual personality traits and their influence on learning styles, which drive the learning process. Each stage is officially described by complex terminology and is imbued within specialist psychology and educational discourses. At its simplest, the cycle can be represented as the four stages of learning shown in Figure 5.1. Each stage is unlikely to occur in complete isolation or to be unidirectional, instead there is likely to be considerable overlap and the cycle can operate in a multidirectional basis.

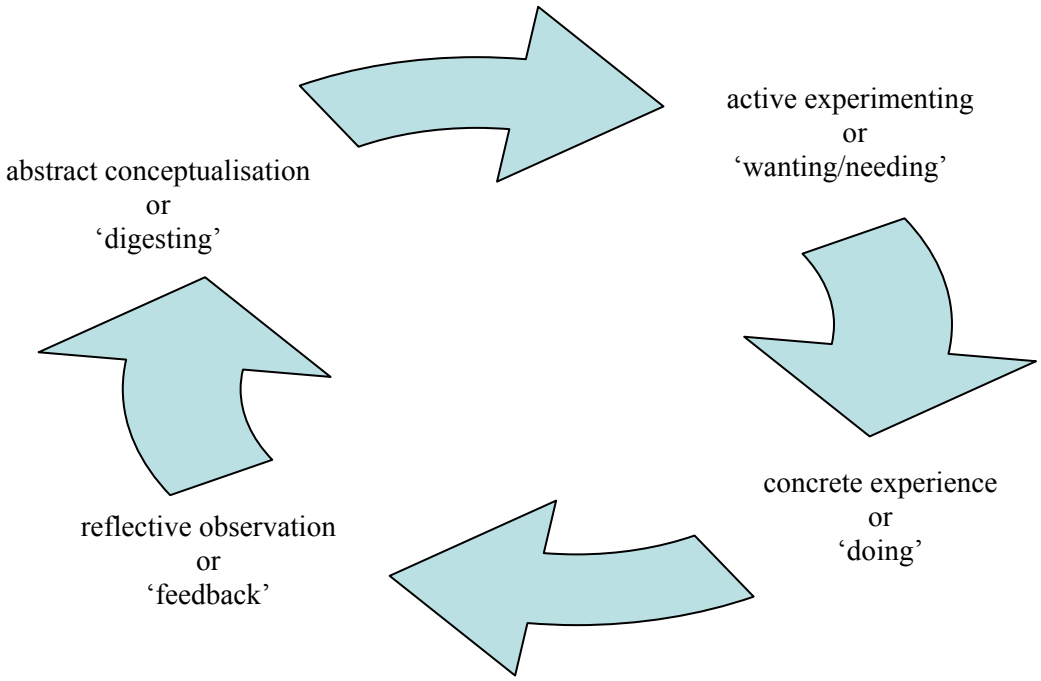

Figure 5.1 Kolb's circle of learning imposed with Phil Race's interpretation. Adapted from: Race, P. 2001. The Lecturers Tool Kit, 2nd edition. Page 10.

In the present example, the presentation would serve as fulfilling a need that had been identified. For some individuals, it may even stimulate or motivate them to find out more about the topic, i.e. the 'doing' part of the cycle. Despite none of the students receiving any direct feedback about their performance (i.e. their knowledge base), there may be some individuals who will attempt to reflect what they had

learned from the presentation at a later date. (Perhaps by consulting the PowerPoint slides which were made available to them via the class co-ordinator.) This will have provided the students with an opportunity to refresh and 'digest' the information at their own pace. It is therefore reasonable to assume that the format of this one-off presentation will allow some degree of learning and hence the transfer of knowledge to occur.

Nevertheless, since the second questionnaire was administered almost immediately after the presentation, it could be argued that the post presentation responses were merely a test of short term memory. Ideally, the second questionnaire should have been administered a few days or weeks after the presentations as this would have been a better indicator of any change in knowledge. Unfortunately, this cohort of students was due to graduate and there was no system in place which would allow effective follow up at a later date. The general consensus amongst those involved in the study was that even if the post training questionnaire was delivered immediately after the session it would still allow some element of evaluation.

It is also worth stressing that motivation is a key aspect to the learning process (Race, 2001). Individuals undertaking CPD and attending such training events are likely to possess considerable motivation, so the presentation format of the training should have some impact on the overall learning experience. In the present study, even if the student teacher's motivation had been low, their perceived 'need' is likely to have been high, especially since they were aware that they would be questioned (albeit anonymously) about the subject after the presentation. Again, this would suggest that this methodology was conducive to the learning process.

If the methodological issues and their effect on the validity of the findings are set aside, it can be argued that since no significant differences were found between pre and post presentation mean values for any of the attitudinal statements, that the presentation had limited effect on the views and attitudes of the student teachers. The Collins English Dictionary's definition of the word attitude is "*the way a person views something or tends to behave towards it, often in an evaluative way*". Most

attitudes tend to consist of three main components: a cognitive component: which is what we know or believe about the object; an affective component: which relates to our feelings about the object and a physical component: which is directional (for or against) and varies in intensity (Lovell, 1980). Attitudes are also influenced by how a particular viewpoint sits in terms of its centrality to an individual's mind set. It is often harder to shift attitudes than it is to transfer knowledge and hence learning. However, since the students' attitudes had not been identified as being too extreme or conservative before the presentation, it is perhaps not necessary to place too much emphasis on the lack of change.

So, whilst attitudes can be modified or changed, it often requires a fairly detailed exploration of the subject matter. This may explain why the attitudes in this study with the greatest 'shift' were concerned with medication. Perhaps the students were more receptive to change (or shift) because the presentation was based upon scientifically derived information that addressed some misconceptions or beliefs they previously held about the disorder or its treatment. The fact it was being delivered by a pharmacist and lecturer in mental health pharmacy may have also given the subject matter further credibility or authenticity. It is perhaps not too surprising to find that the statements which dealt with the diagnostic and aetiological issues, which were largely ignored in this presentation, were also the statements with the smallest differences between pre and post mean values.

The study also found little difference in responses between the two student cohorts even though they consisted of students from different years of study. The students in both cohorts are likely to be representative of the wider student teacher population, which suggests that knowledge of ADHD issues is poor amongst PGDE students as a whole. This would imply that student teachers are an appropriate target for this type of training. The study therefore highlights the potential of the training package, which is fairly inexpensive and only takes a few hours to deliver, as a practical and effective model for the education of student teachers on ADHD issues.

5.5.1.2 Evaluation by focus group discussions

Focus Groups are a method of generating qualitative data and consist of a group of people discussing a common theme or topic. The methodology has been likened to group interviews but their essence is totally different. In focus groups, the objective is for the participants to engage with one another instead of directing their comments solely to the moderator. The moderator is often the individual running the group but their influence on the dynamics of the conversation amongst participants should be minimal (Barbour, 2008). It could be said that in doing so the moderator is indulging in some 'structured eavesdropping' (Powney, 1998). A Focus Group would have been an ideal medium by which to ascertain if the students had applied any of their new found knowledge into practice in the classroom. Unfortunately, the low number of potential participants meant the approach had to be abandoned. It is likely that scheduling the Focus Groups for the month of May, when the students were sitting their final examinations, limited the number of potential participants. Time constraints and impending deadlines made it difficult to pursue this line of enquiry. However it is still desirable that the training DVD is evaluated and a mechanism for doing so is discussed in the next chapter.

5.5.2 Pilot training session

5.5.2.1 Delivery and recoding of session

All the speakers were experienced in delivering lectures and the whole process was easily recorded onto DVD. Unofficial feedback from attendees of the session was that they found the event extremely useful and interesting. For many teachers, it may have been the first time they had heard about the medical treatment of the condition and what that actually involved. The majority of the audience are likely to have received information, if any, from an educational perspective, with emphasis on the classroom management of ADHD behavioural traits. It may have been reassuring for them to hear from a clinician the intensive assessment process that occurs before a diagnosis is made and to learn more about the effects and side effects of the medication. The teachers were also very interested in which ADHD websites to consult and how to access them. After the session, many audience members tried to speak to the support teacher (Mrs Smith). It seemed they were able to relate to her

more and quizzed her directly about managing specific cases in their own classes. The parent (Mrs Thomson) also received a large number of questions. Teachers were overheard to say that they tend to only have contact with the parents when pupils become difficult or problems occur in the classroom. They were encouraged to find that parents generally want closer team working with school personnel. Mrs Thomson also left details of her support group, which many of the teachers were keen to access.

There were several problems during the production of the final DVD, which caused delays. The UoS audio visual recording team were responsible for the recording and transfer onto DVD. Unfortunately, the formatting equipment that they used rendered the DVD incompatible with PCs that are installed with a basic Windows package. This compromised the potential wider dissemination of the DVD and was unacceptable. Considerable time was spent by the author consulting various IT specialists to uncover the reasons why the disk would not operate on standard PCs. It appears that the dye used on the disk was "too thick", which made it difficult for the computer to read the digital material. Ultimately, a different brand of disk was used and a PC compatible product was produced. On viewing, the DVD is a well presented product. The cover photo, which was transposed onto the face of the DVD, was taken from a still during the live recording. There were no criticisms concerning the content of the DVD but there was one minor complaint (from course presenters) which becomes apparent when viewing the DVD. The physical surroundings and background that could be viewed during the question and answer (Q&A) session appeared poorly maintained and in the author's opinion compromised the professionalism of the session. The session had been delivered in a large classroom in one of the UoS buildings. Although the room was often used for meetings and lectures, it had not been modernised and the interior was quite dilapidated and basic. However, colleagues in the education faculty were less concerned and reassured the author that teachers are well-used to training DVDs where 'experts' are interviewed or give talks from various school locations, including classrooms or private offices. In fact, it could be argued that the less than glamorous surroundings in this DVD added to the authenticity of the content of the

training and it may even serve to reinforce the fact that the venture had not been sponsored by the pharmaceutical industry for marketing purposes.

The main outcome of this study was the creation of an original piece of training material that school teachers can use as part of their CPD requirements. The DVD provided relevant information that school teachers can use to improve their knowledge and understanding of ADHD and the medication used in its treatment.

5.6 Conclusions

The main findings of this chapter are:

- Student teachers generally lack knowledge about ADHD and its medical treatment.
- A training session encompassing a lecture delivered by a specialist mental health pharmacist accompanied by a visual presentation can have a positive impact on student teachers' knowledge of ADHD.
- The multi-disciplinary 'health care' team is effective at delivering CPD-type training to school teachers.

Chapter 6

Adaptability of the Strathclyde Website Evaluation Form in other medical conditions

6.1 INTRODUCTION

To demonstrate the adaptability of the Strathclyde Website Evaluation Form (SWEF), an evaluation of internet sources of information on cystic fibrosis (CF) and schizophrenia was undertaken.

6.1.1 Cystic Fibrosis

6.1.1.1 CF aetiology

CF, also known as mucoviscidosis, is an autosomal recessive disorder characterised by abnormal mucus production in the exocrine glands primarily affecting the pancreas, lungs and digestive system (Waller *et al*., 2005). CF is predominantly found in the Caucasian population and is particularly prevalent in Western Europe and North America. Approximately 1 in 25 UK adults are carriers of the defective gene, which results in 1 CF child in every 2500 births (Elborn *et al.,* 1991).

CF is caused by a single cell mutation on the long arm of chromosome 7. This defective gene encodes the cystic fibrosis transmembrane conductance regulator (CFTR). The CFTR is a chloride ion channel found in epithelial cell membranes such as salivary glands, glands of the intestine, pancreas, gallbladder and skin and plays a key role in the production of digestive juices, mucus and sweat. When the CTFR is faulty, chloride transport is impaired, which leads to reduced sodium and water transport in and out of the cells. As a result, secretions are thicker causing obstruction and ultimately destruction of exocrine ducts. As the glue-like mucus builds up in the lungs, breathing difficulties, wheezing and a chronic productive cough are common, as are recurring chest infections (since the mucus creates an ideal environment for bacterial growth). Sinusitis and nasal polyps are also common. There is a sustained and exaggerated inflammatory response to infection, which ultimately results in non reversible damage evident by the presence of cysts and tissue scarring, also known as pulmonary fibrosis (Waller *et al*., 2005).

The other symptoms of CF are mainly gastrointestinal (GI) in nature and related to the GI tract. As the ducts of the pancreas become blocked by mucus, the pancreatic

enzymes struggle to reach the intestine to aid digestion. The lack of food digestion can result in failure to thrive. Malabsorption and vitamin deficiencies, especially of fat soluble vitamins, can ultimately lead to growth problems and weight loss. About 20% of people with CF develop diabetes as the islets of Langerhans become damaged due to chronic pancreatic fibrosis. The prevalence of CF related diabetes is increasing with the increasing life expectancy of patients with CF. Osteoporosis, another condition of later life, is also becoming increasingly common due to chronic vitamin malabsorption and long term steroid use. Some individuals develop distal intestinal obstruction syndrome (DIOS). DIOS is caused by an accumulation of mucus, partially digested food and faecal material within the ileum (Mason, 2005).

CF symptoms can appear at any stage from birth onwards. The severity of the condition is associated with the mutation of the (CFTR) transporter gene. Death in 90% of CF patients is due to progressive lung disease. In some situations, organ transplants, namely lungs or heart and lung, pancreas and in some cases, liver transplants are possible, but these are usually reserved as a last resort when the original organ is too damaged and can no longer function.

6.1.1.2 CF diagnosis

All newborn babies in Scotland are screened for CF using a heel prick method known as the Guthrie Test. This test measures the amount of immunoreactive trypsin (IRT) in the general circulation. IRT is an enzyme produced in the pancreas and raised concentrations are associated with CF. A positive result indicates potential diagnosis. The tests can include a 'sweat test' where the amount of sodium in the sweat is measured. Since patients with CF have raised concentrations of sodium in their sweat, a high value indicates a potential diagnosis of CF. For confirmation, a DNA test may be performed on cells taken from the inside of an individual's cheek and analysed for mutations on chromosome 7 (the area where the CFTR gene is found).

6.1.1.3 Treatment of CF

CF is no longer considered a disease of childhood. Improvements in treatment have increased life expectancy rapidly in the past few decades. In 1938, approximately 70% of CF babies died in their first year of life. By 2006, the predicated average age of survival was 37 yrs, with most people with CF leading fairly active lives (CF Trust, 2006). There is no cure for CF, so treatment is mainly supportive using medication and physiotherapy.

- Physiotherapy

Physiotherapy, incorporating airway clearance techniques, forms the cornerstone of CF management. The objective is to dislodge the thick sputum and encourage expiration. Therapy consists of firm patting or massage of the patient's back and chest area, known as 'clapping' or 'percussion'. This occurs for approximately one hour, two to three times a day. The treatment can be given at home or hospital.

- Pharmacological treatment

1. Antibacterial agents

The thick mucus produced in the lungs is an ideal environment for the growth of respiratory pathogens leading to acute and chronic respiratory infections. Chronic infections caused by *Pseudomonas aeruginosa* require a prolonged treatment period of up to 3 months using oral, intravenous or nebulised antibacterial therapy. Combination treatments are used in almost all cases so that a wider spectrum of microorganisms may be treated.

2. Corticosteroids and bronchodilators

Corticosteroids are used to suppress chronic inflammation in the airways. Oral corticosteroids reduce the rate of decline in lung function and reduce the frequency of inflammation, but side effects restrict their long term use. Bronchodilators, such as long or short acting beta agonists, are also given and help with wheezing or bronchospasm. Combination inhalers containing a long acting beta agonist and a corticosteroid, such as Seretide® (salmeterol & fluticasone) are commonly used.

3. Dornase alfa (Recombinant human deoxyribonuclease I; rhDNase I)

DNA released from dying cells in the airways contributes to the increased viscosity of sputum in CF patients. Dornase alfa is an enzyme that can digest the extracellular DNA, breaking it down into shorter molecules, thereby reducing sputum viscosity. It is given by nebulisation, usually on alternate days. By reducing sputum viscoelasticity and sputum clearance, it improves lung function in the short term and results in fewer exacerbations of lung disease.

4. Pancreatic enzyme supplements (Pancreatin)

Thick sticky mucus in the pancreas means that digestive enzyme secretions are blocked, restricting the digestion of fat from foods and making it difficult for the patient to gain weight. Pancreatin consists of amylase, lipase and protease; which are the enzymes normally secreted by the pancreas to aid digestion. Pancreatin is usually given with meals, which allows the enzymes to mix with the food and facilitates absorption. Since gastric acid inactivates pancreatic enzymes, the formulations used to deliver the medication mainly comprise enteric coated tablets or granules enclosed within a capsule. Sometimes an antacid or a H_2 receptor antagonist is administered concomitantly. The dose of enzyme is tailored to each individual and is dependent on the size, number and consistency of their stools.

- Gene Therapy

Gene therapy consists of replacing the defective CFTR gene with a copy of a normal gene. To prevent the lung manifestations of CF, only 5-10% of the normal CFTR gene needs to be present. Gene therapy is currently a growing research area and shows much promise (Griesenbach and Alton, 2009).

6.1.1.4 Information needs, cystic fibrosis and the internet

Due to increased life expectancy there are now likely to be a greater number of people in society coming into contact with individuals with CF. Whereas previously, the onus for information provision was the needs of parents and carers (Henley and Hill, 1990), more recently this has focused on the needs of adult patients, including those who are diagnosed after age 18 (Widerman, 2003). Regardless of the target

audience, it would appear that most desire information about the psychosocial and future implications about the disease as well as its medical treatment. Twelve percent of Widerman's sample indicated that they used the internet for information after consulting health professionals (42%) and other reading materials (28%).

A study in 2002 measured adherence of CF websites to American Medical Association (AMA) guidelines for internet based health information (Anselmo *et al.*, 2004). The top 100 CF websites identified by the Google™ search engine were evaluated with respect to the four areas highlighted by the AMA; privacy and confidentiality, content, advertising and sponsorship, and e-commerce. Each quality area was evaluated by 15 questions that required a simple yes/no answer. Unfortunately, no information was provided on the nature and quality of clinical information contained on the site, however, the study did find that fewer than half of the sites listed an author or displayed a review date for the material. A third of the sites displayed a disclaimer and about a quarter (27%) provided references for the statements made. The sale of goods or services via the internet (e-commerce) is another potentially problematic area and the study found that 13 of the 100 sites offered information about complementary or alternative medicines for CF treatment, and 7 of these sites offered products for online sale. The majority of sites identified in the study were American (76%) and only 9 were UK sites. As no further details are provided, it is difficult to comment on the usefulness of these sites particularly for a UK audience.

6.1.2 Schizophrenia

6.1.2.1 Definition and diagnosis

Schizophrenia is a mental disorder characterised by impairments in perception or expression of reality, which manifest as hallucinations and paranoid or bizarre delusions (Stahl, 2008b). It is conceptualised as consisting of five symptom dimensions: positive symptoms; negative symptoms; affective symptoms; aggressive symptoms; and cognitive symptoms. However, it is mainly discussed within the framework of positive and negative symptoms. Positive symptoms are often the most dramatic and intrinsically reflect a loss of touch with reality. These include delusions, often of a paranoid or persecutory nature; hallucinations (auditory, visual,

olfactory, gustatory and tactile) and an overall pattern of illogical or disorganised behaviour or speech. The negative symptoms reflect a loss of general functioning and expression of feelings, including withdrawal, both emotionally and socially, poverty of speech, desire and motivation. It is the extent and severity of negative symptoms which have an overall bearing on the course and outcome of the illness (Taylor, 2006a).

The classification and subsequent diagnosis of schizophrenia according to the WHO International Classification of Disease (ICD-10) requires the presence of positive symptoms for a minimum of one month, whereas the classification system favoured by the American Psychiatric Society, the Diagnostic and Statistical Manuel (DSM-IV) requires the combination of positive and negative symptoms for at least 6 months. Schizophrenia is relatively uncommon, affecting 1% of the population, but it has a high mortality and morbidity rate. Between 25 and 50 percent of schizophrenia patients attempt suicide; 10% eventually succeed. Symptoms of the illness tend to appear in late adolescence or early adulthood and whilst it occurs equally in both sexes, it has an earlier onset in males (peak age 20-25 years) compared to females (peak age 26-32 years) (Lewis and Buchanan, 2000). Life expectancy compared to the general population is much shorter, in some cases by 20-30 years. The biggest cause of death is usually cardiovascular disease. There are a number of reasons for this, but it appears that genetic factors, lifestyle choices (cigarette smoking, an unhealthy diet and lack of exercise) and side effects from antipsychotic medication (i.e weight gain resulting in obesity or diabetes) all act in combination, thereby increasing the risk of cardiovascular complications in this vulnerable population (Taylor and McAskill, 2000).

6.1.2.2 Aetiology

The exact cause of schizophrenia is unknown. However, some factors have been identified as potentially causative (Taylor, 2006b).

- Genetics: The lifetime risk in an individual of developing schizophrenia when both parents have the illness is 50%. The risk is even higher in identical twins.

Although there is little doubt that the illness is genetically transmitted, the mechanism for this has yet to be discovered.

- Environment: Schizophrenia is often associated with urban and migrant populations. This suggests that feelings of alienation within society may have some role to play in subsequent development of the illness.
- Cannabis use: The active ingredient in cannabis (delta-9-tetrahydro cannabinol) can produce symptoms of psychosis. In some individuals, cannabis use in adolescence is associated with a later diagnosis of schizophrenia. However, a direct casual link has yet to be established.
- Obstetric: Maternal complications during pregnancy and labour are associated with an increased incidence of schizophrenia amongst offspring. It is postulated that hypoxic events at birth trigger specific neurochemical changes which affect brain neurochemistry and ultimately produce the anatomical changes that are often seen in the brains of individuals with schizophrenia.

It would appear that schizophrenia is the unfortunate culmination of a variety of factors. The generally accepted theory is that there is an underlying genetic pre-disposition to the illness which is only expressed under certain environmental conditions (Stahl, 2008b; Taylor, 2006b).

6.1.2.3 Treatment

Overactivity of dopamine in the brain's mesolimbic system was previously thought to be responsible for the positive symptoms; but it is now considered too simplistic a theory and increasingly the symptoms of schizophrenia are explained in terms of several dysfunctional neurotransmitters, including serotonin and glutamate (Stahl, 2008b). Pre 1950s, treatment largely consisted of barbiturates, bromides and paraldehyde and was given mainly to sedate or reduce agitation. It was the serendipitous discovery of chlorpromazine in 1952 that heralded the antipsychotic era. Chlorpromazine was originally developed as an antihistamine and was found to make individuals more subdued and emotionally unresponsive without causing sedation.

There are now two types of antipsychotics available for the treatment of schizophrenia. They are generally known as the typical and atypical antipsychotics.

1. Typical antipsychotics

Typical antipsychotics include chlorpromazine, haloperidol, flupentixol and zuclopentixol. The antipsychotic effect from all of the typical drugs was originally thought to be due to dopamine receptor blockade, specifically dopamine receptors (D_2) in the mesolimbic area i.e D_2 receptor antagonism. Unfortunately, the antagonistic effects are not restricted to one area; instead there is indiscriminate blockade of D_2 receptors, most notably in the nigrostriatal and tuberoinfundibular brain pathways. The nigrostriatal pathway is associated with the regulation of movement. When D_2 receptors are blocked in this area, disorders of movement similar to those seen in Parkinson's disease become evident. Since the nigrostriatal pathway is part of the extrapyramidal nervous system, the resultant movement disorders are also known as extrapyramidal side effects (EPSE).

There are four types of EPSE consisting of;

- dystonia: abnormal involuntary movements such as muscle spasms or torticollis;
- akathisia (restlessness): a subjective, almost compulsive need for constant motion;
- pseudoparkinsonism: loss of facial expression/tone, rigidity and tremor;
- tardive dyskinesia: this occurs after several years of treatment and consists of involuntary, repetitive movements, most commonly of the facial and tongue muscles.

The tuberoinfundibular pathway is the dopamine pathway from the hypothalamus to the pituitary gland. Since dopamine inhibits prolactin release, D_2 receptor blockade in this pathway causes a rise in prolactin levels resulting in galactorrhoea, gynaecomastia, amenorrhoea and generalised sexual dysfunction.

2. Atypical antipsychotics

Atypical antipsychotics include clozapine, olanzapine, risperidone and aripirazole. They are so called because they tend not to cause EPSE and have low affinity for D_2 receptors, in other words, they do not conform to type. The first atypical antipsychotic was clozapine, which was introduced in the 1960s but its lack of causing EPSE, which at the time was considered a pre-requisite for antipsychotic activity, meant its use was limited. In 1975, reports of blood dyscrasias and agranulocytosis severely restricted its use to a named patient basis only. Its efficacy in treatment resistant schizophrenia demonstrated by Kane *et al.*, (1988) led to its wide scale re-introduction with the caveat that it could only be prescribed under strict criteria concerned with regular blood monitoring. White blood cells, namely neutrophils, are monitored on a weekly, fortnightly or monthly basis depending on how long the patient has been receiving clozapine and their subsequent neutrophil count.

The atypical antipsychotics are not a homogenous group and have differing receptor profiles and a range of side effects. As a group (excluding clozapine), they do not have a detrimental effect on neutrophils nor do they demonstrate superior efficacy in treatment resistant schizophrenia. Whilst the side effects from atypical antipsychotics are not as obvious as those arising from D_2 receptor blockade, they can be just as problematic because of their unspecific and serious nature. Although each drug has its own unique side effects (due to specific receptor antagonism or agonism) there are some side effects that are common to the group as a whole. These include:

- Weight Gain

Almost all the atypical antipsychotics induce weight gain and the greatest increases are usually seen with clozapine and olanzapine (5 kg or more). Various mechanisms have been implicated, for example, increased sedation due to antagonism at serotonin ($5HT_{2C}$) and histamine (H_1) receptors, causing lack of physical activity; hyperprolactinaemia; interference with the release and action of leptin (a protein responsible for regulation of body fat) (Correll and Malhotra, 2004; Baptista, 2000).

Risk of weight gain also appears to be related to clinical response and may have a genetic basis (Czobor *et al.,* 2002).

- Diabetes or impaired glucose tolerance

Individuals with schizophrenia are more likely than the general population to experience hyperglycaemia, diabetes mellitus and ketoacidosis (Bushe and Holt, 2004). The exact mechanism for this is unknown but when it is considered alongside the propensity of atypical antipsychotics to cause weight gain, it becomes a particular cause for concern.

- Cardiac effects

These include postural hypotension, tachycardia and prolongation of the cardiac QTc interval. The QT interval is the time taken to complete the depolarisation and repolarisation cycle of the ventricles and can be read from the electrocardiogram (ECG). Atypical antipsychotics block cardiac potassium channels hence delaying the repolarisation phase, which can lead to fatal ventricular arrhythmias (Taylor, 2003).

- Miscellaneous

These include excess sedation, constipation and sexual dysfunction and occur due to the receptor specific effects of the different atypical antipsychotics.

6.1.2.4 Schizophrenia and the internet

Schizophrenia may be one of the most stigmatised mental health conditions alongside alcoholism and drug dependence (Crisp *et al.,* 2005). It is also poorly understood by the British public who often refer to it as having a 'split or multiple personality' (Luty *et al.,* 2006). Since the internet is a popular source of information for embarrassing or stigmatised conditions (Berger *et al.,* 2005) it is likely that patients, their carers, friends and the wider public will use the internet to seek information about schizophrenia.

Kisely *et al.,* (2003) in their review of US schizophrenia websites, found that agreement with evidence based practice ranged from 2 to 55% depending on the recommendation. They found that whilst there was high agreement on the use of antipsychotic medication, few websites mentioned other types of interventions. Furthermore, the site material required a 'high' reading level to be understandable.

This is important because people with schizophrenia tend to have poorer language comprehension than the general public (Condray *et al.*,1992) and so information aimed specifically at them needs to be easy to read. Another study that looked exclusively at the readability of 20 schizophrenia websites (Kalk and Pothier, 2008) confirmed Kilsey's findings that readability of information about schizophrenia on the internet is poor. They classified 40% of their sample as 'very difficult', 55% as 'difficult' and 5% as 'fairly difficult' when calculated by the Flesch Reading Ease score. However, they did not examine or comment on other properties of their websites.

6.1.3. Rationale for using these conditions to demonstrate the adaptability of the SWEF.

Both conditions were chosen because of their similarity with issues also associated with ADHD. For example, CF is a chronic, albeit physical health condition that is also diagnosed in childhood and which is managed by a variety of treatments and medication. Schizophrenia like ADHD is a chronic mental health disorder that is poorly understood by the general population. It is also largely treated and managed by medication. As the SWEF is biased towards evaluating information about drug therapy, it was thought that these two conditions would lend themselves particularly well to evaluation, especially since there are no published evaluations of current sources of internet information on CF or schizophrenia. A further commonality with ADHD is that the impact of both conditions is rarely restricted to just the patient. Families, friends and colleagues are all likely to be affected and hence may turn to the internet for information. Although both conditions are very different from each other, the use of drug therapy, and paediatric drug therapy in the case of CF, leads to similarities with ADHD and so provide good examples of the potential adaptability of the SWEF.

6.2 AIMS

To characterise and evaluate UK websites on cystic fibrosis and schizophrenia using modified versions of the original SWEF.

6.2.1 Objectives

1. To redesign the SWEF to allow evaluation of UK internet sources of information on cystic fibrosis and schizophrenia.
2. To identify and characterise UK internet sources of information on CF and schizophrenia.
3. To evaluate the contents of the identified websites with respect to the information provided on medication and the physical properties of the site.
4. To produce a list of the Top Ten highest scoring websites based upon their total SWEF score.

6.3 METHODS

6.3.1 Development of the SWEF-CF

A CF specialist pharmacist (IM) was consulted to help identify the main issues associated with the treatment of CF. An approach similar to that taken in the production of the original SWEF (SWEF-ADHD) was adopted and a list of desired clinical attributes was compiled. The actual words used in the clinical section changed significantly but the ethos and nature of the individual attributes remained, i.e. how thoroughly medication was described with regard to side effects, dosing information, formulations. Scores were allocated as before, i.e. 0, 1 or 2 for missing, partial and complete, according to how closely the information corresponded with the attribute statement.

During the re-design process, it became apparent that a quality indicator concerning accountability was missing from the original SWEF. No judgement had been made as to the nature or credibility of any references that may be provided to substantiate the website information. An assessment of this kind was considered necessary in the evaluation process and could be measured alongside other physical attributes. A new criterion was therefore developed as shown below.

References:

(i)	No references given, references incomplete or from dubious sources	0
(ii)	References from credible sources but lacking in detail.	1
(iii)	Comprehensive, credible and accurate references.	2

The new SWEF-CF was checked for content and face validity by an NHS consultant physician specialising in respiratory medicine. The specialist did not identity any problems with the content or language used in the SWEF-CF. A copy of the SWEF-CF can be found in Appendix 5.

6.3.1.1 SWEF-CF Pilot study and inter-rater reliability

The SWEF-CF was piloted in a similar manner to the original SWEF (section 2.3.1.4) and inter-rater reliability was established on a sample of non UK sites using

the post-pilot SWEF-CF. Sites were scored by the author and the CF specialist pharmacist.

6.3.2. Development of the SWEF-Schiz

Section 1 of the SWEF was adapted to reflect issues pertaining to the treatment of schizophrenia. As before, the focus was on medication and whether descriptions of the different antipsychotics, their associated side effects and mechanism of actions were adequately described. Scores were allocated as previous versions of the SWEF. No changes were made to Section 2, which measured the physical attributes. Content validity was performed by a specialist mental health pharmacist who did not identify any issues or problems. A copy of the SWEF-Schiz can be found in Appendix 6.

6.3.2.1 SWEF-Schiz pilot study and inter-rater reliability

The SWEF-Schiz was piloted and inter-rater reliability was determined as before by the author and another pharmacist (AO).

6.3.3 SWEF-CF main study

The phrase cystic fibrosis was entered into Google™, Ask™ and MSN™ search engines on 16th January 2008. Sites for evaluation were identified as before, i.e. first 10 pages from each search engine results (to give 100 URLs) and an assessment made towards their appropriateness and inclusion into the study (as in section 2.3.2).

6.3.4 SWEF-Schiz main study

Sites for evaluation were identified on 17th December 2008 in the same manner as before, using the phrase ‘schizophrenia’,

6.3.5 Data analysis

Data for both studies were analysed using SPSS V16. Differences in mean scores between host categories were compared by analysis of variance (ANOVA) using (post hoc) Bonferroni correction for multiple tests with the significance level set at $p<0.05$.

6.4 RESULTS

6.4.1 SWEF-CF pilot study and inter-rater reliability

Changes were made to the wording of some criteria and the corresponding distribution of scores. In the pharmacological treatment section, treatment with bronchodilators and corticosteroids were initially two separate statements but the pilot study found that they were usually mentioned together. It was therefore decided to combine the statements and to allocate the distribution of scores accordingly. Antibiotic therapy was initially assessed as one criterion but the pilot study indicated that there was a need to account for prophylactic and acute treatment separately, since different drugs were used. The scoring for the criteria on pancreatic enzyme supplements was also changed so that dosing and administration information received a higher score than management of side effects.

In the physical section, the criterion measuring 'links to other sites' was quantified using a more standardised approach,

(i) No links to other relevant sites or links do not work	0
(ii) < 3 links present, some to external sites	1
(iii) > 3 links present, some to external sites	2

The total SWEF scores for the 3 CF sites evaluated are shown in Table 6.1.

Table 6.1 Total SWEF scores obtained by both raters

Websites	GA Total Score	IM Total Score
www.cysticfibrosis.ca	28	28
www.cfnz.org.nz	15	15
www.cysticfibrosis.org.au	24	26

The calculated Kappa value was 0.872, indicating a very high level of agreement between the two raters, one of whom was a non expert (GA) and the other a specialist pharmacist in CF (IM).

6.4.2 Quality of CF websites

Thirty-two sites were identified for evaluation and characterised as before. (The URLs of all 33 websites can be found in Appendix 5). The largest category (n = 12, (38%)) contained sites by charities and support groups, including the CF Trust. The second largest was the miscellaneous category (n = 10, (31%)) and mainly consisted of internet based health organisations, such as Netdoctor or i-village. Five of the six government/professional sites belonged to or were affiliated with the NHS. Of the remaining four commercial sites, two belonged to the manufacturers Baxter and Solvay Healthcare. Overall, the SWEF scores followed a normal distribution with a mean (SD) total score of 23.9 (7.1) out of a possible 48 (Table 6.2). The government/professional sites performed the best with a mean score of 26 (1.8). No significant differences were found in mean scores among the different host categories $F_{(3,28)} = 0.23$, $p = 0.87$.

Table 6.2 summarises the mean scores per host category for the different types of information investigated.

Table 6.2 Mean (SD) SWEF-CF scores according to website host category.

Website Category	**SWEF Mean (SD) Total Score (max 48)**	**SWEF Mean (SD) Content Score (max 28)**	**SWEF Mean (SD) Physical Score (max 20)**
Charities/Support Groups *(n = 12)*	23.3 (7.9)	12.2 (6.9)	11.1 (1.7)
Commercial org *(n = 4)*	24.2 (6.2)	10.6 (5.7)	13.5 (3.1)
Government Professional *(n = 6)*	26.0 (1.8)	13.8 (2.5)	12.2 (3.1)
Miscellaneous *(n = 10)*	23.4 (8.8)	13.0 (6.6)	10.4 (2.7)
Total *(n = 32)*	**23.9 (7.1)**	**12.6 (5.9)**	**11.4 (2.3)**

6.4.2.1 CF site clinical contents

The mean (SD) SWEF score for site contents was 12.6 (5.9) out of 28. As shown in Table 6.2, the government/professional sites scored highest with a mean (SD) score

of 13.8 (2.5). A quarter of the sites evaluated (n = 8) did not provide any information about the prevalence of CF, however, 18 sites not only provided details about the UK prevalence of the condition but also details of CFTR gene carriers. The aetiology and prognosis of the disease was mentioned in all but 4 sites. Just under half of the sample (n = 13) provided a detailed explanation about the complications associated with CF, i.e., likelihood of diabetes, liver damage and infertility. All the sites mentioned the need for and role of physiotherapy, but only five sites mentioned lung transplantation. Medication was generally poorly described. Most sites did mention the different types of drugs used but the descriptions were usually brief. For example, only 3 sites mentioned the rationale for bronchodilators or corticosteroids and which side effects to expect from their use. Information about antibiotic treatment was similarly poor; only 4 sites named specific antibiotics, their side effects or dosing details. The need for supplementation with vitamins or enzymes was briefly mentioned on most sites, but again only a limited number (n = 6) elaborated on the specific types of supplements and their particular uses.

6.4.2.2 CF site physical properties

The mean (SD) SWEF score for physical attributes e.g presentation and accountability was 11.4 (2.3) out of 20. Authorship details were missing on most sites, with only 4 sites displaying the author's name, professional credentials and contact details. Just over half (n=17) of all sites had been updated or created within the previous three years (05 - 08). Although the target audience could be deduced easily on most sites, it was extremely difficult to gauge on one site. Most sites were easy to use and navigate through with a high proportion also having a search or help facility. The majority (n = 27) also had links to other CF organisations; in most cases to 3 or more external sites. Advertising was generally absent or subtle but was intrusive on three occasions. Graphic images were largely absent, but where present, it was largely to provide a visual representation of how genetic material is transferred. Over 80% (n = 28) of sites did not provide any references to support any of their statements or information. A disclaimer and advice to consult a health professional was visible on twenty sites. Six sites used specialised terminology without providing a glossary and three sites achieved and FRES of >60. These sites

belonged to a support group (www.pwcf.net), a media organisation (www.gmtv.medicdirect.co.uk/diseases) and a manufacturer of enzyme supplements (www.creoninfo.co.uk).

6.4.2.4 Highest scoring sites

The URLs of the 10 highest scoring sites are presented in Table 6.3. Total scores ranged from 41 to 27. Several websites share their final positions because of similar scores.

Table 6.3 Top ten CF websites according to their total SWEF score

Position	Website URL	Total Score
1	http://www.cftrust.org.uk/aboutcf/whatiscf/	41
2	http://www.gpnotebook.co.uk/simplepage.cfm?ID=919601157	39
3	http://www.cysticfibrosismedicine.com/#	37
4	http://gmtv.medicdirect.co.uk/diseases/default.asp?pid=1379&step=4	31
4	http://www.netdoctor.co.uk/diseases/facts/cysticfibrosis.htm	31
5	http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=118	28
5	http://www.patient.co.uk/showdoc/27000674/	28
5	http://hcd2.bupa.co.uk/fact_sheets/Mosby_factsheets/Cystic_fibrosis.html	28
6	http://www.medicinechest.co.uk/site/medicinechest/index.aspx?P=231&H=cystic%20fibrosis	27
6	http://www.nhs24.com/content/default.asp?page=s5_5&articleID=118	27

Additional details including the number of sites scoring the maximum of 2 points per criteria can be found in Table 6.4.

Table 6.4 CF Website numbers and their corresponding scores as per criterion under investigation *(n = 32)*

	Scores		
Criterion Under Investigation	0	1	2
Criteria measuring clinical attributes(site contents)			
UK and CFTR gene prevalence figures provided	8	6	18
Aetiology mentions CFTR genes & details of prognosis	4	15	13
CF complications include diabetes, liver probs or infertility	4	15	13
Physiotherapy & transplantation mentioned as non-pharmacological treatments	15	12	5
Pharmacological Treatment			
Rationale for using bronchodilators & corticosteroids with explanation of mechanism of action	25	5	3
Dosing information & rationale for antibiotic prophylaxis	25	4	3
Dosing information & rationale for oral & IV antibiotics	25	3	4
Dosing information and rationale for inhaled dornase alfa	23	5	4
Nutritional needs discussed (including vitamins & supplements)	8	18	6
Dosing information, side effects & administration details for pancreatic supplements	23	3	6
Detailed information about new treatments & developments	11	15	5
Disclaimer & advice to consult health professional visible	3	9	20
Links/contact details of further support or advice	3	8	21
Criteria measuring physical attributes			
Author named, professional credentials & contact details	22	6	4
Site developed or posted <3 yrs ago	10	5	17
Target audience clearly stated	1	11	20
Comprehensive, credible and accurate references supplied	27	1	4
Site easy to navigate & search facility provided	1	6	25
Advertising absent or subtle	3	11	18
Good layout of text, easy to read & follow	4	9	19
Appropriate, useful, relevant images present	17	10	5
Use of appropriate terminology, glossary or minimal jargon	2	4	26
Readability Statistics			
FRES <30	4		
FRES 30-60		25	
FRES>60			3

6.4.3 SWEF-schiz pilot study and inter-rater reliability

Minor changes were made to the language used in the description of two criteria which were concerned with (i) the prognosis of the condition and (ii) the description

of antipsychotic mechanism of action. The total SWEF scores for the 3 evaluated sites are shown in Table 6.5.

Table 6.5 Total SWEF-schiz scores by both raters

Websites	GA Total Score	AO Total Score
www. nmha.org	35	34
www. schizophrenia.ca	33	32
www. phac-aspc.gc.ca	34	37

The calculated Kappa value was 0.727, indicating substantial agreement between the two raters, one of whom was a mental health expert (GA) and the other a non expert (AO).

6.4.4 Quality of schizophrenia sites

Thirty-three sites were identified and were categorised as before. (The URLs of all 33 websites can be found in Appendix 5). The commercial and government/professional categories contained 9 sites each, followed by the charity/support groups (n = 8) and the miscellaneous category contained 7 sites. The total SWEF scores for the sample were normally distributed with a mean (SD) total score of 26 (8) out of a possible 52. The miscellaneous sites scored highest with a mean value of 30 (9.3). No significant difference was found in mean scores among the different host categories, $F_{(3, 29)} = 1.44$, $p = 0.25$.

Table 6.6 Mean (SD) SWEF-Schiz scores according to website category.

Website Category	**SWEF Mean (SD) Total Score (max 52)**	**SWEF Mean (SD) Content Score (max 32)**	**SWEF Mean (SD) Physical Score (max 20)**
Charities/Support Groups *(n = 8)*	23.6 (6.5)	12.6 (6.2)	11.0 (1.7)
Commercial org *(n = 9)*	23.0 (7.4)	13.4 (5.8)	9.6 (2.9)
Government Professional *(n = 9)*	27.9 (8.8)	15.4 (5.7)	12.4 (3.3)
Miscellaneous *(n = 7)*	30.1 (9.3)	20.4 (7.3)	9.7 (2.7)
Total *(n = 33)*	**26.0 (8.2)**	**15.3 (6.6)**	**10.7 (2.9)**

6.4.4.1 Schizophrenia site clinical contents

The mean (SD) SWEF score for contents was 15.3 (6.6) out of 32 (Table 6.6). The miscellaneous category scored the highest with a total mean (SD) score of 20.4 (7.3). The majority of sites provided detailed information about UK prevalence and incidence and mentioned the difference between genders regarding the onset of symptoms. Just under half of the sample (48.5% (n = 16)) provided a detailed explanation of the causes of the condition and stated that these are mainly multi-factorial. The prognosis, however, was poorly described with only nine sites discussing it in any depth. All the sites described the positive symptoms and 16 sites also mentioned other conditions in which positive symptoms, such as psychosis, may be evident. Most sites mentioned antipsychotic medication but only a few (n=10) described in detail the differences between the two types of antipsychotics. All the websites mentioned clozapine but only five provided details of its specific blood related side effects and only two sites mentioned how the supply of clozapine is intrinsically bound to the profile of the blood results. The majority (n=26, 79%) of websites did not mention injectable formulations and only three sites mentioned both Risperdal Consta (a new long acting formulation) and the older depots. The majority of websites (82%) did allude to the long term nature of antipsychotic therapy. Eight sites mentioned the need for good compliance with medication and its importance for avoiding relapse.

6.4.4.2 Schizophrenia site physical properties.

The mean (SD) SWEF score for physical properties was 10.7 (2.9) as shown in Table 6.6. The government/professional bodies scored highest with a mean value of 12.4 (3.3). Few sites (21%) provided details of site authorship and only two sites displayed the author's name, professional credentials and contact details. Currency was good, with 20 sites indicating that the material had been updated or entered less than 3 years ago. Nine sites did not display any information on date. Just under half of the sites clearly stated who the information was aimed at. Almost all the sites were easy to navigate and over half (n=19) provided a search facility on the main or home page. A high number of sites (n = 28) had links to external sites, most notably to the RCPsych and to the NHS Direct website. Advertising was generally absent or

extremely limited. There were three occasions where it was considered obtrusive. One was the GMTV site which involved numerous pop-ups about other 'interesting topics' seen on the programme. The other two sites were from the miscellaneous category and both belonged to online diagnosis or 'Dear Dr' sites. Graphic images were largely absent and the majority of information was provided as written text. Although twenty sites displayed both a disclaimer and advice to consult a health professional, there were ten sites in which no such information was visible. Readability was also poor with only four sites recording a FRES >60. These were www.lilly.co.uk, www.bbc.co.uk, www.makingspace.co.uk (a support group) and www.surgerydoor.co.uk (an internet based health site).

6.4.4.3 Highest Scoring sites

The URLs of the 10 highest scoring sites are given in Table 6.7. Total scores ranged from 30 to 43. Several websites share their final positions because of similar scores.

Table 6.7 Top ten schizophrenia websites according to their total SWEF score

Position	Website URL	Total Score
1	http://www.rcpsych.ac.uk/mentalhealthinformation/mentalhealthproblems/schizophrenia.aspx	43
2	http://www.nhs.uk/Conditions/Schizophrenia/Pages/Introduction.aspx?url=Pages/what-is-it.aspx&r=1&rtitle=Schizophrenia+-+Introduction	40
2	http://www.netdoctor.co.uk/diseases/facts/schizophrenia.htm	40
3	http://en.wikipedia.org/wiki/Paranoid_schizophrenia	39
4	http://www.thesite.org/healthandwellbeing/mentalhealth/otherconditions/schizophrenia	35
5	http://www.makingspace.co.uk/	32
5	http://www.patient.co.uk/showdoc/23069111/	32
6	http://www.psychiatry24x7.com/bgdisplay.jhtml?itemname=schizophrenia_about	30
6	http://www.oneinonehundred.co.uk/	30
6	http://mentalhealthcare.org.uk/content/?id=188	30

Additional details including the number of sites scoring the maximum 2 points per criteria can be found in Table 6.8.

Table 6.8 Schizophrenia website numbers and their corresponding scores as per criterion under investigation. *(n=33)*

	Scores		
Criterion Under Investigation	0	1	2
Criteria measuring clinical attributes(site contents)			
Details on UK prevalence, incidence & age of onset provided	6	8	19
Aetiology theory mentions genes & environment	5	12	16
Information about prognosis includes age & symptomatology	7	17	9
+ve & -ve symptoms, cognitive decline all mentioned	3	14	16
Pharmacological Treatment			
Both types of APs mentioned & differences between them	10	13	10
Detailed explanation of AP mechanism of action	11	16	6
Typical SEs mentioned & rationale for using anticholinergic medication	11	12	10
At least 4 Atypical APs side effects mentioned	13	6	4
Clozapine indication and practical use well explained	24	0	9
At least 3 clozpine SEs (including agranulocytosis) mentioned	25	3	5
Explanation of why blood results dictate dispensing/supply of clozapine.	26	5	2
Both types of injectable APs mentioned & differences between them	26	4	3
Long term nature of AP therapy & importance of compliance with treatment mentioned	8	19	8
Disclaimer & advice to consult health professional visible	10	3	20
Links/contact details of further support or advice	5	5	23
Criteria measuring physical attributes			
Author named, professional credentials & contact details	26	5	2
Site developed or updated <3 yrs ago	9	4	20
Target audience clearly specified	1	16	16
Site easy to navigate & search facility provided	1	13	19
Advertising absent or subtle	3	8	22
Good layout of text, easy to read & follow	3	19	11
Appropriate, useful, relevant images	25	6	2
Use of appropriate terminology, glossary or minimal jargon	2	16	15
Readability Statistics			
FRES <30	4		
FRES 30-60		25	
FRES >60			4

Key: AP = antipsychotic

6.5 DISCUSSION

6.5.1 CF websites

Over 80% of Sawicki *et al's* (2007) sample reported information on 'how to manage infection and lung problems' as highly important. Assuming a UK population will have similar information needs then these are unlikely to be adequately met by the websites evaluated in this study. In fact, the majority of websites were quite limited in information about the drug treatment of CF. Pharmacological treatments were mentioned either very briefly or not at all. Although the important treatments, such as antibiotics, were reasonably well represented, information about less common treatments, especially dornase alfa, was generally missing. The omission of information about a therapy could be construed as a lack of its importance, which in this case, is untrue; so it is imperative that information is as complete and comprehensive as possible. If awareness of a particular treatment is increased, it may allow patients or parents to initiate discussions about its use with their doctor. However, it is important that websites do not become a proxy advertisement for a particular product as increasing its awareness may lead to increased (and hence costly) or inappropriate prescribing.

Few websites provided information about inhaled therapies. Since the SWEF did not make a distinction between corticosteroids and beta agonists, a maximum score was only assigned if the website provided full details of both types of medication. This approach may have discriminated against those sites that provided comprehensive details for only one type of inhaled therapy, but the pilot study had shown that this was rarely the case and both therapies were either mentioned in detail or not at all.

Even though only six websites provided information about the pancreatic enzyme supplements, they did describe it in a very comprehensive manner, i.e. details about side effects, dosing and administration times. The small number of sites providing this information is disappointing especially since it is known that 'when and how to take pancreatic enzymes' was specifically identified as a topic in need of more information in a sample of parents attending a CF clinic in Cape Town (Henley and

Hill, 1990). Very few of the sites scored the maximum 2 points in their descriptions of the various pharmacological treatments. Since complicated treatment regimens are common in the management of CF, it is unfortunate that information about medication was so vague on most sites. As most treatment regimens are individualised and depend on a combination of different drugs, perhaps website authors deliberately chose not to provide detailed information about medicines. However, since one of the main reasons for consulting health based websites is for 'medicines information', it is an area that should not be ignored.

Information about new developments or forthcoming treatments in CF was also lacking. Yet this was identified as the most important topic by Sawicki's (2007) sample and was ranked in 7th place by Widerman's (2003) respondents. Alternatives to contemporary treatment such as gene therapy were not mentioned to any great detail, and whilst this study did not determine use of complementary or alternative treatments, Widerman (2003) did identify this to be an information need in her sample.

There was a lot of duplication of site contents; particularly with the NHS sites. All the NHS sites had different URLs and all were accessible from many different sources. However, their content was largely similar. It is not surprising that site content and information is standardised across any one organisation, but this can also have some limitations. NHS sites are likely to be held in higher esteem by health professionals and the public and these may be the only sites that some individuals choose to consult. In this case, subsequent visits to various NHS sites would not increase knowledge base by much. Sites by the pharmaceutical industry performed particularly badly but this was mainly because they tended to only offer information on their own CF product and did not provide many details about other treatment options. This was particularly so for Solvay Healthcare. Solvay manufacture Creon (pancreatic supplements) and their website was extremely informative, detailing the different strengths of Creon and it even had a link to Creon's Summary of Product Characteristics via the electronic medicines compendium

(http://www.emc.medicines.org.uk/). However, the site did not mention any other type of pharmacological treatment.

All the categories scored relatively highly when evaluated for their physical properties. Of the physical attributes, authorship and currency details were poorly described, which is regrettable as these are probably the most important of all the physical attributes. Most websites were easy to use (navigate) and provided a search facility. Unlike Anselmo *et al.,* (2004) where information was supported by references in 38% of their sample, only 4 sites provided comprehensive or credible references in this study. This study also confirms other investigations of internet based health information in that readability of website material is high, suggesting that a higher level of education is required for proper understanding of website material.

Overall, government based websites or those by professional bodies were found to be the most informative, although there was very little difference among the categories in their final and clinical (content) scores. Within the top ten sites, there was little variation in total scores. Most of these websites were from the miscellaneous category, although the 'best' website was hosted by the Cystic Fibrosis Trust. The CF Trust is the UK's only national charity for CF and has a large portfolio of activities, including providing basic information about the disorder, fundraising and supporting research.

6.5.2 Schizophrenia websites

Online information about schizophrenia and its symptoms is generally well described, but information about the medication, especially atypical antipsychotics, is found to be rather superficial. Atypical antipsychotics are increasingly being used as first line treatment for psychosis (NICE, 2002). However, the websites under investigation failed to reflect this increased popularity and usage and instead placed a lot of emphasis on typical antipsychotics. Where sites mentioned atypical antipsychotics, only a few detailed that the difference was mainly due the nature and type of side effects. Information about medication side effects is a common reason

for ‘online health seeking behaviour’ (Peterson-Clark *et al.,* 2004) and exposure to information about side effects can have a positive effect towards medication compliance (Kweon *et al*., 1984; Howland *et al*., 1990). Perhaps, information about the typical antipsychotics dominates because their side effects are thought to be more serious as they are more noticeable (for example, akathesia, and tardive dyskinesia) and mainly irreversible. However, side effects from the atypical antipsychotics can be equally serious and there appears to be no justifiable reason for the lack of information about them. In a survey conducted by the National Schizophrenia Fellowship (Rethink, 2000) half the sample (n = 260) reported that they had not been given any information about antipsychotic side effects from their doctor (psychiatrist). It is therefore quite likely that individuals will turn to the internet for this information which sadly is found to be lacking.

A significant proportion of individuals with schizophrenia may not respond to conventional antipsychotics and hence are likely to become possible candidates for clozapine. Due to the risk of agranulocytosis, clozapine can only be used if the patient undergoes regular blood monitoring. The frequency of blood monitoring is dependent on the overall duration of treatment and the patient’s neutrophil count. The neutrophil count must also fall between a given range of values, which are further characterised into levels of risk: red, amber and green. Clozapine can only be dispensed to the patient when the neutrophil count corresponds to a value in the green range. The monitoring procedure and dispensing arrangements of clozapine can become fairly complicated and one can see the benefits of this information being made more widely available to patients and their carers. This was not the case in the majority of websites. A possible reason for the lack of detailed information about clozapine could be due to the absence of its UK manufacturers, i.e Novartis or Merz, in the evaluation study. Perhaps if the phrase clozapine had been used as a search term, then clozapine specific websites would have been identified. However, medication specific searching would have resulted in a deviation from the predefined study methodology and so was not utilised. Similarly, very little information was available on injectable forms of antipsychotics. Injectable antipsychotics are seen as a convenient alternative to regular oral medication and are particularly useful in

individuals with poor oral compliance. It seems a wasted opportunity that their exact benefits were not overtly stated. The lack of reference to the long acting risperidone injection (Risperdal Consta™) is also unfortunate. Unlike the traditional depot injections, Risperdal Consta™ does not provide antipsychotic cover from the day it is administered. This is due to its unique formulation which utilises microsphere nanotechnology and is dependent upon the rate of dissolution of the microspheres which release active medication (Janssen-Cilag, 2007). Any deviation from the fortnightly cycle can leave the individual without any antipsychotic cover. This important, albeit technical, information was not mentioned on any site. Patients or the carers may not appreciate the reasons for such rigid adherence to the fortnightly cycle and may mistakenly assume that being a couple of days 'out of synch' will have no real consequence. Perhaps if the mode of action of different drugs was better explained, uptake and compliance with the regime may improve.

The charities and support groups performed particularly poorly but this seems to be due to the methodology. Some of the larger charities such as Mind and Rethink have entire webpages (or pdf copies of factsheets) devoted to antipsychotics. However, many of these pages are not 'linked' to the corresponding page indentified from the original search of schizophrenia sites and so were not evaluated. The highest scoring site was hosted by the Royal College of Psychiatrists (RCPsych). The RCPsych has in recent years made a concerted effort to address discrepancies in information provision in mental health, for example, the 'Defeat Depression' (www.rcpsych.ac.uk/campaigns/previouscampaigns/defeatdepression.aspx) and 'Changing Minds' campaigns (www.rcpsych.ac.uk/default.aspx?page=1424). Unfortunately, the profession is not always viewed as a neutral source of information (Breggin, 1994; Nasser, 1995) and some individuals may view information on the RCPsych website with suspicion.

In general, individuals are found to be more receptive to health information on websites developed by governments or professionals (Peterson *et al.*, 2003). Unfortunately, the government/professional category was not the highest scoring category in this study. A possible reason why, could be, that some government sites

belonged to government agencies unrelated to health, for example the Department for Work and Pensions. These sites are aimed at people who may be claiming benefits caused by mental illness, so whilst there may have been some information on the site about the disorder and its treatment, detailed descriptions, especially about medication, were largely absent. There were also a number of (health) professional organisations specialising in counselling and other psychological therapies. Since the onus of these sites was not on the medical treatment, they contained little, if any, information about medication, which influenced the overall mean score for that category.

The miscellaneous category scored the highest with three of its sites in the top five. In this instance the web based free content encyclopaedia; Wikipedia was also included. Admittedly, the site is not strictly a UK resource but as it featured in the original search results and may be accessed directly by an individual, it was decided that its inclusion into the evaluation process would be helpful.

The physical components of the sites were generally well addressed. Most of the sites were relatively up to date, although a few did not display any date. This makes it difficult to assign credibility to the information as one cannot be sure as to its relevance. In keeping with the literature, most sites scored poorly when judged against the FRES. However, for reasons already discussed in chapter 2, the scientific or polysyllabic nature of the language used, could unduly influence the score. However, four of the sites in this study scored above 60 unlike the Kalk & Pothier (2008) sample. The URLs and specifics of their sites are unknown so it is difficult to comment as to why this discrepancy arose.

6.5.3 Study limitations

The major limitation of both studies is the reproducibility of the results. The reasons for this have been discussed in chapter 2. Nevertheless, this chapter does show that the SWEF is an easily adaptable valid instrument for the evaluation of internet based health information. Its challenge lies in the design process, notably identifying the issues which determine the attributes. However, these can be compiled fairly easily

if one is aware of the main issues within the speciality and their importance or relevance in the day to day management of the condition. Any of these identified attributes should be verified, preferably by an expert in the field. The attribute should then be defined in appropriate evaluation language using the correct terminology and precise wording. Once this is done, the evaluation itself is not a difficult task and can be performed by a non expert. This is evident by the high degree of correlation seen between the scores obtained by experts and novices. This specification of the SWEF can pose limitation on its applicability, but it also adds to its strength. As the SWEF is customised according to the condition under investigation, it allows a more accurate and specific assessment to be made of the information. This approach also identifies deficiencies in information which can be just as important as knowing what information is presented.

6.6 CONCLUSIONS

The main findings of this chapter are:

- Information about the pharmacological treatment of CF or schizophrenia on UK websites is basic and limited.
- Readability of website material is high which suggests it is unlikely to be understood by the majority of the population.
- The majority of sites provide links to other external sites, mainly to those by government/professional organisation e.g. the NHS, or to the main charities associated with the condition, e.g. the CF Trust.
- There appears to be a degree of duplication between the various NHS sites even though they are produced by different organisations within the NHS and have unique URLs.

Chapter 7

Overall Conclusions and Recommendations for Future Work

7.1 Overall Conclusions and Recommendations for Future Work

The research impetus for this thesis was a conversation between the author and a schoolteacher on the effects of medication used in ADHD. A multi-method approach was therefore applied to explore the quality of internet and printed sources of information on ADHD and school teachers' knowledge about the disorder, in particular, its medical treatment. In doing so, an assessment tool for the evaluation of websites (known as the SWEF) was developed and a training package was designed and partially evaluated. This final chapter draws together the salient conclusions from each of the empirical studies and lays the foundations for future work.

7.1.1 Evaluation of internet sources of information

Internet based information on medication used in the three conditions studied in this thesis is mainly incomplete and basic. Whilst most websites do provide information about side effects, it is usually rudimentary, and contains little detail about the administration of the medication (e.g. dosing frequency, how to deal with missed doses, etc.) or the relevance and availability of different formulations. Website authors might see these as minor points but they are fundamental to the effective management of any health condition. For example, providing information about expected effects or side effects is futile if it transpires that the particular product is incompatible with an individual's (swallowing) needs. Similarly, some individuals may not wish to alert their doctor to the fact that they have missed a dose of their medicine or taken it at the wrong time. The anonymous nature of internet makes it an ideal medium for imparting this type of information.

All the website evaluation studies in this thesis were performed using the SWEF (a standardised tool with predefined 'quality' criteria). Whilst the usefulness and adaptability of the SWEF for the evaluation of paper (printed) and internet sources of medicines information has been adequately demonstrated, a major limitation of this approach is the currency and hence, the relevance of any findings. For example, the ADHD evaluation was conducted in Jan 2007; given the fluid and transient nature of

websites, it is possible that some of the contents or even whole pages have changed since the study was conducted. There is, however, little that can be done about this. One should be mindful of the fact that any website evaluation study is at the mercy of time and hence can only provide a snapshot of the status of the field at that particular time. The studies in this thesis have done precisely that, i.e. by using the SWEF, a baseline assessment can be made as to the nature, content and ultimately the quality of medicines information on the internet. Since no other UK studies were identified in the topic areas investigated, it is intended that these studies act as guides towards the quality of websites and, more importantly, that deficiencies in information provided have been identified.

Other limitations of the findings are related to the methodology. Had a different search strategy been used then it is possible that different results would have been found. For example, if the name of the medicine had been used as the search term then more detailed medication specific pages / websites may have been identified. However, such an approach requires prior knowledge of the name of the medicine, which is not always possible and, as the literature suggests, most searches begin with the name of the disease / condition. Nevertheless, it would be interesting to compare those websites identified by using the name of the medication as a search term against those that were identified by the search strategy used in this thesis and see what, if any, differences there are in type and quality of information. It may also be useful to reconsider the categorisation of the websites, but this time to base characterisation upon site authorship and not the host category. In doing so, it would allow comparisons to be made between different professional groups involved in writing the information (medical doctors, psychologists, etc.) and determine whether any differences exist in the type of information they provide. The findings of such a study could be further investigated possibly by using qualitative research techniques. The parents of children with ADHD or adolescents who have the disorder could be interviewed and their authorship preferences explored and whether this has any impact on how they use any information accessed from the internet.

It also became apparent during the course of this thesis that there is little difference in the nature and type of information on health websites, regardless of whether the site is for a physical health condition or a mental health condition. For example, the CF, ADHD and schizophrenia websites were all devoid of detailed information about medication. However, since only one physical health condition was investigated, it cannot be said for certain that this is always the case, but it is an area ripe for further investigation. Similarly, there seems to be little difference in the content of websites for conditions diagnosed mainly in childhood compared to those diagnosed in adulthood. Further studies with parents could identify whether they have a particular need for certain types of information, for example, they might appreciate advice on what to do if doses of medication cannot be administered at school.

It would also be useful to conduct further evaluations in other commonly occurring conditions, such as diabetes and asthma, and hence create a 'bank' of high performing websites. The SWEF would however need to be modified accordingly but if this was done in consultation with a clinical expert, then the process should not be too laborious as demonstrated in this thesis. Details of high performing sites could be held centrally within the disease specific pages of generic NHS information websites so that the wider health care team could access them and, where appropriate, forward the details to their patients as reliable sources of information. Again the currency of the information would need to be addressed. Any bank of websites would require regular review and updating. Such a task should not be too onerous once the original websites have been identified and the task itself could easily be incorporated into the work plan of individuals with responsibility for website content.

As one of the main themes of the thesis was to investigate the provision of information on ADHD, a national survey of NHS clinicians with responsibility for ADHD was conducted.

7.1.2 Clinician knowledge and provision of information resources and views about school teachers' understanding of ADHD

A multi-method approach was used to investigate the nature of information provided by the treating clinician to the parents / carers of children with ADHD. Since the condition is managed in a multi-professional manner, it was important to survey both paediatricians and psychiatrists. Such an approach was thought to bring greater validity to the findings and allowed comparisons to be made between the professions.

A main finding of this chapter was that even though most clinicians provided information to the parents (carers) of their patients, there was variation in the nature, type and quality of the information. The closed question approach used in the questionnaire limited the extent of probing into the matter. However, the topic could be further investigated using semi-structured interviews with clinicians to find out their motives for providing information. For example, do they think it is their responsibility, and should information be standardised throughout NHS Scotland? Barriers to the provision of information by clinicians could also be investigated and potential solutions to these barriers identified and tested. Parents, or young people with ADHD, could also be consulted and asked for their opinions regarding the usefulness of the information resource that is provided by the clinicians. A more in-depth study with this group around issues concerned with access and availability of information about ADHD would also be extremely useful, particularly for clinicians.

Clinicians' lack of familiarity with internet sources of ADHD information is also an area warranting further investigation. Their perceived ignorance of many of the ADHD websites coupled with their reluctance to use the online questionnaire suggests that there may be particular reasons or issues behind clinicians' use and uptake of technology. Knowledge of these potential barriers would help to ensure that any future research projects with this population are not similarly compromised.

A topic which was tentatively investigated in the current chapter and merits more in-depth study is the attitude of clinicians towards schoolteachers' knowledge and understanding of ADHD issues. It seems that clinicians have little faith in school teachers' abilities, yet these groups are increasingly expected to work together during the assessment and treatment phases. A national postal survey of clinicians could be

conducted but it is likely that a more informative and detailed account would be unearthed if clinicians were invited to take part in focus groups were these issues were discussed. By participating in a focus group, clinicians could voice any concerns and possibly highlight issues or prejudices that they hold about school teachers' involvement in the assessment / treatment process. It would also be useful to know if clinicians are deliberately choosing not to consult school teachers. Do they think schoolteachers lack competency or it is more to do with professional elitism?

The role of school teachers in the management of ADHD could be investigated further, perhaps even comparing the outcomes of children with the disorder whose teachers are actively involved with the medical team in its management with those children whose teachers are not.

Given the role of teachers in the identification and management of the disorder and the apparent lack of faith shown by clinicians in their abilities, it was decided to ascertain from school teachers themselves what they knew about the disorder and what, if any, gaps existed in their knowledge.

7.1.3 Knowledge and attitudes of qualified and student teachers

In chapter 4, student and qualified teachers were surveyed using a self administered questionnaire. The survey found that schoolteachers were inadequately informed about ADHD. The small sample size is a major limiting factor, so it would be appropriate to conduct another survey with a larger and more varied sample. Nonetheless, this is one of the first studies of this type and the teachers investigated are likely to be representative of Scottish teachers in general. The most interesting and perhaps major finding of this chapter was that so few of the teachers possessed useful knowledge of the disorder, yet almost all had contact with children diagnosed with ADHD. This raises uneasy questions as to the competency of teachers who are supposed to be appropriately qualified in this area. This finding suggests that any future work should investigate whether knowledge and practice differs between teachers holding qualifications in Additional Support Needs compared with teachers

who do not hold this qualification. Such a project could also serve as an unofficial evaluation of post graduate courses offered in this area and allow individuals to assess whether their courses are indeed fit for purpose. Another potential outcome of this type of study would be that employers of school teachers (who fund their attendance at such courses) would be able to judge for themselves if they receive value for their money.

It would also be worthwhile to determine whether teachers who work in primary schools, where it is easier to implement the behavioural techniques for managing ADHD, are any more knowledgeable in medical treatment of ADHD, than those teaching in secondary schools, where the environment is often less suited to the needs of a child with ADHD.

This chapter highlighted the need for suitable training for teachers. In an effort to address this, a training package was developed.

7.1.4 Delivery of training session to school teachers

One of the outcomes of the teacher study was that teachers wanted to receive their training in different aspects of ADHD in lecture format. A whole day training event delivered by members of an ADHD multidisciplinary team seemed like the most appropriate manner in which to address this. The logistics of organising such an event are being investigated by the author, with a view to delivering it in the middle of the school term. All the original speakers are in regular contact with the author and are keen to continue their involvement with this project. A more thorough evaluation of the training package (including the DVD) should be possible after this event. For example, participants attending the course could be asked to leave their contact details so that they may be approached at a later date to take part in a focus group to discuss the training. The content of the package, its delivery and utility could all be investigated and the findings used to implement improvements, where identified.

It is acknowledged that school teachers and the wider profession are subjected to what seems a constant deluge of new policies, teaching practices and styles and health initiatives, e.g. Health Promoting Schools as part of the Schools Health (Promotion & Nutrition) (Scotland) Act, 2007 (Learning Teaching Scotland, 2010). The delivery of many of these initiatives is often within the guise of 'expanding the role of the teacher' and it is likely some teachers may be suffering from 'training fatigue' (Bartlett, 2004). Pressures of this kind and the lack of funding available to undertake CPD might make it difficult for teachers to become enthusiastic about the package or engage in its evaluation. Nevertheless, the potential of the package as a meaningful training resource should not be underestimated and it continues to be a priority for the author. The fact that the training programme is also available as a DVD means that a comparative study in which the knowledge of teachers receiving the training by DVD only could be compared with teachers who receive it face to face. This secondary aspect of the validation / evaluation process could be used to inform local authority spending on teachers' training budgets.

Any subsequent training sessions could be developed so that they encompass the DVD alongside other written materials, possibly with a multiple choice type assessment at the end, and make the whole package available online. In doing so, the 'course' could be delivered and accessed by individuals unable to attend specific events and they could work through it at their own pace. Developing an online CPD resource would require collaboration with IT personnel who would provide the expertise on the logistics of such a venture. It may also be useful to find out if the training has any effect on school teachers' stress levels in the classroom. For example, Barberesi and Olsen (1998) used the Index of Teaching Stress (a self administered 90 item questionnaire) pre and post delivery of the CHADD training package and found that stress scores declined after the intervention.

A more important consequence of the training would be to assess if the package, by improving the school teacher's knowledge, has any effect on the child's clinical outcome. A simple case-control study could be used, providing any confounding factors were adequately controlled, to investigate whether increasing the knowledge

that school teachers have of ADHD is beneficial. If it is successful, then there may be scope to increase the range of topics offered to school teachers to include other medical conditions commonly found in the classroom, such as asthma.

7.2 CONCLUSION

To conclude, the compilation of studies in this thesis have shown that the provision of information about medication on the internet is basic and incomplete for the conditions investigated. In the case of ADHD, there appear to be a variety of printed resources available but their distribution to patients and parents tends to be sporadic.

School teachers were identified as potential beneficiaries of a training programme delivered by a multi-disciplinary ADHD team. The impact of the training was investigated and it was shown to have a positive effect on teachers' knowledge of the role of medication used in ADHD

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Appendices

Appendix 1

Documents relating to Chapter 2

The Strathclyde Website Evaluation Form (SWEF ADHD)

Details of ADHD websites evaluated by SWEF

Breakdown of website scores according to SWEF and DISCERN evaluations

The Strathclyde Website Evaluation Form

Web site address (URL):

Host organisation:

1. Commercial organisations
2. Government/Professional bodies
3. Charity/Support Groups
4. Miscellaneous

Date accessed:

Choose ONE score which best describes the characteristics of the website.

Clinical Attributes	Score
1. Prevalence	
(i) No details about UK prevalence (score 0 if US or worldwide figures only)	0
(ii) Must state UK prevalence (US, worldwide, gender breakdown optional)	1
(iii) UK AND gender prevalence information present	2
2. Aetiology and prognosis	
(i) Minimum or no details on aetiology	0
(ii) Basic details on aetiology (at least 2 theories mentioned)	1
(iii) Thorough details on aetiology (some mention of outcomes)	2
3. Description of symptoms	
(i) Symptoms or characteristics of disorder briefly mentioned	0
(ii) Distinction of subtypes made and corresponding core symptoms	1
(iii) as (ii) but fuller description with greater variety of symptoms	2
4. Treatment via Psychosocial Interventions	
(i) None or very brief mention of psychosocial interventions	0
(ii) Some examples of interventions for management in home or school	1
(iii) Detailed examples of psychosocial interventions in a variety of situations	2
Pharmacological Treatment	
5. Medication	
(i) Stimulants mentioned but no rationale for use or how they work	0
(ii) Stimulants mentioned and mechanism of action described	1
(iii) Stimulants AND atomoxetine mentioned with explanation of differences between both	2
6. Long term use of psychostimulant medication	
(i) No mention of limitations of clinical trial safety data	0
(ii) Brief mention that safety data on long term stimulant use is unavailable	1
(iii) Specific mention that safety data on stimulants is limited to 2 yrs	2
7. Side effects of psychostimulants	
(i) No mention of side effects or incorrect	0
(ii) Some side effects mentioned including: insomnia, reduced appetite, abdominal pain, headache, dizziness and/or indication of expected occurrence	1
(iii) More than 4 side effects listed with indication of expected incidence	2

8. Psychostimulant Formulations	
(i) No mention or distinction made between different formulations	0
(ii) Brief mention of different formulations and uses/benefits	1
(iii) Thorough details of different formulations (c.f doses or administration)	2
9. Contraindications to stimulant treatment	
(i) No details or information about contraindications	0
(ii) Brief mention but no explanation	1
(iii) Detailed information AND explanation of nature of contraindications	2
10. 2nd line treatment	
(i) No mention of alternatives to stimulants or atomoxetine	0
(ii) Passing comment about 2nd line treatment, (could mention clonidine, TCA's)	1
(iii) Detailed information about 2nd line treatment AND unlicensed nature	2
11. Co-morbidity	
(i) No mention of co-morbidity (disorders or prevalence)	0
(ii) Brief mention of co-morbidity, limited description of associated symptoms	1
(iii) Thorough description of associated co-morbidities (at least one from list: anxiety, depression, tics, Tourette's, ODD, CD)	2
Clinical Attributes cont'd	
12. Terminology	
(i) Incorrect or inappropriate use of jargon. No explanation of terms or glossary	0
(ii) Some inappropriate use of jargon	1
(iii) Appropriate language used throughout (glossary may be provided)	2
13. User support	
(i) No details of additional support/help available on website	0
(ii) Basic details of additional support/resources e.g ADHD organisations	1
(iii) Comprehensive details of support/resources e.g contact details and /or discussion group/message board facility	2
14. Disclaimer	
(i) No disclaimer or reference to consult health professional for further advice	0
(ii) Disclaimer OR reference to consult health professional clearly visible on website	1
(iii) Disclaimer AND reference to consult health professional clearly visible on website	2
Physical Attributes	
15. Authorship	
(i) No mention of site author, if named, no details regarding status or credentials	0
(ii) Author named with details of professional credentials	1
(iii) as (ii) including contact details	2
16. Currency	
(i) No details of when site originally developed or updated	0
(ii) Date provided for site development/update but > than 3 years ago	1
(iii) as (ii) but ≤ 3 years ago	2

17. Target Audience	
(i) Not stated or clearly obvious who the target audience is meant to be	0
(ii) Not clearly stated but can guess who target audience could be	1
(iii) Target audience clearly specified	2
18. Ease of Use	
(i) Rather difficult to navigate or use	0
(ii) Easier than (i) but without a search facility on webpage	1
(iii) As (ii) with additional features such as search/help facility	2
19. Advertising	
(i) Overused and obvious (may occur anywhere on page)	0
(ii) Advertising present but not intrusive	1
(iii) Advertising absent or subtle, no interference with text	2
20. Layout	
(i) Poor layout, minimal use of (sub)headings, paragraphs	0
(ii) Better than (i) but still difficult to read or follow in places	1
(iii) Good layout of text, easy to read and follow	2
21. Images	
(i) Absence of any images/pictures/animation	0
(ii) Some images present, not all useful or overuse of pictures or diagrams	1
(iii) Images present on site which are useful and/or relevant	2
22. Links	
(i) No links to other relevant sites, if present, links do not work	0
(ii) < 3 links present, some to external sites	1
(iii) > 3 links present, some external sites	2
23. Readability Statistics (Based upon Flesh Reading Ease Score)	
<30	0
30-60	1
>60	2

Final Score= /46

Details of the ADHD websites evaluated by SWEF *(n=48)*

Category	URL
1. Charities/Support groups	
Rethink	www.rethink.org/about_mental_illness/who_does_it_affect/ children_and_mental_illness/adhd.html
Mind	www.mind.org.uk/Information/Booklets/Understanding/Understanding+ADHD. htm
Mental Health Foundation	www.mentalhealth.org.uk/information/mental-health-a-z/adhd/
Contact A Family	www.cafamily.org.uk/Direct/a81.html
YoungMinds	www.youngminds.org.uk/adhd/p2.php
ADD National	www.addiss.co.uk/
ADHD is real	www.adhdisreal.co.uk/reality1.htm
UK ADHD Alliance	www.adhdalliance.org.uk/
Luton Churches Educational Trust	www.lcet.org/adhd/
Family Support Centre	www.addcentre.co.uk
Young ADHD People Matter	www.yadhdpm.co.uk/
ADDvice.	www.addvice.co.uk/
Hi 2 U	www.hi2u.org/
Developmental Adult Neuro-Diversity Association	www.danda.org.uk
ADHD Support Groups based in Essex, Milton Keynes, Gateshead, Aberdeen, Sheffield Liverpool, Plymouth Lincoln	www.addingsupport.org www.mkadhd.org.uk/home.html www.gatesheadadhdsupport.co.uk/whatis.html www.adhd-aberdeen.org.uk www.adhdsupportsheffield.org.uk/ www.liverpooladhd.org.uk www.welcometowednesdays.co.uk/ beehive.thisislincolnshire.co.uk/default.asp?WCI=SiteHome&ID=3499
2. Commercial Organisations	
Eli Lilly	www.adhdcarepathway.co.uk/adhd/what_is_adhd/
Janssen-Cilag psychiatry	www.psychiatry24x7.com/homes/adhd.jhtml;jsessionid=Q04US1CWYPKBQCUCERDBXCQ
Janssen-Cilag products	www.janssen-cilag.co.uk/bgdisplay.jhtml?itemname= parents_background_ adhd&_requestid=1343815&s=1
Tinsley House Clinic	www.tinsleyhouseclinic.co.uk/add-adhd.htm
The Studio	www.studioadhdcentre.org.uk/
Assessment & Therapy Service	www.therapyinpraxisltd.co.uk/html/adhd___add.html
BUPA Healthcare	www.hcd2.bupa.co.uk/fact_sheets/html/ attention_deficit.html
ADDSuccess Life Coaching	www.addsuccess.co.uk/
Food & Behaviour Research	www.fabresearch.org/view_item.aspx?item_id=82&open2=false
PeakMind	www.peakmind.co.uk/what-is-ADHD.htm
3. Government/Academic bodies	
NHS Direct	www.nhsdirect.nhs.uk/articles/article.aspx?articleId=40&sectionId=27010
NICE ADHD appraisal	www.nice.org.uk/guidance/TA98/guidance/pdf/English/download.dspx
Social Care Institute for Excellence	www.scie.org.uk/publications/briefings/briefing07/index.asp
Northern Ireland Education Dept	www.education-support.org.uk/index.asp?pgid=7279
Office for Advice, Assistance, Support & Information	www.oaasis.co.uk/images/ADHD%2001_07.pdf
Royal College of Psychiatrists	www.rcpsych.ac.uk/mentalhealthinformation/mentalhealthandgrowingup/5adhdhyperkineticdisorder.aspx
Learning Assessment & Neurocare Centre	www.lanc.uk.com/what_is_adhd.htm
BMA Best Treatments	www.besttreatments.co.uk/btuk/conditions/10235.jsp
BMA Clinical Evidence	www.clinicalevidence.com/ceweb/conditions/chd/0312/0312.jsp
4. Miscellaneous	
Netdoktor Health Portal	//premium.netdoktor.com/uk/adhd/index.jsp
Raising Kids	www.raisingkids.co.uk/1_4/tod_fit01.asp
Educational Psychologist	www.educational-psychologist.co.uk/adhdcklist.htm
BBC	www.bbc.co.uk/health/conditions/adhd2.shtml
Channel 4	www.channel4.com/health/microsites/F/family/problems/adhd.html

Breakdown of website scores according to SWEF and DISCERN evaluations

	SWEF Total score (max 46)	SWEF Clinical (max 28)	SWEF Physical (max 18)	DISCERN Total score (max 80)	DISCERN Clinical (max 35)	DISCERN Overall (1-5)
C 1	15	10	5	34	10	2
C 2	23	11	12	57	25	4
C 3	26	15	11	57	27	3
C 4	12	6	6	37	14	1
C 5	29	16	13	46	16	3
C 6	23	13	9	48	23	3
C 7	22	9	13	59	20	3
C 8	17	7	10	23	9	1
C 9	14	4	10	25	10	1
C 10	9	1	8	26	15	1
C 11	16	3	13	39	10	2
C 12	20	6	14	43	11	2
Gov/Pro 1	34	19	15	68	27	5
Gov/Pro 2	20	10	10	50	20	2
Gov/Pro 3	29	16	13	62	29	4
Gov/Pro 4	29	15	14	58	21	4
Gov/Pro 5	22	10	12	41	14	2
Gov/Pro 6	27	15	12	56	23	3
Gov/Pro 7	25	13	12	35	13	3
Gov/Pro 8	21	12	9	41	13	2
Gov/Pro 9	24	12	12	56	21	3
Misc 1	29	21	8	58	25	4
Misc 2	20	5	15	34	14	2
Misc 3	11	3	8	28	14	1
Misc 4	22	10	12	39	11	3
Misc 5	23	12	11	46	22	3
C SG 1	17	5	12	39	15	2
C SG 2	20	10	10	52	21	3
C SG 3	11	6	5	37	12	2
C SG 4	22	9	13	39	10	2
C SG 5	23	10	13	55	26	4
C SG 6	13	3	10	27	8	1
C SG 7	16	5	11	38	14	2
C SG 8	16	3	13	39	10	2
C SG 9	21	11	10	42	14	2
C SG 10	26	14	12	57	24	4
C SG 11	27	15	12	58	26	4
C SG 12	20	12	8	43	20	3
C SG 13	15	6	9	26	8	2
C SG 14	21	9	12	43	17	3
C SG 15	15	4	11	30	11	2
C SG 16	17	3	14	30	8	2
C SG 17	14	4	10	29	9	2
C SG 18	17	6	11	37	16	3
C SG 19	21	8	3	33	11	2
C SG 20	20	11	9	43	21	3
C SG 21	26	15	11	49	26	3
C SG 22	18	7	11	46	17	3

C = commercial organisations selling products or services
Gov/Pro = Governmental/NHS or academic professional bodies
CSG = Charities & Support Groups

Appendix 2

Documents relating to Chapter 3

E-mail message from NHS COREC

Letter of invitation sent to Psychiatrists in NHS Scotland

Letter of invitation sent to Paediatricians in NHS Scotland

Online / postal questionnaire

E-mail message from NHS COREC advising of status of clinician study.

Gazala Akram

From: Queries [queries@corec.org.uk]
Sent: 20 December 2006 12:07
To: Gazala Akram
Subject: RE: advice regarding an application
Attachments: Audit_or_Research_table_Nov06.pdf

Thank you.
The following reply has been provided by Jo Downing, Information Officer

Thank you for your query.

When asked to advise on the requirement for ethical review by an NHS Research Ethics Committee (REC) we consider the information sent to us and use the criteria in the attached table to reach a conclusion.

Based on the information provided, our advice is that the study may be classified as service evaluation. On this basis it does not require review by a NHS REC. The main remit of NHS RECs, as set out in paragraph 3.1 of the Governance Arrangements for NHS Research Ethics Committees (GAfREC), is to review research involving NHS patients. GAfREC is available on our website at

Although independent ethical review by an NHS REC is not necessary in this case, all types of study involving human participants should be conducted in accordance with basic ethical principles for example informed consent and respect for the confidentiality of participants. When processing identifiable data there are also legal requirements under the Data Protection Act 2000. When undertaking an audit or service evaluation, the investigator and his/her team are responsible for considering the ethics of their study with advice from within their organisation. You may find it helpful to discuss your study with the relevant R&D Office and your Data Protection Officer.

Where exceptionally an audit or service evaluation is felt to raise significant ethical issues and the host organisation considers independent ethical review to be essential, an application may be made to an NHS REC under GAfREC paragraph 3.2.

I hope this helps.

Regards

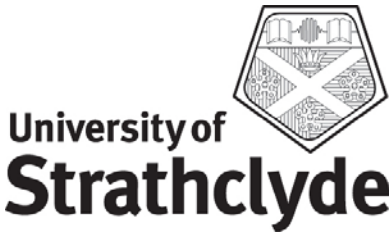
Queries Line
Central Office for Research Ethics Committees (COREC)
National Patient Safety Agency
Website:

Ref: 041/01
**
An information leaflet on the New Operational Procedures for NHS Research Ethics Committees from 1 March 2004 is available at Request printed copies from the COREC office by email to:_

**
This reply may have been sourced in consultation with other members of the COREC team.
***

07/01/2007

Letter of invitation sent to psychiatrists in NHS Scotland



Information Provision in ADHD

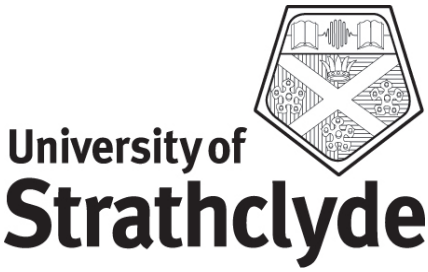
Dear Consultant Psychiatrist,

I am a lecturer in the Strathclyde Institute of Pharmacy and Biomedical Sciences at the University of Strathclyde and Honorary Specialist Pharmacist in Child Psychiatry, NHS Greater Glasgow and Clyde. As part of my research I am trying to establish the nature of information provided by psychiatrists and paediatricians to the parents of children diagnosed with and/or receiving medication for Attention Deficit Hyperactivity Disorder (ADHD). The practice and opinions of both professions are being determined by a national survey and will be compared. This survey is available electronically via an anonymous online questionnaire and can be accessed via a secure webpage hosted by the University of Strathclyde. Confidentiality is guaranteed and the study protocol and design comply with relevant University and NHS research practices and procedures. Your participation is entirely voluntary, but it would be extremely helpful if you could spare the time to complete the questionnaire. This should only take about ten minutes.

The Royal College of Psychiatrists (Scottish Division) have approved the study design and questionnaire and have agreed to distribute these letters of invitation. Your contact details and other personal information are therefore unknown to the researchers. Your help with this survey would be very much appreciated. If you require any additional information on any aspect of this study please feel free to contact me at 0141 548 4980 or by email: gazala.akram@strath.ac.uk. Thank you in anticipation for your help.

To participate in this study, please visit the site below http://spider.science.strath.ac.uk/gasurvey/ and enter the password : psychadhd

Letter of invitation sent to paediatricians in NHS Scotland



Information Provision in ADHD

Dear Paediatrician,

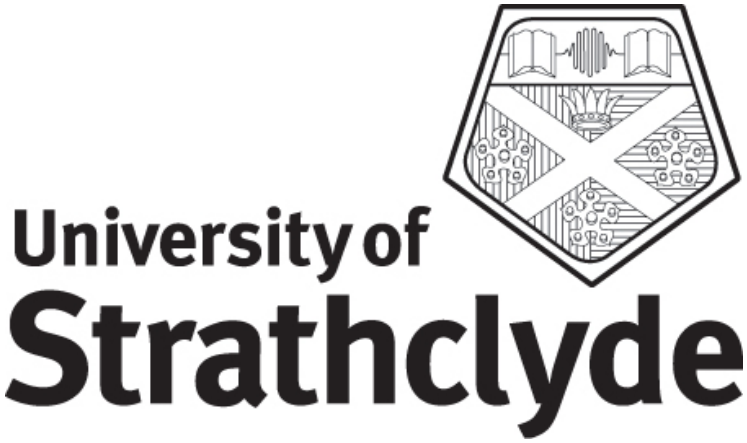
I am a lecturer in the Strathclyde Institute of Pharmacy and Biomedical Sciences at the University of Strathclyde and Honorary Specialist Pharmacist in Child Psychiatry, NHS Greater Glasgow and Clyde. As part of my research, I aim to establish the nature of information provided by psychiatrists and paediatricians to parents of children diagnosed with and/or receiving medication for ADHD. The practice and opinions of both professions are being determined by a national survey and will be compared. This survey is available electronically via an anonymous online questionnaire and can be accessed via a secure webpage hosted by the University of Strathclyde. Confidentiality is guaranteed and the study protocol and design comply with relevant University and NHS research practices and procedures. Your participation is entirely voluntary, but it would be extremely helpful if you could spare the time to complete the questionnaire. This should only take about ten minutes.

The Royal College of Paediatricians and Child Health (Scottish Division) have approved the study design and questionnaire and have agreed to distribution of these letters. It is an anonymous questionnaire and your help will be much appreciated. If you require additional information on any aspect of this study please feel free to contact me at 0141 548 4980 or by email: gazala.akram@strath.ac.uk. Thank you in anticipation for your help.

To participate in this study, please visit the site below

http://spider.science.strath.ac.uk/gasurvey/ and enter the password: paedadhd

On-line / postal questionnaire.



Information Provision in ADHD

This questionnaire is concerned with your day to day practice when dealing with children aged **twelve years and younger** who have been diagnosed or are receiving treatment for ADHD. Please answer each question to the best of your knowledge. All responses will be analysed anonymously.

Before proceeding with the questionnaire, please answer the questions below.

Are you? ☐ Male ☐ Female

How many years have you been working as a **child** psychiatrist?

☐ < 5yrs ☐ 6-15yrs ☐ 16-24yrs ☐ + 25yrs

1. Do you provide written information about ADHD to the parents (carers) of your patients? *(Please tick the appropriate response)*

☐ Always ☐ On most occasions ☐ Sometimes ☐ Rarely ☐ Never

If you do not provide written information about the condition or its treatment, please go to question 10. Otherwise, continue with question 2. Questions 2 – 9 are concerned with the characteristics of the printed information resource that you provide most often to parents/carers.

2. Is the printed information resource (*Please tick the appropriate response):*

☐ A Fact sheet (single or double sided) ☐ A Leaflet (up to 10 pages)

☐ A Booklet (up to 30 pages) ☐ A Book (+30 pages) ☐ Other

3. Is this information resource originally produced or distributed by *(Please tick the appropriate response)*

☐ A pharmaceutical company ☐ Government/Health Professional body

☐ A generic mental health charity ☐ A specialist ADHD charity e.g ADDISS

☐ Other (please specify)……..

4. Which of the topics below are specifically mentioned in the information resource? *(Please tick all responses that apply)*

☐ Description of the symptoms of ADHD

☐ Details about the diagnostic process

☐ Symptom management using behavioural techniques

☐ Symptom management using medication

☐ Other (please describe)……

5. Which of the following aspects of medication are specifically mentioned? *(please tick all responses that apply)*

☐ The generic name of the medication

☐ Dosing information

☐ Explanation of how the medication works

☐ Effect of treatment and/or its limitations

☐ Common side effects

☐ Less common side effects

☐ Limitations of drug treatment

☐ Any other information (related to medication, please specify)……

6. Have you identified any gaps or deficiencies in your information resource that could be addressed? ☐ Yes ☐ No

b) If yes, please describe what these gaps are……

It would be helpful if you could provide details of this printed information resource, so that it may be accessed.

Title: ……..

Author (publisher) …….. Date of publication:……..

For questions 7-11, you are presented with a statement. Please indicate your level of agreement or disagreement with each statement by ticking the relevant box.

7. The information resource I provide is appropriate and useful to **parents**.

☐ Strongly Agree ☐ Agree ☐ Undecided ☐ Disagree ☐ Strongly Disagree

8. The information resource I provide to parents is also appropriate for children.

☐ Strongly Agree ☐ Agree ☐ Undecided ☐ Disagree ☐ Strongly Disagree

9. The information resource I provide to parents is also appropriate for school teachers.

☐ Strongly Agree ☐ Agree ☐ Undecided ☐ Disagree ☐ Strongly Disagree

10. In my experience, school teachers are trained to recognise the symptoms of ADHD

☐ Strongly Agree ☐ Agree ☐ Undecided ☐ Disagree ☐ Strongly Disagree

11. In my experience, school teachers have sufficient understanding of the purpose of stimulant medication

☐ Strongly Agree ☐ Agree ☐ Undecided ☐ Disagree ☐Strongly Disagree

12. Are there any areas/topics about ADHD and its treatment that you think school teachers would particularly benefit from through additional education or training? ☐ Yes ☐ No If yes, please describe what these may be……

13. Please indicate from the list below what you think would be the most effective medium for information provision

☐ Printed material (leaflet/book) ☐ Audio Visual resource (CD, DVD, video)
☐ Online/web page ☐ Other (please describe)……..

The following section is concerned with your knowledge of ADHD resources

14. Please indicate yes or no if you have ever visited the websites below

a) **Janssen Cilag ADHD website** ☐ Yes ☐ No

(http://www.janssen-cilag.co.uk/bgdisplay.jhtml?itemname=adhd_gateway)

b) **ADD Success Coaching and Training Consultancy Service** ☐ Yes ☐ No
(http://www.addsuccess.co.uk/)

c) **BMJ Best Treatments website** ☐ Yes ☐ No
(http://www.besttreatments.co.uk/btuk/conditions/10235.jsp)

d) **NHS Direct common health questions page** ☐ Yes ☐ No
(http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=40&sectionId=27010)

e) **Mental health charity MIND ADHD information page** ☐ Yes ☐ No
(http://www.mind.org.uk/Information/Booklets/Understanding/Understanding+ADHD.htm)

f) **National ADHD information & support service** ☐ Yes ☐ No
(http://www.addiss.co.uk/index.html)

g) **Netdoktor online health information resource** ☐ Yes ☐ No
(http://premium.netdoktor.com/uk/adhd/index.jsp)

h) **Raising Kids online parental support service** ☐ Yes ☐ No
(http://www.raisingkids.co.uk/1_4/tod_fit01.asp)

15. In the past year, have you visited any other ADHD specific websites**?**
☐ Yes ☐ No
If yes, please describe what these were or give their URLs……..

16. Do you routinely recommend any ADHD or mental health websites to parents/carers?
☐ Yes ☐ No
If yes, please provide details of the site……..
b) Why do you recommend these sites?.....

17. Do you provide any other resources or information about ADHD?
☐ Yes ☐ No
If yes, please describe what these are……..

Thank you for completing this questionnaire.

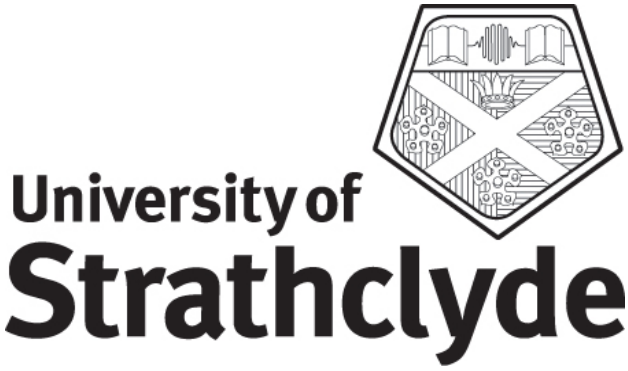
Appendix 3

Documents relating to Chapter 4

Questionnaire completed by student and qualified teachers

Approval letter from Faculty of Education Ethics Committee

Questionnaire completed by student and qualified teachers



School Teachers Knowledge and Understanding of ADHD and its Treatment

We are currently investigating school teacher's knowledge and understanding of ADHD and the medication used in its treatment. Completion of the questionnaire is entirely voluntary and anonymous. The researchers are grateful for your cooperation and are willing to provide an overview of findings, on request, to any respondent.

Thank you.

Marion McLarty, Senior Lecturer, Dept of Educational and Professional Studies
Gazala Akram, Lecturer, Strathclyde Institute of Pharmacy & Biomedical Sciences

Before proceeding with the questionnaire, please could you answer the questions below.

1. Are you? ☐ Male ☐ Female
2. What Qualifications do you currently hold? _____
3. How many years have you been teaching? _____
4. What classes / primary stages do you have experience of teaching?
   _____
5. In what context are you currently teaching e.g. mainstream / ASN unit / segregated school?
   _____

Section A: ADHD Resources

1) Did your initial teacher education (ITE) include...

a) information about ADHD ❒ YES ❒ NO

b) skill development to manage children with ADHD classroom? ❒ YES ❒ NO

2) Have you received any additional training regarding ADHD since you began teaching?

❒ YES ❒ NO

If yes, b) what was the nature of this training? _____

3) Have you ever taught a child with ADHD? ❒ YES ❒ NO

If yes, a) How many have you taught in the past? _____

4) Where do you currently look for information about ADHD?

_____

5) Do you use/consult any of these resources for information about ADHD?

❒ Teaching colleagues

❒ Specialised literature

❒ Training courses

❒ Medical personnel

❒ Support teachers

❒ The Internet

❒Other, please specify _____

6) Have you ever visited any of these websites for information about ADHD?

a) www.handsonscotland.co.uk ❒ YES ❒ NO

b) www.addiss.co.uk ❒ YES ❒ NO

c) www.mind.org.uk ❒ YES ❒ NO

d) www.nhs24.com ❒ YES ❒ NO

e) www.janssen-cilag.co.uk ❒ YES ❒ NO

f) www.besttreatments.co.uk ❒ YES ❒ NO

g) Have you visited other websites for information about ADHD? ❒ YES ❒ NO

if yes, please provide details of the site(s)_____

Section B: Knowledge Regarding ADHD

The questions below are designed to assess your knowledge of ADHD.

For each statement, please tick True, False or Don't Know, to indicate your response.

		T	F	DK
1.	There are a greater number of boys than girls with ADHD	❒	❒	❒
2.	If medication is prescribed, educational interventions are often unnecessary	❒	❒	❒
3.	Approximately 5% of Scottish school-aged children have ADHD	❒	❒	❒
4.	ADHD can be inherited	❒	❒	❒
5.	There are 3 main subtypes/categories of ADHD	❒	❒	❒
6.	ADHD is a medical disorder that can only be treated with medication	❒	❒	❒
7.	Medical procedures such as blood tests, x-rays magnetic resonance imaging or EEG are useful in the diagnosis of ADHD	❒	❒	❒
8.	If a child responds to stimulant medication (e.g., Ritalin) then they probably have ADHD	❒	❒	❒
9.	When stimulants are used they improve a child academic performance	❒	❒	❒
10.	Medication is a cure for ADHD	❒	❒	❒
11.	Antidepressants can be used to treat ADHD symptoms	❒	❒	❒
12.	Research has shown that prolonged use of stimulant medications leads to increased addiction (i.e., drugs, alcohol) in adulthood	❒	❒	❒
13.	Almost 30% of children with ADHD do not respond to stimulant medication	❒	❒	❒
14.	The availability of different formulations of stimulants means doses do not have to be taken during the school day	❒	❒	❒
15.	Controlled drugs are often used to treat ADHD symptoms	❒	❒	❒
16.	Medication for ADHD has the following effect(s)	❒	❒	❒
	a) Improves concentration	❒	❒	❒
	b) Decreases impulsiveness	❒	❒	❒
	c) Increases peer interactions	❒	❒	❒
	d) Improves long term memory	❒	❒	❒

Medication for ADHD has the following effect(s)	T	F	DK
e) Improves classroom performance	❒	❒	❒
f) Stimulant medication has the following side effects	❒	❒	❒
g) Decreased appetite	❒	❒	❒
h) Insomnia or trouble sleeping	❒	❒	❒
i) Day dreaming	❒	❒	❒
j) Headache	❒	❒	❒
k) Drowsiness	❒	❒	❒
l) Stomach problems	❒	❒	❒
m) Irritability	❒	❒	❒
n) Low mood/sadness	❒	❒	❒
o) Anxiety	❒	❒	❒
p) Tics/nervous movements	❒	❒	❒
q) Dizziness	❒	❒	❒
r) Euphoria	❒	❒	❒
s) Addiction	❒	❒	❒

Section C: Beliefs & Attitudes Regarding ADHD

This section assesses your beliefs and attitudes about children with ADHD in your classroom. For each statement, tick to indicate your response, SA (Strongly agree), A (Agree), Undecided (U), D (Disagree) or SD (Strongly Disagree).

	SA	A	U	D	SD
1. ADHD is a valid diagnosis	❒	❒	❒	❒	❒
2. School teachers are trained to recognise the symptoms of ADHD	❒	❒	❒	❒	❒
3. ADHD is a behavioural disorder that should not be treated with medication	❒	❒	❒	❒	❒

		SA	A	U	D	SD
4.	Medication should only be used as a last resort	❒	❒	❒	❒	❒
5.	School teachers have sufficient understanding of the purpose of stimulant medication	❒	❒	❒	❒	❒
6.	All children with ADHD should take medication	❒	❒	❒	❒	❒
7.	Some ADHD medication can cause mood swings	❒	❒	❒	❒	❒
8.	School teachers should be aware of the side effects of ADHD medication	❒	❒	❒	❒	❒
9.	Too many children are prescribed stimulants	❒	❒	❒	❒	❒
10.	School teachers should be able to providing feedback to parents and doctors on a child's response to medication	❒	❒	❒	❒	❒
11.	School teachers should be more involved in monitoring a child's response to medication	❒	❒	❒	❒	❒
12.	Drugs other than stimulants are used in the treatment of ADHD	❒	❒	❒	❒	❒
13.	I am able to tell if one of my pupils has not taken their ADHD medication that morning/day	❒	❒	❒	❒	❒

Section D: Further Training

1) Do you feel you could benefit from additional training regarding ADHD? ❒ YES ❒ NO

If yes, please tick below what aspects you would like more information on

❒ Causes ❒ Prevalence

❒ Assessment and diagnosis ❒ Symptoms

❒ Medication ❒ Classroom management

❒ Other *(please specify)* _____

2) What would be the best way for you to receive this further training?

Please number the options below in order of preference (1 = most preferred way)

❒ Lecture Presentation ❒ Written (booklet/leaflets)

❒ Audio Visual e.g as a CD ❒ As a web page (via the internet)

Other *(please specify)* _____

Thank you for taking the time to complete this questionnaire.

Approval letter from Faculty of Education Ethics Committee

University of Strathclyde
Education

Notice of Departmental Ethics Committee Decision

Date: 18th January 2008

Applicant: Marion McLarty

Project Title: School teachers' knowledge and understanding of ADHD and its treatment.

Approval Of Investigation

The Departmental Ethics Committee confirm ethics approval for the above investigation strictly within the terms as advised on the application.

When your investigation is completed we would welcome a short note indicating completion and advising of any ethical matters that may have arisen but which were not anticipated within your application.

The committee wishes you success in your investigation.

For the Departmental Ethics Committee

David Wallace

David Wallace (Chair)

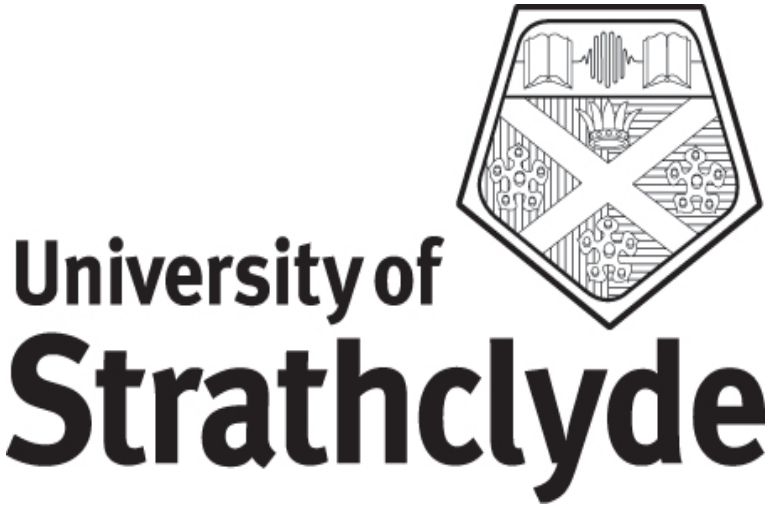
Appendix 4

Documents relating to Chapter 5

Questionnaire used to evaluate Pharmacist led training session

DVD containing multidisciplinary training session entitled: ‘Paying Attention to ADHD’

Questionnaire used to evaluate Pharmacist led training session



School Teacher's Knowledge and Understanding of ADHD and its Treatment

This questionnaire forms part of a larger investigation of the training needs of school teachers for ADHD. Participation and completion of the questionnaire is entirely voluntary and anonymous. Please try to answer as many questions as possible.

Thank you.

Gazala Akram, Lecturer, Strathclyde Institute of Pharmacy & Biomedical Sciences

Before proceeding with the questionnaire, please answer the questions below.

1. Are you? ☐ Male ☐ Female

2. What qualifications do you currently hold? _____

Section A: ADHD Resources

1. During your initial teacher education (ITE) have you received information about ADHD?

❒ YES ❒ NO

2. Have you ever taught a child with ADHD? ❒ YES ❒ NO

3. Have you ever completed a behaviour checklist or rating scale for a child with ADHD?

❒ YES ❒ NO

4. Where do you currently go/look for information about ADHD?

_____

5) Do you use/consult any of these resources for information about ADHD?

❒ Teaching colleagues

❒ Specialised literature

❒ Training courses

❒ Medical personnel

❒ Support teachers

❒ The Internet

❒Other, please specify

_____

6) Have you ever visited any of these websites for information about ADHD?

a) www.handsonscotland.co.uk ❒ YES ❒ NO

b) www.addiss.co.uk ❒ YES ❒ NO

c) www.mind.org.uk ❒ YES ❒ NO

d) www.nhs24.com ❒ YES ❒ NO

e) www.janssen-cilag.co.uk ❒ YES ❒ NO

f) www.besttreatments.co.uk ❒ YES ❒ NO

g) Have you visited other websites for information about ADHD? ❒ YES ❒ NO

if yes, please provide details of the site(s)_____

Section B: Knowledge Regarding ADHD

The questions below are designed to assess your knowledge of ADHD.

For each statement, please tick True, False or Don't Know, to indicate your response.

	T	F	DK
16. There are a greater number of boys than girls with ADHD	❒	❒	❒
17. If medication is prescribed, educational interventions are often unnecessary	❒	❒	❒
18. Approximately 5% of Scottish school-aged children have ADHD	❒	❒	❒
19. ADHD can be inherited	❒	❒	❒
20. There are 3 main subtypes/categories of ADHD	❒	❒	❒
21. ADHD is a medical disorder that can only be treated with medication	❒	❒	❒
22. Medical procedures such as blood tests, x-rays magnetic resonance imaging or EEG are useful in the diagnosis of ADHD	❒	❒	❒
23. If a child responds to stimulant medication (e.g., Ritalin) then they probably have ADHD	❒	❒	❒
24. When stimulants are used they improve a child academic performance	❒	❒	❒
25. Medication is a cure for ADHD	❒	❒	❒
26. Antidepressants can be used to treat ADHD symptoms	❒	❒	❒
27. Research has shown that prolonged use of stimulant medications leads to increased addiction (i.e., drugs, alcohol) in adulthood	❒	❒	❒
28. Almost 30% of children with ADHD do not respond to stimulant medication	❒	❒	❒
29. The availability of different formulations of stimulants means doses do not have to be taken during the school day	❒	❒	❒
30. Controlled drugs are often used to treat ADHD symptoms	❒	❒	❒
16. Medication for ADHD has the following effect(s)	❒	❒	❒
t) Improves concentration	❒	❒	❒
u) Decreases impulsiveness	❒	❒	❒
v) Increases peer interactions	❒	❒	❒
w) Improves long term memory	❒	❒	❒
Medication for ADHD has the following effect(s)	T	F	DK

x) Improves classroom performance	❒	❒	❒
y) Stimulant medication has the following side effects	❒	❒	❒
z) Decreased appetite	❒	❒	❒
aa) Insomnia or trouble sleeping	❒	❒	❒
bb) Day dreaming	❒	❒	❒
cc) Headache	❒	❒	❒
dd) Drowsiness	❒	❒	❒
ee) Stomach problems	❒	❒	❒
ff) Irritability	❒	❒	❒
gg) Low mood/sadness	❒	❒	❒
hh) Anxiety	❒	❒	❒
ii) Tics/nervous movements	❒	❒	❒
jj) Dizziness	❒	❒	❒
kk) Euphoria	❒	❒	❒
ll) Addiction	❒	❒	❒

Section C: Beliefs & Attitudes Regarding ADHD

This section assesses your beliefs and attitudes about children with ADHD in your classroom. For each statement, tick to indicate your response, SA (Strongly agree), A (Agree), Undecided (U), D (Disagree) or SD (Strongly Disagree).

	SA	A	U	D	SD
14. ADHD is a valid diagnosis	❒	❒	❒	❒	❒
15. School teachers are trained to recognise the symptoms of ADHD	❒	❒	❒	❒	❒
16. ADHD is a behavioural disorder that should not be treated with medication	❒	❒	❒	❒	❒
	SA	A	U	D	SD

17. Medication should only be used as a last resort	❒	❒	❒	❒	❒
18. School teachers have sufficient understanding of the purpose of stimulant medication	❒	❒	❒	❒	❒
19. All children with ADHD should take medication	❒	❒	❒	❒	❒
20. Some ADHD medication can cause mood swings	❒	❒	❒	❒	❒
21. School teachers should be aware of the side effects of ADHD medication	❒	❒	❒	❒	❒
22. Too many children are prescribed stimulants	❒	❒	❒	❒	❒
23. School teachers should be able to providing feedback to parents and doctors on a child's response to medication	❒	❒	❒	❒	❒
24. School teachers should be more involved in monitoring a child's response to medication	❒	❒	❒	❒	❒
25. Drugs other than stimulants are used in the treatment of ADHD	❒	❒	❒	❒	❒

Thank you for completing this questionnaire. If you would like to take part in a focus group discussion about ADHD training needs and are available for a few hours in May 2009, please provide your contact details below.

Name: Tel. No: / e-mail

DVD containing multidisciplinary training session entitled: ‘Paying Attention to ADHD’

Appendix 5

Documents relating to Chapter 6

Strathclyde Website Evaluation Form for Cystic Fibrosis (SWEF-CF)
Details of CF websites evaluated by SWEF
Strathclyde Website Evaluation Form for Schizophrenia (SWEF-Schiz)
Details of Schizophrenia websites evaluated by SWEF

Strathclyde Website Evaluation Form for Cystic Fibrosis (SWEF-CF)

Web site address (URL):
Date accessed:

Host organisation:
1. Commercial organisations
2. Government/Professional bodies
3. Charity/Support Groups
4. Miscellaneous

Choose ONE score which best describes the characteristics of the website

Clinical Attributes	Score
1. Prevalence	
(i) No information on UK prevalence or US/worldwide figures only	0
(ii) UK prevalence figures provided	1
(iii) As (ii) & information on prevalence of CFTR gene carriers	2
2. Aetiology and Prognosis	
(i) No details on aetiology	0
(ii) Some details; MUST mention genetics or CFTR gene AND prognosis	1
(iii) As (ii) but additional information about causes AND prognosis	2
3. Complications of CF	
(i) No mention of CF complications	0
(ii) Brief mention: limited description of associated symptoms MUST discuss lung disease/symptoms or nutrition/pancreatic insufficiency or DIOS.	1
(iii) As (ii) but more detailed AND mention of diabetes, liver problems or infertility	2
4. Non Pharmacological Treatment	
(i) Physiotherapy mentioned	0
(ii) Physiotherapy techniques mentioned AND lung transplantation	1
(iii) As (ii) but in more detail	2
Pharmacological Treatment	
5. Bronchodilators/Corticosteroids	
(i) Bronchodilators and/or corticosteroids briefly mentioned	0
(ii) As (i) with 2 examples of possible side effects of one treatment	1
(iii) As (ii) AND rationale for treatment or mechanism of action explained	2
6. Antibiotic Prophylaxis	
(i) No mention of antibiotic therapy	0
(ii) As (i) AND dosing information and/or side effects mentioned	1
(iii) As (ii) AND rationale for treatment and/or specific drugs mentioned	2
7. Antibiotic Treatment	
(i) Oral AND IV antibiotic treatment mentioned	0
(ii) As (i) AND dosing information and/or side effects mentioned	1
(iii) As (ii) AND rationale for treatment and/or specific drugs mentioned	2

8. Inhaled Dornase Alfa/Pulmozyme/DNAse	
(i) Dornase alfa/Pulmozyme/DNAse mentioned	0
(ii) As (i) AND dosing information and/or side effects	1
(iii) As (ii) AND rationale for treatment (or limitations) and/or how it works	2
9. Nutritional Needs	
(i) No mention of nutritional requirements or treatment	0
(ii) Brief mention of nutrition, vitamins or nutritional supplementation	1
(iii) Detailed information about nutritional requirements MUST mention vitamins and nutritional supplements	2
10. Pancreatic Enzyme Supplements	
(i) Supplements mentioned	0
(ii) As (i) AND side effects and/or how to manage these	1
(iii) As (ii) AND dosing and/or administration details	2
11. New Treatments – Gene Therapy	
(i) No mention of new or future developments for treatment	0
(ii) Mention of at least one new or in development CF treatment	1
(iii) Detailed and accurate discussion of new OR future treatments for CF	2
Clinical Attributes cont'd	
12. Terminology	
(i) Incorrect or inappropriate use of jargon. No explanation of terms or glossary	0
(ii) Some inappropriate use of jargon	1
(iii) Appropriate language used throughout (glossary may be provided)	2
13. User Support	
(i) No details of additional support/help available on website	0
(ii) Basic details of additional support/resources eg CF organisations	1
(iii) Comprehensive details of support/resources eg contact details and or/discussion group/message board facility	2
14. Disclaimer	
(i) No disclaimer or reference to consult health professional for further advice	0
(ii) Disclaimer OR reference to consult health professional clearly visible on site	1
(iii) Disclaimer AND reference to consult health professional clearly visible on site	2
Physical Attributes	
15. Authorship	
(i) No mention of site author, if named, no details regarding status or credentials	0
(ii) Author named with details of professional credentials	1
(iii) as (ii) including contact details	2
16. Currency	
(i) No details of when site originally developed or updated	0
(ii) Date provided for site development/update but > than 3 years ago	1
(iii) as (ii) but ≤ 3 years ago	2

17. Target Audience		
(i) Not stated or obvious who the target audience is meant to be		0
(ii) Not clearly stated but can guess who target audience could be		1
(iii) Target audience clearly specified		2
18. Ease of Use		
(i) Rather difficult to navigate or use		0
(ii) Easier than (i) but without a search facility on homepage		1
(iii) As (ii) with additional features such as search/help facility		2
19. Links		
(i) No links to other relevant sites or links do not work		0
(ii) < 3 links present, some to external sites		1
(iii) > 3 links, some external sites		2
20. Advertising		
(i) Overuse of adverts/pop ups, interfering with actual text		0
(ii) Some advertising present but doesn't interfere with body of text		1
(iii) No commercial advertising present		2
21. Layout		
(i) Poor layout, minimal use of (sub) heading, paragraphs		0
(ii) Better than (i) but still difficult to read or follow in places		1
(iii) Good layout of text, easy to read and follow		2
22. Images		
(i) Absence of any images/pictures/animation		0
(ii) Some images present, not all useful or overuse of pictures or diagrams		1
(iii) Images present which are useful or relevant		2
23. References		
(i) No references given/ references incomplete or from dubious sources		0
(ii) References from credible sources but lacking in detail		1
(iii) Comprehensive, credible and accurate references		2
24. Readability Statistics (Based upon Flesh Reading Ease Score)		
(a) Flesh Reading Ease Score	<30	0
	30-60	1
	>60	2

Final Score = /48

Details of CF websites evaluated by SWEF-CF *(n=32)*

Category	URL
1. Charities/Support Groups	
CF Trust	www.cftrust.org.uk/aboutcf/whatiscf/
Genetic Interest Group	www.gig.org.uk/genesandyou_CF.htm
UK CF gene therapy groups	www.cfgenetherapy.org.uk/cysticfibrosis.htm
People With Cystic Fibrosis	www.pwcf.net/
The Henry Spink Foundation	www.henryspink.org/cystic_fibrosis.htm
Contact A Family	www.cafamily.org.uk/Direct/c93.html
Dream Holidays	www.cfdreamholidays.co.uk/
Butterfly Trust	www.butterflytrust.org.uk/
Support group based in Gloucester	//beehive.thisisgloucestershire.co.uk/default.asp?WCI=SiteHome&ID=3822
Ableize (disability resources)	//www.ableize.com/specific-disabilities/Cystic-Fibrosis/
The Wellcome Trust	http://genome.wellcome.ac.uk/doc_wtd020856.html
CF medicine	www.cysticfibrosismedicine.com/#
2. Commercial Organisations	
Solvay Healthcare	www.creoninfo.co.uk/pages/homepage.asp
Baxter	www.baxterhealthcare.co.uk/conditions/sub/cystic_fybrosis.html
BUPA Healthcare	http://hcd2.bupa.co.uk/fact_sheets/Mosby_factsheets/Cystic_fibrosis.html
MedicineChest	www.medicinechest.co.uk/site/medicinechest/index.aspx?P=231&H=cystic%20fibrosis
3. Government/Professional	
NHS Direct	www.nhsdirect.nhs.uk/articles/article.aspx?articleId=118
National Library for Health	www.library.nhs.uk/genepool/viewResource.aspx?catID=8930&dg=164&resID=83901
NHS choices	www.nhs.uk/Conditions/Cystic-fibrosis/Pages/questionstoask.aspx?url=Pages/Questions.aspx
NHS 24	www.nhs24.com/content/default.asp?page=s5_5&articleID=118
NHS Clinical Knowledge Summaries	//cks.library.nhs.uk/patient_information_leaflet/cystic_fibrosis
Univ of Newcastle, Medical Oncology Depart.	//cancerweb.ncl.ac.uk/cgi-bin/omd?cystic+fibrosis
4. Miscellaneous	
Netdoktor Health Portal	www.netdoctor.co.uk/diseases/facts/cysticfibrosis.htm
VideoJug	www.videojug.com/interview/cystic-fibrosis-2#what-is-cystic-fibrosis
GMTV Health page	//gmtv.medicdirect.co.uk/diseases/default.asp?pid=1379&step=4
i-Village	www.ivillage.co.uk/pregnancyandbaby/baby/babyhealth/articles/0,,30_177632,00.html
GP Notebook	www.gpnotebook.co.uk/simplepage.cfm?ID=919601157
Medic8	www.medic8.com/healthguide/articles/cysticfibrosis.html
Patient UK	www.patient.co.uk/showdoc/27000674/
Optimus Education Homepage	www.teachingexpertise.com/articles/cystic-fibrosis-1233
Lab Tests Online	www.labtestsonline.org.uk/understanding/conditions/cystic_fibrosis.html
BBC Health page	www.bbc.co.uk/health/conditions/cystic1.shtml

Strathclyde Website Evaluation Form for Schizophrenia (SWEF-Schiz)

Web site address (URL):
Date accessed:

Host organisation:
1. Commercial organisations
2. Government/Professional bodies
3. Charity/Support Groups
4. Miscellaneous

Choose ONE score which best describes the characteristics of the website

Clinical Attributes	Score
1. Prevalence	
(i) No information on UK prevalence	0
(ii) Details of UK prevalence or incidence provided	1
(iii) As (ii) & information about age of onset	2
2. Aetiology	
(i) No mention of aetiology	0
(ii) Basic details including chemical abnormality or genetics	1
(iii) Detailed including mention of environmental influences	2
3. Prognosis	
(i) No mention of prognosis	0
(ii) Superficial mention	1
(iii) Detailed including effect of age of onset, severity of symptoms etc	2
4. Diagnosis	
(i) No description of symptoms OR only description of positive symptoms	0
(ii) At least 2 positive symptoms AND mention of negative symptoms	1
(iii) As (ii) & details of symptom duration or differential diagnosis or effects on cognition	2
Pharmacological Treatment	
5. Medication	
(i) Antipsychotics not mentioned or where mentioned no distinction made between different types e.g typical and atypical	0
(ii) Both typical & atypical mentioned	1
(iii) Detailed reference to both with explanation of difference	2
6. Mechanism of action	
(i) No information about mechanism of action	0
(ii) Brief mention including receptors or regulation of neurotransmitters	1
(iii) More detailed than (ii) with information about time for onset of therapeutic effect	2
7. Side effects from Typical Antipsychotics (APs)	
(i) Not mentioned or superficial details	0
(ii) At least 2 side effects mentioned & explanation of their causes	1
(iii) As (ii) & rationale for anticholinergic treatment to treat side effects	2

8. Side effects from Atypical APs	
(i) Not mentioned or superficial details	0
(ii) At least 2 side effects mentioned	1
(iii) At least 4 side effects mentioned, one of which MUST be weight gain	2
9. Clozapine	
(i) No rationale/conditions given for clozapine use	0
(ii) Brief mention of indication for clozapine or its advantage over other APs	1
(iii) As (ii) & need for regular blood monitoring	2
10. Clozapine cont'd	
(i) No mention of clozapine related side effects	0
(ii) At least 3 side effects mentioned, including hypersalivation or constipation	1
(iii) As (ii) including risk of seizures & agranulocytosis	2
11. Clozapine monitoring	
(i) Need for regular blood monitoring mentioned [same as 9 (iii)]	0
(ii) Details of monitoring frequency provided	1
(iii) As (ii) & explanation of traffic light system related to medication supply	2
12. Depot and other injectable forms of treatment	
(i) No mention of depot injections or mentioned in passing only	0
(ii) Depot OR other long acting forms mentioned with explanation of mode of action	1
(iii) Both forms mentioned & explanation of difference between the two	2
13. Compliance with therapy/avoidance of relapse	
(i) No mention of continuous nature of AP treatment to avoid relapse	0
(ii) Brief mention of life long nature of AP therapy & importance of compliance	1
(iii) as (ii) but more detailed	2
Clinical Attributes cont'd	
14. Terminology	
(i) Incorrect or inappropriate use of jargon. No explanation of terms or glossary	0
(ii) Some inappropriate use of jargon	1
(iii) Appropriate language used throughout (glossary may be provided)	2
15. User Support	
(i) No details of additional support/help available on site	0
(ii) Basic details of additional support/resources eg charities/organisations	1
(iii) Comprehensive details of support/resources eg contact details and or/discussion group/message board facility	2
16. Disclaimer	
(i) No disclaimer or reference to consult a health professional visible	0
(ii) Disclaimer OR reference to consult health professional visible	1
(iii) Disclaimer AND reference to consult health professional clearly visible	2
Physical Attributes	

17. Authorship		
(i) No mention of site author, if named, no details regarding status or credentials		0
(ii) Author named with details of professional credentials		1
(iii) as (ii) including contact details		2
18. Currency		
(i) No details of when site originally developed or updated		0
(ii) Date provided for site development/update but > than 3 years ago		1
(iii) as (ii) but ≤ 3 years ago		2
19. Target Audience		
(i) Not stated or clearly obvious who the target audience is meant to be		0
(ii) Not clearly stated but can guess who target audience could be		1
(iii) Target audience clearly specified		2
20. Ease of Use		
(i) Rather difficult to navigate or use		0
(ii) Easier than (i) but without a search facility on webpage		1
(iii) As (ii) with additional features such as search/help facility		2
21. Links		
(i) No links to other relevant sites or links do not work		0
(ii) < 3 links present, some to external sites		1
(iii) > 3 links, some external sites		2
22. Advertising		
(i) Overuse of adverts/pop ups, interfering with actual text		0
(ii) Some advertising present but doesn't interfere with body of text		1
(iii) No commercial advertising present		2
23. Layout		
(i) Poor layout, minimal use of (sub) heading, paragraphs		0
(ii) Better than (i) but still difficult to read or follow in places		1
(iii) Good layout of text, easy to read and follow		2
24. Images		
(i) Absence of any images/pictures/animation		0
(ii) Some images present, not all useful or overuse of pictures or diagrams		1
(iii) Images present which are useful or relevant		2
25. References		
(i) No references given/ references incomplete or from dubious sources		0
(ii) References from credible sources but lacking in detail		1
(iii) Comprehensive, credible and accurate references		2
26. Readability Statistics (Based upon Flesh Reading Ease Score)		
(a) Flesh Reading Ease Score	<30	0
	30-60	1
	>60	2

Total Score = / 52

Details of schizophrenia websites evaluated by SWEF-Schiz *(n=33)*

Category	URL
1. Charities/Support Groups	
Mental Health Foundation	www.mentalhealth.org.uk/information/mental-health-a-z/schizophrenia/
Making Space	www.makingspace.co.uk/
SANE	www.sane.org.uk/
National Schizophrenia Fellowship	www.nsfscot.org.uk/
Rethink	www.rethink.org/about_mental_illness/mental_illnesses_and_disorders/schizophrenia/
Food For The Brain	www.foodforthebrain.org/content.asp?id_Content=1638
MIND	www.mind.org.uk/Information/Booklets/Understanding/Understanding+schizophrenia.htm
Scottish Association for Mental Health	www.samh.org.uk/frontend/index.cfm
2. Commercial Organisations	
BUPA Healthcare	//hcd2.bupa.co.uk/fact_sheets/html/schizophrenia.html
Association of the British Pharmaceutical Industry	//www.abpi.org.uk/publications/publication_details/targetSchizophrenia-2003/default.asp
Otsuka Pharmaceuticals	www.otsuka-europe.com/en/1/schizophreniaquestions.html
Lundbeck	http://ukpharma.lundbeck.com/uk_pharma/products/therapy_areas/schizophrenia/default.asp
Janssen-Cilag psychiatry	http://www.psychiatry24x7.com/bgdisplay.jhtml?itemname=schizophrenia_about
Lilly	http://www.lilly.co.uk/Nitro/newTemplates/general/Content__LBC.jsp?page=1082
Janssen-Cilag	http://www.oneinonehundred.co.uk/
Surgery Door	www.surgerydoor.co.uk/medical_conditions/Indices/S/schizophrenia.htm
Women's Lifestyle magazine	www.nuts4chic.com/nuts4chic_UK_Healthy_Living_Facts_About_Schizophrenia.htm
3. Government/professional	
NHS 24	http://www.nhs24.com/content/default.asp?page=s5_4&articleID=303
NHS Choices	www.nhs.uk/Conditions/Schizophrenia/Pages/Introduction.aspx?url=Pages/what-is-it.aspx&r=1&rtitle=Schizophrenia+-Introduction
NHS Clinical Knowledge Summaries	http://cks.library.nhs.uk/patient_information_leaflet/schizophrenia
Royal College of Psychiatrists	www.rcpsych.ac.uk/mentalhealthinformation/mentalhealthproblems/schizophrenia.aspx
Depart for Work & Pensions	http://www.dwp.gov.uk/medical/med_conditions/major/schizophrenia/
Scottish Government	http://www.seemescotland.org.uk/facts/include/downloads/factsheets/Schizophrenia%20Factsheet.pdf
Institute of Psychiatry	http://mentalhealthcare.org.uk/content/?id=188
Breathing Space (Scottish Gov)	http://www.breathingspacescotland.co.uk/bspace/105.3.24.html
Database of UK counsellors	http://www.counselling-directory.org.uk/schizophrenia.html
4. Miscellaneous	
Netdocktor Health Portal	www.netdoctor.co.uk/diseases/facts/schizophrenia.htm
GMTV Health page	www.gm.tv/index.cfm?articleid=3090
Patient UK	www.patient.co.uk/showdoc/23069111/
Medic8	www.medic8.com/healthguide/articles/schizophrenia.html
Wikipedia	//en.wikipedia.org/wiki/Paranoid_schizophrenia
BBC Health Page	www.bbc.co.uk/health/conditions/mental_health/disorders_schiz1.shtml
Channel 4	www.channel4.com/health/microsites/0-9/4health/mind/wwr_schizophrenia.html

Publications and Conference Posters

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