

Manuscript Number: IJMI-D-14-00471R2

Title: ADHD & You: evaluation of an educational website for parents of children with ADHD

Article Type: Original Article

Keywords: parent education; internet; ADHD; attention deficit/hyperactivity disorder; educational website

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Abstract: ADHD is a relatively common neuro-developmental condition characterized by hyperactivity, impulsivity and inattention. The provision of timely and accurate information about the condition and about strategies to manage it is vital especially because of widespread misconceptions about it.

AIM: To see the effect of an educational website on i) parental perceptions ii) knowledge levels, and to obtain feedback to optimise user-experience.

METHOD: Parents whose children had ADHD (or were close to diagnosis) were recruited. Following a 30-item baseline knowledge test parents/carers were directed to an educational website on ADHD. After this they were re-contacted for follow up testing and feedback.

RESULTS: n=172, 14 were lost to follow up. Ninety-one (59.4 %) participants were known to have accessed the website at follow up. The majority of carers accessed the website just once or twice (32.7%). Of those who did not access the website 65% cited a lack of time as the reason while 29% cited they were unable to access the internet at the time. The majority (74%) of those accessing the site were just browsing for general information. Parents showed increased knowledge post website use $p=0.000$. Of those accessing the website the majority (85.5%) felt it was relevant to them and would use it again (90.8%). Content analysis of open-ended feedback identified eight core themes including website appearance, content, functionality, perceptions, target audience, usability, usage patterns with areas for improvement noted in four areas.

CONCLUSION: Websites can be used as an adjunct to information given at clinic. Although a majority of parents will access them, there are still barriers to access e.g. time. Websites do seem to improve parent/carer knowledge levels.

*Revision Notes

Editorial comments: we have addressed each of the points listed.

We did not use multiple correction testing after seeking statistical advice.

Reviewer 2: We understand the final comment here about the underpinning pedagogy/engagement model and would very much be interested in this. The main reason we have not placed emphasis on this is because we were independent evaluators/researchers of the site and much of this information was not shared with us. We were employed to understand if the credibility and quality of such a website would be well used when recommended by healthcare professionals.

To the editor

This original research paper reports on a project that evaluates the use of healthcare professional recommended educational websites for parents of children with attention deficit/hyperactivity disorder.

It evaluates if parent knowledge can be improved with the use of such websites and outlines parental perceptions and feedback.

Word count: 5825excluding references and abstract

Tables: 3

The authors declare no conflicts of interest.

Title page

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Title:

Evaluation of an educational website for parents of children with ADHD

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Abstract

ADHD is a relatively common neuro-developmental condition characterized by hyperactivity, impulsivity and inattention. The provision of timely and accurate information about the condition and about strategies to manage it is vital especially because of widespread misconceptions about it.

AIM: To see the effect of an educational website on i) parental perceptions ii) knowledge levels, and to obtain feedback to optimise user-experience.

METHOD: Parents whose children had ADHD (or were close to diagnosis) were recruited. Following a 30-item baseline knowledge test parents/carers were directed to an educational website on ADHD. After this they were re-contacted for follow up testing and feedback.

RESULTS: n=172, 14 were lost to follow up. Ninety-one (59.4 %) participants were known to have accessed the website at follow up. The majority of carers accessed the website just once or twice (32.7%). Of those who did not access the website 65% cited a lack of time as the reason while 29% cited they were unable to access the internet at the time. The majority (74%) of those accessing the site were just browsing for general information. Parents showed increased knowledge post website use $p=0.000$. Of those accessing the website the majority (85.5%) felt it was relevant to them and would use it again (90.8%). Content analysis of open-ended feedback identified eight core themes including website appearance, content, functionality, perceptions, target audience, usability, usage patterns with areas for improvement noted in four areas.

CONCLUSION: Websites can be used as an adjunct to information given at clinic. Although a majority of parents will access them, there are still barriers to access e.g. time. Websites do seem to improve parent/carer knowledge levels.

Keywords: Attention deficit/hyperactivity disorder; internet; parent education

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2
3 **1.0 Introduction**
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6 *1.1 Attention Deficit Hyperactivity Disorder (ADHD)*
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9 *"ADHD is a heterogeneous behavioural syndrome characterised by the core symptoms of*
10 *hyperactivity, impulsivity and inattention"* [1]. In the United Kingdom (UK) an estimated 3-
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12 9% of children are diagnosed with ADHD, 1% of children in a school year likely to be
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14 diagnosed with **severe** symptoms of ADHD, with many more presenting with less severe
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16 symptoms [1, 2]. The symptoms expressed by children and young people with ADHD have a
17
18 wider impact on health and well-being; leading to increased stress levels for parents and the
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20 family unit [3]. It is widely accepted that successful management of ADHD can be achieved
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22 with shared and informed decision making along with behavioural and pharmacological
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24 interventions [1].
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31 *1.2 Information needs of parents*
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34 NICE [1] suggests that healthcare professionals should provide people with ADHD and/or
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36 their families with relevant information (including written information) about ADHD at every
37
38 single stage of their care. Sethuram & Weerakkody [4] further suggest that parents of
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40 children with neurobehavioural disorders have particular needs for relevant and accessible
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42 information. However, parents still continue to have unmet needs for information about
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44 their child's condition and treatment [5-8]. With increasingly stretched services and limited
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46 consultation time in clinics, there is less opportunity for professionals to provide adequate
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48 information for parents [9].
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53 Relevant and accurate information is essential for parents and young people to make
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55 informed, shared decisions about their [potential] diagnosis and care, and without adequate
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57 and accessible information this can lead to uncertainty and anxiety. Cues to action and
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1 treatment seeking can depend significantly on levels of knowledge and awareness of a
2 condition; the more informed, the more likely someone is to take appropriate action [8,9].
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4 A research study by Bussing et al [9] found that many parents had misconceptions about
5 ADHD despite a relatively high self-perceived knowledge. Research studies provide further
6 evidence that parents may gain misconceived ideas about the diagnosis and treatment of
7 ADHD from unreliable sources of information and emphasise the need for high quality
8 evidence for parents to access [5-7].
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17 It is argued that information provided by healthcare professionals, is the most trusted
18 source of information for parents. Literature further suggests that healthcare professionals
19 should be 'prescribing' and directing parents and young people to accurate, high quality
20 information sources [9, 11-15]. Well-informed and shared decisions have been shown to
21 improve health, wellbeing and longer term outcomes [16]. There is a wide range of
22 information sources but the internet is becoming increasingly popular for parents to easily
23 and quickly access ADHD specific advice [8, 12, 15, 17, 18].
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33 *1.3 The internet and websites as a source of information*

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37 Several studies have identified patient use of the internet for seeking health information and
38 in associated decision making processes [21]; 97% of parents sourced the internet to know
39 more about their child's condition [22]. Bianco et al [15] found that 85% of individuals use
40 the internet to source information about their own or a member of their family's medical
41 condition.
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50 While Tuffrey & Finlay [23] suggested that those with a confirmed diagnosis are most likely
51 to use the internet to seek advice about family health more recent research argues that
52 information seeking behaviour on the internet can occur pre-consultation, during the
53 process of diagnosis and as part of an on-going chronic condition [8, 22, 24, 25]. Sciberras et
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al [13] found that parents often wanted information as early as possible during their diagnosis journey.

There are risks associated with using the internet as a source of information, with many websites presenting irrelevant, inaccurate or inappropriate information, for example blogs and wikis which present un-evidenced data, personal discussions or guidance more specifically relevant in another country. The importance of the concept of 'quality' for parents when sourcing information is of essence if they are to make well informed decisions about their child's care [9, 18, 26-28]

Parents look to healthcare professionals for advice and guidance and prefer sources of information that are recommended by their paediatrician or nurse in order to improve knowledge, awareness and inform decision making [8, 9, 11, 13, 14, 22, 29]. Healthcare professionals therefore have a responsibility to direct or 'prescribe' internet sources that are of high quality and relevant, and that this may be done as part of the consultation process [11, 12, 15, 18, 23, 30].

It is therefore suggested that an educational internet resource could be utilised by healthcare professionals and for parents/carers of children with ADHD.

1.4 The website

'ADHD & You' [31] is an educational, information based website developed by professionals at Shire Ltd. (a pharmaceutical company) as an information source and aims to support, advise and educate patients, carers and professionals on the basic principles and management techniques for ADHD in the UK (there is also an American version of the site [31]). It is not intended to substitute standard care or current services but complement and improve [early] access to useful, current and accurate information on ADHD and its management. The site is informative rather than pedagogically designed as a formal educational tool; however the principle of this site is that it contains reliable, up-to-date

1 information for those using it and enables specialist healthcare professionals to direct
2 parents to reliable, high quality information.
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4
5 There are four sections of the website which are focused on information for parents,
6 healthcare professionals, individuals with ADHD and education staff. Each section has
7 tailored information to the target group with links to external resources such as NICE
8 guidance. There are also downloadable resources such as reward charts.
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11 This project aims to implement a healthcare professional recommended, educational
12 website, evaluate the potential benefits to improving knowledge and assess the perceptions
13 of this educational website from a parent's perspective.
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26 *1.5 Aims, research questions and hypotheses*

- 27 • To **evaluate** parent perceptions and use of an educational website for ADHD
- 28 • To **examine** the feasibility of an e-learning website to improve knowledge of ADHD
- 29 • To **identify** any improvements or additional information required within the website

30 *1.5.1 Research question*

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32 Can the use of an educational website improve the knowledge of parents/carers caring for a
33 child or young person with suspected or diagnosed ADHD?
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36 *1.5.2 Primary hypothesis*

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38 H₀:- Parents/carers who access an educational website will not have a significant
39 improvement on knowledge of ADHD in parents/carers
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43 H₁:- Parents/carers who access an educational website at least once will significantly
44 improve knowledge of ADHD
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2.0 Method

This project employed a single cohort pre-test, post-test survey design to explore the perceptions, experience, knowledge improvement and usage patterns for 'ADHD & You' [31] educational website.

2.1 The intervention

Individuals who met the inclusion criteria (see 2.2) were advised about the website in consultant and/or nurse led community outpatient paediatric clinics and given plastic key fobs and credit card sized information with details about how to access the 'ADHD & You' website. The participant information sheet identified Shire AG Ltd. as the funder of this evaluation and owners of the website. They were invited to visit this as frequently as they wished over a 4 week period.

The use of posters in clinic and appropriate service settings were utilised to promote the research study and provide contact details for the research team if potential participants wished to contact them directly.

2.2 Sample and sampling frame

Participants were recruited through out-patient paediatric clinics over a 7 month period in 2013, across three NHS sites geographically spread over the East Midlands, West Midlands and South of England, UK.

Inclusion criteria:

- Parent or carer caring for a child or young person 4-18 years of age with a confirmed or suspected diagnosis of ADHD
- Aged 18 years or over
- Provides informed consent

1 Participants were excluded if they were unable to understand basic levels of written or
2 spoken English [based on website content and ability to provide informed consent].
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5 In order to detect an effect size [small-medium] $d=0.3$ and power of 80%, a minimum of 90
6 participants had to complete the study [32]. A total of 158 participants completed follow up
7 with 91 of these choosing to access the website.
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10 11 12 *2.3 Data collection and measures* 13

14 Data was collected at two time points. At day 0 the parent/carer was provided with a
15 participant information sheet outlining the study. This was done through the post [prior to
16 the appointment] or during their consultation. A member of the research team took
17 informed consent. A baseline 30 point true or false knowledge questionnaire (an adapted
18 version of the validated AKOS-R) [33] was amended to reflect up to date website content.
19 This was a self-completion questionnaire but research staff supported participants were
20 required. Demographic and diagnosis status details were also collected.
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23 One month later participants were contacted in clinic, via telephone or via mail (preferred
24 method of contact was identified at day (0) and the true-false knowledge questionnaire was
25 completed along with a website evaluation relating to usability, content. Participants were
26 also asked to identify how many times they had accessed the site. If participants did not
27 access the site they were asked to provide a reason. This aimed to understand the barriers
28 to access and if this type of information is acceptable from the parent's perspective.
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31 Information from this feedback can also be used to improve the website navigation, content
32 and usability.
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35 36 37 *2.4 Data analysis* 38

39 Quantitative data was recorded on the paper based, pre-coded questionnaires. Data was
40 entered into SPSS v19.0. The knowledge questionnaire was scored by attributing a value of
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1: correct, 1.5: unsure and 2: incorrect response. The maximum score was 60 and minimum score was 30; the closer the score was to 30, the higher the knowledge.

The study aimed to examine any statistical significance between number of times the website was accessed (or not), diagnostic status of child and knowledge difference and also patterns of use e.g. relationship between age of participant and number of times accessed.

Chi-squared was also used to analyse relationships between categorical variables such as diagnostic status, reasons for having accessed the website (specific question or to 'browse') and number of times accessed.

The significance alpha level was taken to be 0.05 with a 95% confidence interval. Two-tailed tests were conducted unless otherwise stated in the results analysis. A missing value analysis was conducted prior to results analysis.

2.5 Ethical considerations

NHS Trust Research and development (R&D) approvals from all three sites involved and NHS ethical approval were sought through the UK Integrated Research Application System (IRAS).

All participants were provided with a participant information sheet and were given the opportunity to ask questions prior to signing an informed consent form. All participants were able to withdraw from the study at any time up to the point of data analysis; there were none who opted to withdraw formally although some participants were lost to follow up. The confidentiality of participants was ensured via the use of a unique participant number and all identifiable data was stored in accordance with Data Protection Act [35] and trust policy, separate to any data collected as part of the study.

If parents chose not to participate in the study they were still offered the details of the website as a resource.

2.6 Validity and reliability

1 The true-false knowledge questionnaire was adapted from part of a validated tool, AKOS-R
2 [33] that has been widely used in the field of ADHD. Three team members ran follow-ups
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4 and post-test and the knowledge scores were calculated by the co-investigator.
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7 **3.0 Results**

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10 A total of n=172 participants were recruited into the study. The lead site screened 204
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12 eligible parents/carers; 78 did not participate as 34 had incorrect contact details and could
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14 not be contacted and the remaining 44 either refused or were not eligible to participate.
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17 The second recruiting site approached 26 participants and one refused to participate. The
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19 third site recruited 21 participants but did not record how many were initially approached.
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21 Of those consented only 14 were lost to follow up, leaving 158 participants who completed.
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23 91 of these participants actually accessed the website. The remaining participants either did
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25 not respond to this question or did not access the website; 5 and 62 respectively.
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29 *3.1 Participant characteristics*

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32 An overview of participant characteristics is provided in Table.1.
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36 *Insert table.1*
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39 *3.1.1 Age*

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42 Participant age and age of the child with ADHD was recorded. Participant's mean age = 41
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44 s.d. 8.817 and mean age of child = 10 s.d. 3.342. Shapiro-wilk tests for normality showed
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46 that age was not normally distributed across both groups. Participants, 0.975 df 148
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48 p=0.008 and child's age, 0.953 df 148 p=0.000.
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51 *3.1.2 Participant relationship to child*

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1 Of all participants 130 (76%) were the child's mother, 25 (14.6%) were fathers and 16 listed
2 as 'other', which included carer/foster parent, grandparents, sibling, aunt/uncle. As the
3 majority were mothers this limited analysis to a single group rather than across sub-groups.
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6 7 *3.1.3 Ethnicity* 8

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10 One hundred and sixty (94%) participants declared their Ethnic group to be White-British,
11 which meant that analysis across ethnic groups was not appropriate.
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14 15 *3.1.4 Diagnostic status* 16

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18 Of the 172 participants, 40 (23.8%) had suspected ADHD, 21 (12.5%) were diagnosed less
19 than 6 months ago and 107 (63.7%) had been diagnosed for 6 months or more.
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22 23 *3.1.5 Qualification level* 24

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26 Thirty nine (24%) of participants declared no qualification, 53 (33%) had at least secondary
27 compulsory education, 28 (17%) had post-16 education and the remaining 41 (26%) had a
28 higher education or professional qualification (including post-graduate and doctoral study).
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34 35 *3.2 Access patterns* 36

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38 Of all participants 40.5% never accessed the website, 59.4% of participants accessed the
39 website at least once, with the majority just once or twice.
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43 Due to the low number of responses in 5-6 and 7+ times data was also analysed based on
44 whether an individual did or did not access the website; 91 (59.5%) and 62 (40.5%)
45 respondents respectively. The characteristics of participants who did and did not access the
46 website can be seen in table.2
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52 53 *Insert table.2* 54

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56 Chi-square and Cramer's V testing was carried out to determine any relationship between
57 number of times accessed and diagnostic status and length of time diagnosed and number
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1 of times accessed; these were shown to be insignificant. There were no significant findings
2 relating to age of participant and likelihood of accessing the website, nor was there a
3
4 relationship between highest qualification level and likelihood of access.
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7 Chi-square testing and Cramers V tests were conducted to test the hypothesis that parents
8 with a confirmed diagnosis are more likely to have accessed the website; Chi-square 5.258 df
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12 $p=0.022$, Cramer's V 0.187, $p=0.022$ shows that there was a moderately significant
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14 relationship between having a confirmed diagnosis and having accessed the website.
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16 Therefore, those participants who had a suspected diagnosis were less likely to have
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18 accessed the website than those with a confirmed diagnosis.
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22 Mann Whitney-U testing was conducted to test the hypothesis that parents of younger
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24 children were more likely to access the website $p=0.023$ showed moderate significance and
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26 rejection of the null hypothesis. Therefore, parents of younger children were more likely to
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28 have accessed the website.
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32 *3.3 Knowledge scores*

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36 To test the primary hypothesis the mean difference between pre and post scores was
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38 calculated for all participants. The mean difference in pre and post scores was also
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40 calculated for only those individuals who accessed the website [excluding those who did not
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42 access the website]. These two approaches were chosen as many parents requested not to
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44 complete the knowledge questionnaire if they had not accessed the site.
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48 Table.3 illustrates the mean pre and post scores for those who did and did not access the
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50 website. A Mann-Whitney U test showed no significant difference in knowledge at day 0
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52 between those who went on to access the website and those who did not. A Mann-Whitney
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54 U test of post scores -2.473, $p=0.013$ showed a moderately significant difference in
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56 knowledge between those who did and did not access the website. Those who accessed the
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58 website were more likely to have a lower score and hence, higher knowledge.
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Insert Table.3

Pre-test post-test knowledge scores were assessed for normality distribution using Shapiro-wilk 0.914, $p=0.000$. The mean score difference of participants was not normally distributed and therefore a Wilcoxon signed rank test was used to analyse significance of knowledge difference; $Z= -4.799$, $p=0.000$ suggested an increase in knowledge with a moderate but significant effect size, $d=-0.503$ This rejected null hypothesis H_0 :- Accessing an educational website will not have a significant improvement on knowledge of ADHD in parents/carers.

There was no significant relationship found between knowledge score difference and highest qualification level or diagnostic status.

There was not significant relationship found between knowledge score mean difference and number of times the website was accessed.

3.4 Website feedback

Of those participants who did not access the website the main reason for not doing so was 'not having time' (65.1%), unable to access the internet (28.6%), used another source of information (0.03%) and other (3%).

Those who did access the website mainly did so to browse general information on ADHD (74.2%) rather than to obtain a specific answer to a query (5.4%). 20.4% of those who used the website used it to both browse and obtain an answer to a specific question.

Where individuals did require an answer to a specific question 81.2% agreed or strongly agreed that this was answered. Conversely, when participants used the website to browse information 76% agreed or strongly agreed that they had learned more about ADHD.

A Kruskal-Wallis analysis of knowledge difference between pre- and post- use, those individuals who self-reported an increase in knowledge $df 3$, $p=0.044$ showed weak

1 significance, possibly suggesting that a self-reported increase in knowledge reflected the
2 increase in knowledge between their pre and post score.
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5 Participants felt that the website was relevant to them (85.5%) and that they would use it
6 again (90.8%) which included willingness to recommend the website (92.9%).
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10 Approximately 40% of participants had not used any other source of information, followed
11 by the internet (29.8%) [or the internet plus another source]. Most importantly 91% of
12 participants agreed that they were happy to be provided with health information via a
13 website directed by their healthcare professional.
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19 *3.5 Content analysis of qualitative feedback*

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21 A content analysis of open-ended feedback in the questionnaire was conducted. Eight core
22 themes and a heading under 'improvements' was found. The eight themes were:
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- 26 • Appearance: design, text, colours
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- 28 • Content
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- 30 • Functionality
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- 32 • Perceptions
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- 34 • Target audience
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- 36 • Usability
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- 38 • Usage patterns
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- 40 • Miscellaneous
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48 Within the improvements category there were three sub-themes: functionality, content and
49 appearance.
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51 *3.5.1 Appearance*

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54 There were three sub-themes in this category. Of the sixteen comments made only two
55 were negative. These mainly focused on improving the background colour for individuals
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1 with disability e.g. dyslexia but also ensuring that font size and typeface were suitable for
2 those with learning disabilities. There was also a comment requesting that the designers
3 consider those who may be partially sighted as the fonts may be too small and not
4 adaptable. The majority of participants liked the colours and felt that the layout and design
5 was appropriate for the target audience.
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10 11 12 *3.5.2 Content*

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15 Sixty five participants made comments about the content of the website. Only 11 were
16 negative comments. These included comments about the lack of information and relevance
17 to older children and adolescents or that it would be difficult for children to engage with
18 (particularly those with ADHD). There were also conflicting comments relating to content
19 such as too much detail, not enough detail and the information being overwhelming which
20 seemed to be dependent on the individual's personal requirements. The majority of
21 comments felt that the information on the site was very useful, simple and clear to
22 understand. The video of Liam's story and downloadable reward charts were particularly
23 favoured.
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36 37 *3.5.3 Functionality*

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40 Participants made 20 comments about the functionality of the website. Nine comments
41 were negative and related to downloadable files not working or that they were unable to
42 print these. This included some of the videos (Liam's story). The most positive feedback
43 was as a result of participants being able to access the different sections for different roles
44 e.g. parents, healthcare professionals, and education staff.
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52 53 *3.5.4 Perceptions*

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56 Fifteen participants provided some information about their perceptions of the site. Four
57 were negative and included:
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“UK version felt Americanised”

“I was insulted by the section which said parents were to blame for ADHD if they smoked or drank alcohol during pregnancy”

“I knew most of the information”

“website was too positive”

The rest of the participants felt that there was a ‘positive tone’ to the site, that they were ‘happy’ with it and felt it was a good way to disseminate information.

3.5.5 Target audience

Twenty comments were made in relation to target audience. Three were negative. The negative comments reflected some of the negative content comments that the site was not engaging enough or appropriate for children, particularly those of 11 years upwards.

Another comment said that the site was only good for those going through diagnosis or newly diagnosed. Conversely, many users felt that this was positive for parents who were new to ADHD with one person commenting:

“I wish I had this when my son was being diagnosed”

Several users felt that the site would be particularly useful to share with educational staff.

3.5.6 Usability

All 44 usability comments were positive. People widely commented that the site was “easy to use” and find information on.

3.5.7 Usage patterns

Patterns of use covered a range of suggestions. Twenty one comments were made about ‘what I liked most about the site’ on the topic of usage. Many people used this as a family

1 and a range of comments showed that parents, grandparents and children were using this
2 together to share information. Two parents shared information on the website with their
3 school. They felt it was good to recommend this website to families and users also
4 commented that they would recommend it to family and friends to enable them to
5 understand things that they found difficult to explain e.g. behaviours. Several people said
6 that they would continue to use the website as a source of up to date reference.
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14 3.5.8 Miscellaneous 15

16 Miscellaneous comments did not fit any other category and there were insufficient numbers
17 of these to create additional categories. Three comments were made in this category:
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22 *“school refused to use it as it was from a drug company and they claimed that healthcare
23 professionals were funded to promote their material...”*
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27 This parent also went on to state that they were in dispute with their school as they do not
28 follow current guidance to support her child.
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32 *“the key rings were good to remind you of where to go”*
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36 *“many schools do not follow the advice on this website and it is useful for them to use”*
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40 It is interesting that two of these comments related to school approach to children with
41 ADHD.
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45 4.0 Discussion and conclusions 46

47 4.1 Discussion of findings 48 49 50

51 In this study the primary hypothesis tested was to examine if the use of an educational
52 website increased the knowledge of parents/carers of ADHD. A significant increase in
53 knowledge was found by those who accessed the website. This is similar to findings by
54 Montoya et al [9] who found that higher quality and perceived credibility of a website
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1 helped to increase parental knowledge of ADHD. Bussing et al [8] found that parents had
2 high self-perceived knowledge levels. When asked the majority of participants who
3
4 accessed the website suggested that their knowledge of ADHD had improved, and there was
5
6 a significant relationship between responding yes to this statement and their knowledge
7
8 score. This suggests that browsing credible, accurate and up to date websites can help to
9
10 increase parental knowledge of ADHD and inform any associated decision making process.
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14 The internet was found to be a main source of information for participants. This reflects
15
16 other studies which showed that despite having less trust in internet sites it still remained
17
18 one of the most commonly used sources of health information [8, 12, 15, 34]. Hu, Bussing et
19
20 al and ONS [8, 19, 36] highlighted that individuals reported less use of the internet for
21
22 finding health information during 2010-2012 compared to figures reported pre 2010 and
23
24 post 2012. This may have reflected some of the concerns about trust and accuracy of
25
26 websites found, particularly as internet searches [google] may not always produced the
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28 most accurate and credible sources [18].
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34 It is therefore widely suggested that healthcare professionals should direct or 'prescribe'
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36 accurate and high quality websites [8, 9, 12, 18, 24, 30, 37]. This is also reflected in the
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38 results from this study where the majority of participants were happy for healthcare
39
40 professionals to provide information in this way, particularly for those who were undergoing
41
42 diagnosis or were 'new' to ADHD. Literature has reported inequitable access to the internet
43
44 and that those from lower socio-economic groups may not be able to easily access the site if
45
46 prescribed in this way [8]. However, there were no significant findings in this study and the
47
48 most commonly reported reason for non-use of the website was 'not having time'.
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53 Conversely, Ofcom and ONS [19, 20] suggests that the increase in mobile technology and
54
55 broadband services in the UK means that those in socio-economic groups D and E [unskilled,
56
57 semi-skilled workers] are one of the fastest growing group of users of the internet and 95%
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1 of those 16-34 years use the internet. Therefore, prescribing internet-based information
2 may not be as inequitable as previously perceived; especially as the internet becomes more
3
4 accessible to the wider population.
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7 Gender, age and education level have been correlated with likelihood of using the internet
8
9 to access health information [15, 17, 24, 34, 38-40]. Those who are younger, female and
10
11 have a higher education level are more regular users of the internet [for health information].
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14 In this context, it may be as a result of mothers commonly being the primary care giver for
15
16 children; 76% of participants were the child's mothers. However, this study found no
17
18 correlation between educational level and choice to access, nor did it find any relationship
19
20 between age of the participant and likelihood of accessing the website. Some participants
21
22 even reported accessing the website with their partner, child or grandparent. Therefore,
23
24 these findings may be as a result of the internet becoming more accessible and acceptable
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26 as a source of information or related to the site being promoted by a healthcare
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28 professional; therefore was viewed as more trustworthy and relevant.
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34 Conversely, the age of the child with ADHD was significantly related to the likelihood of the
35
36 participants accessing the website. Bernhardt & Felter and Khoo et al [11, 18] reported
37
38 similar findings; parents of younger children were more likely to access health information
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40 on the internet. These studies did not relate directly to ADHD and one focused on
41
42 emergency department admissions but the findings together may support wider use of
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44 healthcare professional promoted websites to provide accurate and reliable health
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46 information. In these papers parents used information to inform and support their actions
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48 and or decisions and this study found some parents also attempted to use the website
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50 information in the same way with educational staff; possibly suggesting that this knowledge
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52 empowered them/gave them the confidence to take further action.
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1 Weaver et al and Bianco et al [8, 34] suggest that parents do generally browse the internet
2 to self-diagnose, research alternative treatments or medication but also to seek access to
3
4 support groups/social media. There is indication that health seeking behaviours are based
5
6 on more general topics or themes rather than specific questions. These behaviours were
7
8 both reflected in this study; most parents chose to browse the site and many were
9
10 particularly interested in medications or scientific explanations of the condition. However, a
11
12 range of qualitative comments requested the implementation of a 'search facility' so that
13
14 individuals can search for specific topics or themes easily, reducing the need to search
15
16 through for information required; emphasising the need for 'choice' and flexible
17
18 functionality. The implementation of online discussion or support groups was advocated in
19
20 qualitative feedback. This suggests that parents do browse information but also value the
21
22 ability to ask specific questions and share experiences. Further reflected in the positive
23
24 comments received from the real life case study video on the website; being able to receive
25
26 positive messages, seek reassurance and view success stories seems to be of particular
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28 importance.
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36 Qualitative feedback further indicates the importance of and requirement for age specific
37
38 information, not just for parents but also for young people with ADHD. Many of the
39
40 participants suggested that the website was 'boring' or disengaging, particularly for those
41
42 children 11 years and over. Conversely, some participants felt it inappropriate for younger
43
44 children and suggested introducing interaction games. Website designers should consider
45
46 children with ADHD and the most successful ways of engaging them in educational activities
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48 on the internet; McKnight [41] discusses some key points in designing materials for children
49
50 with ADHD. In addition, NICE [1] specifically emphasises the need for professionals to
51
52 provide and direct parents to age relevant information. However, the results from this study
53
54 show that even accurate, up to date websites do not always meet these requirements.
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1 Therefore, if developing or considering promotion of websites as part of care healthcare
2 professionals should be mindful of this.
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5 Research literature has discussed parent's use of the internet based on stage of diagnosis.
6
7 Rice, Van Deursen & Dijk, Finney et al, Bianco et al and Thackeray et al [8, 25, 38-40] found
8 that those experiencing chronic illness or on-going symptoms are more likely to use websites
9 for health information but there is also evidence to suggest use of the internet to 'self
10 diagnose', or pre consultation. Tuffrey & Finlay [23] earlier suggested that those with a
11 confirmed diagnosis are more likely to use the internet than those without. Although, there
12 is evidence to suggest a need and requirement for information from suspected diagnosis of
13 ADHD (1) and that parents have consistently unmet information needs, the study here found
14 conflicting results between the quantitative and qualitative data. Quantitative results
15 indicate that those with a confirmed diagnosis of ADHD were significantly more likely to use
16 the website promoted by their healthcare professional, however qualitative responses show
17 that many participants felt the site most useful as reference, for those who are 'new' to
18 ADHD or those in the diagnosis process.
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36 *4.2 Limitations*

- 37 1. Only 28 +/- 5 days were available from recruitment to post-testing for ADHD and so the
38 study did not tell us anything about how the usage patterns analysed here would
39 actually translate into long-term use of the website. It is possible to speculate that the
40 site would be used less infrequently in the short term once parents had acquired basic
41 information, or alternatively it could be surmised that the site would be used more
42 frequently to look up additional information as time went on and new questions arose.
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44 Ideally a longer study time would have helped to tell us this, however the duration for
45 study was a pragmatic time period chosen to ensure certain practicalities could be met
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like participants being able to remember how often they had logged on in the previous month.

2. Recall bias (as mentioned above with respect to people remembering how often they used the site) may have played an effect in the analysis of some of the results although we think that over a month this would have been minimal.
3. The website was in English only and we excluded parents/carers with language limitations for this reason. As such this study can only comment on patients and carers with a certain command of English. It would be useful however to see if this study could be extended beyond these boundaries in the future as those patients with limited English skills may be those who would most benefit from a website written in a non-English language.
4. Only 14 patients were lost to follow, we do not believe that this is likely to have compromised our conclusions significantly. However a number of patients reported not being able to access the internet during the period of study – this highlights that easy access to the internet even well into the 21st century is not guaranteed- and this did limit how much feedback could be obtained about the website design and practicality.
5. As per our study design, the intervention (access to an ADHD website) was available to all participants alongside any other sources of information, which included information gained at clinic as well as information gained from other sources. And so while we are able to state that access to the website was associated with modestly improved levels of knowledge we would not be able to state this was due solely to the website outside of a longitudinal randomised controlled trial (whose conduct would have presented practical difficulties) especially as there was not a statistically significant relationship between knowledge and frequency of website access.
6. Further research could examine the website usage data e.g. number of visits, ‘click’ patterns and which links/resources were most or least used.

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3 **4.3 Conclusion**
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6 Most participants would recommend a high quality website to family, friends or educational
7 staff and reported that they would use it as a form of reference; it is valued by those early in
8 the diagnosis process but used widely by those parents whose child has a confirmed
9 diagnosis; particularly downloadable resources which can be employed in daily activities to
10 improve behaviour e.g. reward charts. Participants valued the ease of use and accessibility
11 of an educational website but also emphasised the need for age specific information and
12 engaging content for a wide range of target groups. Websites that are informative, using
13 real life case studies, examples of behaviour management and discussion groups also seem
14 to be favoured. These aspects together suggest the need for well considered and
15 collaborative website design. Overall this study found that an accurate and high quality
16 educational website promoted by healthcare professionals is widely accepted, utilised and
17 improves knowledge of those who use it. Further research should explore design features
18 and methods to engage children and young people of all ages but also the provision of age
19 specific information, and tailored information for diagnostic stages for parents/carers. In
20 addition, a more robust control study comparing cohorts who use and do not use the
21 intervention and its impact on knowledge over a longer period of time would enable more
22 firm conclusions to be made.
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48 **Acknowledgements**
49

50
51 Thank you for Shire AG International for providing the grant funding for this project.
52
53 Leicestershire Partnership NHS Trust acted as sponsor for this study and provided NHS
54 approvals and research governance processes.
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1 The Families, Young People and Children’s Services Research Team were essential to the
2 success of this project; Gail Melvin, Lynne Hartwell, Tom Pringle, Ruth Beardsley, Julie
3
4 Rybicki. The Principal Investigators acknowledge the support of the National Institute of
5
6 Health Research Clinical Research Network (NIHR CRN).
7
8

9 Thank you to Sussex Community NHS Trust and Coventry & Warwickshire Partnership NHS
10
11 Trust for their contribution and recruitment to this project.
12
13

14 **Trial registration**

15
16 Registered on National Institute for Health Research portfolio, United Kingdom Clinical
17
18 Research Network ID 13980
19
20

21 <http://public.ukcrn.org.uk/Search/StudyDetail.aspx?StudyID=13980>
22
23

24 **Conflict of interest**

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29 None to declare
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UPA

*Author Contributions

All authors have made substantial contributions to all of the following:

(1) the conception and design of the study, acquisition of data, analysis and interpretation of data,

(2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted

AUTHOR DECLARATION

We wish to draw the attention of the Editor to the following facts which may be considered as potential conflicts of interest and to significant financial contributions to this work. [OR] We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all of us.

We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of publication, with respect to intellectual property. In so doing we confirm that we have followed the regulations of our institutions concerning intellectual property.

We further confirm that any aspect of the work covered in this manuscript that has involved human patients has been conducted with the ethical approval of all relevant bodies and that such approvals are acknowledged within the manuscript.

We understand that the Corresponding Author is the sole contact for the Editorial process (including Editorial Manager and direct communications with the office). He/she is responsible for communicating with the other authors about progress, submissions of revisions and final approval of proofs. We confirm that we have provided a current, correct email address which is accessible by the Corresponding Author and which has been configured to accept email from g.ryan@derby.ac.uk

Signed by all authors as follows:

Mrs Gemma S Ryan
Dr Munib Haroon
Mrs Gail Melvin

*Highlights (for review)

- Parents respond positively to healthcare professional recommended educational websites
- These websites have the potential to raise parent awareness and knowledge of ADHD
- Content needs to be age and diagnostic stage specific and websites should be collaboratively designed and developed to meet the needs of the end user
- Further research into the long term use of educational websites as a resource at all stages of care is recommended

Table 1 - All participant characteristics

PARTICIPANT AGE (YEARS)	Mean	41
AGE OF CHILD (YEARS)	Mean	10
RELATIONSHIP	Mother	130 76.0%
	Father	25 14.6%
	Other	16 9.4%
DIAGNOSTIC STATUS	Suspected ADHD	40 23.8%
	Diagnosed less than 6 months ago	21 12.5%
	Diagnosed 6 months ago or more	107 63.7%
NUMBER OF TIMES ACCESSED	Never	62 40.5%
	1-2 times	50 32.7%
	4-5 times	27 17.6%
	5-6 times	6 3.9%
	7+	8 5.2%

Table 2 - Characteristics of participants who did and did not access the website

NEVER	PARTICIPANT AGE (YEARS)	Mean	41
	AGE OF CHILD (YEARS)	Mean	11
	RELATIONSHIP	Mother	42
			68.9%
			10
			16.4%
	DIAGNOSTIC STATUS	Suspected ADHD	9
			14.8%
			8
			13.1%
NUMBER OF TIMES ACCESSED	Never	44	
		72.1%	
		62	
		100.0%	
YES	PARTICIPANT AGE (YEARS)		41
	AGE OF CHILD (YEARS)		10
	RELATIONSHIP	Mother	74
			81.3%
			12
			13.2%
	DIAGNOSTIC STATUS	Suspected ADHD	5
			5.5%
			28
			31.1%
NUMBER OF TIMES ACCESSED	Diagnosed less than 6 months ago	11	
		12.2%	
		51	
		56.7%	

Table.3 Mean pre and post knowledge scores for those participants who completed follow up and did/did not access the website

DID OR DID NOT ACCESS WEBSITE		N	Minimum	Maximum	Mean	Std. Deviation
NEVER	SCORE AT DAY0	53	31.00	42.00	35.5094	2.51818
	SCORE AT DAY 28	53	31.00	41.00	34.8962	2.41262
	DIFFERENCE IN PRE-POST SCORE	53	-3.50	6.00	.6132	1.67171
YES	SCORE AT DAY0	91	30.00	41.00	34.5989	2.40280
	SCORE AT DAY 28	91	30.00	41.00	33.9615	2.21514
	DIFFERENCE IN PRE-POST SCORE	91	-2.50	5.00	.6374	1.46072

*Summary points

Summary points:

What is known?	What this adds?
<ul style="list-style-type: none">• Parents of children with ADHD have unmet information needs about diagnosis, treatment and prognosis• National guidance recommends the provision of this information, by healthcare professionals early on and throughout their journey• Healthcare professionals have limited time to provide detailed and individual information• The internet is a major source of information for parents but carries risks associated with credibility, accuracy and relevance of information	<ul style="list-style-type: none">• Parents respond positively to healthcare professional recommended educational websites• These websites have the potential to raise parent awareness and knowledge of ADHD• Content needs to be age and diagnostic stage specific and websites should be collaboratively designed and developed to meet the needs of the end user• Further research into the long term use of educational websites as a resource at all stages of care is recommended