Remote monitoring of ADHD symptoms using mobile phones

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Background

Attention Deficit Hyperactivity Disorder (ADHD) is characterised by impaired levels of inattention, hyperactivity and impulsivity. ADHD affects between 3-5% of school-age children and young people in the UK, with symptoms continuing into adulthood for the majority.

Better outcomes are achieved with high quality medication management which includes individual and carefully monitored increases in drug dosage to the optimal therapeutic dose with regular follow-up.

NICE recommends regular review, especially at dose changes, aiming to reach optimum dosage in 4-6 weeks. However, constraints on clinic time and resources mean that meeting NICE guidance may be difficult in many NHS trusts.

Aims: To explore the value of using mobile technology to promote timely treatment optimisation through the completion of clinically useful outcome measures and remote communication between the clinician and the patient.

Methods: See study flowchart (figure 1). A prototype system was developed by an industry partner, Qbtech Ltd (figure 2). Perspectives on this system were explored through an initial user workshop and a series of focus groups (see table 1) with four stakeholder groups:

- NHS staff working with people with ADHD
- Adults with ADHD
- Young people with ADHD
- Parents of children and young people with ADHD

Prototype design

The initial concept for the remote monitoring approach was an online system managed from the clinic. Its features are:

- Personalised clinician dashboard
- Ability to add new patients individually
- Range of standardised outcomes available including symptom and side effect measures
- Ability to set personalised schedules for each patient
- Patients receive a text message with link to each questionnaire (figure 2)
- Internet required to access, complete and submit questionnaire (figure 2)
- Clinician receives an email notification upon completion or after a specified time if not completed

Table 1: Focus group participants

<table>
<thead>
<tr>
<th>Location</th>
<th>Staff</th>
<th>Adult</th>
<th>Young people</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nottinghamshire</td>
<td>N = 9</td>
<td>N = 4</td>
<td>N = 2</td>
<td>N = 2</td>
</tr>
<tr>
<td>Leicestershire</td>
<td>N = 7</td>
<td>N = 7</td>
<td>N = 6</td>
<td>N = 7</td>
</tr>
<tr>
<td>Derbyshire</td>
<td>N = 7</td>
<td>N = 7</td>
<td>N = 6</td>
<td>N = 7</td>
</tr>
<tr>
<td>Total (N=51)</td>
<td>23</td>
<td>11</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>

Figure 1: Technology development cycle

Prototype development (Jan 2014)  \(\rightarrow\) Revision (Jan 2015 onwards)  \(\rightarrow\) Data analysis (Sept – Dec 2014)  \(\rightarrow\) User workshop (Feb 2014)  \(\rightarrow\) Focus groups (May – August 2014)

Figure 2: Screenshots from prototype system

Figure 3: How satisfied were you with the process when you/your child started medication?

<table>
<thead>
<tr>
<th>Level</th>
<th>Not at all</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rating</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Findings

Primary unmet need = Delay to diagnosis

For adults with ADHD and parents of children with ADHD, delay to diagnosis is their main problem. People described lengthy processes, often over a number of years, struggling with the consequences of the condition and trying to access services. The difficult and often traumatic experience of reaching a diagnosis dominates the ADHD journey.

Varying experiences of medication optimisation

Having experienced lengthy delays to diagnosis, experience of starting medication and finding their optimal dose was considered relatively less problematic by parents and adults. Satisfaction with treatment optimisation varied widely depending on the NHS trust and the individual professional responsible for their care (figure 3).

Staff reservations towards a clinic managed system

- Quantitative information (e.g. symptom measures) alone is not sufficient when changing dosage; need for additional qualitative information
- Increased workload and disruption adopting the system without a clear benefit to them
- Concerns over accountability if side effects are reported remotely

Support for tracking treatment response over time

Across all the groups, most support was received for recording treatment response over time e.g. reports of regular outcome measures in a diagram or graph. This was deemed to be helpful for the patient/parent as well as aiding communication with clinicians and others (see quotes below).

Conclusion

Testing out the ideas for the initial prototype system with the different stakeholder groups has been of great value. While all groups are supportive of using new technologies, there was limited support for such a system, especially from NHS staff.

As a result of this, we are moving away from our initial concept of a clinic managed system. Instead, we will explore options for a patient-led self-monitoring tool. Information collected can then be shared with clinicians and others involved with a person’s care and support, as preferred by the patient.