

## Patient Group Submission Form

The Scottish Medicines Consortium (SMC) is committed to working in partnership with patient groups to capture patient and carer experiences, and use them to inform decision-making.

### Before you make a submission

You are required to complete a Patient Group Partner Registration Form before you make a submission. The registration form requests general information about your organisation. It only needs to be completed once (and annually updated) and should save you time with any further submissions to SMC. If you have not already completed a registration form, please do this before you make your submission.

You will find it helpful to read our Guide for Patient Group Partners, which gives details about the type of information you need to capture in the submission form. **Please read this before you make your submission and use it to help you complete each question.**

You can find the Registration Form and Guide for Patient Group Partners here:

[https://www.scottishmedicines.org.uk/Public\\_Involvement/Submission\\_form\\_and\\_guidance](https://www.scottishmedicines.org.uk/Public_Involvement/Submission_form_and_guidance)

### Contact us

If you have any more questions after reading the guide, the SMC Public Involvement Team can support you throughout the submission process. You can email us at: [hcis.SMCPublicInvolvement@nhs.net](mailto:hcis.SMCPublicInvolvement@nhs.net) or phone: **0141 414 2403**. Please do not hesitate to get in touch, as we are here to help you.

**Name of medicine:**

Intuniv (guanfacine hydrochloride)

**Indication:** (what the medicine is used for)

Attention Deficit Hyperactivity Disorder (ADHD)

**Submission date:**

27 November 2015

**Name of organisation making submission:**

ADHD Parent Support West Glasgow, Dundee & Angus, Perth & Kinross and Mindroom

**Who is the main contact for submissions to SMC?**

Name:

#####

Position held in organisation:

Chair - ADHD Parent Support West Glasgow

Email address:

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Phone number:

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Postal address:

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## Summary of Key Points

**Please summarise the key points of your submission which you would like to emphasise to SMC Committee – bullet points may be helpful.**

(See P11 of A Guide for Patient Group Partners)

300 words maximum

ADHD is a very real condition which has a profound impact on children diagnosed with it, not just in childhood but in terms of reduced life chances resulting from poor performance at school, school exclusion, poor self esteem, risk taking behaviour and difficulties in sustaining relationships. ADHD also has a huge impact on the parents, siblings and wider family of the child, leading in many cases to marital conflict, stress, anxiety and even family breakdown. Due to low diagnosis rates of ADHD in Scotland (ADHD Services over Scotland report 2012), those diagnosed with ADHD through CAMHS teams tend to have more severe forms of ADHD.

Parents are naturally reluctant to medicate their children and many in the survey we conducted to inform this submission expressed the view that more non-pharmacological approaches should be available (including more information and training for parents, psychological support and better training and information for teachers). However, the vast majority of parents in our support groups do give their children ADHD medication (in virtually all cases stimulant medication) and most report benefits which significantly outweigh any side effects. There is no doubt that effective medication for ADHD makes a huge difference to children and their families.

In our view, having an additional medication option in the form of Intuniv would be very beneficial to children with ADHD, particularly those who cannot tolerate the stimulant medications.

**Please provide details of any individuals who have had a significant role in preparing your submission and who have an interest to declare.**

(See P11 of A Guide for Patient Group Partners)

N/A

300 words maximum

**Please tell us how you gathered information about the experiences of patients and carers to help inform your submission.**

(See P11 of A Guide for Patient Group Partners)

300 words maximum

Four Scottish ADHD Parent Groups (ADHD Parent Support West Glasgow, Mindroom, Dundee and Angus ADHD Support Group and Perth & Kinross ADHD Support Group) have collaborated to make this joint submission. We undertook a rapid online survey of parent members of our groups in order to inform our responses. Together with ADHD Support West Lothian, we sent the survey out to parents we are in contact with of children aged 6 - 18 with a confirmed diagnosis of ADHD.

The survey was circulated on 9<sup>th</sup>/10<sup>th</sup> November 2015. By the closing date of 20<sup>th</sup> November, 87 responses had been received representing 92 children with ADHD. 64 respondents were mothers, 5 were fathers and 7 were foster carers/grandparent carers. A full report of the survey results, which make very informative reading, is available separately.

## 1. How does this condition affect the day-to-day lives of people living with it? (See P11 of A Guide for Patient Group Partners)

500 words maximum

ADHD has a profound effect on children with it and on their wider families. Our survey showed that the main difficulties cited were:

- poor short term memory and inability to concentrate;
- hyperactivity, being constantly on the go and problems with sleep;
- children being labelled, misunderstood by teachers, peers, other parents and extended family members, problems making/keeping friends, low self-esteem, poor confidence, anxiety;
- impulsive or risky behaviour leading to harm for the child or trouble at school (including exclusions);
- disorganisation, forgetfulness and constantly losing things and, for some, anger and violent behaviour.

Typical quotes from parents were:

"My son struggles at school, social situations and in relationships. Disorganisation, forgetfulness and losing items are also a major problem. Hyperactivity creates problems with sitting still through class."

"Complete lack of concentration making everyday tasks almost impossible without support."

"My son has no friends and his progress at school is slow. He can't sit still enough to finish a meal. He has to be supervised at all times as he can become very hyper and hurt himself. He finds listening and following instructions near impossible and he does not sleep well."

"My child falls behind at school because he can't concentrate and retain information. Teachers constantly punish him without trying to understand his difficulties."

For parents and the wider family, problems include anxiety, stress and exhaustion, impact on siblings, social isolation, marital breakdown and difficulties in parents' sustaining employment.

"D. has limited capacity to manage activities of daily living. I worry a great deal about how he will cope with the adult responsibilities. At times caring for D., managing his impetuosity, his frustration and anger has taken attention away from his siblings."

## 2. How well do medicines which are currently available in NHSScotland help patients manage this condition? (See P12 of A Guide for Patient Group Partners)

500 words maximum

Parents worry a great deal about putting their children on psychoactive medication. However, in our survey we found that 75% of respondents' children were taking ADHD medication. Almost all (63 out of 65) were taking stimulant medication and only 4 out of 65 were taking the non-stimulant atomoxetine (two in combination with a stimulant), reflecting psychiatrists' preference for the stimulants based on performance in clinical trials. 65% of respondents agreed or strongly agreed that the benefits of medication outweighed the drawbacks for their child, 71% said the medication had improved their family life and 73% that it had improved their child's performance at school.

Typical quotes included:

"He is able to concentrate more and finish work especially at school. Not so hyperactive. Able to sit for longer periods of time and not chat uncontrollably."

"The medication makes him dramatically calmer, and because so much of the agitated, aggravating behaviour goes away, it enables him to focus much more and for his real sunny personality to come through."

However, side effects are a serious concern. 20% of children who had taken ADHD meds at some point at changed or stopped taking meds due to side effects. Of those using medications now, 56% reported appetite/weight loss, 13% sleep problems and 13% mood/emotional difficulties. One parent who had to stop stimulant medication for her son reported:

"The medication markedly reduced my son's appetite and he was skin and bone. The meds stopped him from being able to sleep so he was also on melatonin to combat the insomnia. He was like two different people."

**3. Have you been able to consult with patients who have used this medicine?** (See P12 of A Guide for Patient Group Partners)

Yes

No

**4. Would this medicine be expected to improve the patient's quality of life and experience of care, and if so, how?**

(See P12 of A Guide for Patient Group Partners)

500 words maximum

An effective ADHD medication, provided it does not have unacceptable side effects, will have a dramatic effect on the quality of life of children and young people with ADHD and their experience of education. It is for the SMC, rather than us as parent organisations, to judge whether Intuniv is clinically effective. We note that the head to head studies have compared it to atomoxetine, a non-stimulant medication, rather than the stimulants, of which we have most direct experience.

The benefits of effective medication for children with ADHD are improved focus and concentration at school along with calmer and less impulsive behaviour. This can in turn lead to better educational performance, with associated improvement in life chances, reduced school exclusion, improved relationships with peers, family and teachers and reduced levels of anxiety and low self-esteem.

Given that many children with ADHD (55% in our survey) have also been diagnosed with at least one other neuro-developmental disorder such as autistic spectrum disorder, dyslexia, oppositional defiant disorder, dyspraxia or Tourette's syndrome, having an effective treatment for their ADHD can be a major step towards improving life. Typical quotes from our survey about benefits include:

"His school behaviour is 100% better which gives him the chance of a good education."

"Increased focus at school and in sporting activities. Much greater ability to sit through a meal."

However, problems with side effects mean that, for some children, currently available ADHD medications are not suitable. Hence the availability of more medication options for discussion with parents by treating psychiatrists would be very beneficial.

## 5. What kind of impact would treating a patient with this medicine have on the patient's family or carers? (See P13 of A Guide for Patient Group Partners)

500 words maximum

Similarly, for those children without an acceptable medication available, having an additional, effective medication option available would improve life for their wider families. 72% of parent survey respondents said it would be of benefit to have more medication options for treating ADHD and only 18% said it would make no difference to them.

Parents told us how much stress and anxiety was caused by ADHD in their families:

"It was so heart-breaking seeing him struggle, especially before diagnosis. Trying all sorts of parenting techniques."

"I have to spend a great deal of time with both my children with ADHD making sure they get tasks done such as chores and homework. Things get lost, things get damaged and broken. I have suffered from depression and we have had marriage problems. We are often at appointments to check progress. People think you are a bad parent and that the children are badly behaved. To try and quantify the impact in a few words is impossible."

"ADHD has had a massive impact on our family life. When my son was diagnosed I got the diagnosis also at 35yrs. My husband has ADD. Family life is very stressful and we have had marital problems unfortunately resulting in a breakup."

"ADHD is awful to live with, every day it is the same arguments, repeating yourself 100 times, avoiding friends because Z. is having a bad day, avoiding restaurants because the inevitable kick off is not worth it, missing out on holiday breaks with friends who have kids because Z. is too much to handle and the kids get tired of her behaviour. My relationships with friends, partners etc are all impacted, my social life is impacted - the true extent of ADHD is vast."

## 6. Are there any disadvantages of the new medicine compared to current standard treatments? (See P13 of A Guide for Patient Group Partners)

500 words maximum

Our understanding from the manufacturers' summary of information about Intuniv is that the 'very common' side effects seen in trials are somnolence, headache, fatigue, abdominal pain and sedation. These are very different side effects from those most commonly experienced by our parents with stimulant medications - appetite loss and sleeplessness - both of which are manageable for most families to deal with through practical mitigating strategies (for example giving the child extra calories in the evening when the medication wears off, managing sleep through regular bedtime routines).

One of the main concerns that parents have about giving their children psychoactive medication is that their essential personalities or level of awareness may be changed or dulled. In our view, if children taking Intuniv did experience the side effects reported in trials, this would make it unacceptable to most parents. However, we are aware that all children respond to medicines differently, and so for those who find the side effects of stimulants intolerable, having this additional option to try would be helpful.

We note that Intuniv is a long acting formulation taken just once a day. This makes it comparable to the extended release stimulant medications which only need to be taken at the start of each day: this is a major benefit for children who are at school who may be stigmatised by having to take medication in the middle of the school day (or the medication may be missed if the school is not well organised).

**7. Is there any additional information you think may be useful for the SMC committee to consider?** (Optional)

500 words maximum

Additional information on ADHD and services in Scotland can be found in the report ADHD Services Over Scotland 2012. This report noted that rates of diagnosis and treatment of ADHD in Scotland is highly variable between health boards and remains well below the level which would be expected based on global prevalence estimates for ADHD.

**8. Do you consent for a summary of your submission to be included in the Detailed Advice Document for this medicine?**

Yes  No

Thank you for completing this form.

Please email it to: [hcis.SMCPublicInvolvement@nhs.net](mailto:hcis.SMCPublicInvolvement@nhs.net)

If you are unable to email this form to us, please send by post to the address below:

Public Involvement Team  
Scottish Medicines Consortium  
Healthcare Improvement Scotland  
8<sup>th</sup> Floor  
Delta House  
50 West Nile Street  
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The Public Involvement Team is available to advise you on how to complete this form to ensure the patient and carer experience is fully captured, to help inform the SMC decision making process. If you have any questions about completing this form call us on: 0141 414 2403.