

# Results of a survey of a survey of parents of children with ADHD in Scotland

Undertaken to inform a submission to the Scottish  
Medicines Consortium

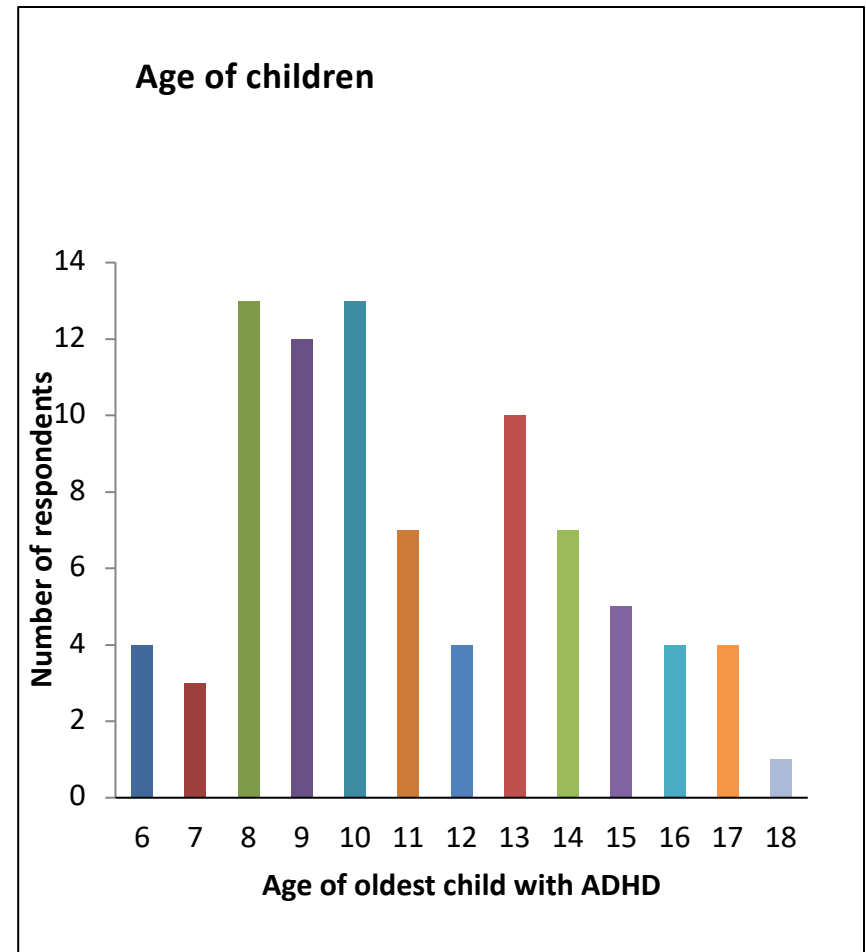
**updated 24 November 2015**

# Introduction

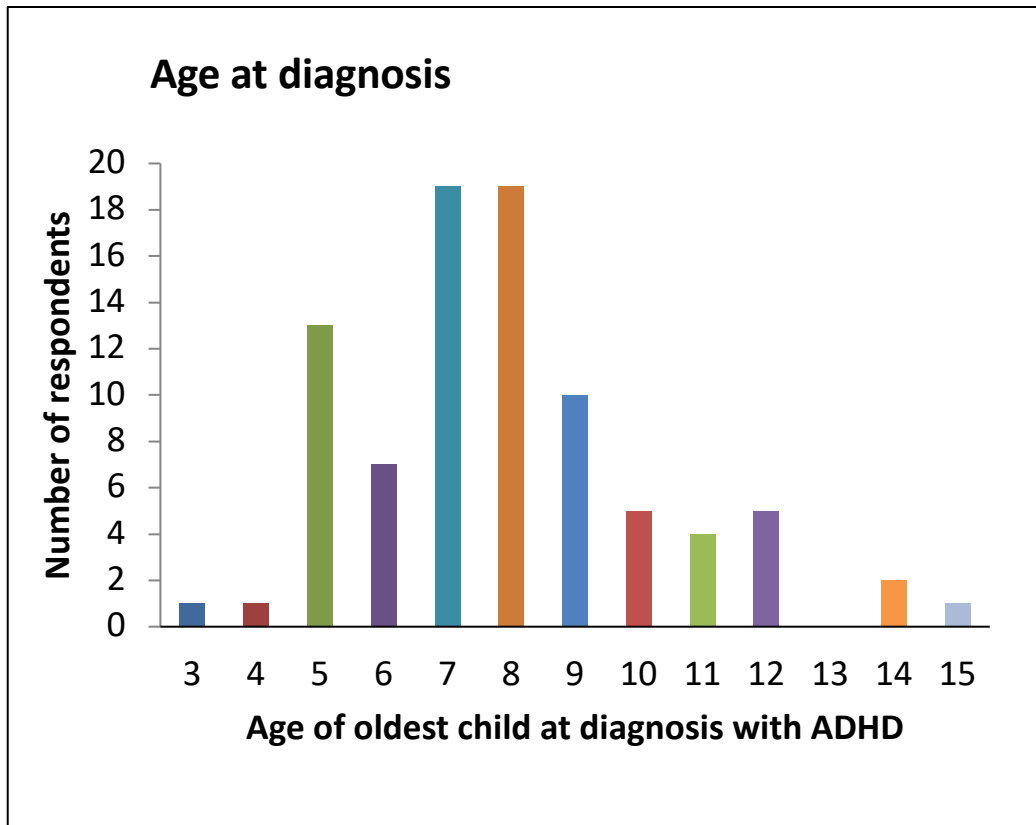
- In October 2015, the Scottish Medicines Consortium invited comments from patient / parent organisations to contribute to their appraisal of Intuniv (guanfacine hydrochloride), a new non-stimulant medication for ADHD.
- Four Scottish ADHD Parent Groups (ADHD Parent Support West Glasgow, Mindroom, Dundee and Angus ADHD Support Group and Perth & Kinross ADHD Support Group) collaborated to undertake a rapid online survey of parents in order to inform their consultation submission. Together with ADHD Support West Lothian, they sent the survey out to parents they were 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 (64 mothers, 5 fathers and 7 foster carers/grandparent carers)
- The results were collated by Geraldine Mynors of the Glasgow group, and used to inform the joint submission to the SMC (which can be downloaded from <http://www.adhdglasgow.org/smc-consultation/4591231089>).

# The respondents to the survey were 87 parents/ primary carers of 92 children with ADHD

- 5/87 parents had two children with a diagnosis
- Parents with more than one child with ADHD answered questions in relation to their oldest child.
- Respondents' children are spread in age from 6 to 18 with most being of primary school age.



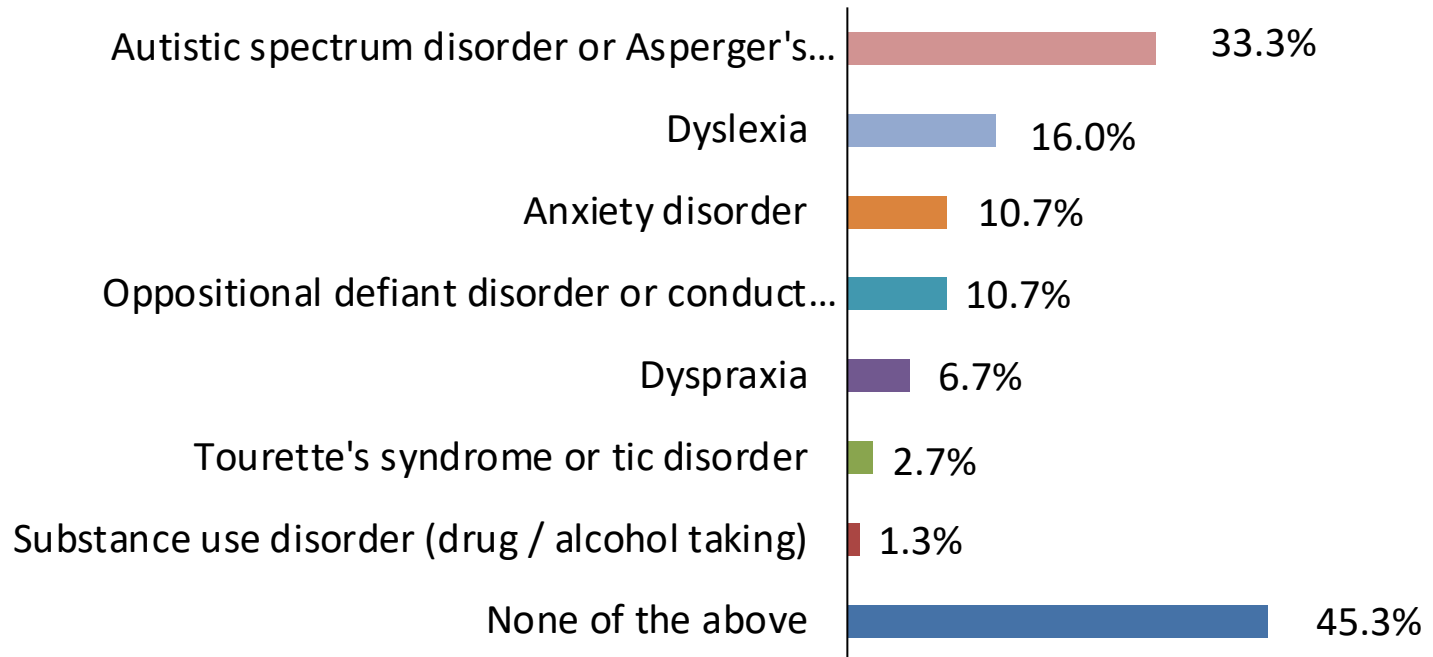
# The time since diagnosis ranged from 1 to 11 years, with an average of 3.2 years



- Median age of children at diagnosis was 8 (average 7 years and 10 months)

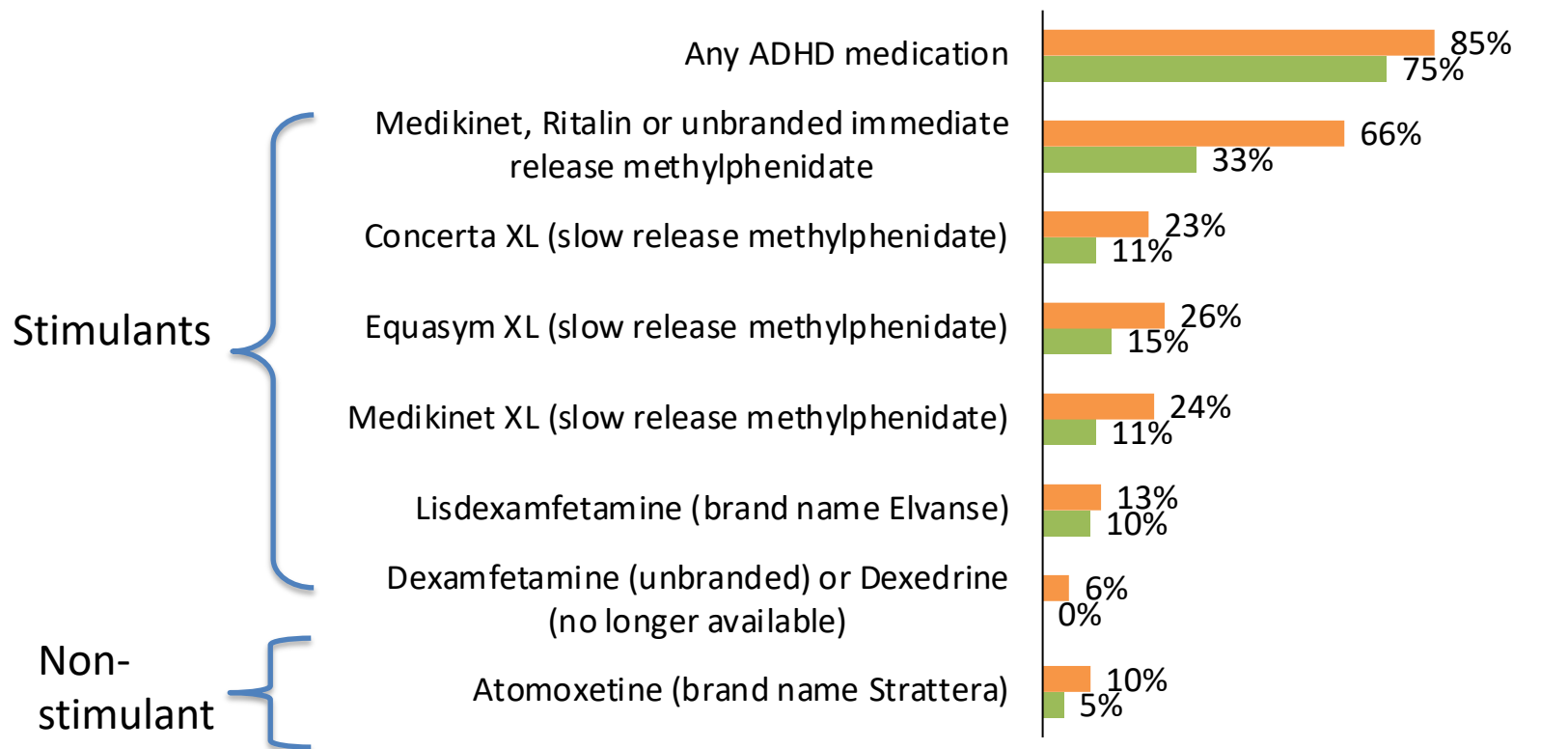
# Most children have been diagnosed with other neuro-developmental conditions alongside ADHD

Has your child also been diagnosed with any of these other conditions which can sometimes go along with ADHD? (n=75)



**75% of children were taking an ADHD medication now.  
63 of 65 are taking a stimulant, and 4 are taking a non stimulant\***

**% of respondents' children taking different kinds of ADHD medication (n=87)**



\* 2 reported they were using a combination

# Respondents provided 74 qualitative descriptions of the impact ADHD had had on their child

## Main themes:

- Poor short term memory and inability to concentrate
- Hyperactivity, being constantly on the go and problems with sleep
- Being labeled, misunderstood by teachers, peers, other parents and extended other family members
- Problems making/keeping friends and conflict with peer group
- Low self-esteem, poor confidence, anxiety
- Impulsive or risky behaviour leading to harm for the child or discipline / trouble with authority
- Disorganisation, forgetfulness and constantly losing things
- Anger, tantrums, violence, oppositional behaviour

# Selected quotes about impact on the child

- *My son struggled at school, social situations and peer 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. Medication helps with this.*
- *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 daughter struggles with her emotions and being able to talk about any worries she has. Without medication she is very hyper and struggles to calm down and behave appropriately in school and home.*
- *Causes problems at school, clubs, with family. My child falls behind at school because he can't concentrate and retain information. Teachers constantly punish him without trying to understand his difficulties.*
- *Cannot hold a conversation on one subject for long, dangers on crossing roads, quick to temper. Not listening to instructions.*



# 73 respondents also provided descriptions of the impact that ADHD had had on their wider family

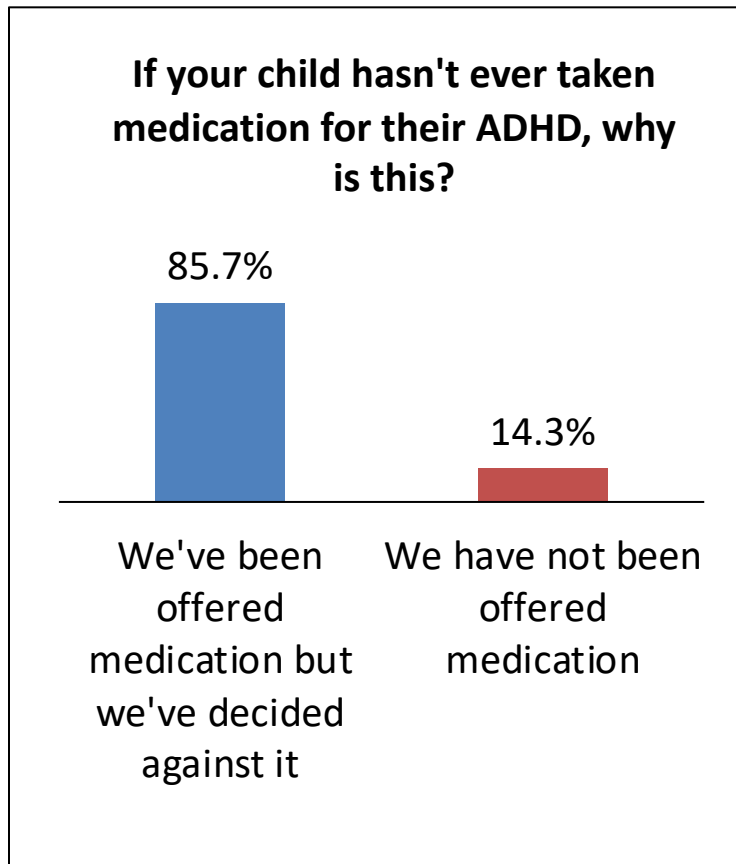
## Main themes:

- Parental anxiety, stress and exhaustion
- Impact on other children in the family
- Difficulty planning outings or social events due to unpredictable behaviour, leading to social isolation
- Marital difficulty and breakdown
- Conflict and arguments with the child and within the family
- Time commitment of attending numerous appointments and school meetings putting strain on ability to sustain employment

# Selected quotes about impact on family life

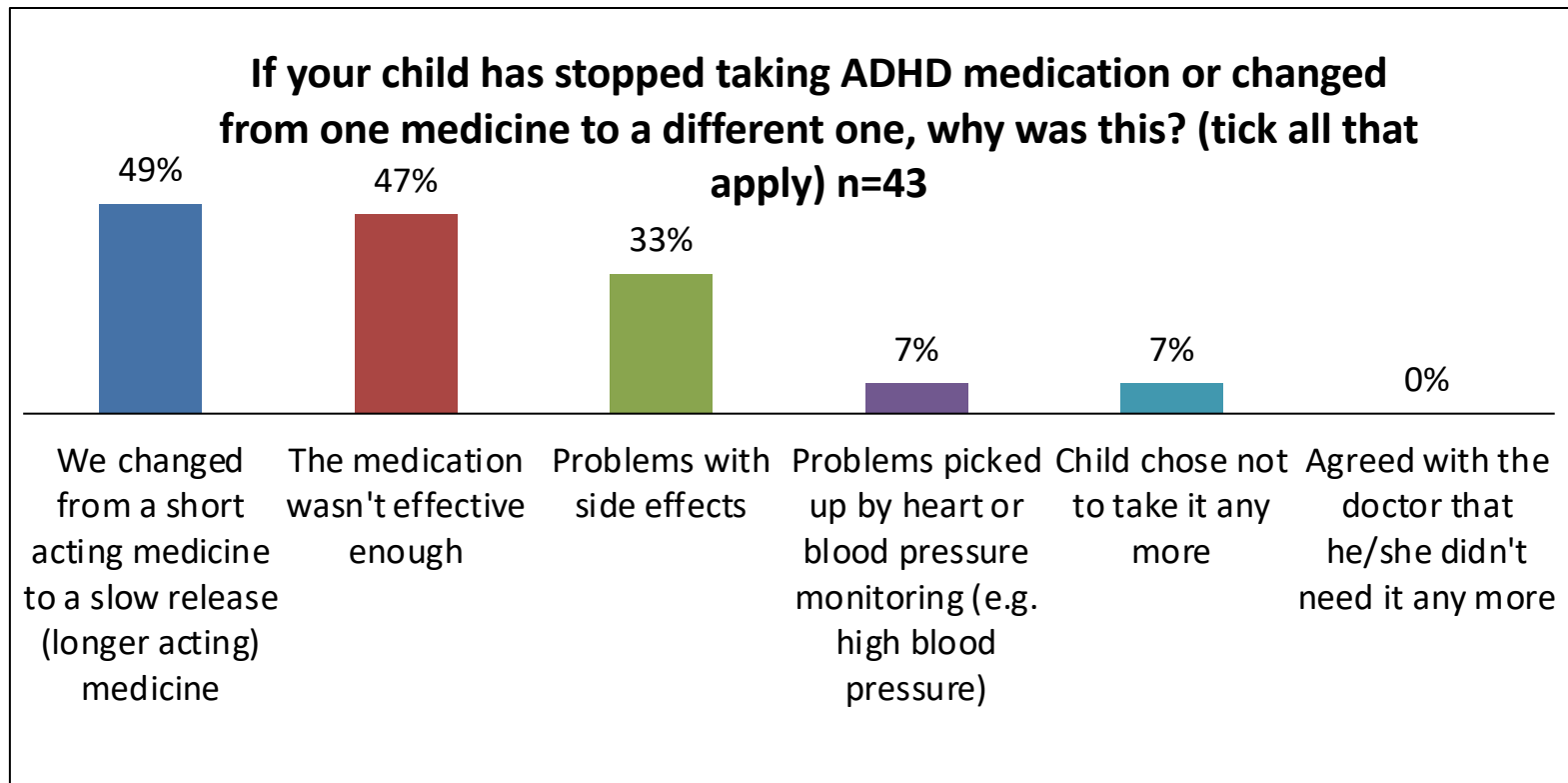
- *Feeling tired and drained not being able to go out for a meal as a family or days out as his behaviour can become unmanageable. Being excluded from family occasion as people don't always understand his behaviour.*
- *He never stops so it's tiring and always challenging, often leads to friction within the family - I feel like a UN peacekeeper most days.*
- *D. has limited capacity to manage activities of daily living. I worry a great deal about how he will cope with the rigours of adult responsibilities. At times caring for D, managing his impetuosity, his frustration and anger has taken attention and time away from his siblings.*
- *Constant judgement from others, very stressful as a large proportion of my time is spent looking after my son or attending appointments for him which deprives my youngest son of time and makes me feel guilty. Some days I feel like not getting out of bed as I know what the day in front will be like. I feel anxious going into social situations at times and always have my guard up.*
- *It affects everything from popping into a cafe for a cup of tea to visiting relatives, people in general struggle to deal with how hard work he is.*
- *I have to constantly "walk on eggshells" when dealing with my child; speak to teachers, go to numerous school meetings, medication reviews, psychology reviews. Have to educate family members about ADHD and explain why my child acts the way he does.*

# Of the respondents whose child had never taken ADHD meds, most had decided against it



- *My child can't swallow tablets.*
- *We have read masses of information which highlights the negative side effects of using the medication for ADHD/ADD, Ritalin. The medical professional involved in their care said there was no alternative and after we declined this form of treatment, they were less inclined to help us in future. We now manage ADHD with no help from the NHS.*
- *I am wary of the side effects of ADHD medication.*
- *I have decided against medication for my daughter as I feel that I would like to continue with our life skills approach.*

# 43 out of 74 children who had taken ADHD meds at some point had changed or stopped for the following reasons. 9 had stopped taking medicines completely.

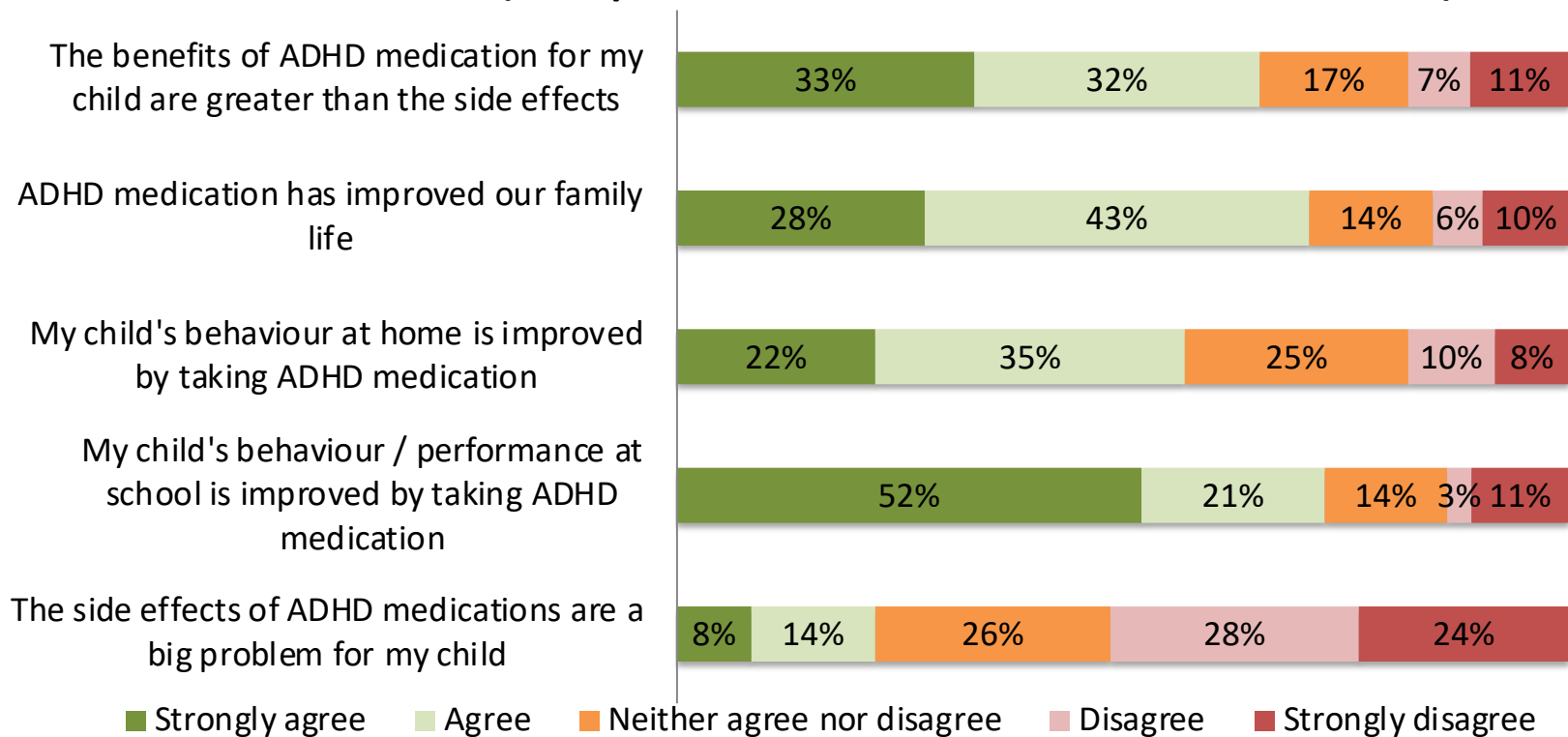


# The 15 respondents who had changed or stopped medications due to side effects gave the following reasons

- *Anxiety, suicidal*
- *Child's mood and general demeanour was adversely affected. Very low. Sleep pattern was hugely disturbed and appetite was suppressed. Lack of nutrition during the day exacerbated poor mood and inability to concentrate.*
- *Fast heart rate*
- *Had severe emotional swings either sobbing inconsolably or very angry*
- *He started hearing and seeing things*
- *Her eye sight got really blurry but it was thought that she was on too high a level of Solifenicen mixed with the Medikinet which caused the reaction. Her Solifenicen dose was reduced and she went back on and there are no side effects now.*
- *Low mood, weight loss*
- *Mood changes, tearful etc and not effective*
- *My son tried both medications, the Ritalin caused his heart to race and made him short of breath and the dexamfetamine cause unwanted side effects of confusion, upset and anger*
- *One particular brand seemed to exacerbate all the symptoms and had to be stopped.*
- *Problems with sleep, eating and paranoia.*
- *Sore tummy headaches loss of appetite*
- *The medication markedly reduced my sons 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. One on the medication, one off. We found this hard to cope with as did he. He would get emotionally labile as the meds were leaving his system. He could be extremely tearful to extremely angry and violent. At worst he had suicidal behaviour and tried to hang himself several times when he was 9 years old.*
- *Tired, tearful, autistic symptoms exaggerated*

# Overall, the majority of respondents whose children have used medication feel that the benefits of medication outweigh the drawbacks

**How much do you agree or disagree with these statements about ADHD medication? (n=72 parents of children who have used medication)**



# 66 parents provided examples of ways in which the medication had helped (1 of 2)

- *His school behaviour is 100% better which gives him the chance of a good education.*
- *Increased focus at school and during sporting activities at the weekend. Much greater ability to sit through a meal.*
- *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 allows my son to concentrate in school and at his social clubs. Without the medication my son finds it difficult to sit down for more than a few minutes.*
- *The medication makes him dramatically calmer, and because so much of the agitated, aggravating behaviour goes away, I would say that it enables him to focus much more and for his real sunny personality to come through. It helps him very much at school - without it I'm sure he wouldn't be achieving much at all academically, and might well have been excluded from school much more than he has been.*
- *There is a massive difference and progress within school*
- *Well behaved, can have a conversation, listens.*
- *Able to engage with school and social events.*
- *Calmer, not as fidgety, doesn't argue as much, can hold more reasonable conversation. Focus is improved.*



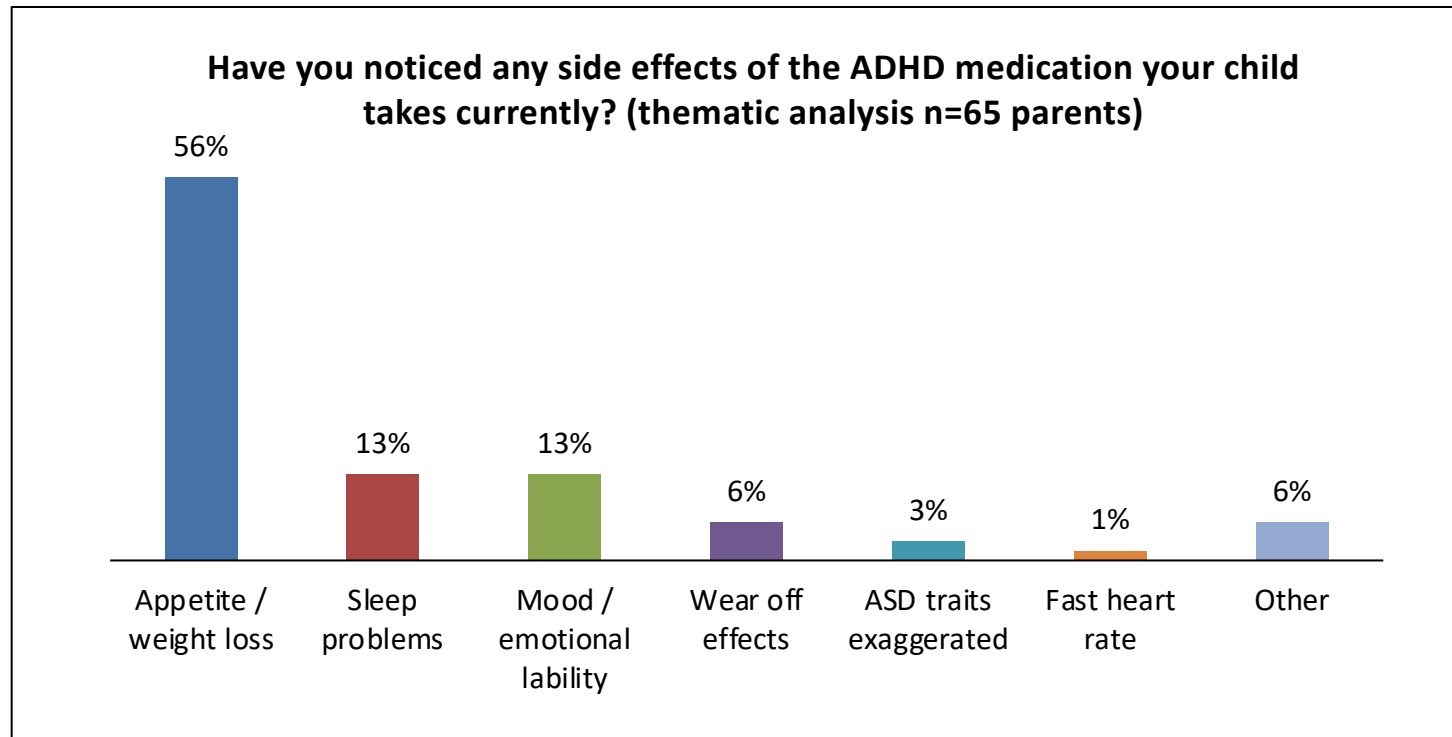
# 66 parents provided examples of ways in which the medication had helped (2 of 2)

- *Better at school, feels emotions, is able to think more about consequences, happier.*
- *Calmer , more level headed , concentration improved, better at coping with her friendships.*
- *Has gained better concentration at school, he is able to build friendship and he is will to take part in social activities e.g. school football team.*
- *He is more focused in all his day to day activities and you see a notable difference in him when the mess have worn off just as he comes home from school to having his evening meds at 4pm. He is happier as he is now able to put onto paper in school what has been in his head.*
- *Helps him process situations before reacting, help him enjoy social situations positively , helps him concentrate at school . All his words.*
- *He told me it helps him to 'think clearer and understand stuff quicker'. To me he seems more settled, can be more focused and organised, shows more initiative and appears to be more accepting of others points of view.*
- *My son couldn't complete tasks, couldn't sit and colour in or build with Lego. Since taking his medication he can do these things. He was always in trouble at school, for ever getting bad reports. Now it's like a different child (words of his teacher).*



# Of the 65 parents of children currently taking meds, 54 (83%) cited at least one side effect

- The following is based on a thematic analysis of the free text comments of parents about side effects – they were not given a tick list.



# Comments from parents about side effects

**Appetite loss and problems sleeping are very common but many parents said they were manageable**

- *Appetite changes, during the day less hungry by 4pm is ravenous.*
- *Goes to bed much later and catches up on food at the end of the day. Both are manageable.*
- *Initially his appetite was suppressed when he first started on medication but no longer has this effect.*
- *Loss of appetite. difficult to get to sleep*
- *Medication has been very positive for us , only side effect we've noticed is weight loss*
- *The medication definitely causes loss of appetite during the day, so we have to add lots of calories early morning and late evening so he keeps his weight up.*

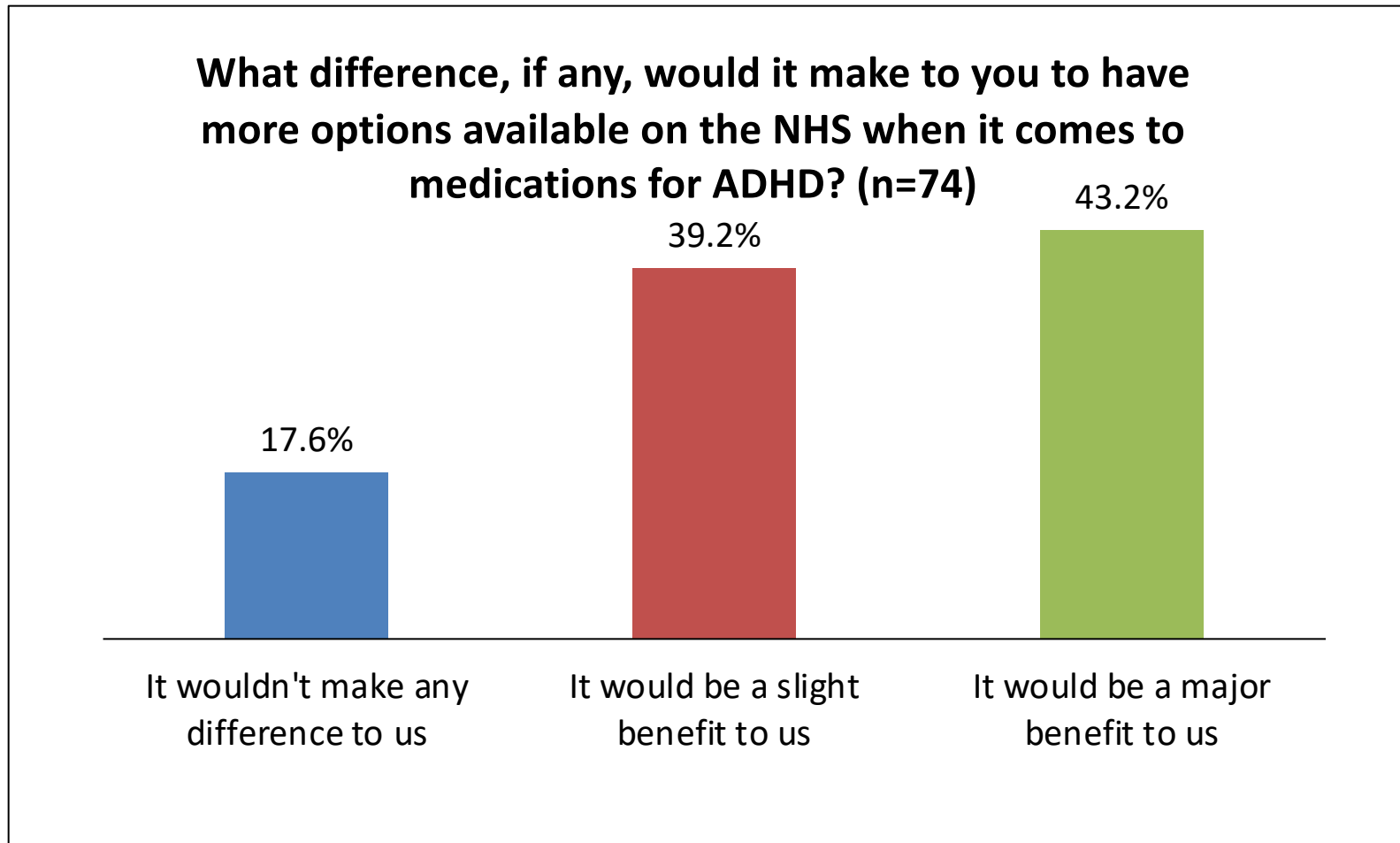
**Some parents mentioned problems with emotions and mood, but these are also common in ADHD**

- *He can seem out of sorts - upset, withdrawn*
- *Tics, more angry at times*
- *Heightened anxiety.*

**Wearing off effects are an issue for some, though it's unclear whether these are really a side effect**

- *Can be more irritable in the evenings, have had some major meltdowns. We manage them by having a routine for homework (regular short bursts) and lots of after school sports activities.*

# A majority of respondents thought it would be useful to have more medication options available



## Finally, although the focus of the survey was medicines, many respondents made comments that more non-pharmacological approaches should be available (1 of 2)

- *I'd like to see more focus on the collaboration between the use of meds backed up with psychological/alternative therapies*
- *We need better funding for medication, faster diagnosis process, more family support and counselling, better training in schools, better transitional support into adulthood.*
- *Diagnoses should happen earlier*
- *Parents need to be given better information to help them cope with daily life.*
- *GP should be trained, skilled and educated to prescribe and support parents. They are not interested in this illness, almost don't take you seriously*
- *Having a better range of medication for our kids would help, we can compare and make informed choices between medications.*
- *More time should be spent with families on complimentary therapies and more time spent with kids explaining that medication is not the only thing needed*
- *Once a child is diagnosed with ADHD then they should immediately be assessed for ALL associated conditions otherwise the child and their family spend countless YEARS trying to get the help a support that their child clearly needs but the initial diagnosis if ADHD does not entitle them to.*

## Finally, although the focus of the survey was medicines, many respondents made comments that more non-pharmacological approaches should be available (2 of 2)

- *Melatonin should be more readily available to those diagnosed with ADHD as sleep difficulties only compound an already complex condition. It was a blessing when we finally got that prescribed via GP; even though CAMHS service felt it beneficial for my son it took a lot of pushing before GP agreed.*
- *The amount of time on the waiting list to see a specialist needs improving.*
- *We need availability of a consistent doctor at CAMHS, other treatments other than medication.*
- *The support needs to be extended to schools! Once diagnosed and on medication [my daughter] went from getting ASN's and regular meetings with support staff to being dropped again, she has gone back to the "irritation" that she was considered before her diagnosis, this is incredibly frustrating!*
- *The waiting time to see CAMHS was far too long as they are under-resourced. People in education need more or better training on how to manage children with ADHD.*
- *Transparency regarding the positives and negatives of any drug should be open to discussion to all. Ritalin has been 'pushed' onto parents as the only way.*

# Respondent Health Board and how they had received the survey invitation

