# All Age Autism and Attention Deficit Hyperactivity Disorder (ADHD) Strategy

2025 - 2030





#### **Foreword**

This strategy sets out our aim for Kingston to be a place where autistic people and people with ADHD have the right opportunities and support to live their lives well.



Autism and ADHD are both Neurodevelopmental conditions. Over half of autistic people also meet the criteria for ADHD. Some symptoms also overlap and many support needs are the same. For this reason the strategy includes both conditions.

The National Autistic Society has said that around one in 100 people are autistic and the National Institute for Health and Care Excellence (NICE) tells us that five in every 100 people have ADHD. These are estimates and we know the true figures are likely to be higher.

One of our core values in developing this strategy was to work with people who have lived experience of using services, so we can plan well for the future. It has been driven by community feedback and expert opinion from Kingstons Autism and ADHD board. The strategy seeks to address the needs of people with autism and ADHD across the areas that have been highlighted as important to local people.

This report uses the terms 'people with autism' and 'people with ADHD' which are terms used by the National Autistic Society and ADHD UK, however we understand language around neurodiversity is changing, and people may use different words to describe themselves or others.

This plan does not include all Neurodiverse conditions however a key aim is for Kingston becomes a neuro-inclusive borough where people have the same opportunities as everyone else.



### A word from our Co-chairs

- Jean-Marc Le Tissier: Co Chair of the Autism and ADHD board Expert by Experience (EbE)

- Sam Morrison: Co Chair of the Autism and ADHD board

Executive Director of Adult Social Care & Health at Kingston Council

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### **National Policy and Guidance**

National strategy for autistic children, young people and adults 2021 to 2026<sup>1</sup>

A National Strategy replaces the previous 'Think Autism' strategy for Adults. The strategy links to the key priorities set out in this Strategy and focuses on the following aims:

- improving understanding and acceptance of autism within society
- improving autistic children and young people's access to education, and supporting positive transitions into adulthood
- supporting more autistic people into employment
- tackling health and care inequalities for autistic people
- building the right support in the community and supporting people in inpatient care
- improving support within the criminal and youth justice systems

It is important to note that the strategy recognises that many people with **autism** also have **ADHD**. It emphasises the importance of integrated and individualized support for people with multiple neurodevelopmental disorders.

National Institute for Health and Care Excellence (NICE) guidance 2018<sup>2</sup>

The National Institute for Health and Care Excellence (NICE) guidelines provide recommendations and highlights the importance of diagnosis and management, including specialist assessments, and to consider other conditions that people may have such as anxiety/mood disorder and depression.

 $\frac{https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026}{}$ 

<sup>&</sup>lt;sup>2</sup> https://www.nice.org.uk/guidance/ng87

### What is Autism?

Autism is a lifelong condition that affects how people communicate and interact with the world<sup>3</sup>.



The criteria for autism includes social communication, repetitive and restrictive patterns of behaviour or interests. However, the way autistic people experience their environment can lead to areas of strength or difficulty that vary between individuals.

For example, autistic people can have;

- strong attention to detail
- above average technical or creative skills.
- character strengths, such as honesty and loyalty
- difficulty predicting what will happen next
- difficulty knowing or understanding what other people think or feel.
- differences in sensory processing, including over- and under-sensitivity



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<sup>&</sup>lt;sup>3</sup> Unsplash image, free to use

#### What is ADHD?

ADHD (Attention Deficit Hyperactivity Disorder) is a condition that impacts the parts of the brain that help people plan, focus on, and carry out tasks.



People with ADHD often show a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with day-to-day functioning and/or development<sup>4</sup>.

ADHD by name refers to hyperactivity, this might look different at older ages. For example, in adults, hyperactivity may appear as extreme restlessness or wearing others out with their activity. It is also often more difficult to diagnose in girls and adults. People with ADHD may have different areas of strength or challenges including;

- having strong creative thinking, often having unique ideas
- having a lot of enthusiasm for things they are passionate about
- having trouble staying focused or get distracted easily.
- finding it hard to stay still.
- doing things without thinking and interrupting others.



<sup>4</sup> https://adhduk.co.uk/about-adhd/

### **Co-occurring conditions**

A co-occurring condition is when a person has more than one condition or illness at the same time.

Research by Autistica<sup>5</sup> has identified that ADHD and autism frequently co-occur. Many people with one of the two diagnoses show elevated traits of both ADHD and autism.



Autistic people and people with ADHD may have difficulty functioning in a world that is made for neurotypical brains. Sensory issues and issues with memory, attention, and thinking. can make daily tasks challenging.

Š 100

21%

Approximately 21% of children with ADHD are also autistic, with others having heightened autistic traits

% 100

28%

Around 28% of autistic children also meet criteria for ADHD

<sup>&</sup>lt;sup>5</sup> https://www.autistica.org.uk/what-is-autism/adhd-and-autism

<sup>&</sup>lt;sup>6</sup> Hollingdale, J. et al., (2019) <u>Autistic spectrum disorder symptoms in children and adolescents with attention-deficit/hyperactivity disorder: a meta-analytical review.</u>

<sup>&</sup>lt;sup>7</sup> Lai, M et al., (2019) Prevalence of co-occurring mental health diagnoses in the autism population

#### Other Health conditions

It is important to recognise that Autism and ADHD are not mental health conditions, and not every person with a neurodevelopmental condition will have mental health difficulties. However, research by the King's College London has found that having a neurodevelopmental condition does mean that people are more likely to develop mental health problems.

The National Autistic Society says that 70% of autistic people have a mental health condition<sup>8</sup> and autistic people are up to four times more likely to have anxiety disorder, and twice as likely to have depression.

Research indicates that suicide is a major cause of early mortality in autistic people and people with ADHD<sup>9</sup>. It has also been shown that autistic people and people with ADHD are more vulnerable to negative life experiences, which may also impact mental health.

#### Neurodevelopmental conditions:

Autism and ADHD are both neurodevelopmental conditions (brain development has been affected in some way). That means both conditions affect the central nervous system, which is responsible for movement, language, memory, and social and focusing skills.



Autistic people and people with ADHD may experience symptoms of other neurodevelopmental conditions such as dyslexia, and dyspraxia.

Delays in language development are common in both conditions, and up to 30% of autistic people are non-speaking (completely, temporarily, or in certain contexts).

<sup>8</sup> https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Adult-Mental-Health.pdf

<sup>&</sup>lt;sup>9</sup> "Lancet Psychiatry" individuals with ADHD are more likely to die prematurely (Dalsgaard et al., 2015)

### **Local Picture**

Although there is data available for autistic children and adults at a national or a local level, there is little regular collection of data for people with ADHD.

By applying what we know about the prevalence of Autism and ADHD to the population of Kingston (170,000 people), there would be an estimated

- ★ 1,700 autistic children and adults
- ★ 8,500 children and adults with ADHD



The true number of autistic people and people with ADHD in Kingston is likely to be higher, with research suggesting that for every three children with a diagnosis of autism there are another two children who have the condition but have not been given a formal diagnosis<sup>10</sup>

Research that suggests that there are a significant number of adults who have ADHD do not know that they have it<sup>11</sup>. Data from the Department of Education shows that autistic children and young people make up the largest level of need within Education and Health Care plans.

<sup>10</sup> https://www.autism.org.uk/advice-and-guidance/what-is-autism

<sup>&</sup>lt;sup>11</sup> Management of ADHD in adults, Lenard A Adler

#### Assessment and support

In the period 2023-24. 'Your Healthcare<sup>12</sup>' neurodevelopmental services received

- ★ Autism 427 referrals (across the 2 Boroughs of Kingston and Richmond), 71 which were for assessments
- ★ ADHD 798 referral, of which 150 were assessments

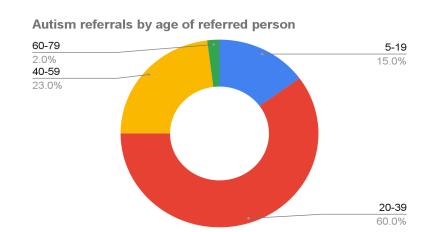


#### **Ethnicity**

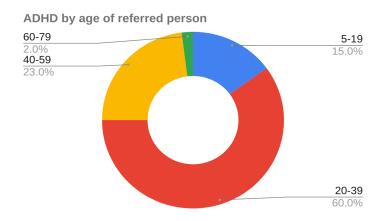
Due to a large number of referrals not containing ethnicity data, it was not possible to form conclusions from this data.

#### <u>Age</u>

The largest number of referrals for Autism were for the 20-39 years age-range, the lowest number of referrals with in age groups was the 60-79 range (2%)



Referrals for ADHD mirrored those of the Autism referrals with the exception that 66% were for age group 20-39 and 18% were for the age range 40-59.



<sup>&</sup>lt;sup>12</sup> Your Healthcare CIC, formerly part of NHS Kingston is a not for profit social enterprise

#### Education

Nationally, the most common type of primary need for those with an Educational Health Care plan (EHCP)<sup>13</sup> is autism and for those with SEN support is speech, language and communication needs. ADHD is not captured as a condition as part of statutory recording for SEN or EHCP's.

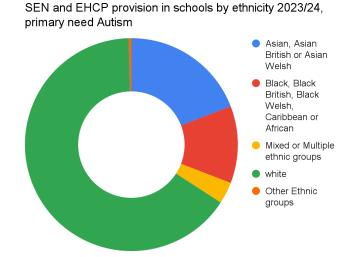


#### In Kingston there were;

- ★ 2,798 children with an EHCP in the 2023 academic year who had a primary need of Autism<sup>14</sup>.
- ★ 2,742 autistic children and young people receiving Special Educational Needs (SEN) support.

#### **Ethnicity (SEN and EHCP)**

The greatest difference when comparing ethnicity data to the 2021 Census is that whilst Black, Black British, Black Welsh, Caribbean or African young people and children made up 2.8% of the population of Kingston, they represented 11.7% of those who had an EHC plan or SEN support.<sup>15</sup>



#### Gender

For both EHC plans and SEN support there are fewer females supported where the primary need was Autism. For EHCP plans 2023/24, 71% were male and for SEN support 63% were male.

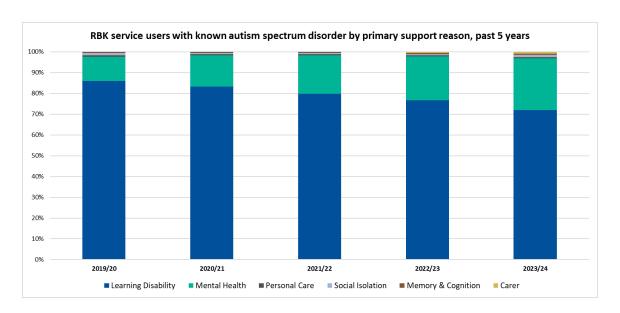
<sup>&</sup>lt;sup>13</sup> An EHCP describes and puts in place the educational provision and support that they need

<sup>&</sup>lt;sup>14</sup> DfE Secondary need, by type of SEN provision and type of need: academic year 2023/24

<sup>&</sup>lt;sup>15</sup> DfE Reporting year 2024 Education, health and care plans: New plans - characteristics

#### **Adults**

During 2023-24 there were 189 autistic adults receiving Social Care support. This has remained in line with population growth over the last five years. The biggest change is that the number of people whose primary support need of Learning Disability has decreased over the last five years, while the proportion with a primary support reason of Mental Health has been increasing.<sup>16</sup>



Some people have more than one service which means there was a total of 329 services in place. Most services were for support to live more independently (community supported living care packages), followed by day support, direct payments and long-term residential care.

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<sup>&</sup>lt;sup>16</sup> Data extracted from Kingston Social Care database

### Why do we need a strategy?



The Autism Act 2009 requires local authorities to have a strategy for improving services for adults with autism spectrum conditions. We have set out over the last year, to work with people with lived experiences of services in Kingston to identify what is important to the residents of Kingston.

Autistic people and people with ADHD, have told us that there are examples of things working well in Kingston, but to enable more people to live their best lives we need to make changes.

We know we need to better understand the inequalities autistic people and people with ADHD face, so we can take action to improve people's health. The strategy will help us to bring together local organisations and the wider

community to raise awareness of Neurodiversity, identify people's needs earlier and help to improve their physical and mental health.

This strategy includes a plan that focuses on the changes that are important to the people of Kingston. We will be effective, by working with services that have similar aims, by joining up our resources and by committing to take action,

The action plan has been developed from our engagement work over the last 12 months and will involve working across Health, Housing, Social care, Education, Voluntary organisations and other services.

# Outcomes of our engagement

In developing this strategy, we spoke to residents, Experts by Experience (EbE's), community organisations and experts to develop our priority areas.

We considered national policy<sup>17</sup>, previous engagement with the Autism and ADHD board, wider work including the 2022 Pulse Check report<sup>18</sup> and the work of other boroughs.



We asked people to share their thoughts on what's working well in Kingston (so we can do more of it), and what could be improved. We asked people on changes that we make to ensure Kingston is a place that people can live healthy and fulfilling lives

Toolkits were provided to enable local organisations to run focus groups, promotion was undertaken across Kingston using the 'Let's Talk' portal.

<sup>&</sup>lt;sup>17</sup> Statutory guidance to support implementation of the Adult Autism Strategy (2015); National Strategy for autistic children, young people and adults 2021-2026; DoH Think Autism strategy governance refresh 201 <sup>18</sup> Pulse Check report: Neurodiversity and health and care services 2022: Healthwatch

# Respondents were asked to provide feedback on three key questions:

- 1. Which priority is most important?
- 2. Why?
- 3. Is there anything you think should be added or changed?



- ★ Overall 140 people gave their feedback, 80% who were Experts by Experience.
- ★ 59% of the organisations worked with adults and 41% worked with children and young people.
- ★ Over half of the people responding to the resident/ EbE survey were between the ages of 35-54.
- ★ We heard proportionally less feedback who chose Asian or Asian British as their ethnicity (5.9%), in comparison with 17.8% in the 2021 Census for the borough of Kingston.

### **Our Priorities**

The following priorities were chosen by people who shared their views during the engagement period and will inform the action plan.

#### Autistic people and/or people with ADHD:



Will be involved in planning and developing services



Will be supported into employment



Will easily find information and support



Will feel safe and included in their community



Will be given the right support at the right time, including diagnosis.

#### Kingston Council and partners:



Will support young people as they move to adulthood



Will increase the awareness of Autism & ADHD

#### What we heard

Many people said all the priorities were important and that many of the priorities were linked. It was clear that everyone's experience of Autism and ADHD was different. Out of 140 people who shared their views, 112 were experts by experience (over 80%).



- 'Will be given the right support at the right time including diagnosis' This was selected by Experts by Experience and organisations as the most important priority for them.
- 'Increasing the awareness of Autism and ADHD' was important to people especially young people and young adults, and this was reflected in further feedback.

'It would be nice to see really positive autism and neurodivergence posters not being referred to as a condition or something with lots of negatives, let's celebrate differences'

• 'Will be supported into employment' was also heard through wider feedback as important, including young adults. We also told us that supporting young people (and families) as they move to adulthood is an important area to focus on.



### What's working well?



We heard people's experiences of some great work taking place in Kingston. These are some of the quotes from focus groups and surveys;

★ 'Great **Kingston GP** made our referral quickly and efficiently"



- ★ 'The **Kingston adult autism and ADHD tea**m are great (Your Healthcare), engaging and really positive'
- ★ 'Local colleges seem to be well informed about the needs of autistic people and seem willing to engage actively to make accommodations'



★ 'I feel as though the services do make a good effort to include people with disabilities and (I) have felt **included** and heard.'



★ 'The borough is one of the **safest areas** in London.... My daughter has a travel card that allows her to use public transport without paying and the public transport system in Kingston is good. Bus drivers recognise the Sunflower lanyard which can be useful.



### We also heard where things were not working well





'Accessing **healthcare** is a nightmare for me - I find it hugely stressful (e.g. the online triage process to access a GP) and there is no real understanding of why I struggle to engage with health professionals'



'I have been on an ADHD **assessment** waiting list for over 3 years. I just received an ADHD diagnosis, and I am now told that I will need to wait at least another 9 months'



'There is very little **housing** for young adults with autism/ADHD who want to develop their independence, particularly if they are still living with their parents'



'Its a strange and intimidating world, lots of rules which are hard to follow with autism' - feedback from a young person in relation to needing support around **employment**.



'Reasonable adjustments to meet people's complex needs vary widely across organisations working with/supporting/employing people with hidden difficulties'

### Ideas to make things better...





'Go back to telephone requests for a **GP appointment**. Online forms are <u>okay</u>, just don't make it the only way of doing this'



**'Early assessments** to identify potential indicators (of Autism and ADHD). School teachers need to be well trained in spotting possibly signs and especially in how to support'



'Have regular **user groups** set up with residents who can provide timely and practical feedback on processes, procedures, forms'



'More leaflets and pamphlets in coffee shops and local papers.

Not everyone has a computer or can use one. Also, bear in mind that people with neurodiversity may prefer more group face-to-face activities than being on their own and reading information.'



'Quieter spaces, such as libraries and parks, are a haven to people with sensory sensitivity. These should be preserved not just for their cultural importance to RBK but also because of their medical/well being importance'



'More parent groups for ideas and **information sharing**, coffee mornings, WhatsApp groups, as often parents don't know what is available'

### Key areas to focus on..

#### **Diagnosis and Support**

There is a need to reduce wait times for therapy and diagnostic assessments to prevent worsening symptoms and increased distress. There is a need for more accessible and timely assessment pathways, especially for late diagnoses, and the development of clear service directories.



# Healthcare and Wellbeing



There is a demand for improved mental health services in schools and communities, more accessible GP appointment options, and better-trained healthcare professionals.

Respondents advocated for holistic and trauma-informed care for neurodivergent patients, improved access to ADHD medication, and increased neurodiversity training for medical staff.



Comprehensive mental health support, including specialist counseling and therapy, and personalised physical therapy services were also highlighted as crucial needs.

#### **Education and Training**

Early assessment and support for children were seen as critical to preventing long-term mental health issues. People urged for the inclusion of early intervention courses in school, proactive support in schools for children with ADHD and autism, and increased training in alternative therapies.



People called for transparency in support options, more involvement of parents, and Neurodiverse-friendly activities and events. Educating educators on neurodiversity challenges and advocating for fair treatment of students with SEND were also key points.



#### **Adult Support and Employment**

Promoting neurodivergent-friendly employment practices and making reasonable adjustments to support those in work were highlighted as current challenges.

There was a call for colleges and schools to make accommodations for students with autism and ADHD and for businesses to offer real work opportunities and internships for neurodiverse individuals. People also emphasised the need for better service coordination and accessibility, including integrated needs assessments, inclusive practices, and improved communication systems.

### Our Plan

The development of Kingston upon Thames' All Age Autism and ADHD strategy is driven by community feedback and expert insights. Our plan aims to address the needs of autistic people and ADHD across the areas that have been highlighted.



People who engaged in focus groups and surveys told us about the challenges in education, healthcare, access to services, employment, mental health and housing. The feedback directly influences the work streams within an action plan.

By having an action plan that covers all ages, within health, social care and the wider reach of the council we will work towards becoming a more inclusive and supportive community for people with autism, people who have ADHD, and other neurodivergent conditions, ensuring their needs are met as children, young people and adults.

### Our principles

We have developed key principles that support the key areas. This means that where we can establish what good practice looks like, we share this across all our work.



- **1. Advocacy and Awareness** Ensure accessible and easy to find information on autism and ADHD specific activities and services. Increase the awareness of neurodivergent conditions.
- 2. Accessibility and Service Coordination includes council services and customer journeys e.g housing, council tax, needs assessments, transitions from childrens to adults services. Consideration of accessible booking for appointments including reminders, consistent application of reasonable adjustments. Specific training and awareness raising for health, social care and educators. Sharing knowledge and best practice across the system.
- 3. Community (feeling safe) and transport: Affordable and accessible transport options including promotion of blue-badge scheme, Integrating neurodiversity into urban planning to improve public space safety, protect quiet spaces like parks and libraries in Kingston to mitigate sensory overload, ensure event planning includes risk and equity impact assessments that consider the needs of autistic and ADHD individuals.
- **4. Digital and Data -** We need better data about autistic people and people with ADHD in Kingston to inform service planning. We know that not all services currently collect good data about autism and ADHD. Workstreams will seek to improve autism data collection, and to find ways to share data effectively while maintaining good information governance.

### Areas of work (workstreams)

Over the next five years we will be working across four key areas to focus our resources on making changes with our partners from Health, Education, Social care, Voluntary Community Sector Enterprise's (VCSE) and other organisations.

#### 1. Diagnosis and Support

Key partners: Health, Education, Social care, VCSE partners

- timely access to diagnostic assessments
- mapping the available resources and support whilst waiting for a diagnosis, and after diagnosis
- ensuring we have the right services in place to meet the needs of our local population

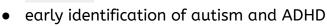
#### 2. Healthcare and Wellbeing

Key partners: Health, Education, VCSE partners

- ensure there are accessible ways to make appointments
- focus on well designed environments

#### 3. Education and Training

**Key partners:** Health, Education, VCSE partners, Local business networks



- creating and sharing resources with parents
- transition between stages including primary to secondary and critical periods such as GCSE's.

#### 4. Adult Support and Employment

Key partners: Education, VCSE partners, Local business networks

- practical support in securing employment
- financial support including support to fill in forms
- promotion of neurodivergent-friendly employment practices
- encourage businesses to offer real work opportunities and internships.







# Making it real

The statements in the table below have been developed by listening to feedback shared with us, and have been adapted from Think Local Act Personal 'Making It Real' statements<sup>19</sup>. They are a set of co-produced statements that describe what good care and support looks like.

They are aligned to the Care Act 2014, and built into the CQC Single Assessment Framework.

I statements	We statements
'I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process'	'We work together with other services to provide joined-up support and to give people useful information, at the right time'
'I want to have the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible'	'We work in a person-led way, which considers people's strengths and talk to them about how they want to be supported'
"I want services and commissioners to understand how my autism and/or ADHD affects me differently throughout my life. I want to be supported through big life changes such as the transition from school, getting older or when a person close to me dies."	'We involve people with lived experience of services before we make changes to those services. We will regularly ask for feedback to see what we are doing well and what could be different to support people to live their lives well'
I want to know how to connect with other people. I want to be able to find local autism and ADHD peer 'groups, family groups and low-level support'	'We make sure people have the information, advice and support they need to think about what is best for them'

<sup>19</sup> https://makingitreal.org.uk/

#### 'I and We statements' - continued

I statements	We statements
I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism and ADHD'	'We make sure that there is a good awareness of autism and ADHD in the services that we manage and that people have the right training'
"I want to know that my family can get help and support when they need it"	'We make sure that people know how to find their local health, social care and housing services'
'I want to be supported through big life changes such as the transition from school, getting older or when a person close to me dies'	'We support young people and their families as they move into adulthood by talking to them about changes and providing information, advice and support'

### How will we know if it is working?

We will work in partnership with local services including health services, education, preparing for adulthood, employment, independent living, and the criminal justice system to make sure Kingston is welcoming, supportive and inclusive for everyone.



The implementation of the strategy will be overseen by the Autism and ADHD Partnership Board and measures may include:

- 1. **Quality of life surveys** for people with neurodivergent conditions to establish a baseline and improvement in key areas of the action plan.
- 2. **Annual reporting** back against the key themes, including metrics like wait times and the number of people accessing specialist services.
- 3. **Tracking employment rates** and job retention for individuals with autism and ADHD.
- 4. **Establishing a community of practice** to share best practice across social care, education, health and community led services.
- 5. **Developing better local data** gathering on the number of children, young people and adults with autism and/or ADHD in Kingston.
- 6. **Providing regular updates** on the work of the Autism and ADHD board, including developments of the action plans on Kingston Councils website.

# References and Further information

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If you need more information please contact us by: Email: adultscommissioning@kingston.gov.uk

If you would like this information in large print, Braille, on CD or in another language please contact us on: info@connectedkingston.uk