

**NATIONAL INSTITUTE FOR HEALTH AND CARE
EXCELLENCE**

INDICATOR DEVELOPMENT PROGRAMME

Consultation report

Indicator area: Autism

Consultation period: 8 February – 8 March 2017

Date of Indicator Advisory Committee meeting: 6 June 2017

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Summary of indicators included in the consultation

ID	Indicator	Evidence source
GP5	The practice establishes and maintains a register of all people on the autistic spectrum	Autism (2014) NICE QS51

GP5: Register

The practice establishes and maintains a register of all people on the autistic spectrum

Rationale

Autism is often overlooked by healthcare, education and social care professionals which can create a barrier to receiving appropriate services and support. It is anticipated that implementation of a register of people with autism could provide a number of opportunities to improve care and outcomes including:

- measuring access to wider care services
- identifying where there is evidence of unequal access
- enabling services to make reasonable adjustments for people with autism
- providing an identifiable population to assess and measure longer term health outcomes and care process indicators.

Summary of consultation comments

There was strong support for this indicator from all stakeholders with comments that it was an important step to improving the care of people with autism by improving recognition in general practice and having a greater understanding of the local population with autism.

Stakeholders highlighted that this indicator could be a useful tool to reduce perceived inequalities in diagnosis rates particularly for women and people from black, Asian and minority ethnic groups.

There was concern amongst stakeholders of the ability to code autism accurately in general practice, given there is not a single Read code or consistently used set of codes for autism. They felt the creation of a register would present an opportunity to rationalise the coding of autism leading to the development of a nationally recognised and used clinical code set for all types of autism.

Stakeholders highlighted that while this is a positive step to improve care of people with autism, further indicators should be developed which focus on care processes and outcomes for this population.

They also felt that some people with autism may be uncomfortable with their personal data forming part of a register, though a recent survey carried out on behalf of the [Westminster Autism Commission](#) (2016) found that 95% of people with autism wanted their GPs to have an electronic note about their diagnosis. Stakeholders did

suggest that some thought needs to go into how the role and purpose of the register is promoted and explained to people.

Stakeholders also highlighted the need for greater collaboration between services so diagnostic information can be shared in a timely way with general practice to ensure that the registers are up to date and accurate.

Considerations for the advisory committee

The committee is asked to consider:

- concerns around the coding of autism in general practice and what recommendations should be made to deal with this issue
- whether further indicators should be developed that focus on the care and outcomes for people with autism
- how best to promote the role and purpose of the register.

Appendix A: Consultation comments

ID	Proforma question no.	Stakeholder organisation	Comment
Question 5.1: Do you think there are any barriers to implementing the care described by this indicator?			
GP5	5.1	Autism NI	<p>1.The Autism Act (NI) 2011 mandates the lifelong Northern Ireland Autism Strategy and the significance of reliable data in that process: [Clause 2 (3) “The Department must request every HSC trust to provide data on the prevalence of autism in its area in order– (a) that it can publish and update the strategy; and (b) that the Northern Ireland departments can effectively implement the strategy”].</p> <p>2.Given the changes over time in the terms used to describe Autism, GPs should be explicitly told to include all diagnoses of Autism, autism spectrum disorder (ASD), autism spectrum condition (ASC), autistic spectrum, atypical autism, classic autism, Kanner autism, pervasive developmental disorder (PDD), high-functioning autism (HFA), Asperger syndrome and pathological demand avoidance (PDA).</p> <p>3. Consideration should be given to how diagnostic information will flow from mental health services and in particular from education services where a substantial proportion of childhood diagnoses are made.</p> <p>4. There is concern at the current read codes available to GPs to record Autism, as several of them reflect out-of-date terminology and there is no single code for “Autism”. The register offers the opportunity to rationalise the read codes, hence improving the chance of the register being comprehensive. The success of this</p>

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			<p>indicator will rely on good quality coding by GP practices. It should go alongside clear communication around the reasons for the indicator and how to accurately record a diagnosis on systems</p> <p>5. Targeted education/training (online with passcode registration and CPD credits to encourage full participation) should be mandated - autistic people can struggle to access the support that they need and report that health professionals, including GPs, do not understand Autism and do not make the adjustments that autistic people may need.</p> <ul style="list-style-type: none"> • The Autism Act (NI) 2011 amended the DD Act (NI) mandating therefore that reasonable adjustments are made for autistic people in Northern Ireland. • Autism NI is association with the RCGPs in Northern Ireland and Leicestershire County Council produced a hard copy file resource which was distributed to all GPs in Northern Ireland. • The online training (referenced above) would have reinforced this physical resource.
GP5	5.1	Autism Together	<p>The bullets points identified by Tim from the NAS are extremely relevant and appropriate.</p> <p>In addition however, feedback from those on the spectrum who have been directly affected by ineffective communication with their health practitioners indicate that lack of knowledge of the condition not only by GPs but also other support staff within the practice can bewilder, intimidate and overwhelm individuals... and that can be before they even meet the doctor or get an appointment.</p> <p>A sound, at least, basic knowledge of the condition from all</p>

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			<p>contacts within the practice is fundamental in ensuring the person on the autistic spectrum understands how best to facilitate accessing their health service.</p> <p>As has been always the case regarding the governments Autism strategy, a register of all people on the autistic spectrum is difficult to assimilate - unless only those with a diagnosis are being included – as, for every one receiving a diagnosis, there will be at least one person more struggling to come to terms with the lack of understanding of their autism by others in their community.</p> <p>Many more have the condition but feel “invisible” and therefore overlooked, owing, not only to the apparent lack of insight into recognising the characteristics by the health professionals with whom they are coming into contactbut also with an inability to convey their confusion, lack of understanding of any procedures identified.</p> <p>Furthermore, the person them self may be unaware that they have autism and if this isn't readily picked up by knowledgeable, trained personnel alert to the possibility, the introduction of a register may be at best only a rough indication of the size of the provision required to meet needs.</p>
GP5	5.1	Autistica	<p>Consideration should be given to how diagnostic information will flow from mental health services and in particular from education services where a substantial proportion of childhood diagnoses are made.</p> <p>Given the changes over time in the terms used to describe autism, GPs should be explicitly told to include all diagnoses of autism, autism spectrum disorder (ASD), autism spectrum</p>

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			<p>condition (ASC), atypical autism, classic autism, Kanner autism, pervasive developmental disorder (PDD), high-functioning autism (HFA), Asperger syndrome and pathological demand avoidance (PDA).</p> <p>We are concerned at the current read codes available to GPs to record autism, as several of them reflect out-of-date terminology and there is no single code for “autism”. The register offers the opportunity to rationalise the read codes, hence improving the chance of the register being comprehensive.</p>
GP5	5.1	British Medical Association	This is unlikely to be an up-to-date register in view of the time delays in many areas in obtaining the formal diagnosis once concerns have been raised.
GP5	5.1	Caudwell Children	No
GP5	5.1	Lincolnshire Autism Partnership Board	<p>One of the main issues is that most adults who would qualify for a diagnosis of autism have never actually been diagnosed and many are probably unaware that their difficulties are caused by being autistic.</p> <p>In order to be meaningful, would the register need to take account of the 'spectrum' nature of the condition? For example, there may be a need for the register to contain further information on how the condition affects individuals and situations that they are likely to find challenging.</p> <p>It should also be recognised that some individuals may not wish to be on such a register.</p>
GP5	5.1	Individual comment - GP	<ul style="list-style-type: none"> Individual practices may feel that they are already maintaining an adequate register. Their perception may be correct as they have their autistic patients coded such that they will be included in a register. Nevertheless their register may include patients

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			<p>whose original autism diagnostic code is using outdated or archaic autism linked codes that were used at a time when coding and diagnostic terminology was less focussed.</p> <ul style="list-style-type: none"> • Accurate coding using recommended SNOMED codes is crucial; practices may be reluctant to update and validate registers without appropriate encouragement and support • Individual practices and clinicians may be unaware of the significance of autism and associated poorer health outcomes including increased mortality rates (recent Swedish study).
GP5	5.1	NHS Medway Clinical Commissioning Group	A register is not a care indicator.
GP5	5.1	Royal College of General Practitioners (RCGP) Clinical Priority Group for Autism	<ul style="list-style-type: none"> • Individual practices may feel that they are already maintaining an adequate register. Their perception may be correct as they have their autistic patients coded such that they will be included in a register. Nevertheless their register may include patients whose original autism diagnostic code is using outdated or archaic autism linked codes that were used at a time when coding and diagnostic terminology was less focussed. • Accurate coding using recommended SNOMED codes is crucial; practices may be reluctant to update and validate registers without appropriate encouragement and support • Individual practices and clinicians may be unaware of the significance of autism and associated poorer health outcomes including increased mortality rates (recent Swedish study).
GP5	5.1	Royal College of Nursing	No
GP5	5.1	The National Autistic Society	Over many years of campaigning, the National Autistic Society has highlighted how autistic people can struggle to access the support that they need. Many autistic people tell us that health professionals, including GPs, do not understand autism and do not make the adjustments that autistic people may need.

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			<p>The success of this indicator will rely on good quality coding by GP practices. It should go alongside clear communication around the reasons for the indicator and how to accurately record a diagnosis on systems.</p> <p>Linked to this, the read codes relating to autism that have been developed over time can be inconsistent and many rely on out-dated language. GPs should be told to include all diagnoses of autism, autism spectrum disorder (ASD), autism spectrum condition (ASC), atypical autism, classic autism, Kanner autism, pervasive developmental disorder (PDD), high-functioning autism (HFA), Asperger syndrome and pathological demand avoidance (PDA). We understand that NICE has commissioned a pilot of this indicator. This work should inform information that should be provided to GP practices about what codes to use to create a local register.</p> <p>This also presents an opportunity to rationalise the read codes that are used, as recommended in the Department of Health's Think Autism adult autism strategy, as well as the opportunity to support the implementation of wider Government policy, including the strategy.</p> <p>The NAS has had the opportunity to work with the Royal College of General Practitioners' Clinical Priority Group on autism over the past three years, driving forward calls for improved GP data. We therefore support their comments in response to this consultation.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
GP5	5.1	The Royal College of General Practitioners	<ul style="list-style-type: none"> • Whilst there are a number of READ codes and SNOMED codes used to describe autism spectrum disorders the GP computer system can easily create the search • There is potential for a number of very small children with a vague diagnosis at a young age that later in line may be incorrect • Resource implications in primary care • There are many difficulties in patients being diagnosed with autism - in particular there are very long waiting lists for autism assessments
Question 5.2 : Do you think there are potential unintended consequences to implementing / using this indicator?			
GP5	5.2	Autism NI	<p>As a group with a long history of being discriminated against, autistic people are often understandably concerned about how their personal data might be used. It should be made clear to autistic people and their families that the introduction of a register is intended to improve services for them and that there will be safeguards against inappropriate disclosure of an individual's autism diagnosis.</p> <p>A recent survey carried out by the Westminster Autism Commission found that 95% of respondents want doctors to have a note on their computer screen to tell them that the patient is autistic</p>
GP5	5.2	Autism Together	<p>A number of those with autism have co-morbidities which can mask their autism if the additional conditions present in more obvious manifestations. In this case if the autism is “treated” secondary, all other treatments are likely to be ineffective if the person requires autism specific approaches to communicate.</p>
GP5	5.2	Autistica	<p>As a group with a long history of being discriminated against, autistic people are often understandably concerned about how</p>

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			their personal data might be used. It should be made clear to autistic people and their families that the introduction of a register is intended to improve services for them and that there will be safeguards against inappropriate disclosure of an individual's autism diagnosis.
GP5	5.2	Caudwell Children	No
GP5	5.2	Lincolnshire Autism Partnership Board	Is the register being introduced so that there is simply a better understanding of the demographics of people diagnosed with autism in order to help with planning service need? Or is the intention to improve the healthcare received by individuals? As mentioned in 5.1 above, in order to improve individuals' experience when coming into contact with health professionals who don't already know the person (e.g. A&E staff, etc.), the register would need to contain additional information about the nature of how the condition affects them personally.
GP5	5.2	Individual comment - GP	<ul style="list-style-type: none"> • Some patients may be concerned that identifiable information about them could leave the practice. This clearly is not an issue if data is only extracted in an aggregated manner. • In addition, this indicator is appropriate for a Clinical Commissioning Group (CCG) indicator, as by definition the sum of all the CCG's practices' aggregated registers will effectively be a CCG indicator. • This indicator will continue to be significant and relevant even if the Quality and Outcome Framework is withdrawn
GP5	5.2	Royal College of General Practitioners (RCGP) Clinical Priority Group for Autism	<ul style="list-style-type: none"> • Some patients may be concerned that identifiable information about them could leave the practice. This clearly is not an issue if data is only extracted in an aggregated manner. • In addition, this indicator is appropriate for a Clinical Commissioning Group (CCG) indicator, as by definition the sum

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			<p>of all the CCG's practices' aggregated registers will effectively be a CCG indicator.</p> <ul style="list-style-type: none"> • This indicator will continue to be significant and relevant even if the Quality and Outcome Framework is withdrawn
GP5	5.2	Royal College of Nursing	No
GP5	5.2	The National Autistic Society	<p>Some autistic people may feel concerned about the ways that the information this indicator collects will be used. It is important that clear information about how the indicator will be implemented is produced – and that it is accessible. Our charity would be happy to help NICE, NHS Employers and NHS England to develop this.</p> <p>However, despite some concern, a recent survey carried out by the Westminster Autism Commission found that 95% of respondents want doctors to have a note on their computer screen to tell them that the patient is autistic. When we communicated news about this consultation, the majority of comments and responses were overwhelmingly positive.</p> <p>We think this proposal is a positive step. However, it is not the only answer. It must go alongside better understanding of autism among GPs and requirements on training in the statutory guidance implementing the adult autism strategy must be followed.</p>
GP5	5.2	The Royal College of General Practitioners	<ul style="list-style-type: none"> • There are some members of the autism community who have expressed dismay at the idea of being “on a register” but recent independent surveys have shown a majority in favour of the creation of a register. There are no potential unintended consequences of a register

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<p>Question 5.3 : Do you think there is potential for differential impact (in respect of age, disability, gender and gender reassignment, pregnancy and maternity, race, religion or belief, and sexual orientation)? If so, please state whether this is adverse or positive and for which group.</p>			
GP5	5.3	Autism NI	<p>The register could benefit under-represented groups such as women with Autism and BME autistic people. The collection of accurate data will give us for the first time a comprehensive view of the autism community and a better understanding of how needs may differ between groups.</p> <p>The Autism Act (NI) 2011 requires all Health and Social Care Trusts in Northern Ireland to collect and share data on ASD (lifelong) as an instrument of assessing need and planning services. However, due to the current immature stage of IT data gathering systems and software used, there is still a heavy reliance on the school census data from Education instead. This indicator would therefore be a key step towards meeting this mandated target in a more inclusive way and in tackling the unacceptable health inequality that autistic people current face as a result of their disability.</p> <p>It is important that the register captures children as well as adults. The learning disability register does not include those under 18, but we know that autistic children (and indeed those with LD) are at increased risk of both mental and physical co-morbidities with significant impact on morbidity and mortality.</p>
GP5	5.3	Autism Together	<p>It is inevitable that there will be differential impact on all these areas as co – conditions of those on the autistic spectrum. There are indications, for instance, that those on the spectrum already have a reduced life span and it is still unclear as to how dementia impacts on who have autism. However, the introduction of a</p>

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			<p>register to begin the process of trying to meet the needs of those living with this condition, is a step in the right direction if total communications takes place between all parties involved in moving this forward.</p> <p>A significant number of people with autism go onto develop a mental health condition mainly through their autism not being understood or supported effectively. Given the issues that age, disability, gender, race religion or sexual orientation etc bring to those who are neuro-typical, it is not surprising that when applicable to those on the autistic spectrum, far more complex outcomes materialise.</p> <p>The potential for differential impact is both positive and negative and affects all groups... as does autism. Positive in respect of a step towards something being done which will hopefully benefit all and negative in respect of the loss of confidence that those on the spectrum experience from yet another initiative taking so long to be realised that progress is difficult to measure resulting in lack of confidence that anything will be accomplished.</p> <p>However, it is an important stride forward into better supporting those with autism and in the joined up thinking that is essential between health services to give consistent and effective support to those on the autistic spectrum.</p>
GP5	5.3	Autistica	<p>The register could benefit under-represented groups such as women with autism and BME autistic people. The collection of accurate data will give us for the first time a comprehensive view of the autism community and a better understanding of how needs may differ between groups.</p> <p>It is important that the register captures children as well as adults.</p>

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			The learning disability register does not include those under 18, but we know that autistic children (and indeed those with LD) are at increased risk of both mental and physical co-morbidities with significant impact on morbidity and mortality.
GP5	5.3	Caudwell Children	Yes – positive for those with autism.
GP5	5.3	Lincolnshire Autism Partnership Board	<p>It needs to be recognised that there are differences in the way in which autism presents in males and females; potentially there is under-diagnosis in females rather than it being a more prevalent condition for males. This may also extend to different age groups. With autism being such a comparatively 'new' condition, many older people may have previously been mis-diagnosed with other conditions.</p> <p>The likelihood is that this proposed register could have a positive impact on those more disabled by autism but could lead to an adverse impact for those people only disabled in certain circumstances (high functioning). In these cases, the perception of need may be detrimentally altered on the basis that a diagnosis of autism has been flagged up.</p>
GP5	5.3	Individual comment - GP	Recent Swedish study that identified that people with autism are more than twice as likely to die prematurely in almost all 'cause-of-death categories'] Hirvikoski, et al (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238. More focus on individuals with autism along the lines of the recent annual medical examinations for individuals on the Learning Disabilities register is worth considering, although any such scheme must be evaluated. Any such focus is positive, in terms of reviewing lifestyle and undiagnosed conditions such as hypertension.

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ID	Proforma question no.	Stakeholder organisation	Comment
			<p>Autism is more difficult to identify and diagnose in:</p> <ul style="list-style-type: none"> • Women • Older individuals • Black, Asian & ethnic minority groups <p>Increased awareness as a consequence of autism registers is positive</p>
GP5	5.3	Royal College of General Practitioners (RCGP) Clinical Priority Group for Autism	<p>Recent Swedish study that identified that people with autism are more than twice as likely to die prematurely in almost all 'cause-of-death categories'] Hirvikoski, et al (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238. More focus on individuals with autism along the lines of the recent annual medical examinations for individuals on the Learning Disabilities register is worth considering, although any such scheme must be evaluated. Any such focus is positive, in terms of reviewing lifestyle and undiagnosed conditions such as hypertension.</p> <p>Autism is more difficult to identify and diagnose in:</p> <ul style="list-style-type: none"> • Women • Older individuals • Black, Asian & ethnic minority groups <p>Increased awareness as a consequence of autism registers is positive</p>
GP5	5.3	Royal College of Nursing	No
GP5	5.3	The National Autistic Society	<p>The National Autistic Society sees this indicator as a key step towards tackling the unacceptable health inequality that autistic people current face as a result of their disability. This health inequality has been recognised by its inclusion in the Government's latest Mandate to NHS England, alongside mental</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
			<p>health and learning disability.</p> <p>Additional barriers due to ethnicity Within the estimated 600,000 autistic people in England, there are many people who face additional barriers to support and services, including:</p> <ul style="list-style-type: none"> - Gender – women appear to be underrepresented in the numbers of people diagnosed as autistic. This can mean that they miss out on the support they need. We also hear anecdotally from those who relay GP misunderstandings about autism, including that autism is a male condition. This indicator could help GPs identify if they have identified an expected number of autistic women, which could indicate that better training or awareness of diagnostic pathways is required. <p>According to a 2012 survey conducted by the NAS, just one fifth of girls with Asperger syndrome or high functioning autism who responded to the survey were diagnosed by the age of 11, as compared to half of males (Bancroft, K et al (2012) The Way We Are, NAS). The survey also suggests that that females are more likely to be misdiagnosed, with 42% of females being diagnosed with another condition as compared to 30% of males.</p> <ul style="list-style-type: none"> - Our 2014 Diverse Perspectives report also identified significant barriers faced by people from black, Asian and minority ethnic (BAME) communities, including meeting professionals and their perceptions. This indicator could highlight to GPs that a BAME individual is autistic ahead of an appointment and check their communications are fully accessible and that support is promoted

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			<p>to them. (Slade (2014), Diverse Perspectives, NAS).</p> <p>- In 2015, the NAS hosted a roundtable of autistic people and their families from diverse backgrounds to find out more about the barriers they face in getting support. GP understanding of autism was highlighted as a key issue. This indicator could help GPs better understand the diverse community of autistic people in their practices, and ensure that all reasonable adjustments are made.</p> <p>When these reasonable adjustments are made, autistic people will be better able to access primary care, which is crucial for their health and wellbeing.</p> <p>Emerging evidence on mortality We are particularly aware of research from Sweden, highlighted by Autistica in their Personal tragedy, public crisis report that autistic people in Sweden appear to be at greater risk of dying prematurely. A lack of comparable data in the UK means that we don't know how the UK compares to Sweden but it is highly unlikely that we are performing better. Without better evidence, it remains hard to tell the NHS nationally or locally what specific action they should be taking to make sure that autistic people are identified early and supported appropriately to manage particular health conditions or illnesses. However, we do know that getting the right support from a GP will be key to staying healthy and well. This indicator, and an associated register is an important step in making a difference.</p>

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			<p>In recent years, a similar approach has been tried to identify patients with a learning disability, after research found that they were at risk of having poorer health and of dying earlier. It has enabled the NHS to put programmes in place to tackle this health inequality and to make the health of people with a learning disability a priority. We believe that a similar approach could help target public health interventions – e.g. around heart disease, cancer and mental health – better at autistic people, and ensure that they benefit from an equality of health outcomes.</p> <p>Age</p> <p>It is also important that this register captures a diagnosis of both children and adults on the autism spectrum. The learning disability register does not include those under 18, but we know that autistic children are at increased risk of both mental health co-morbidity. Research suggests that 71% of children on the autism spectrum have mental health problems, such as depression, anxiety or obsessive compulsive disorder. 40% have two or more. (Simonoff et al (2008) Psychiatric disorders in children with autism spectrum disorders: prevalence comorbidity, and associated factors in a population derived sample. Journal of American Academy and Adolescent Psychiatry 47: 4: 921-929))</p>
GP5	5.3	The Royal College of General Practitioners	<ul style="list-style-type: none"> • The register will have a positive impact on the whole population with autism as their additional needs will be recognised and appropriate adjustments made to allow equitable access to health care services. This will include the diagnosis being available to secondary care and specialist services when a referral is made
Question 5.4: Do you have any general comments on this indicator?			

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ID	Proforma question no.	Stakeholder organisation	Comment
GP5	5.4	Autism NI	<p>We strongly welcome this new indicator.</p> <p>In addition to the RCGP, Autistica, National Autism Project, National Autistic Society, the Westminster Commission on Autism, The All Party Group on Autism at the Northern Ireland Assembly (APGA), Autism NI has been calling for improved GP-level data collection on Autism for some time.</p> <p>Autism NI (in association with Lei</p> <p>The publication of new data (Hirvikoski 2016) and Autistica’s report into premature mortality in Autism (Personal tragedy, public crisis, 2016) highlighted the issue further.</p> <p>A register is a potentially powerful tool to understand autistic people’s contact with healthcare services, to map outcomes longitudinally and to provide a framework for establishing the efficacy of new interventions and policies.</p> <p>By facilitating research, this indicator could have a profound impact on outcomes of great concern in autism, including mental health, physical health and engagement with services, timely diagnosis and mortality.</p> <p>Ensuring that a diagnosis of Autism is flagged in an person’s GP records could enable a number of positive steps to be taken by individual GPs and practices:</p> <ol style="list-style-type: none"> 1. That necessary reasonable adjustments are made in support of the Autism Act (NI) 2011. 2. The Autism Act (NI) 2011 requires all Health and Social Care Trusts in Northern Ireland to collect and share data on ASD (lifelong) as an instrument of assessing need and planning

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			<p>services. However, due to the current immature stage of IT data gathering systems and software used, there is still a heavy reliance on the school census data from Education instead. This indicator would therefore be a key step towards meeting this mandated target and in tackling the unacceptable health inequality that autistic people current face as a result of their disability.</p> <p>Planning the right services. Decision makers cannot plan services locally unless they know how many people need to use the services. Anonymised data from GP records would provide decision makers with the data that they need to plan effectively.</p> <ul style="list-style-type: none"> - Acting on evidence that suggests autistic people may be at risk of particular illnesses or conditions. - Making sure the health service is accountable for what it provides. <p>3. Research from Sweden, highlighted by Autistica in their Personal tragedy, public crisis report that autistic people in Sweden appear to be at greater risk of dying prematurely. A lack of comparable data in the UK means that we don't know how the UK compares to Sweden but it is highly unlikely that we are performing better. Without better evidence, it remains hard to tell the NHS nationally or locally what specific action they should be taking to make sure that autistic people are identified early and supported appropriately to manage particular health conditions or illnesses. However, we do know that getting the right support from a GP will be key to staying healthy and well. This indicator, and an associated register is an important step in making a difference.</p> <p>4. We do not believe that this indicator will have financial</p>

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			consequences. National Audit Office research suggests that by identifying and supporting autistic adults early, the public purse can make significant savings (National Audit Office, Supporting people with autism throughout adulthood (2009)).
GP5	5.4	Autism Together	It is a welcome step towards addressing the lack of equality with which those on the autistic spectrum have been treated in the past but it would be difficult not to ponder on the very slow progress in the autism strategy criteria implemented since Think Autism was introduced in 2010. January 2016, in the progress report on Think Autism, it was mooted that this register was introduced. A year later it is still in the planning stage with the identification of what skills and information health staff should have about autism is still mentioned but not realised.
GP5	5.4	Autistica	<p>We strongly welcome this new indicator.</p> <p>In addition to the National Autistic Society, RCGP, National Autism Project and Westminster Commission on Autism, Autistica has been calling for improved GP-level data collection on autism for some time, since the publication of new data (Hirvikoski 2016) and our own report into premature mortality in autism (Personal tragedy, public crisis, 2016). A register is a potentially powerful tool to understand autistic people’s contact with healthcare services, to map outcomes longitudinally and to provide a framework for establishing the efficacy of new interventions and policies.</p> <p>By facilitating research, this indicator could have a profound impact on outcomes of great concern in autism, including mental</p>

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			health, physical health, engagement with services, timely diagnosis and mortality.
GP5	5.4	British Medical Association	The educational and resource implications of this diagnosis can lead to different diagnostic criteria being applied in the private and public sectors
GP5	5.4	Caudwell Children	This indicator should improve recognition of people with autism and aid in meeting their needs by facilitating reasonable adjustments.
GP5	5.4	Lincolnshire Autism Partnership Board	<p>General thoughts from the Lincolnshire Autism Partnership Board are that this is a positive proposal. The register needs to be individualised if it is to be most useful and should be accessible to other health care professionals.</p> <p>There is a need to try and ensure that autistic people are aware that this is being introduced and to give people the opportunity to opt out of being on the register if they so wish.</p>
GP5	5.4	Individual comment - GP	<p>Local authority considerations</p> <ul style="list-style-type: none"> • In common with other local authorities, Hampshire County Council is keen to be able to plan effectively for the wellbeing of its citizens with autism. In order to do so, it essential to know the number of individuals with confirmed autism within different age and gender brackets. • The most accurate registers are based on general practice registers, which when aggregated enable us to estimate the “pick up” rate for individuals who have been formally diagnosed with autism. • During the next 5-10 years, joint or shared co-commissioning between local authorities and health bodies such as CCGs is going to increase especially individuals with complex needs including autism.

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			<ul style="list-style-type: none"> • The recent Transforming Care Partnership (TCP) programme is an example of a program that both Hampshire County Council and the West Hampshire CCG have been implementing • A key group of individuals at risk are those who have autism without learning disabilities. Traditionally, these individuals have less support and are often invisible to the system, although may have needs that need to be addressed. • Relevant local authority departments include Adult Services, Public Health, Children’s Services, Education (including Special Educational Needs) and Safeguarding, all of whom would benefit from accurate timely data about the prevalence of autism. The main significance of an autism register and associated indicators is to enable: <ul style="list-style-type: none"> • Potential to be used in national indicator sets including General Practice High Level Indicators (GPHLI) and General Practice Outcome Standards (GPOS) datasets • Potential to be reviewed elsewhere, for example, by the Indicator and Methodology Assurance Service (IMAS) including both general practice and CCG levels • Compliance with NHS Five Year Forward View (5YFV) to tackle health inequalities • Compliance with NHS Mandate 2016-17 to: <ul style="list-style-type: none"> o Address poor outcomes and inequalities (Objective 1) o Prevent ill health & support people to live healthier lives (Objective 4) o Support research... (Objective 7) o “To close the health gap between people with mental health problems, learning disabilities and autism and the population as a whole” (Annex paragraph 6.3)

ID	Proforma question no.	Stakeholder organisation	Comment
			<p>o “Increase in people with learning disabilities/autism being cared for by community not inpatient services, including implementing the 2016-17 actions for Transforming Care” (Annex paragraph 6.3)</p> <ul style="list-style-type: none"> • Ability to study morbidity and co-morbidity in individuals with autism along lines of: <ul style="list-style-type: none"> o Recent Swedish study that identified that people with autism are more than twice as likely to die prematurely in almost all 'cause-of-death categories'] Hirvikoski, et al (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238. o Data extraction that demonstrated increased morbidity in individuals with intellectual disability (Improving Health and Lives(IHAL) Learning Disabilities Observatory (LDO), Public Health England)) o IHAL-LDO report showing that people with learning disabilities have a significantly higher admission rate for Ambulatory Care Sensitive Conditions (ACSC) than people without learning disabilities • Ability to monitor the Transforming Care Partnership (TCP) programme, where it overlaps with general practice: <ul style="list-style-type: none"> o The recent TCP programme is about transforming care for people with learning disabilities and/or autism who have a mental illness or whose behaviour challenges services o This programme follows on from the various Winterbourne View investigations and Sir Stephen Bubb’s report o These quality standards and outcome metrics will eventually be reflected in the NHS Standard Contract, the assurance process for Clinical Commissioning Groups (CCGs), and, where

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			<p>appropriate, in data that is published about how local areas are performing.</p> <ul style="list-style-type: none"> o The aim is to transfer these patients from hospital to community care with appropriate care packages, for what are often very complex needs and co-morbidities. Local general practices will have to provide care for these patients in the community o In Hampshire, the SHIP (Southampton, Hampshire, Isle of Wight & Portsmouth area) TCP is trialling “learning disability and autism friendly practices” in 20 practices <p>Clinical Commissioning Group (CCG) aspects</p> <ul style="list-style-type: none"> • The Autism Act 2009 imposes statutory duties on CCG in their capacity as statutory bodies. • CCGs and their Quality Teams could work with these proposed registers to: <ul style="list-style-type: none"> o Provide local support to practices and ensure consistency of coding o Check that each individual diagnosis of autism is correct in the first place o Encourage autism assessment teams to recommend the correct Read or SNOMED codes in correspondence to general practitioners following the autism assessment o Ensure that diagnosis is reviewed at time of transition from children’s to adult services o Most CCGs have Data Quality Officers, and Practice Development Teams, whose skills, responsibilities and remits can be expanded to monitor and enhance autism awareness training in general practices and sub-contractors using autism registers

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			This submission may overlap with other submissions, which reflects the multi-faceted nature of autism.
GP5	5.4	NHS Medway Clinical Commissioning Group	How does having a register alone improve care? Practices will already have some patients coded but how does that relate to predicted levels of autism or to variation in diagnostic rates between clinicians. Looking at variation in diagnostic rate by clinician may be of more value
GP5	5.4	Royal College of General Practitioners (RCGP) Clinical Priority Group for Autism	<p>he main significance of an autism register and associated indicators is to enable:</p> <ul style="list-style-type: none"> • Potential to be used in national indicator sets including General Practice High Level Indicators (GPHLI) and General Practice Outcome Standards (GPOS) datasets • Potential to be reviewed elsewhere, for example, by the Indicator and Methodology Assurance Service (IMAS) including both practice and CCG levels • Compliance with NHS Five Year Forward View (5YFV) to tackle health inequalities • Compliance with NHS Mandate 2016-17 to: <ul style="list-style-type: none"> o Address poor outcomes and inequalities (Objective 1) o Prevent ill health & support people to live healthier lives (Objective 4) o Support research... (Objective 7) o “To close the health gap between people with mental health problems, learning disabilities and autism and the population as a whole” (Annex paragraph 6.3)

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			<p>o “Increase in people with learning disabilities/autism being cared for by community not inpatient services, including implementing the 2016-17 actions for Transforming Care” (Annex paragraph 6.3)</p> <ul style="list-style-type: none"> • Ability to study morbidity and co-morbidity in individuals with autism along lines of: <ul style="list-style-type: none"> o Recent Swedish study that identified that people with autism are more than twice as likely to die prematurely in almost all 'cause-of-death categories'] Hirvikoski, et al (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238. o Data extraction that demonstrated increased morbidity in individuals with intellectual disability (Improving Health and Lives(IHAL) Learning Disabilities Observatory (LDO), Public Health England)) o IHAL-LDO report showing that people with learning disabilities have a significantly higher admission rate for Ambulatory Care Sensitive Conditions (ACSC) than people without learning disabilities • Ability to monitor the Transforming Care programme (TCP), where it overlaps with general practice: <ul style="list-style-type: none"> o The recent Transforming Care programme is about transforming care for people with learning disabilities and/or autism who have a mental illness or whose behaviour challenges services o This programme follows on from the various Winterbourne View investigations and Sir Stephen Bubb’s report

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			<p>o These quality standards and outcome metrics will eventually be reflected in the NHS Standard Contract, the assurance process for Clinical Commissioning Groups (CCGs), and, where appropriate, in data that is published about how local areas are performing.</p> <p>o The aim is to transfer these patients from hospital to community care with appropriate care packages, for what are often very complex needs and co-morbidities. Local general practices will have to provide care for these patients in the community</p> <p>o In Hampshire, the SHIP (Southampton, Hampshire, Isle of Wight & Portsmouth area) TCP is trialling “learning disability and autism friendly practices” in 20 practices</p> <p>Clinical Commissioning Group (CCG) aspects</p> <ul style="list-style-type: none"> • The Autism Act 2009 imposes statutory duties on CCG in their capacity as statutory bodies. • CCGs and their Quality Teams could work with these proposed registers to: <ul style="list-style-type: none"> o Provide local support to practices and ensure consistency of coding o Check that each individual diagnosis of autism is correct in the first place o Encourage autism assessment teams to recommend the correct Read or SNOMED codes in correspondence to general practitioners following the autism assessment o Ensure that diagnosis is reviewed at time of transition from children’s to adult services o Most CCGs have Data Quality Officers, and Practice Development Teams, whose skills, responsibilities and remit

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			<p>can be expanded to monitor and enhance autism awareness training in general practices and sub-contractors using autism registers</p> <p>This submission is additional and separate from the submission presented by Tim Nicholls on behalf of the National Autistic Society, which has included consultation with me and the Royal College General Practitioners (RCGP) Clinical Priority Group on Autism.</p> <p>Wherever possible we have avoided duplicating their comments, as our perspective is different, although overlapping.</p>
GP5	5.4	Royal College of Nursing	This is a positive step to recognition.
GP5	5.4	The National Autistic Society	<p>We have campaigned for several years to make sure that GPs are recording a person’s autism diagnosis on their files. Many already do this, but it doesn’t happen consistently. We believe that there would be several benefits for autistic people if all GPs did record this on a person’s file, including:</p> <ol style="list-style-type: none"> 1. Ensuring reasonable adjustments are made. If a doctor sees that someone is autistic before they come in, they should be able to make certain adjustments – for instance, trying hard to make sure that the appointment starts on time and making sure that they communicate clearly (or perhaps have information available in other formats). This is no replacement for training, but it could act as a ‘flag’ telling GPs they need to put their training into action. 2. Ensuring health and wellbeing. People go to the doctor for many things, and sometimes for check-ups to make sure nothing

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			<p>is wrong. But if autistic people don't feel able to go to their GP, we are worried that they will miss out on this. We have been working with NHS England recently to promote things like flu jabs and cervical screening to autistic people, but GPs could do more by looking on their records to check people have been offered and taken up these services. If GPs could see that lots of autistic people weren't taking up these services, they could think about changing their communication with those on the spectrum.</p> <p>3. Planning the right services. Decision makers cannot plan services locally unless they know how many people need to use the services. It is hard to commission an autism service if you don't have accurate information about how many autistic people live in your area, and this can leave autistic people without the right support available to them in their area. Anonymised data from GP records would provide decision makers with the data that they need to plan effectively.</p> <p>4. Acting on evidence that suggests autistic people may be at risk of particular illnesses or conditions. As we said, Swedish research has suggested that autistic people are at risk of dying earlier. The research identified that autistic people with a learning disability were at most risk of dying early due to epilepsy, while a leading cause of early death in people with Asperger syndrome, behind heart disease, was suicide. Because we don't have the data here on autism that they have in Sweden, we can't say for sure if the situation is the same here. It is therefore harder to tell the NHS nationally or locally what specific action they should be taking to make sure that autistic people are being identified early as having particular health conditions or illnesses.</p> <p>5. Making sure the health service is accountable for what it</p>

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			<p>provides. The NHS is there to provide health care to all of us, but we know that some people, including many autistic people, fall through the gaps. If we can show that this is the case using real information, it means we can hold local decision makers to account on the services they provide – or do not provide.</p> <p>We do not believe that this indicator will have financial consequences. National Audit Office research suggests that by identifying and supporting autistic adults early, the public purse can make significant savings (National Audit Office, Supporting people with autism throughout adulthood (2009)).</p> <p>This indicator has widespread support across the autism sector and we have worked with a number of other autism organisations, including the Royal College of General Practitioners Clinical Priority Group on autism and Autistica on this issue.</p> <p>We strongly support the development and implementation of this indicator.</p>
GP5	5.4	The Royal College of General Practitioners	<ul style="list-style-type: none"> • This is an important indicator in many ways. It will not be an onerous task for general practice and will provide data for a variety of purposes. These include research, health inequalities and the chance to offer proactive care for a potentially vulnerable group. It will allow greater implementation of NICE guidelines and quality standards about autism. It will allow the collection of accurate data to focus resources and inform the future development of services. We do not currently have any accurate information about local needs or the incidence of health

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			problems, co-occurring conditions or public health issues affecting those with autism. Autism has been a clinical priority for the RCGP for 3 years and we would endorse this indicator
GP5	5.4	Together for Short Lives	We believe that this indicator is important to make sure that a greater proportion of children with autism are recognised. Children and young people with autism may also have a life-limiting condition. Where this is the case, their autism has an impact on techniques which can be used to manage their symptoms; for example, massage to reduce pain is unlikely to be effective for these children as they do not like to be touched.

Appendix B: Equality impact assessment

Protected characteristics		
<ul style="list-style-type: none"> • Age • Disability • Gender reassignment 	<ul style="list-style-type: none"> • Pregnancy and maternity • Race • Religion or belief 	<ul style="list-style-type: none"> • Sex • Sexual orientation
<p>Note:</p> <p>1) The characteristic of marriage and civil partnership is protected only from unlawful discrimination. There is no legal requirement to consider the need to advance equality and foster good relations.</p> <p>2) The definition of direct discrimination includes less favourable treatment of someone associated with a person with a protected characteristic, such as the carer of a disabled person.</p>		
Socioeconomic factors		
<p>The relevance and nature of socioeconomic factors will vary according to the quality standard topic. They may include deprivation and disadvantage associated with particular geographical areas, or other geographical distinctions (for example, urban versus rural).</p>		
Other definable characteristics		
<p>Certain groups in the population experience poor health because of circumstances distinct from – though often affected by – sharing a protected characteristic or socioeconomic factors. The defining characteristics of groups of this sort will emerge from the evidence (although a quality standard topic will sometimes explicitly cover such a group). Examples of groups identified are:</p> <ul style="list-style-type: none"> • looked-after children • people who are homeless • prisoners and young offenders. 		

Indicator Equality Impact Assessment form

Development stage: Consultation

Topic: Autism

1.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

Stakeholders highlighted that autism is under recognised in older people, women and black, Asian and minority ethnic groups.

1.2 Have any population groups, treatments or settings been excluded from coverage by the indicators at this stage in the process. Are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

No population groups have been excluded at this stage. The indicator will focus on general practice settings only.

1.3 Do any of the indicators make it more difficult in practice for a specific group to access services compared with another group? If so, what are the barriers to, or the difficulties with, access for the specific group?

No – comments from consultation do not suggest that the indicator will make it impossible or unreasonably difficult in practice for a specific group to be part of a register.

1.4 Is there potential for the indicators to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No – comments from consultation do not suggest that the indicator will have an adverse impact on people with disabilities.

Completed by lead technical analyst: Shaun Rowark

Date 23/03/2017

Approved by NICE quality assurance lead: Brian Bennett

Date 06/04/2017