University of Birmingham and University of York Health Economics Consortium (NCCID)

Development feedback report on piloted indicators

QOF indicator area: Autistic spectrum disorder

Pilot period: 1st October 2016 – 28th February 2017

Potential output: Recommendations for NICE menu

Contents

Summary of recommendations

Indicator

1. The contractor establishes and maintains a register of all patients on the autistic spectrum.

Acceptability recommendation:

Band 4: <50% of practices support inclusion

Implementation recommendation:

Band 1: no problems identified during piloting or anticipated to arise. Indicator terms precisely defined.

Cost effectiveness recommendation:

See summary report.

Issues to consider:

Issue	Detail	Mitigating activity
The value of a register	Some practices felt that there was no value to having a standalone register in QOF. In relation to this area they already code the diagnosis so were able to make reasonable adjustments to care in the absence of a register. They were also unconvinced of the need for this to act as a platform for further indicators.	
Lack of service availability	Some practices felt they should be able to offer a referral to adequate care, however most described the services in their area as limited with long waiting lists.	
Overlaps with learning disability diagnoses	There is an overlap between this register, the LD register and the LD health check DES.	

Background

As part of the NICE-managed Quality and Outcomes Framework (QOF) process, all clinical and health improvement indicators are piloted, using an agreed methodology, in a representative sample of GP practices across England, Scotland, Wales and Northern Ireland.

The aim of piloting is to test whether indicators work in practice, have any unintended consequences and are fit for purpose.

Practice recruitment

Number of practices recruited:	29
Number of practices dropping out:	2
Number of practices unable to interview:	0
Number of practices interviewed:	27

[26 GPs, 6 practice nurses, 9 practice managers and 1 health care assistant = 42 primary care staff]

All percentages reported have been calculated using the 29 practices recruited to the pilot as the denominator.

Piloted indicators

1. The contractor establishes and maintains a register of all patients on the autistic spectrum.

Assessment of clarity, reliability, feasibility, and acceptability

Clarity

No concerns about clarity were raised during piloting or the GP focus group.

Reliability and feasibility

We were able to develop business rules to support this indicator.

Issues to be resolved prior to implementation:

Issue	Detail	Mitigating activity
How to handle 'Pervasive Developmental Disorder'	In 2013 the American Psychiatric Association reclassified pervasive developmental disorder not otherwise specified as autism spectrum disorder.	Specialist advice has been sought as to which Read codes capture this concept.

Acceptability

Nine practices (31%) were supportive of this indicator being considered for QOF. These practices viewed the indicator as useful from the perspective of increasing their awareness of the diagnosis so they could make reasonable adjustments in practice. This included adapting their communication style to consider the patient.

"Yeah we already do it." (GP, Practice ID16)

"I think it'd be really good to have a really clear register of the ones that are confirmed". (GP, Practice ID11)

"When you ring up for an appointment, reception knows when you can give an appointment, what's the most appropriate time when it's quiet and calm." (GP, Practice ID04)

"The clinicians are supposed to ask, what is their favoured communication method, whether it's text, email or large print or something like that. So it is important that we have that register so that we can offer them the same services what we do with everybody else, but adapt it slightly so that they better understand, well, we can improve our communication with them." (PM, Practice ID29)

The register was also viewed as useful so practices could calculate the number of people on the autistic spectrum. This was highlighted as being particularly important for service provision.

"We have them on a register just because we know who they are and we know what the number is." (GP, Practice ID16)

"You can look at your disease burden, you can get some figures and then design the services accordingly." (GP, Practice ID07)

A small number of practices also felt a potential advantage of this indicator was patients would have increased employment rights and potential access to government benefits by having a formal diagnosis.

"More often than not when they come to that they want any sort of issue with the benefit you are in a better position to support them... And you can advise their employer." (GP, Practice ID21)

Some practices described the potential overlap between this register and the learning disability register for the Directed Enhanced Service (DES) and felt the indicator was unnecessary for this reason. However, some who chose to include the indicator explained that practices could choose not to take part in the Learning Disability DES so having an additional register for those on the autistic spectrum could be beneficial for those practices. [1]

[1] Participation rates in 2015-16 were about 91%.

"A lot of my patients who've got autistic spectrum disorder will automatically also be on a Learning Disability Register. Does this increase and give anything different to that? I'm not sure it does." (GP, Practice ID10)

"I would say yes because all practices are different, aren't they? We're signed up to that DES so we're very aware of it. It's not compulsory." (PM, Practice ID26)

"I think the way I look at what it is you are making a completed patient profile increasing they do have some form of learning disability so this gives the opportunity to check on that." (GP, Practice ID21)

A further two practices (6.9%) were unsure as to whether this was suitable for inclusion in QOF. However, the majority of practices, 16 (55.2%), were not supportive of this being considered for QOF.

Both practices who were unsure about inclusion and some of those who chose not to include this indicator viewed the register as unnecessary because they were already aware of patients on the autistic spectrum. The presence of a Read code was sufficient for them to identify these patients and make reasonable adjustments when they attended the practice. These practices felt that a register would be redundant for this aspect of care.

"We have a couple of patients like that and what we tend to do is just put a major alert on – so we've already done that. I can mention about five patients that we have, Learning Disabilities and/or autism and then... we tend to put a major alert on and say 'Patient doesn't like waiting in the waiting room. Please put in a side room. Patient doesn't like noisy places'. So we have 5,000 patients; we tend to do that anyway." (GP, Practice ID08)

It was also acknowledged that the register would range from people with milder Asperger's to those with more severe autism. Some practices felt that people with milder Asperger's were usually able to manage their lives successfully and questioned the need for them to be on a register if they had no additional care needs. Concerns were also expressed about labelling people and whether people on the high functioning end of the spectrum may be offended by being on a register. For those with more severe autism, some practices described overlap with learning disability services. One practice explained that the indicator should be included in QOF if it focused on learning disability and people who were more severely autistic rather than milder cases.

"Even if we've got patients who are autistic and who are mild, apart from signposting them to the relevant services, which you could have as a discussion when they come in and they're seeing you, are we going to be just capturing them on a register so that we can signpost them or are we doing anything else with them? Even if you've got mild Asperger's, you can still do a lot of things that everyone else can, so why do I need to put them on a register?" (GP, Practice ID10)

"There are lot of people who are on the autistic spectrum who are high achieving autistic spectrum... highly functional people with Asperger's who are perfectly fine in their day-to-day life; hold down very professional roles who actually, I think could be quite upset by being called in for any sort of review." (PN, Practice ID30)

"If you're going to label everybody, give everybody an official diagnosis on the spectrum, you're perhaps medicalising something that they could live with quite happily without it being medicalised." (GP, Practice ID24)

Most practices commented on the lack of services available for adults on the autistic spectrum and the challenges of obtaining a diagnosis in adulthood. The services for children were described as better than those for adults, however there was usually a long waiting list for having a diagnostic assessment and receiving support. Some practices questioned the value of having a register as a QOF indicator in the absence of adequate support services for adults and children on the autistic spectrum.

"There is a problem with getting access to diagnostic assessments so for the children it takes months and months and months to get through to actually having an assessment and then the assessment's quite longwinded and then eventually you may get a code. So that's quite problematic and obviously quite a few people will fall by the wayside. You have to be really quite determined as a parent to get your child diagnosed...And then they will have more access to services..And then for adults there is a very limited service available at […] but I think it's Autism and ADHD Service." (GP, Practice ID05)

A small number of practices explained that services for people on the autistic spectrum were offered outside primary care so they viewed the GP as having a limited role in their care and therefore questioned whether having a QOF indicator was appropriate.

"Because so many of the interventions for these children or for this group of patients will be with the community multidisciplinary teams, I can't see what we're going to use the register for." (GP, Practice ID14)

Assessment of implementation

Assessment of piloting achievement

As this is a register there is no pilot achievement. Prevalence across the cohort was 0.46%, somewhat lower than the estimated 1.1% prevalence rate although within the 95% confidence interval (0.3%-1.9%).[2] Practice prevalence ranged from 0.2%-1.2%.

[2] Brugha T, Cooper SA, McManus S, Purdon S, Smith J, Scott FJ, Spiers N, Tyrer F. Estimating the prevalence of autistic spectrum conditions in adults.: extending the 2007 adult psychiatric morbidity survey. England: The NHS Information Centre for health and social care, 2012.

Changes in practice organisation

No changes in practice organisation were reported. All practices reported that they were already aware of people in their practice on the autistic spectrum and currently read coded them.

Resource utilisation and costs

Some practices identified the potential need for improved services to be in place for people on the autistic spectrum for the presence of a register to be viable.

Barriers to implementation

No barriers to implementing a register were identified. All practices currently read coded their patients on the autistic spectrum.

Assessment of exception reporting

Not applicable. Exception reporting does not apply to registers

Assessment of potential unintended consequences

Concerns were expressed over causing offence and labelling patients at the high functioning end of the autistic spectrum who did not require additional services. This indicator was criticised for over medicalising this group.

Assessment of overlap with and/or impact on existing QOF indicators

There will be an overlap of patients included on this register with those on the Learning Disabilities register.

Suggested amendments to indicator wording

None.

Appendix A: Practice recruitment

We planned to recruit 34 practices in England and 2 in each of the Devolved Administrations. English practices were to be representative in terms of practice list size, deprivation and clinical QOF score. Given the limited variability in clinical QOF score we excluded practices with a score of ≤ 10th centile. Practice list size and IMD scores were divided into tertiles and a 3x3 matrix created with target recruitment numbers for each cell. These are detailed in the table below.

	List size		
IMD Score	Low	Medium	High
Low	3	4	5
Medium	3	4	4
High	4	4	3

As previously presented to the Committee, practice recruitment has been extremely challenging. At the beginning of this pilot we had recruited 28 practices in England and 3 in the Devolved Administrations (2 in Northern Ireland, 1 in Scotland). Practice recruitment by strata is shown in the table below with cells in bold where we failed to meet target numbers. We also over recruited in one strata which is shown by the numbers in the table. Two practices in England withdrew from the pilot prior to it starting reducing the total numbers of pilot practices to 26 in England, 2 in Northern Ireland and 1 in Scotland.

	List size		
IMD Score	Low	Medium	High
Low	**2/3**	**3/4**	**1/5**
Medium	3/3	4/4	**1/4**
High	5/4	4/4	3/3

Appendix B: Indicator development

Following the June 2016 Advisory Committee meeting the NCCID was asked to develop new indicators focusing upon patients with an autistic spectrum disorder.

GP focus group

A focus group to discuss potential indicators was held on 20th July 2016 where all potential indicators were discussed. Focus group attendees were volunteers recruited via our database of GPs who had responded to previous invitations. From the volunteers we purposively selected 15 GPs to attend the focus group to try to ensure a balance of men and women, representation from minority ethnic groups and a range of ages.

Of those invited, 14 attended the meeting. Nine (60%) were male. Approximately one third of the participants described themselves as being of white ethnicity (n=5). Participants were reimbursed £250 for their attendance.

Anneka Patel and Shaun Rowark attended on behalf of NICE. Gemma Ramsey and Ross Ambler attended on behalf of NHS Digital.

One indicator was presented to the group. The creation of a register was seen as a simple exercise but there was some debate as to its value. However, participants noted that this group were adversely affected by the inverse care law and that it was important to demonstrate that reasonable adjustments were being made. Difficulties of obtain a diagnosis, especially in adults, were also noted.

One indicator was progressed to piloting.

Indicator wording as piloted

1. The practice establishes and maintains a register of all patients on the autistic spectrum.

Appendix C: Acceptability and Implementation recommendations

Acceptability recommendations

One of the following recommendations is made based upon reported acceptability of the indicator to pilot practices.

Band 1: ≥70% of practices support inclusion

Band 2: 60-69% of practices support inclusion

Band 3: 50-59% of practice support inclusion

Band 4: <50% of practices support inclusion.

Implementation recommendations

One of the following recommendations is made based upon an assessment of issues or barriers to implementation reported during piloting.

Band 1: no problems identified during piloting or anticipated to arise. Indicator terms precisely defined.

Band 2: minor problems identified during piloting or anticipated to arise in wider implementation. Problems resolvable prior to implementation through either 1) an amendment to indicator wording, 2) an amendment to the business rules and/or 3) by giving further clarification of indicator terms in associated guidance.

Band 3: major problems identified during piloting or anticipated in wider implementation. Possibly resolvable through the actions described in band 2 but indicator requires further development work and/or piloting.

Band 4: major problems identified during piloting. Not immediately resolvable. Indicator not recommended for wider implementation.