



Royal College of  
General Practitioners



## Quality Improvement Data Report: Patient Safety and Prescribing In Patients With a Learning Disability, Autism Or Both

### Introduction

This report has been prepared in order to provide feedback on what we have found when assessing the data you have provided to CPRD. These data have been extracted from the latest database build; for your practice, these data were extracted on Wednesday 31<sup>st</sup> October, 2018. Due to the lead-in time required for data extraction, processing and analysis, more up-to-date data are likely to be present in your practice system.

This report focuses on prescribing in patients aged 16 and over with a diagnosis of Learning Disabilities, Autism or Both and includes two indicators:

1. Prescription of anti-psychotics
2. Prescription of anti-depressants

These indicators are based on NHS England's Stopping Over-Medication of People with a Learning Disability, Autism or Both (STOMP) project, which aims to improve the quality of life of people with a learning disability, autism or both by reducing the potential harm of inappropriate psychotropic drugs.

The indicator definitions are given in the relevant sections for each indicator. There is a detailed list of the codes used for this report on the CPRD website:

<https://www.cprd.com/generalpractitioner/QualityImprovementProject.asp>.

There is a summary of the STOMP and NICE guidance for this topic after the indicators, along with information on where to find out more.

### Rationale

Public Health England have estimated that on an average day in England, between 30,000 and 35,000 adults with a learning disability, autism or both are taking a prescribed antipsychotic, an antidepressant or both without appropriate clinical indications (psychosis or affective/anxiety disorder). STOMP guidance states that substantial proportion of people with a learning disability, autism or both who are prescribed psychotropic drugs for behavioural purposes can safely have their drugs reduced or withdrawn<sup>1</sup>.

<sup>1</sup>NHS England (2015) Stopping Over-Medication of People with a Learning Disability, Autism or Both: <https://www.england.nhs.uk/wp-content/uploads/2017/07/stomp-gp-prescribing-v17.pdf>

A systematic review of mainly observational studies, which was discussed in NICE's medicines evidence commentary on stopping or reducing antipsychotics in people with learning disabilities who have challenging behaviour<sup>2</sup>, found that antipsychotics can be reduced or discontinued in a substantial proportion of adults with learning disabilities who use them for challenging behaviour<sup>3</sup>.

Side-effects of psychotropic drugs include:

- Weight gain
- Hypertension
- Increased cholesterol
- Feeling tired or 'drugged up'

This patient group suffers from health inequalities. On average, females with learning disabilities have around an 18-year shorter life expectancy than the general population, and males have around a 14-year shorter life expectancy than the general population<sup>4</sup>. The standardised prevalence of diabetes, heart failure, chronic kidney disease and stroke is higher in people with learning disabilities than in the general population<sup>5</sup>.

## Which patients are included in this analysis?

We have searched for all patients aged 16 and over, who have ever been given a diagnosis of Learning Disability, Autism or both. We have used the STOMP definitions for these diagnoses. For Learning Disability, we have noted in the case-finding tables whether patients are on the Learning Disability Register (i.e. have been coded with a QOF code).

<sup>2</sup>NICE (2017) Stopping or reducing antipsychotics in people with learning disabilities who have challenging behaviour: <http://arms.evidence.nhs.uk/resources/hub/1059716/attachment>

<sup>3</sup>NICE (2017) Psychotropic medicines in people with learning disabilities whose behaviour challenges: <https://www.nice.org.uk/advice/ktt19/chapter/Evidence-context#nice-guidance>

<sup>4</sup>NHS Digital (2017) Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017:<https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2016-to-2017>

<sup>5</sup>NHS Digital (2017) Health and Care of People with Learning Disabilities: <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/health-and-care-of-people-with-learning-disabilities>

## Indicator 1: Prescription of anti-psychotics to patients aged 16 and over with a diagnosis of Learning Disabilities, Autism or Both

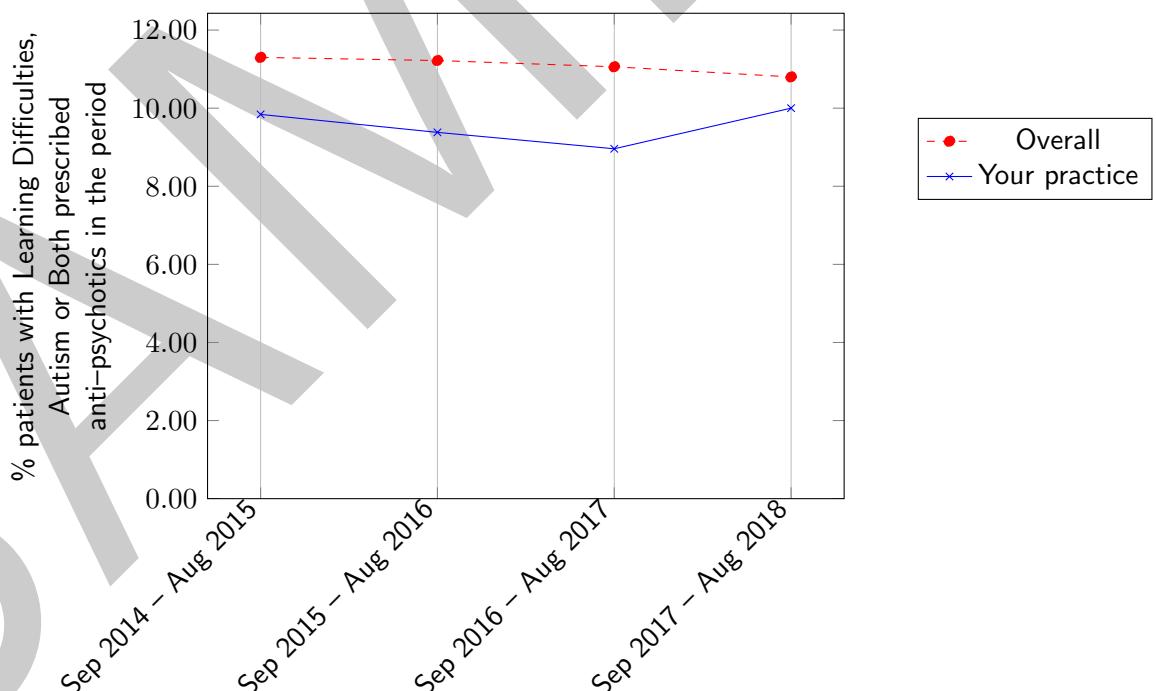
### Benchmarking

The following graphic presents trend lines for the rate of prescribing of anti-psychotics to patients with a diagnosis of Learning Disability, Autism or Both at your practice, compared with the average rate for all practices within our dataset. The blue line shows your practice's rate; the red line shows the average across all practices contributing to CPRD. The graph contains four data points, starting in September 2014 and ending in August 2018. Each data point shows the rate for one 12-month period (September to August).

Patients are identified as having been prescribed anti-psychotics if they have five or more prescriptions in that 12-month period, with at least one in the final three months of the 12-month period.

Please note that the data for GP practices in CPRD has not been adjusted for case mix, deprivation, etc. A lower or higher rate than the average does not necessarily mean that your practice is better or worse than the average GP practice; the information is presented for context.

*Figure 1: Prescribing of anti-psychotics to patients with Learning Disabilities, Autism or Both September 2014 – August 2018*



### Case-finding

From the 6,883 patients registered at your practice on the data extraction date, we found 65 patients with a diagnosis of Learning Disabilities, Autism or Both. Of these, 6 had a record of at least five prescriptions of an anti-psychotic in the last 12 months for which data is available, with

at least one in the most recent three months; these patients are listed in the table below along with the drug(s) prescribed. The most recent prescription is shown in black; other drugs prescribed within the past 12 months have the patient details in grey.

We have searched the patient record for indications of bipolar/mania or psychosis/schizophrenia within the last five years; if found, the most recent are shown in the table.

Patient	Approx. Age	Diagnosis	QOF Register	Indication	Drug
#a4nV	50	LD	Y		Amisulpride 100mg tablets
#a4nV	50	LD	Y		Amisulpride 50mg tablets
#a4nV	50	LD	Y		Aripiprazole 15mg tablets
#aaiz	17	Autism	n		Aripiprazole 5mg tablets
#SJlh	46	LD	Y		Risperidone 1mg tablets
#oKTF	28	LD	n	Psychosis / Schizophrenia	Olanzapine 20mg tablets
#zZik	20	Autism	n	Psychosis / Schizophrenia	Quetiapine 100mg tablets
#zZik	20	Autism	n	Psychosis / Schizophrenia	Quetiapine 25mg tablets
#Yaia	24	LD; Autism	Y		Olanzapine 10mg tablets

## Indicator 2: Prescription of anti-depressants to patients aged 16 and over with a diagnosis of Learning Disabilities, Autism or Both

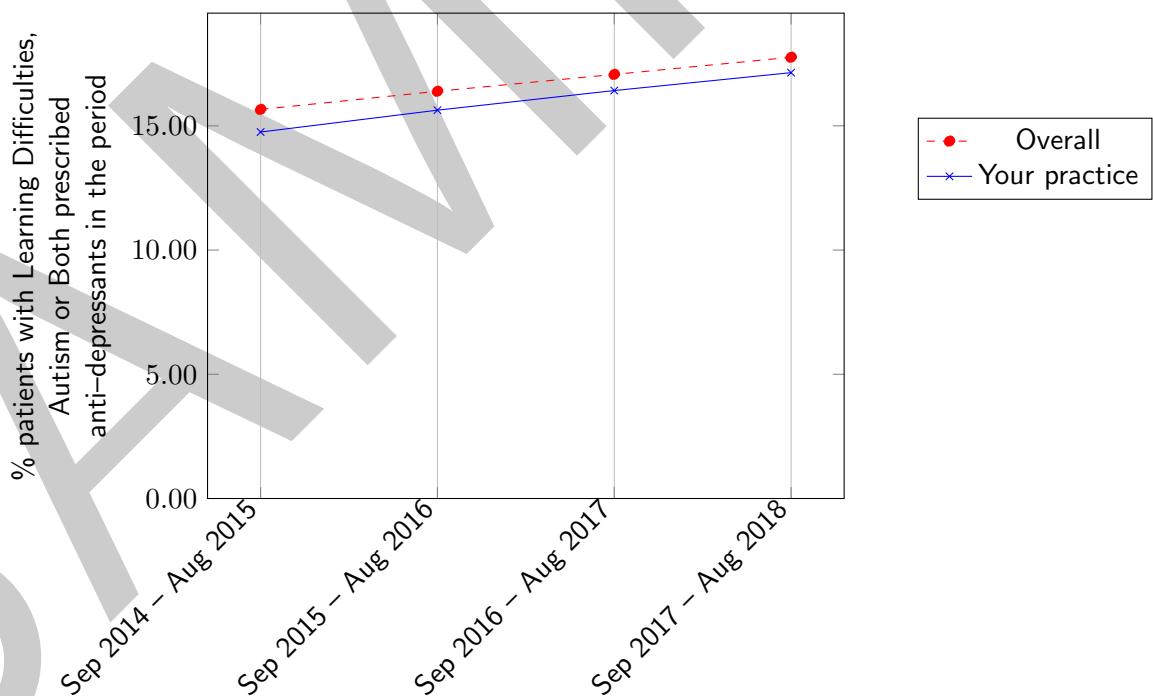
### Benchmarking

The following graphic presents trend lines for the rate of prescribing of anti-depressants to patients with a diagnosis of Learning Disabilities, Autism or Both at your practice, compared with the average rate for all practices within our dataset. The blue line shows your practice's rate; the red line shows the average across all practices contributing to CPRD. The graph contains four data points, starting in September 2014 and ending in August 2018. Each data point shows the rate for one year (September to August).

Patients are identified as having been prescribed anti-depressants if they have five or more prescriptions in that year, with at least one in the final three months of the year.

Please note that the data for GP practices in CPRD has not been adjusted for case mix, deprivation, etc. A lower or higher rate than the average does not necessarily mean that your practice is better or worse than the average GP practice; the information is presented for context.

*Figure 2: Prescribing of anti-depressants to patients with Learning Disabilities, Autism or Both  
September 2014 – August 2018*



### Case-finding

From the 6,883 patients registered at your practice on the data extraction date, we found 65 patients with a diagnosis of Learning Disabilities, Autism or Both. Of these, 12 had a record of at least five prescriptions of an anti-depressant in the last 12 months for which data is available, with at least one in the most recent three months; these patients are listed in the table below along

with the drug(s) prescribed. The most recent prescription is shown in black; other drugs prescribed within the past 12 months have the patient details in grey.

We have searched the patient record for indications of depression or anxiety within the last five years; if found, the most recent are shown in the table.

Patient	Approx. Age	Diagnosis	QOF Register	Indication	Drug
#SFdO	38	LD; Autism	Y		Paroxetine 30mg tablets
#xDFO	70	LD; Autism	Y		Sertraline 100mg tablets
#S6nU	17	Autism	n	Anxiety	Sertraline 100mg tablets
#c53e	26	LD; Autism	Y	Depression	Citalopram 20mg tablets
#fz0W	60	LD; Autism	Y		Venlafaxine 75mg tablets
#Vgrz	27	LD; Autism	Y		Trazodone 100mg capsules
#QzRf	42	Autism	n	Anxiety	Citalopram 40mg tablets
#rXI6	57	LD; Autism	Y		Fluoxetine 20mg capsules
#UM7H	46	Autism	n		Venlalic XL 150mg tablets (Ethypharm UK Ltd)
#iNh6	63	Autism	n	Depression	Venlafaxine 225mg modified-release tablets
#t5Sb	45	Autism	n	Depression	Sertraline 100mg tablets
#WkgO	18	Autism	n	Anxiety; Depression	Fluoxetine 20mg capsules

## Using this report: what next?

Clearly, reduction or withdrawal of psychotropic drugs for patients with learning disabilities and/or autism is challenging. Reduction or withdrawal of medication should only be considered for low-risk patients, but the physical health of patients who continue to be prescribed psychotropic medication can also be improved by careful management of that medication.

The first step will be to conduct an annual health check and medication review, which covers physical as well as mental health.

### Annual review

Patients should have an annual health check and medication review. There is a step-by-step toolkit for these reviews on the RCGP website: <http://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx>

Key aims of the review will include:

- Everyone with a Learning Disability diagnosis should be on the Learning Disability register.
- Add a challenging behaviour code where medication is appropriately prescribed for behaviour where NICE licenses these prescriptions.
- Where a mental health diagnosis is recorded, ensure that it is still valid.
- The physical side effects of psychotropic drugs (such as obesity, cholesterol and hypertension) should be minimised<sup>6</sup>.
- Ensure that you are prescribing in line with licensed dosages - the maximum dosage for certain antidepressants, for instance, has changed.

Many of these patients will be under the care of a psychiatrist, and psychotropic drugs will have been initiated by the consultant. In these cases:

- Refer back to your local Mental Health Team if there is a missing diagnosis and the prescription does not fit the recorded diagnosis.
- Ask your local Mental Health Team to conduct a STOMP review if you have concerns about the side effects of medication.
- For patients not under care of MHT and with uncertain or historic diagnosis, plus long-term prescription, consider psychiatric review.

### Withdrawal or reduction of psychotropic drugs

Anti-depressants and anti-psychotics should only be prescribed if appropriate clinical indications are present. NICE guidance<sup>7</sup>, as summarised in STOMP guidance<sup>8</sup>, advises that specialists should consider prescribing antipsychotic medication to manage behaviour that challenges only if:

- Psychological or other interventions alone do not produce change within an agreed time

<sup>6</sup>The Lester Adaptation 2014 provides a simple framework for identifying and treating cardiovascular and type 2 diabetes risks in patients with psychosis receiving antipsychotic medication: <https://mentalhealthpartnerships.com/resource/lester-uk-adaption/>

<sup>7</sup>NICE (2015) Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges: <https://www.nice.org.uk/guidance/ng11>

<sup>8</sup>NHS England (2015) Stopping Over-Medication of People with a Learning Disability, Autism or Both: <https://www.england.nhs.uk/wp-content/uploads/2017/07/stomp-gp-prescribing-v17.pdf>

- Treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour
- The risk to the person or others is very severe

Antipsychotic medication should only be offered in combination with psychological or other interventions.

A person-centred approach is necessary when reducing or withdrawing psychotropic drugs. If prescribed for behaviours that challenge there is the expectation that the drugs will stop unless:

- There is evidence that the person with a learning disability, autism or both has gained significant benefit from the use of the psychotropic drug(s) and recent attempts to withdraw the drug(s) has resulted in a deterioration.
- The nature of the behaviours experienced prior to prescribing psychotropic drug(s) was so severe that withdrawal is considered clinically inappropriate by the carers and others.

Patients who have anti-depressants withdrawn may suffer side-effects from the discontinuation of their drugs, and these side effects will need to be managed.

For fuller guidance, please refer to STOMP guidance (<https://www.england.nhs.uk/wp-content/uploads/2017/07/stomp-gp-prescribing-v17.pdf>), which contains an algorithm for the review, reduction or stopping of psychotropic drugs in people with a learning disability and/or autism, suggested steps for your practice and how to deal with potential problems.

## Where to find out more

The RCGP has gathered a number of resources on patients with Learning Disabilities, including a step-by-step toolkit to annual health checks for people with a learning disability:

<http://www.rcgp.org.uk/learningdisabilities/>

There are a number of resources to support the STOMP programme, including guidance and case studies for professionals, and information for patients and carers:

<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

NICE publishes guidance on the management of patients covered by the indicators in this report:

- Psychotropic medicines in people with learning disabilities whose behaviour challenges (Key therapeutic topic 19)
  - <https://www.nice.org.uk/advice/ktt19>
- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NICE Guideline 11)
  - <https://www.nice.org.uk/guidance/ng11>
- Learning disabilities: challenging behaviour (Quality standard 101)
  - <https://www.nice.org.uk/guidance/qs101>
- Learning disabilities and behaviour that challenges overview (Pathway)
  - <https://pathways.nice.org.uk/pathways/learning-disabilities-and-behaviour-that-challenges>
- Autism (Quality Standard 51)
  - <https://www.nice.org.uk/guidance/qs51>
- Autism spectrum disorder in adults: diagnosis and management (Clinical guideline 142)
  - <https://www.nice.org.uk/guidance/cg142>



The Royal College of Psychiatrists has published practice guidelines on Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge:

<https://www.rcpsych.ac.uk/docs/default-source/members/faculties/intellectual-disability/id-fr-id-09a589775dcc1c46068372fb8cda3e7c37.pdf>

On the NHS England website there is a summary and overview of the Learning Disability Annual Health Check electronic clinical template: <https://www.england.nhs.uk/wp-content/uploads/2017/05/nat-elec-health-check-ld-clinical-template.pdf>

The Lester UK Adaption 2014 is a clinical resource that provides a simple framework for identifying and treating cardiovascular and type 2 diabetes risks in patients with psychosis receiving antipsychotic medication. It supports collaborative practice across professional disciplines and service settings. The updated 2014 version was co-produced by NHS England, NHS Improving Quality, Public Health England and the National Audit of Schizophrenia team to support the 2014 physical health CQUIN. The original was developed by the Royal College of Psychiatrists Centre for Quality Improvement, the Royal College of General Practitioners Clinical Innovation and Research Centre and the Royal College of Nursing as part of the National Audit of Schizophrenia.

<https://mentalhealthpartnerships.com/resource/lester-uk-adaption/>