



UCL

# Overmedication of people with intellectual disability

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**BILD Restraint Reduction Network**

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- Evidence of overuse of psychotropic drugs
- What happens when we reduce or discontinue antipsychotics used for behaviour that challenges?
- Influences on psychotropic prescribing
- Future directions to improve use of psychotropic drugs

- Research Fellowship funded by National Institute for Health Research
- Expert advisory group member NHS England STOMP monitoring study
- Working group member RCPsych Faculty of ID practice guidelines: psychotropic drug prescribing for people with ID

The views expressed are those of the author(s) and not necessarily those of UCL, the NHS, the NIHR or the Department of Health and Social Care

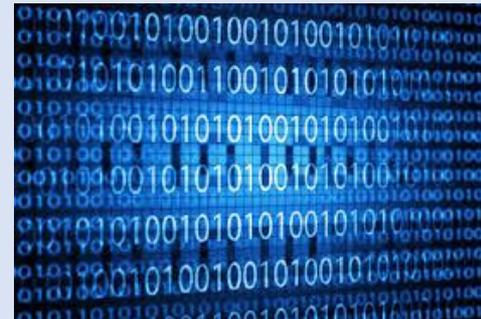
- Longstanding concern related to over-use of psychotropic medication in ID services
- Mainly related to use of antipsychotic drugs for challenging behaviour
- Problematic for several reasons:
  - Little evidence that they work
  - Non-specific sedation
  - Does not address underlying cause of behaviour that challenges
  - Places emphasis on individual rather than environment and context
  - Shifts focus from other interventions
  - Exposes people to adverse drug side-effects

- Early research (1970s onwards) showed high rates of psychotropic use in institutions for people with ID
- Expected reduction with ‘de-institutionalisation’ did not occur (Nottestad, 2003)
- Rates of prescribing may even increase after move to community living (Kelly, 2015)

- Exposure of abuse at Winterbourne View put the care of people with ID high on the political agenda
- Transforming Care authors highlighted “**deep concerns about the overuse**” of psychotropic drugs
- But we had little representative contemporary data

Need high-quality evidence for use of psychotropic drugs in adults with ID

- Electronic Health Record gives opportunities for epidemiological research that did not previously exist (“big data”)
- Several advantages
  - Data already exist (quick)
  - Representative (high participation rate)
  - Statistical power (large numbers)
  - No recruitment or direct participant contact (less expensive)
- Some disadvantages
  - Data collected for clinical care
  - Not able to validate the data (‘real world’ is messy)



# Evidence of psychotropic overuse (Sheehan et al, 2015)

- We used a GP database to investigate rates of psychotropic prescribing
- We compared prescribing, rates of diagnosed mental illness, and behaviour that challenges in 33,016 adults with ID

**RESEARCH**

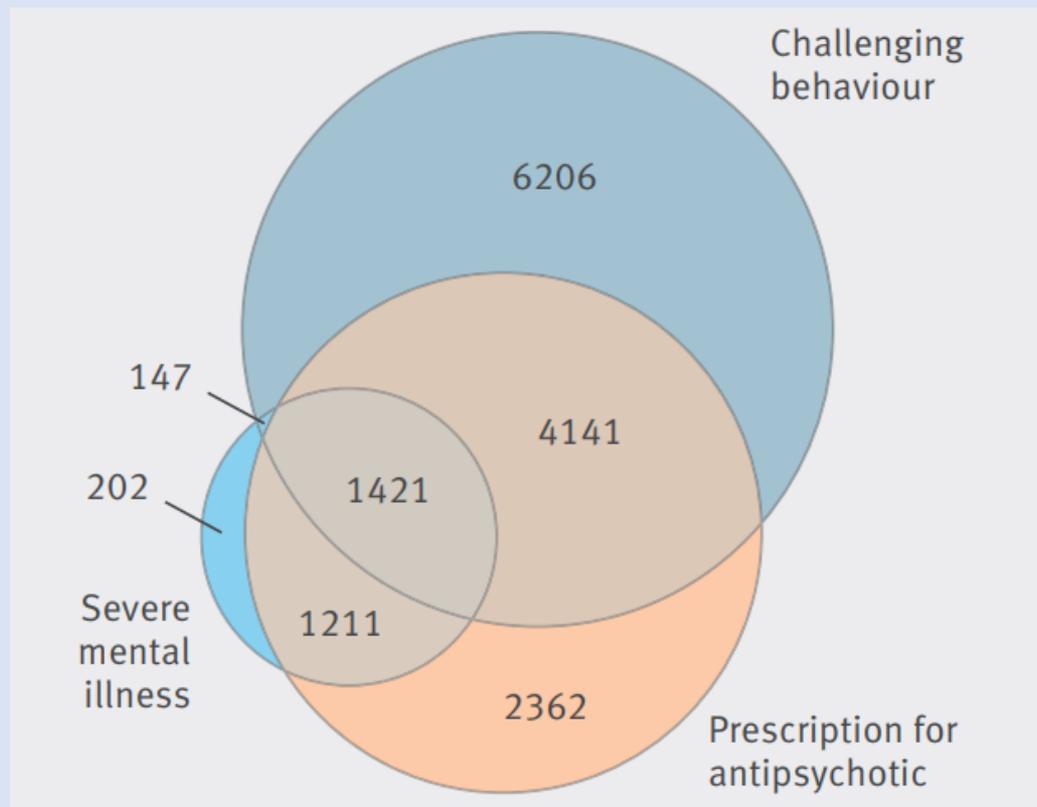
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**Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study**

Rory Sheehan,<sup>1</sup> Angela Hassiotis,<sup>1</sup> Kate Walters,<sup>2</sup> David Osborn,<sup>1</sup> André Strydom,<sup>1</sup> Laura Horsfall<sup>2</sup>

# Evidence of psychotropic overuse (Sheehan et al, 2015)



# Evidence of psychotropic overuse (Sheehan et al, 2015)



- Associations with antipsychotic prescribing suggest off-label use

	Incidence rate ratio	<i>p</i> -value
Severe mental illness	6.7	<0.001
Challenging behaviour	2.1	<0.001
Autism	1.8	<0.001
Dementia	1.4	0.003

- Public Health England study
  - 30,000-35,000 people with ID in England are taking a psychotropic medication when they do not have the health condition the medicines are for



Good evidence for need to improve psychotropic prescribing in people with ID

**'Chemical cosh' scandal': Thousands of patients with no history of mental illness needlessly given cocktail of anti-psychotic drugs**

**Fears that antipsychotic drugs being used as 'chemical cosh' in disability care**

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## People with learning difficulties 'silenced with drugs'

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Over-medication of people with learning disabilities infringes human rights

Medicine should not be used to make people easier to care for – we need to discuss alternatives and how to spread best practice

# The STOMP programme

## Stopping over medication of people with learning disabilities (STOMPLD)

Over-medication, and then lack of review, is a historic problem, but one that nobody knew the true scale of until recently.

It is estimated that on an average day in England, between 30,000 and 35,000 people with a learning disability are being prescribed powerful drugs, with serious potential side effects, without clinical justification and for too long. This is often despite evidence-based alternative interventions being available.

This inequality in care is unacceptable, and it is incumbent on clinicians and every other professional involved in an individual's care to make sure they are acting in their patient's best interest at all times.

**We, the undersigned, representing professionals from across the NHS, therefore pledge to work together, and with people with a learning disability and their loved ones, to take real and measurable steps to stop over-medication.**

**We will each set out the actions our individual organisations will take towards this shared aim, and report regularly on the progress we have made – ensuring that we can be held to account.**

*Hazel Gibson*

**NHS  
England**

*[Signature]*

**The British  
Psychological Society**  
Promoting excellence in psychology

*Sarah Colley*

Endorsed by  
**ROYAL  
PHARMACEUTICAL  
SOCIETY**

*[Signature]*

**RC  
GP** Royal College of  
General Practitioners

*[Signature]*

**The Rt Hon Alistair Burt MP**  
Minister of State for Community and Social Care

Supported by the Challenging Behaviour Foundation

*[Signature]*

**NICD**  
Royal College of Nursing  
Nightingale nursing since 1860

*[Signature]*

**RC  
PSYCH**  
PSYCHIATRISTS



# STOMP activity

- Awareness-raising, galvanizing and empowering stakeholders
- Includes people with ID, carers, statutory and third sector organisations
- Resources to promote appropriate medication use
- Dissemination and spread good practice



FR/ID/09

Psychotropic drug  
prescribing for people  
with intellectual disability,  
mental health problems  
and/or behaviours  
that challenge:  
practice guidelines



## STOMP

Stopping the over medication of  
people with a learning disability,  
autism or both

Everyone working together to stop  
the over use of psychotropic medicines  
and to improve people's quality of life.



## Medication Pathway

### SECTION A

#### Introduction

This resource is for family carers of someone with a learning disability, autism or both who are looking for information about psychotropic medication. The pathway focuses on how to make sure that your relative only takes medication that they need and that your relative is taking medication safely.

### SECTION B

#### Medication Facts and National Guidance

NHS England led a pledge in 2016 to stop over-medication, which is supported by many organisations in health and social care. This was intended as a 'call to action' and a commitment to reducing the levels of inappropriate psychotropic medication prescribed for people with a learning disability, autism or both.

### SECTION C

#### Medication has been suggested

Before medication is prescribed, there are several checks that should be carried out in partnership with your relative and a professional. Medication should not be the **only** option considered in response to challenging behaviour and should **only** be used if alternative strategies have not reduced the behaviour.

### SECTION E

#### When medication is being started

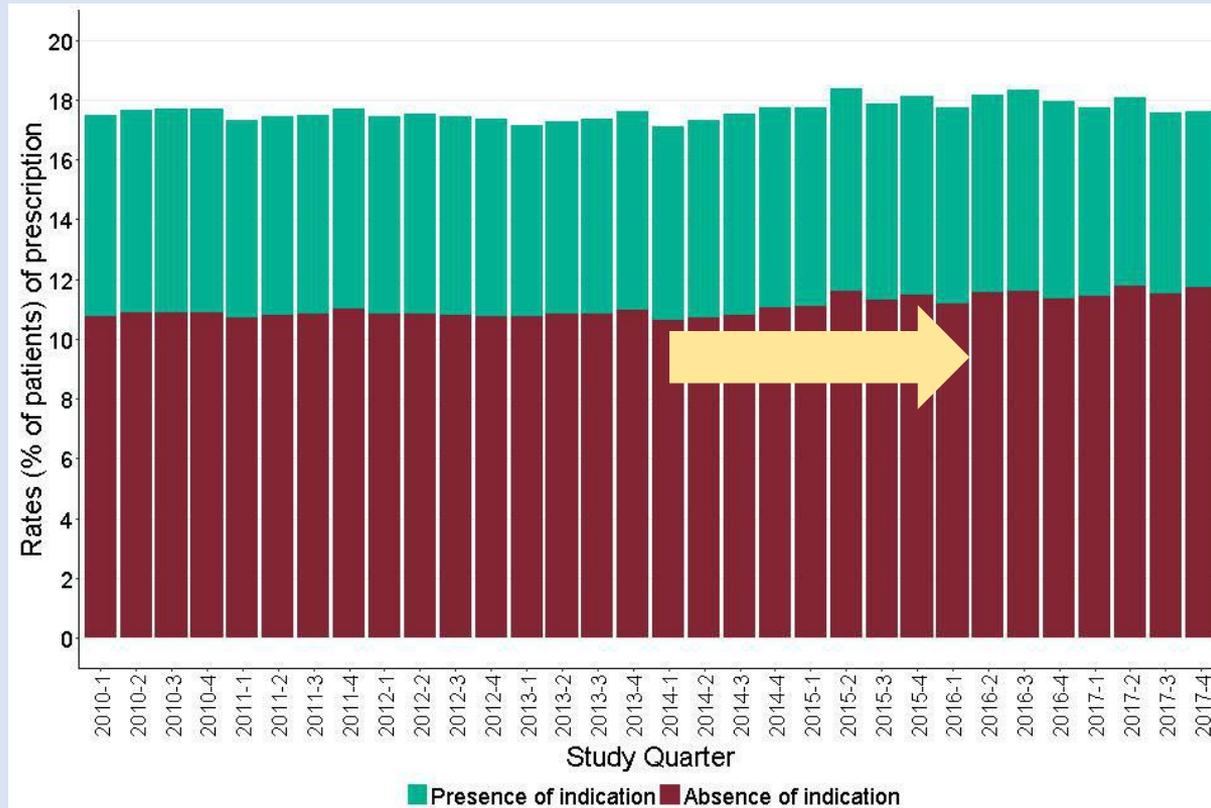
Once someone has started to take psychotropic medication, the doctor should help you to look for any side effects to the medication and to understand whether the medication is helping your relative. You should have an agreed date with your doctor to review the medication and discuss whether it is still the best option for your relative.

### SECTION D

#### Challenging the decision to prescribe medication

When a health professional suggests that psychotropic medication should be prescribed, family carers have the right to object if they do not agree it is the best option for their family member. These rights depend on the age of the individual with a learning disability, autism or both and whether they have the capacity to make the decision for themselves.

# STOMP evaluation (NHS England, 2019)





- Downward trend in overall prescribing since Q2 2016
- Equates to approx. 500 fewer adults with ID being prescribed antipsychotics
- But proportion without a recognised indication increased

- How easy is it to reduce or discontinue antipsychotic medication used for behavior in practice?

# What does the research evidence say?

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## Reduction or discontinuation of antipsychotics for challenging behaviour in adults with intellectual disability: a systematic review

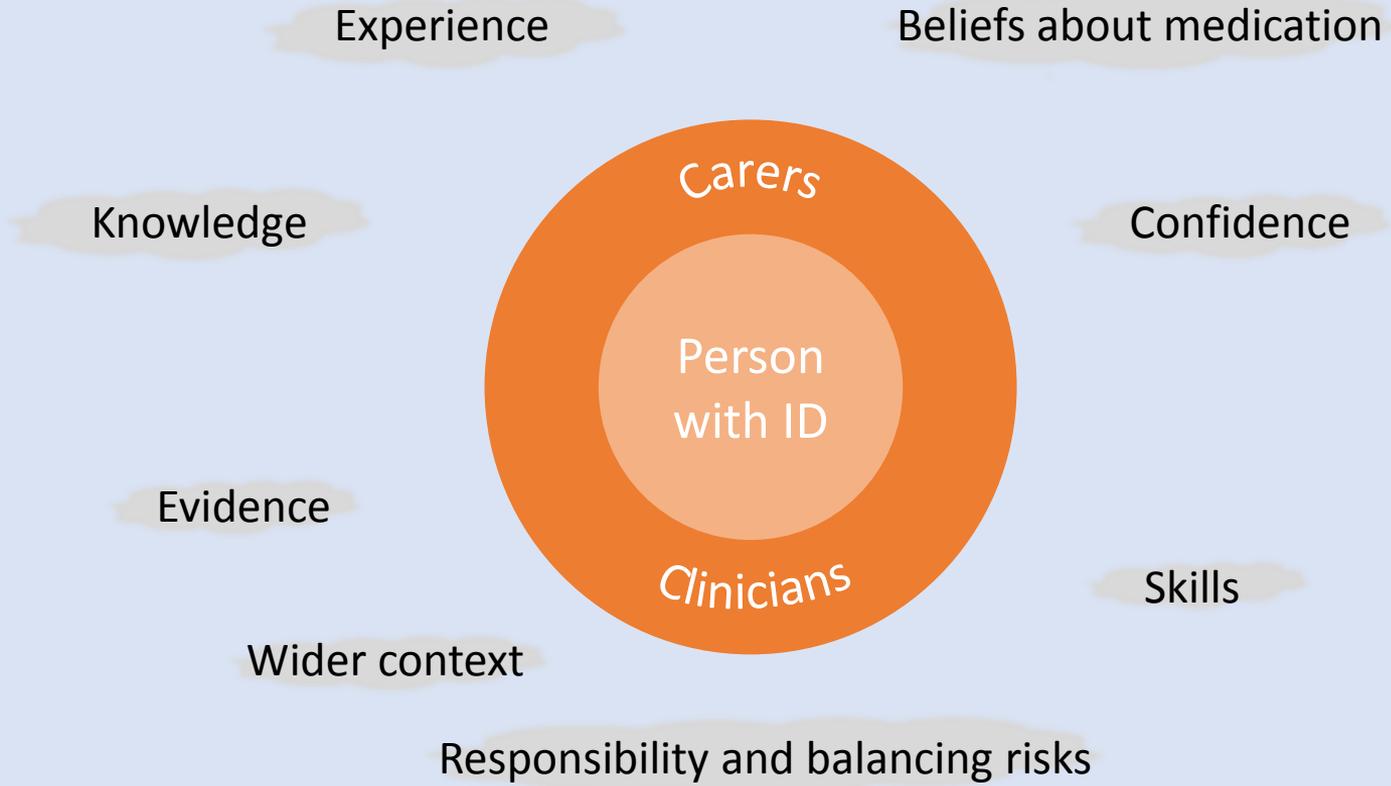
*Rory Sheehan, Angela Hassiotis*



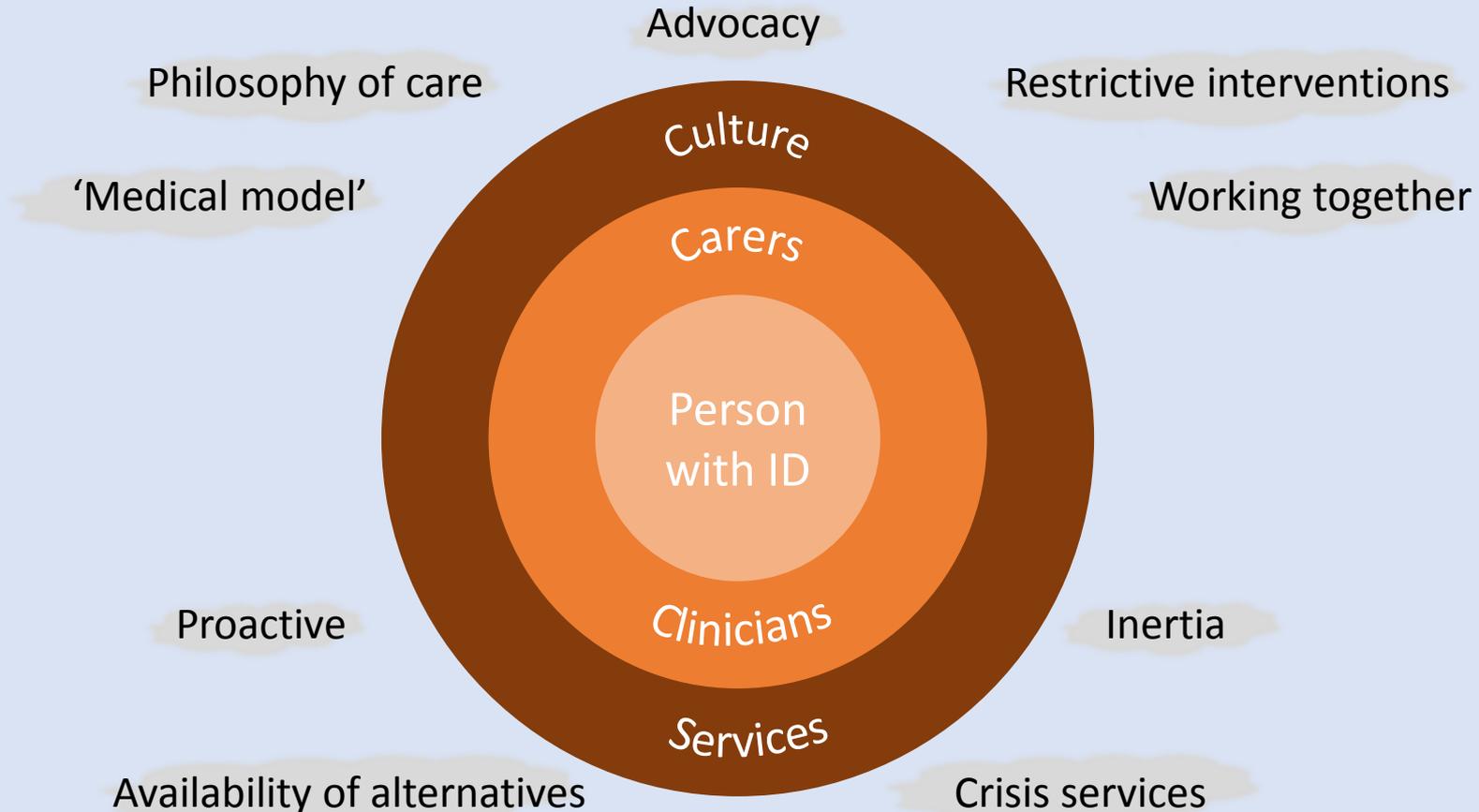
- Can be done in a substantial proportion of cases with...
  - Possible improvements in measures of physical health
  - Suggestion of improvements in adaptive or cognitive function and alertness
- But risks are...
  - Worsening of behaviour
  - Movement side-effects
  - Autonomic dysfunction
- Lots of gaps in evidence

- ANDREA-LD
- Funded by NIHR
- Full trial not possible due to problems with recruitment
- Need for focused support for practitioners, carers and patients, and alternative interventions in conjunction with medication reduction  
(McNamara et al, 2017)

# Wider influences on antipsychotic prescribing



# Wider influences on antipsychotic prescribing



## REVIEW

# Stopping, rationalising or optimising antipsychotic drug treatment in people with intellectual disability and/or autism

Rohit Shankar,<sup>1,2</sup> Mike Wilcock,<sup>3</sup> Katy Oak,<sup>3</sup> Paula McGowan,<sup>4</sup> Rory Sheehan<sup>5</sup>

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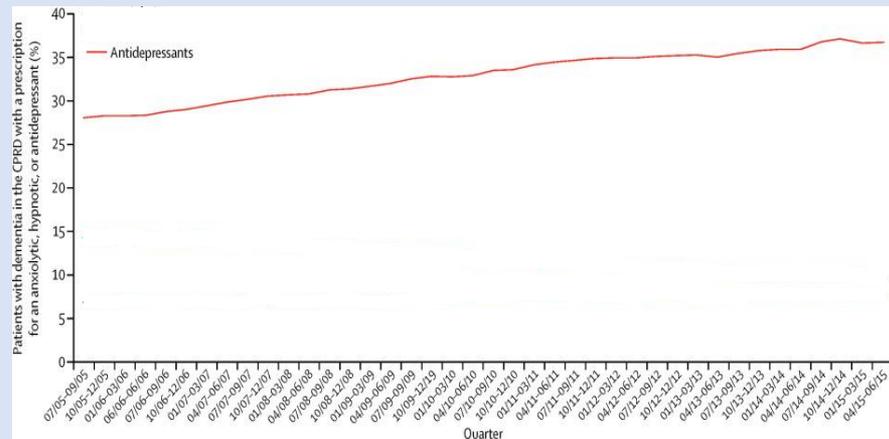
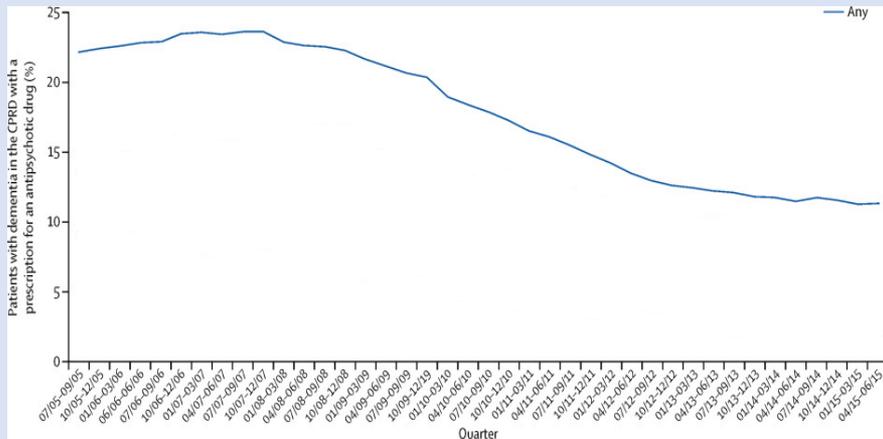
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“Withdrawing medication requires a multidisciplinary approach, consideration of comorbidity, and the involvement of patients and their carers” (Shankar et al, 2019)

# Unintended consequences of medication change



- Substitution of one psychotropic drug class for another (Maust et al, 2018; Donegan et al, 2017)
- Risk of under-treatment



**We know...**

- Clearly a need to improve psychotropic prescribing to people with ID
- Publicity and activity but ?outcomes
- Prescribing is a reflection of a complex and inter-related system of multiple stakeholders
- Refine the model of influences on antipsychotic prescribing in people with ID and challenging behaviour

**We need...**

- Develop and test interventions to reduce anti-psychotics that recognise complexity and systems issues and offer an alternative
- High-level overview of prescribing nationally and think laterally for unintended consequences

# Thank you



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