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Stopping over medication of people with a learning disability and autistic people (STOMP): An overview on antipsychotic use

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Contents

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Background 1: A key paper

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OPEN ACCESS

CrossMark click for updates

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

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ABSTRACT

OBJECTIVES

To describe the incidence of recorded mental illness and challenging behaviour in people with intellectual disability in UK primary care and to explore the prescription of psychotropic drugs in this group.

(P<0.001), and new prescriptions of antipsychotics declined by 4% (3% to 5%) per year P<0.001) between 1999 and 2013. New prescriptions of mood stabilisers also decreased significantly. The rate of new antipsychotic prescribing was significantly higher in people with challenging behaviour (incidence rate ratio 2.08, 95% confidence interval 1.90 to 2.27;

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- 33000 ID adults, 500+ GP practices
- Proportion of people with ID treated with psychotropics exceed the proportion with recorded mental illness.
- Antipsychotics are prescribed for people with no recorded severe mental illness, but with challenging behaviour

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However, the assumption that a person with ID, on antipsychotics, with no recorded psychosis, means that the prescription must be for challenging behaviour may not be entirely accurate.

Background 2: Challenges in ID

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- Increased mental health co-morbidity
- Increased physical health co-morbidity
- Increased psychosocial disadvantage

- Diagnostic overshadowing and under-recognition

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The challenge of ‘challenging behaviour’

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Background 3: Diagnosis

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Read codes, clinical diagnosis, SNOMED CT, etc

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- 9135 pts on antipsychotics, 2362 (26%) had neither challenging behaviour nor a mental illness recorded.

- 71% of those with ID prescribed an antipsychotic had no recorded severe mental illness while 50% of those without ID prescribed an antipsychotic had no recorded severe mental illness.

- Therefore, there is an issue of how psychiatric diagnosis is recorded in case files.

The importance of a full diagnostic evaluation that covers these 10 planes

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1. Degree of ID
2. Cause of ID
3. Autism
4. Other developmental disorders (eg: ADHD)
5. Mental illnesses
6. Personality disorders
7. Disorders related to substance misuse
8. Physical disorders
9. Trauma and psychosocial stressors
10. Types of behaviours that challenge

The 3 patient cohorts and prescribing approaches

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- Challenging Behaviour clearly associated with a mental illness or disorder
- Challenging Behaviour clearly NOT associated with any mental illness or disorder
- Challenging Behaviour associated with some psychiatric symptoms; but they do not quite fulfil the full criteria for a mental illness or disorder

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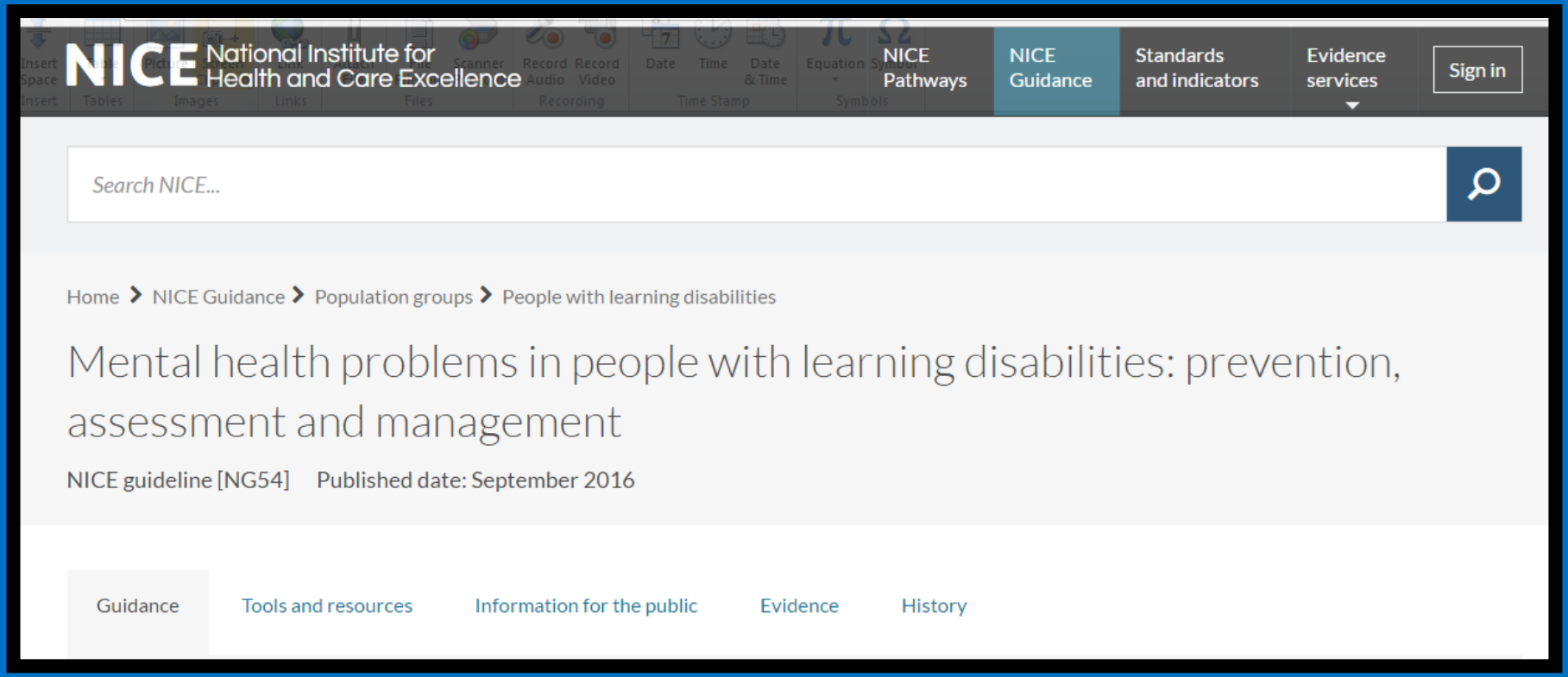

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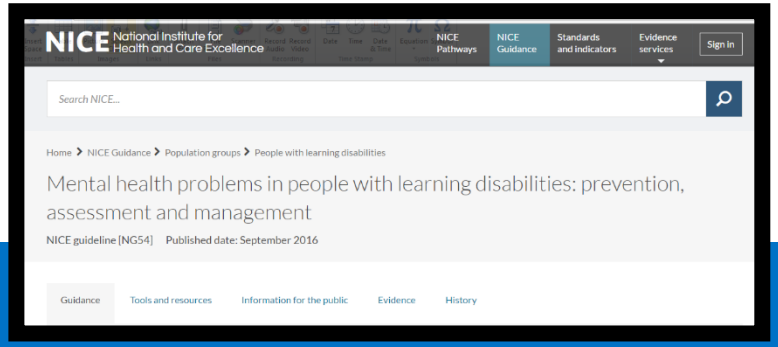

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- Full diagnostic evaluation
- Treat the mental illness
- The judgement on doses: Balancing the need to ‘start low and go slow’ with the need to avoid delaying optimal treatment.

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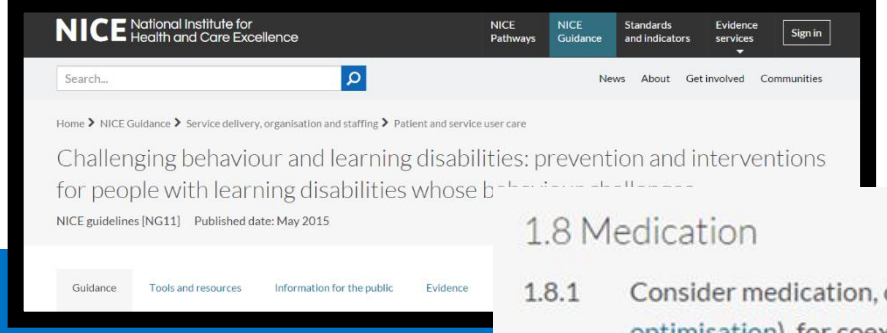

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1.8 Medication

1.8.1 Consider medication, or optimise existing medication (in line with the NICE guideline on medicines optimisation), for coexisting mental or physical health problems identified as a factor in the development and maintenance of behaviour that challenges shown by children, young people and adult with a learning disability (see also recommendation 1.10.1).

1.8.2 Consider antipsychotic medication to manage behaviour that challenges only if:

- psychological or other interventions alone do not produce change within an agreed time or
- treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or
- the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).

Only offer antipsychotic medication in combination with psychological or other interventions.

1.8.3 When choosing which antipsychotic medication to offer, take into account the person's preference (or that of their family member or carer, if appropriate), side effects, response to previous antipsychotic medication and interactions with other medication.

1.8.4 Antipsychotic medication should initially be prescribed and monitored by a specialist (an adult or child psychiatrist or a neurodevelopmental paediatrician) who should:

- identify the target behaviour

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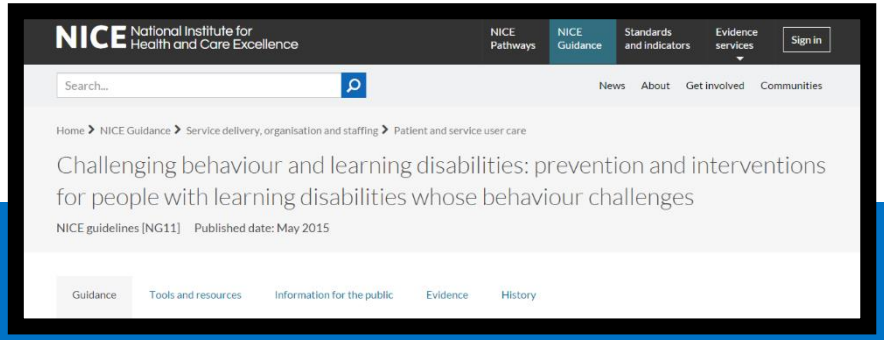

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Strength of evidence for medication and psychological interventions, not very different, in this cohort

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Problems with recording a clear diagnosis in ID (and elsewhere in the mental health field too)

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- There are categories for atypical presentations in all diagnostic systems- ICD, DSM, DMID or DC-LD
- The narrative account of the target symptoms and symptom clusters is important.
- Any prescribing should be based on that narrative account- whether it be syndromal or target symptom/ symptom cluster specific.

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1. Cognitive perceptual

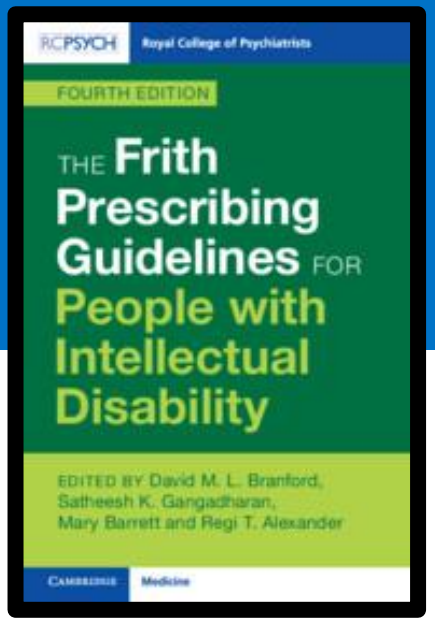
2. Affective dysregulation

3. Anxiety

5 symptom clusters

4. Behaviour dyscontrol (sub types)

5. Self injurious behaviour (sub types)



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1. **Cognitive perceptual**: (*eg: Chronic, low-level features like ideas of reference, pseudo-hallucinations*, *persecutory or self-referential ideas, fleeting hallucinations, etc)*: antipsychotic medication with pre-defined targets for efficacy, discontinue if ineffective

2. **Affective dysregulation**: *(eg: Affective instability, mood swings, chronic dysthymia like features, emotional detachment, etc):* antidepressants, mood stabilisers with pre-defined targets for efficacy, discontinue if ineffective

3. **Anxiety**: *(eg: cognitive and somatic sub-types):* SSRIs

4. **Behaviour dyscontrol:**

- **Affective aggression** (*characterised by impulsivity, angry outbursts, rapid mood changes and often a normal ECG*): consider antidepressant medication, SSRIs or mood stabilisers as first line.
- **Predatory aggression** (*relatively rare in people with intellectual disability and characterised by hostile and cruel behaviour associated with low emotional or physiological arousal*): consider antipsychotic medication. Although there is randomised controlled trial evidence supporting the use of oral Zuclopenthixol for aggression, clinicians and patients may prefer atypical antipsychotics due to a better side effect profile.
- **Ictal aggression** *(characterised by episodic, stereotyped aggression and often associated with epilepsy or abnormal EEGs*): consider mood stabilising antiepileptics as first line.

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5. Self Injurious Behaviour

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1. Extreme tissue damage

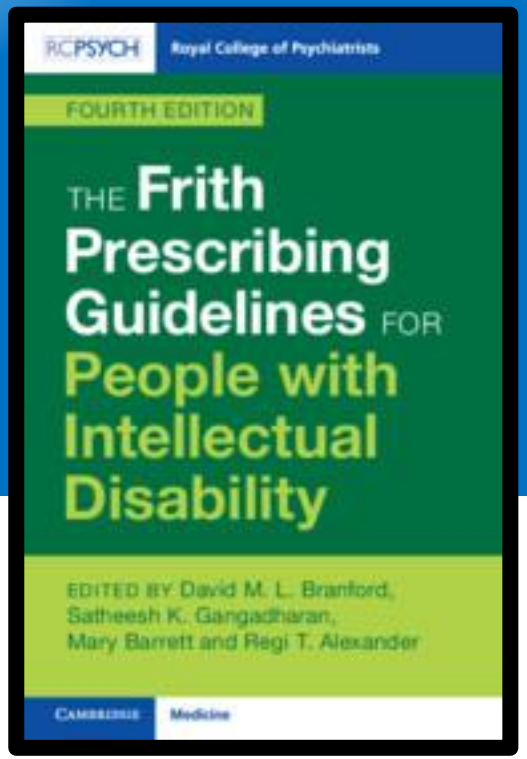
2. Repetetive and stereotypic

3. Agitation when SIB is interrupted

Self-Injurious Behaviour

4. Heightened anxiety

5. Mixed



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1. Extreme self-inflicted tissue damage	Insensitivity to pain	Opiate	
2. Repetitive & stereotypic	Features of autism	Dopamine	
3. Agitation when SIB is interrupted	Obsessive compulsive behaviour	Serotonin	
4. Heightened anxiety	High arousal (Agitation & SIB co-occur)	Noradrenaline	
5. Mixed	Two or more of above subtype	Multiple	

Off label prescribing

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- Part of mainstream medical practice
- Supported, suppositional and investigational
- Examples from paediatrics
- Anticancer drugs
- The NICE guidelines on delirium

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In many of the conditions described earlier

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- Precision of defining the indication
- Diagnostic reliability and validity
- Length of treatment
- Defining end points
- MORE PROBLEMATIC IN PEOPLE WITH ID

Responsibilities of the prescriber (Good practice in prescribing and managing medicines and devices, GMC 2013)

- Overseeing all aspects of treatment
- Record usage carefully
- Inform parents and carers fully

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- Explanation to patients
- Explanation to families and/or carers
- Easy read leaflets and reasonable adjustments

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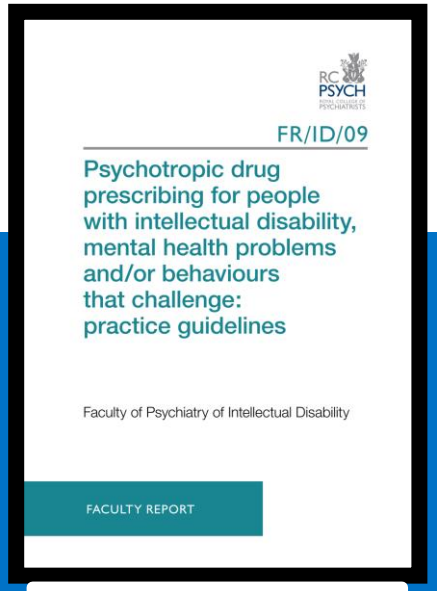
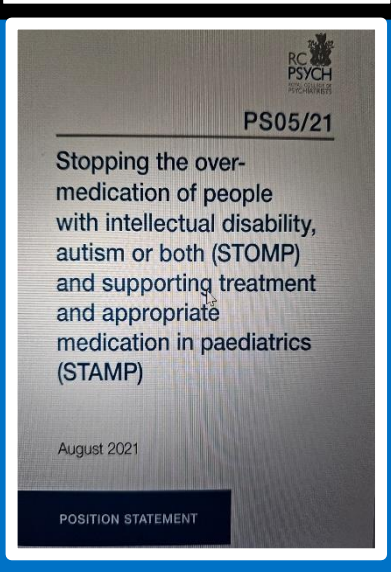
How do you carry out the medication review?





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STANDARD 1:
The indication and rationale for prescribing the psychotropic drug should be clearly stated, including whether the prescribing is off label, polypharmacy, or high dose.

1. Is the prescribing part of a wider multidisciplinary care plan?

2. If the prescription is only for behaviour that challenges, are the NICE guidelines being followed?

3 & 4. Is there off-label prescribing and if so, is the rationale explained?

5 &6. Is there polypharmacy and if so, is the rationale explained?

7 & 8.Is there prescribing over British National Formulary (BNF) advisory maximum limits and if so, is the rationale explained?

STANDARD 2: Consent-to-treatment procedures (or best interests decision making processes) should be followed and documented.

9. Is there evidence of a capacity assessment?

10. If the patient is deemed to lack capacity, is the best interests process followed?

11. Is there evidence that the patient's views about the drug treatment are being recorded?

12. Is there evidence that the carers' or family members' views about the drug treatment are being recorded?

13. If patient is detained (e.g. under the Mental Health Act 1983), are the legal requirements around consent to treatment satisfied?

STANDARD 3: There should be regular monitoring of treatment response and side-effects (minimum every 6 months)*

14. Is there documentation about progress on the target symptoms for treatment?

15. Is there evidence of an objective evaluation of treatment response?

16. Has a standardised tool/ instrument been used for the above?

17. Is there evidence of an objective evaluation of side-effects?

18. Has a standardised tool/ instrument been used for the above?

STANDARD 4: Review and evaluation of the need for continuation or discontinuation of the psychotropic drug should be undertaken on a regular basis (minimum every 6 months)*

19. Is there evidence of an objective evaluation of treatment response?

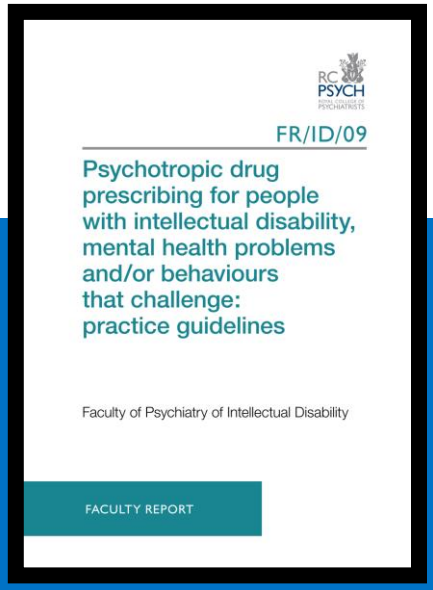
20. Has a standardised tool/ instrument been used for the above?

21. Is there evidence of an objective evaluation of side-effects?

22. Has a standardised tool/ instrument been used for the above?

23. Is there evidence of regular review of the need for continuation or discontinuation of the drug? (This includes discussion of risks and benefits with the patient and/or carer.)

Evaluation:
Checking if your treatment works?



Supplement narrative accounts with standardised measures: eg: CGI - easy to administer, quick, can have multiple raters, can capture balance between effects and side effects

Completed Clinical Global Impression Scale (CGI) of a *Fictitious Patient* (Taken from https://www.carepatron.com/templates/clinical-global-impression-scale-cgi)

Clinical Global Impression (CGI)

Name: Samuel Reznor | Date: December 6, 2021

1. Severity of illness

Considering your total clinical experience with this particular population, how mentally ill is the patient at this time?

- ○ 0 = Not assessed
- ○ 1 = Normal, not at all ill
- ○ 2 = Borderline mentally ill
- ○ 3 = Mildly ill
- ○ 4 = Moderately ill
- ◉ 5 = Markedly ill
- ○ 6 = Severely ill
- ○ 7 = Among the most extremely ill patients

2. Global improvement

Rate total improvement whether or not, in your judgement, it is due entirely to drug treatment. Compared to his condition at admission to the project, how much has he changed?

- ○ 0 = Not assessed
- ○ 1 = Very much improved
- ○ 2 = Much improved
- ○ 3 = Minimally improved
- ○ 4 = No change
- ◉ 5 = Minimally worse
- ○ 6 = Much worse
- ○ 7 = Very much worse

3. Efficacy index

Rate this item on the basis of **drug effect only.** Select the terms which best describe the degrees of therapeutic effect and side effects and record the number in the box where the two items intersect.

EXAMPLE: Therapeutic effect is rated as 'Moderate' and side effects are judged 'Do not significantly interfere with patient's functioning'.

Therapeutic effect		**Side effects**			
		None	Do not significantly interfere with patient's therapeutic patient's functioning	Significantly interferes with patient's functioning	Outweighs therapeutic effect
Marked	Vast improvement. Complete or nearly complete remission of all symptoms	○ 01	○ 02	○ 03	○ 04
Moderate	Decided improvement. Partial remission of symptoms	○ 05	○ 06	◉ 07	○ 08
Minimal	Slight improvement which doesn't alter status of care of patient	○ 09	○ 10	○ 11	○ 12
Unchanged or worse		○ 13	○ 14	○ 15	○ 16

○ Not assessed = 00

Additional notes:

We're going to evaluate Mr. Reznor one more time. If there are no improvements, we might have to change their medication.

Reproduced from Guy W, editor. ECDEU Assessment Manual for Psychopharmacology. 1976. Rockville, MD, U.S. Department of Health, Education, and Welfare

The Evidence Base Problems

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- Very few studies and limited sample sizes
- Ethical issues and the ***psychotropic medication paradox*** in ID research
- The discrepancy between research samples and patients in your practice.

Key message 1

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THE RESPONSIBILITY IS THE PRESCRIBERS'.

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Key message 2

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JUST WRITING “CHALLENGING BEHAVIOUR” MAY NOT BE PRECISE ENOUGH AS A RECORDED INDICATION FOR PRESCRIBING

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Key message 3

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RECORD ALL DIAGNOSES SYSTEMATICALLY AND

THE NARRATIVE THAT UNDERPINS IT.

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Key message 4

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RECORD TARGET SYMPTOMS/ SYNDROMES, HAVE PROVISIONAL TIMEFRAMES FOR EVALUATION AND COMMUNICATE THAT TO ALL CONCERNED.

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Key message 5

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OFF LABEL PRESCRIBING IS NOT INAPPROPRIATE, UNLAWFUL OR UNETHICAL. HOWEVER, IF NOT DONE PROPERLY, IT CAN BE.

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Key message 6

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USE A STANDARDISED OUTCOME MEASURE THAT CAN BE RECORDED QUICKLY AND IMPLEMENTED WIDELY

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Key message 7

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AIM TO PRESCRIBE RATIONALLY. DE-PRESCRIBING IS PART OF THAT RATIONAL PROCESS, NOT AN END BY ITSELF.

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Key message 8

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APPROACHES TO STOMP IN PRIMARY AND SECONDARY CARE HAVE TO BE BASED ON AN UNDERPINNING OF EVIDENCE BASED PRACTICE

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MORE ABOUT IT IN THE NEXT TWO PRESENTATIONS

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