A structured programme to withdraw antipsychotics among adults with intellectual disabilities: Challenges and solutions in primary care

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Aims

- Discuss a structured programme to reduce or withdraw antipsychotics among adults with intellectual disabilities
- Explore two notable publications addressing this
- Discuss the challenges and issues
- Review a pilot study, including approach and outcomes

Debate & Analysis

Challenges and pitfalls of antipsychotic prescribing in people with learning disability

INTRODUCTION

In this opinion piece we highlight the current concerns of prescribing antipsychotics to people with learning disability (PWLD) and propose a system of monitoring of antipsychotic prescribing in general practice that, we argue, will reduce inappropriate antipsychotic use.

Learning disability, synonymous with the term 'intellectual disabilities',[1] affects about 1–2% of the general population[2] and is characterised by significant impairments of both intellectual and adaptive functioning, and an onset before 18 years.[3]

PWLD have high rates of [illegible]

suggested that about 30 000–35 000 PWLD are on antipsychotics or antidepressants, or both, without appropriate indications,[6] and that the proportion of PWLD treated with psychotropic medication exceeds the proportion with recorded mental illness.[7] NHS England has developed a national programme to stop overmedication of PWLD (STOMP).[8] The imperative should be to rationalise clinical practice by carefully balancing the need to stop unnecessary treatment with the possibility of undertreatment that puts the patients or others at risk.[1,4]

[illegible]

or best-interests decision-making processes, regularly monitoring treatment response and side effects, and regularly reviewing the need for continuation based on risks and benefits. These four audit standards incorporate the National Institute for Health and Care Excellence (NICE) recommendation[11] that, if antipsychotics are considered for behaviour that challenges, then they should only be used if: psychological or other interventions alone have not produced change within an agreed time; treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour; or the risk

[illegible]

Introduction to Learning Disabilities and Antipsychotic Prescribing

People with learning disabilities (PWLD) have higher rates of 'challenging behavior' (CB), such as aggression, self-injury, and property destruction.

CB is a social construct that can summarize behavioral or mental patterns affecting quality of living. It is best understood through learning theory and applied behavioral analysis.

Mental illness is a structured diagnostic concept that encompasses a large range of recognised emotional and behavioural disorders. It’s diagnosis requires robust application of diagnostic schedules.

Introduction to Learning Disabilities and Antipsychotic Prescribing

Most PWLD with mental illness have CB; but the majority of PWLD with CB might not satisfy the criteria for mental illness.
Therefore, the therapeutic approach to CB can be very different from a diagnostic one.
However, there is significant overlap between CB and the presence of mental illnesses, with the latter also being higher in PWLD than the general population.

Deficits in communication, atypical clinical presentations, and differences in coding methods means that mental illness can be under-recorded, particularly in those with severe degrees of learning disability.
The clinician needs to be aware not just of what is observed behaviourally, but also whether there is something underlying diagnostically.

A formulation based on both these elements is central to deciding whether there is a need to prescribe medication.

Prescribing of Psychotropic Medication

The vast majority of PWLD with CB and/or mental illness are seen in primary care. There has been concern that psychotropic medication is used inappropriately in this group to deal with the former.

Overmedication Statistics

About 30,000-35,000 PWLD are on antipsychotics or antidepressants without appropriate indications. Proportion exceeds those with recorded mental illness.

STOMP Programme

NHS England has a national programme, STOMP, aimed at stopping overmedication of PWLD.

Clinical Practice Imperative

Rationalise clinical practice by balancing the need to stop unnecessary treatment and avoid under-treatment.

Focus on Antipsychotic Prescribing

Though psychotropic medication can include antipsychotics, antidepressants, mood stabilizers, stimulants, or anxiolytics, particular attention has been focused on antipsychotics.

With recent data from secondary care, for instance, from mental health services, suggesting that antipsychotics are not widely used outside of evidence-based indications in PWLD, there is a need to focus particularly on prescribing in primary care.

Prescribing of Psychotropic Medication

Three major circumstances in clinical practice that lead to antipsychotic prescribing:

- **The patient has a mental illness with psychotic symptoms**
- **The patient has CB**
- **Both of these**

The only acceptable indication is psychosis for longer term prescribing of antipsychotics. The rational for prescribing antipsychotics – either as a definitive diagnosis or a narrative account of target symptoms – has to be clearly recorded.

This recording appears to be problematic in primary care.

Although 71% of those PWLD on antipsychotics did not have the diagnosis of severe mental illness, the comparable figure for the general population was still 50%.

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Although 71% of those PWLD on antipsychotics did not have the diagnosis of severe mental illness, the comparable figure for the general population was still 50%.

Suggests there is a need to improve the recording of the rational for antipsychotic prescribing across the board.

Guidelines and Audit Standards

RCPsych has published audit standards and practice guidelines for prescribing these drugs in PWLD:

- **clearly documenting the indication for prescribing**
- **recording consent or best-interests decision making**
- **regularly monitoring treatment response and side effects**
- **regularly reviewing the need for continuation based on risks and benefits**

Guidelines and Audit Standards

These four audit standards incorporate the NICE recommendation that, if antipsychotics are considered for behaviour that challenges, then they should be used if:

- psychological and other interventions alone have not produced change within the agreed time

- treatment for any co-existing mental or physical health problem has not led to a reduction in the behaviour

- the risk to the person or others is very severe

Guidelines and Audit Standards

It also takes into account NICE guidance which recommends that prescribes should:
- record full details of all medication including the doses, frequency and purpose
- recorded a summary of what information was provided about the medication prescribed to the patient and carers
- consider reducing or discontinuing antipsychotics for PWLD who are not experiencing psychotic symptoms and review their condition
- annually document the reasons for continuing a prescription
- consider referral to a psychiatrist experience in working with PWLD and mental health problems

Guidelines and Audit Standards

These can pose a number of challenges in Primary Care:

1) **Difficulty in changing a long-established prescription that may have been the result of an inappropriate need, an appropriate but poorly recorded need, an unmet need, or resistance from carers or the patient themselves.**
2) **Many prescriptions may have started on recommendation from Secondary Care, but 'new ways of working' have resulted in a large population of PWLD who are on repeat prescriptions without review from (or access to) secondary care (the "vulnerable well")**
3) **Any effort to change the status quo requires further resources to meet any unmet needs, including access to psychological treatments, social care, and other secondary care services.**

Strategies to Address the Problem

A range of views exist from primary care on how this problem needs to be tackled:

- a low threshold for referral to specialist teams to manage CB – though this could overburden specialist services

- the GP, if identifying a mental illness, initially prescribes and assesses outcomes, and refers if concerns persist – but this could lead to a delay in specialised care in a vulnerable adult

- if there is a concern in the context of uncertain or no obvious comorbid mental illness, to make a referral to a specialist community team – but this could potentially foster diagnosis overshadowing

Strategies to Address the Problem

To address the practicalities of this issue, there is a need for close working between primary and secondary care services, involving GPs, community pharmacists, specialist LD teams, and psychiatrists in LD.

An initiative is underway in Cornwall…

The likelihood of their being a single way in which this current burden can be reduced is unlikely, but outcomes of such pilots are best placed to inform how to develop a unified strategy in the future.

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ORIGINAL ARTICLE

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A structured programme to withdraw antipsychotics among adults with intellectual disabilities: The Cornwall experience

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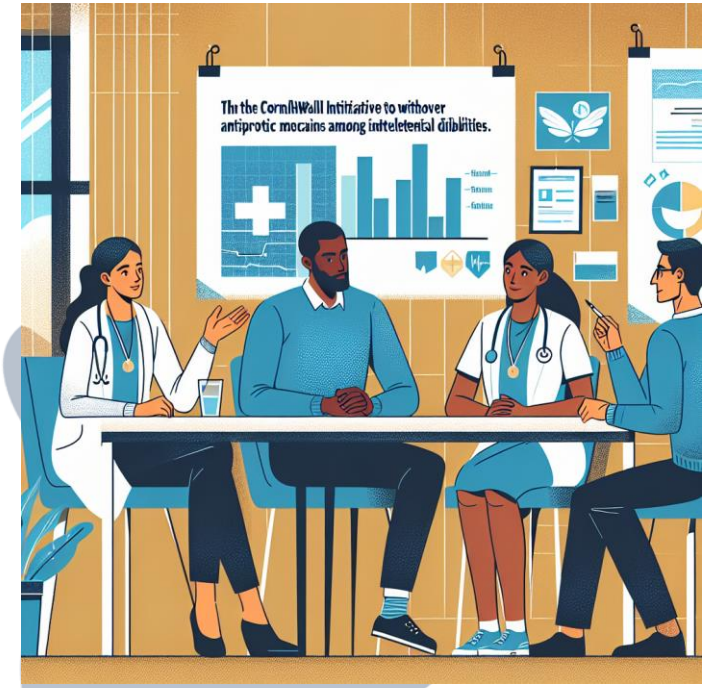
Abstract

Background: Antipsychotic medications are used among 19%–58% of adults with intellectual disabilities to manage challenging behaviour against the NICE guideline recommendations. Studies show that it is possible to completely withdraw antipsychotics in about one third of adults with intellectual disabilities and a dose reduction of 50% or more in another third.

Introduction



The Cornwall initiative aimed at withdrawing antipsychotic medications among adults with intellectual disabilities. The study focused on a structured withdrawal involving multiple stakeholders.

A Structured Programme for Antipsychotic Withdrawal

The Cornwall experience

Overview

The initiative aimed at reducing antipsychotic use among adults with intellectual disabilities through a structured programme.

Goals

Focused on the complete withdrawal or significant dose reduction of antipsychotics.

Stakeholders

Involved people with intellectual disabilities, carers, GPs, community learning disability team members, and pharmacists.

Outcomes

Successfully reduced antipsychotic use with positive engagement from all stakeholders.

Prevalence of Psychotropic Medication Use

Rates of Use

Psychotropic medication use among people with intellectual disabilities ranges from 32% to 85%, with an average of 50%-63%.

Antipsychotic Usage

Antipsychotics account for 20%-45% of psychotropic medications used. Often prescribed off-license in absence of mental illness.

Sources

Key studies: Deb (2016), Doan et al. (2013), Sheehan et al. (2015), Bowring et al. (2017), de Kuijper et al. (2010), Tsiouris et al. (2013).

Off-license Use of Antipsychotics

Antipsychotic Prescriptions in Intellectual Disabilities

Off-license Use

Most common for managing problem behaviours in people with intellectual disabilities.

Usage Statistics

19%-58% of prescribed antipsychotics are for managing problem behaviours.

Guideline Recommendations

NICE & international guidelines recommend non-pharmacological approaches first.

Concerns Relating to Antipsychotic Use and the STOMP Programme

Off-license Use

The use of antipsychotics in people with intellectual disabilities is a major public health concern.

Key Concerns

High use of medication, adverse effects, difficulty in assessment, challenging withdrawal, lack of evidence, higher doses and polypharmacy, long-term use without review, ethical issues, and investigation challenges.

STOMP Campaign

NHS England initiated the 'STopping Over Medication of People with intellectual disability, autism or both (STOMP)' campaign to address these concerns.

Withdrawal Studies

Findings and Challenges

Systematic Review Findings

Withdrawal possible in 4%-74% of individuals (Sheehan & Hassiotis, 2017). US-based studies primarily from long-term institutions.

European Studies

UK and Netherlands studies focus on community settings. Results vary, with some achieving over 60% complete withdrawal. Withdrawal rates: Branford (1996) - 25%, Ahmed et al. (2000) - 33%, de Kuijper et al. (2014) - 37%.

Recent Studies

Open-label discontinuation study in the Netherlands (de Kuipjer & Hoekstra, 2018) showed 61% stopped medication at 16 weeks, decreasing to 40% by 40 weeks. Behavioural relapse led to reinstatement of meds in nearly half of cases.

Challenges

Recruitment issues in placebo-controlled and open-label studies. Success linked to risk assessment and stakeholder involvement (de Kuijper et al., 2014).

Factors Affecting Withdrawal

Branford (1996) Findings

Lower antipsychotic dose, minimal psychopathology, lack of aggression, stereotype, and hyperactivity at baseline help withdrawal.

Ahmed et al. (2000) Insights

Environmental and organisational factors: Experienced full-time staff, low staff turnover, staff training, courses for managing problem behaviour, less reliance on environmental restrictions facilitate withdrawal.

de Kuijper & Hoekstra (2018) Results

Female gender, lower baseline problem behaviors rate, lower baseline dosage favor withdrawal. Severe behavior, autonomic and extrapyramidal symptoms, comorbid autism, higher doses, health deterioration during discontinuation are against withdrawal.

Janowsky et al. (2006 & 2008) Studies

66.3% (55/83) remained antipsychotic-free almost 10 years post-withdrawal. Difficulties in withdrawing medications completely if behavior worsens after one or two attempts.

Withdrawal Symptoms

Overview

Behaviour generally improves after antipsychotic withdrawal, but some attempts fail due to worsening behaviour.

Symptoms

Withdrawal symptoms can include akathisia, dyskinesia, anxiety, sleep problems, and agitation.

Misinterpretation

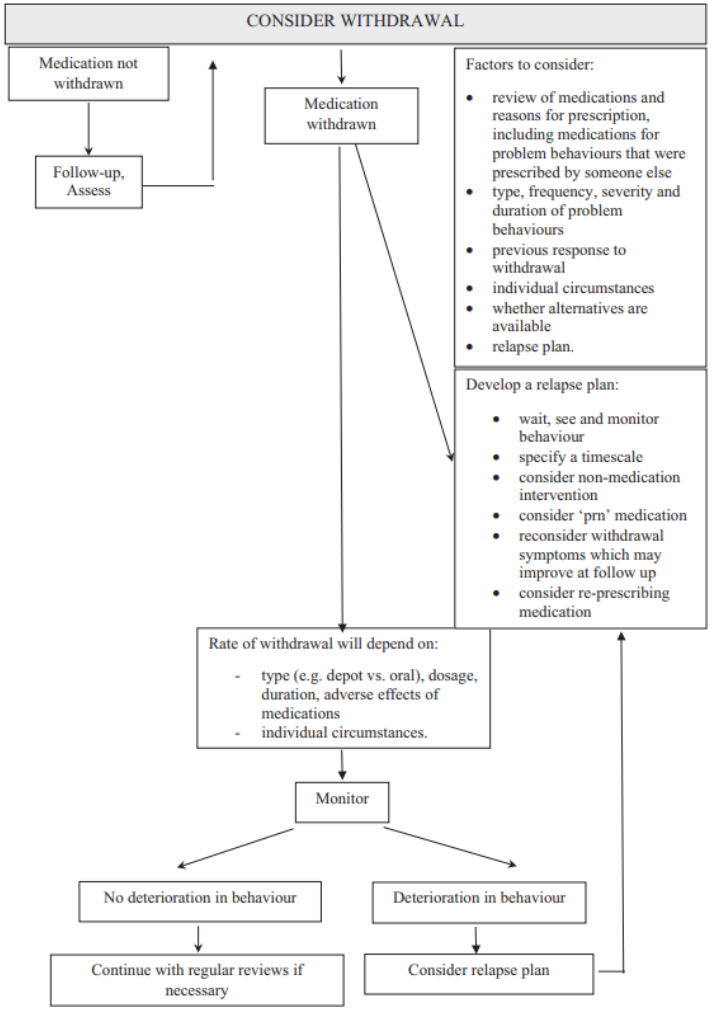
Symptoms might be misinterpreted as recurrence of original behaviours.

Rebound akathisia might appear within the first few days, whereas rebound parkinsonism usually emerges after a week and rebound dyskinesia might only become apparent within a month
Most studies show that emergent extrapyramidal symptoms seem to improve after a few weeks

Recommendation

Clinicians should not reinstate antipsychotics immediately but should wait, potentially using PRN prescriptions, until behaviour improves.

Flow chart… (adapted from Deb et al., 2009)


CONSIDER WITHDRAWAL
Medication not withdrawn
Follow-up, Assess
Medication withdrawn
Factors to consider:
review of medications and reasons for prescription, including medications for problem behaviours that were prescribed by someone else
type, frequency, severity and duration of problem behaviours
previous response to withdrawal
individual circumstances
whether alternatives are available
relapse plan.
Develop a relapse plan:
wait, see and monitor behaviour
specify a timescale
consider non-medication intervention
consider 'prn' medication
reconsider withdrawal symptoms which may improve at follow up
consider re-prescribing medication
Rate of withdrawal will depend on:
- type (e.g. depot vs. oral), dosage, duration, adverse effects of medications
- individual circumstances.
Monitor
No deterioration in behaviour
Deterioration in behaviour
Continue with regular reviews if necessary
Consider relapse plan

Withdrawal Process Flowchart

Considerations and Steps

Follow-up and Assessment

Evaluate the necessity for continued medication or further intervention.

Medication Withdrawn

Key factors to consider include medication review, type, frequency, severity of problem behaviors, alternative treatments, and relapse plan.

Relapse Plan

Monitor behavior, specify timelines, consider non-medication interventions, and reassess withdrawal symptoms. Possibly reintroduce medication.

Monitoring

Continuous monitoring for behavior changes. If no deterioration occurs, continue regular reviews. If deterioration is observed, implement the relapse plan.

Need for a Structured Pathway

Importance and Implementation

Imperative Nature

Following a structured withdrawal pathway is crucial for antipsychotic withdrawal success.

Considerations

Clinicians need to consider patient variables, treatment modalities, medication type and dosage, environment, and psychosocial support.

QI Project

The Cornwall initiative used the PDSA model to guide antipsychotic withdrawal among adults with intellectual disabilities.

Outcomes and Discoveries

Four QI cycles showed a need for new approaches. QI methodology provided guidance and evidence for improvements.

International Guideline Recommendations

Guidelines by Deb et al. (2009)

Pre-Treatment Assessment

Ensure that an assessment has been conducted and recorded before starting treatment. Confirm capacity to consent.

Treatment Planning

Develop an appropriate formulation and treatment plan, considering physical exams and investigations. Engage relevant professionals.

Communication with Patients & Carers

Inform patients and/or their families about off-license prescriptions, the evidence of their effectiveness, and potential adverse events. Provide written treatment plans.

Monitoring & Follow-Up

Set and document methods for assessing treatment outcomes, carry out follow-up assessments, and ensure compliance with legal frameworks.

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QI Project

The Cornwall initiative used the PDSA (Plan, Do, Study, Act) model to guide antipsychotic withdrawal among adults with intellectual disabilities.

PDSA

The “Plan” was to identify all people with intellectual disabilities on APT in Cornwall, having no major mental disorder.
The aim of the first QI cycle was to reduce the antipsychotic burden by 20% of the identified target population in one year and then realign expectations for next cycles subsequently.

“Do” was to undertake a structured reduction plan as identified in the methods section.

“Study” was to collect data post-attempt and compare to see if 20% reduction was achieved and if not why not.
It would also allow an opportunity to reflect on the impact, barriers and what went well of the change and what was learned including looking into what worked and what did not and why.

“Act” was to find solutions to overcome the challenges and to plan the next cycle.

PDSA

Four cycles of PDSA were carried out with the final one leading to using the principals suggested by theoretical evidence established (Shankar, Wilcock, Oak, McGowan, & Sheehan, 2019).

It was recognized during the QI cycles that new approaches and tools need to be developed to overcome the challenges as available methods could not lend itself directly on occasions to the QI improvement cycles.

Method

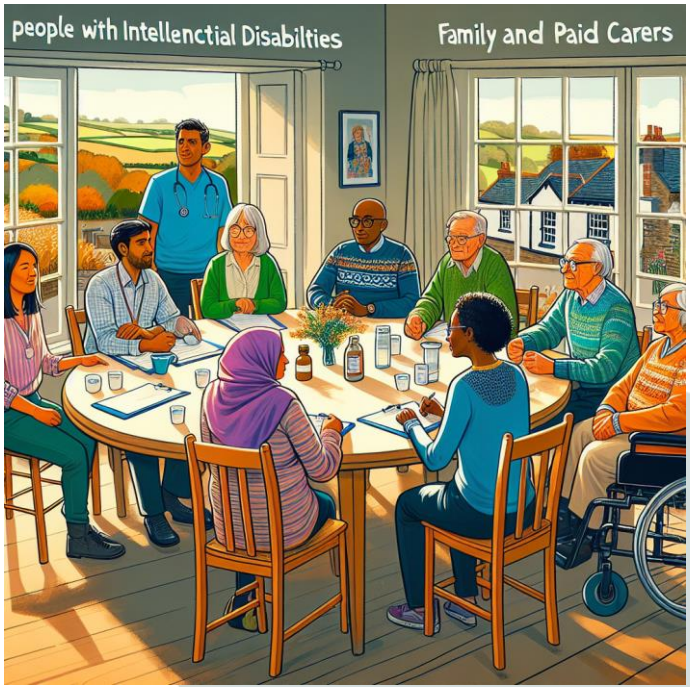
Cornwall, UK

Stakeholder Involvement

Included people with intellectual disabilities, family and paid carers, GPs, pharmacists, and community learning disability team (CLDT) members.

Programme Approach

Executed in several steps to ensure systematic withdrawal.



Process Steps

Step 1: Primary care and identification of the cohort

Invitation

Local GPs invited to a one-hour tutorial on the STOMP initiative and proposal for antipsychotic withdrawal.

Dissemination

A GP prescribing lead from each primary care practice attended to disseminate the learning within their practices.

Follow-up

Follow-up meeting conducted after 12 months of the initial tutorial.

Process Steps

Step 1: Primary care and identification of the cohort

GPs Knowledge Assessment

21-item questionnaire administered to assess GPs' knowledge (Shankar & Wilcock, 2018).

Database Access

GP register-based database facilitated access to relevant data.

Use of Read Codes & ECLIPSE

Read codes identified adults with intellectual disabilities on antipsychotic medication; ECLIPSE software identified those without a recorded mental disorder in 44 practices in Cornwall.

Audit Findings

Audit conducted on people with intellectual disabilities on antipsychotics discharged to primary care (2010-2015) to assess satisfactory medication review during annual health checks (Shankar et al., 2016).

Step 2: Involving All Stakeholders

Engaging Patients and Carers in the Withdrawal Process

Meeting with Stakeholders

A meeting was organized with people with intellectual disabilities and their carers to frankly discuss all withdrawal issues.

Discussion Points

Highlighted benefits and risks, changes in diagnostic systems, potential exposure of undiagnosed mental illnesses, and addressing unmet needs.

Short-term Consequences

Acknowledged that withdrawal might lead to hospital admission in some cases to ensure safety.

Ongoing Involvement

Maintained total involvement of patients, carers, and other stakeholders in the withdrawal and relapse prevention strategy.

Process Steps

Step 3: Secondary Care

CLDT and MDT Involvement

Regular discussions on withdrawal strategy with multidisciplinary team and CLDT members.

STOMP Oversight Committee

Led by clinical director and included service users, primary care liaison nurses, community pharmacists, and more. Established to oversee the whole system approach.

Antipsychotic Prescribing Audit

Conducted audit in October 2015 to analyze patterns associated with prescribing and MDT working.

Process Steps

Step 4: Development of Tools

Risk Assessment Pyramid (RAP)

- describes the factors (personal, behaviour related, drug-related, psychosocial-environment, carer/staff training etc.) associated with a high-risk versus low-risk withdrawal process
- allows triaging and stratification for withdrawal and allows an appropriate risk assessment and communication with people with intellectual disabilities and their carers.

STOMP STAMP

- describes three possibilities after the antipsychotic withdrawal is considered, which may indicate a successful withdrawal (Green) or inability to withdraw (Red)

E-connect

- identify nine commonly identified dimensions of treatment response that are clinically and holistically important and which are commonly discussed in care plan meetings.
- summarizes the outcome score in a visual format

Visual representation of E-Connect summary findings.

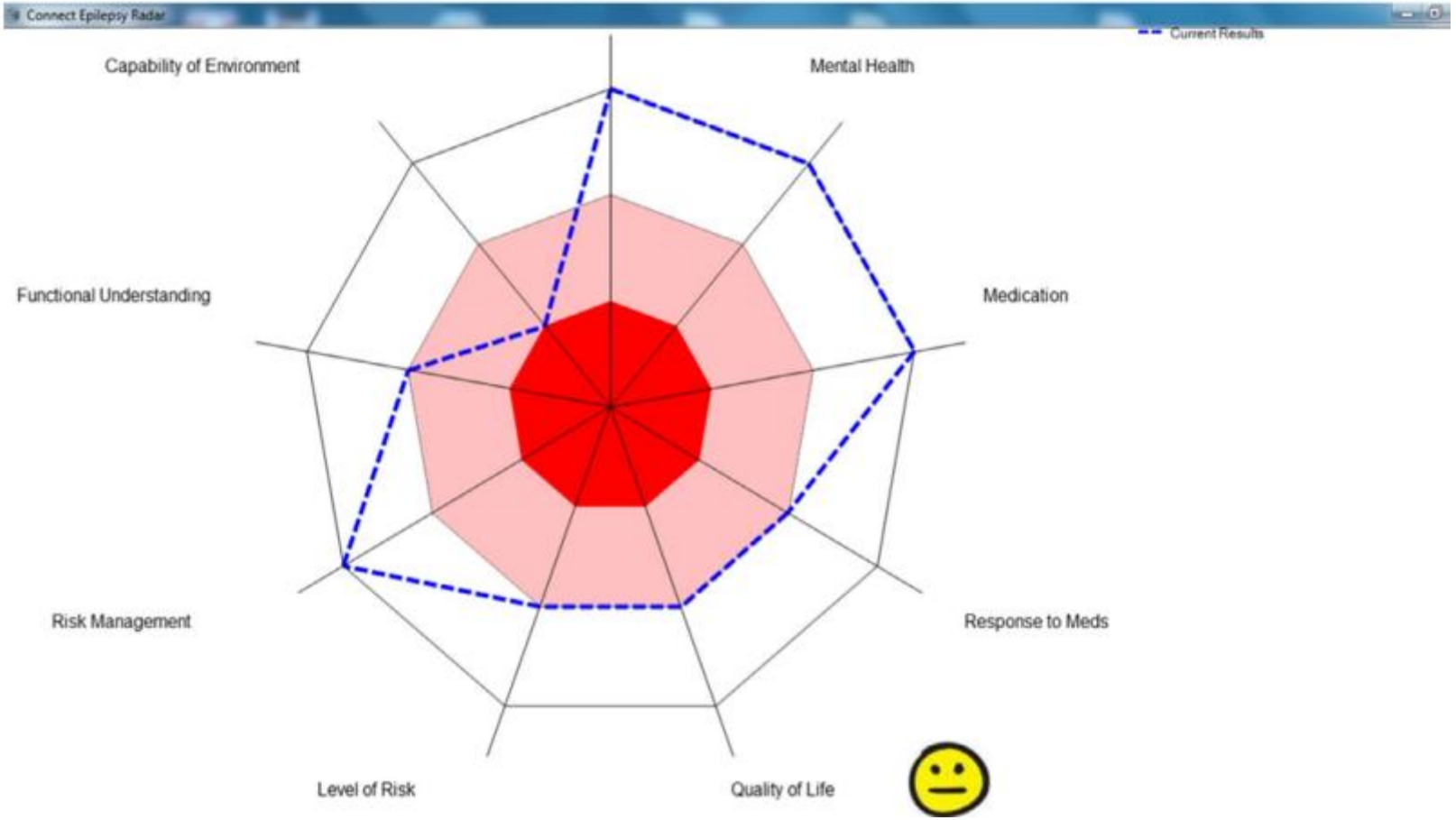


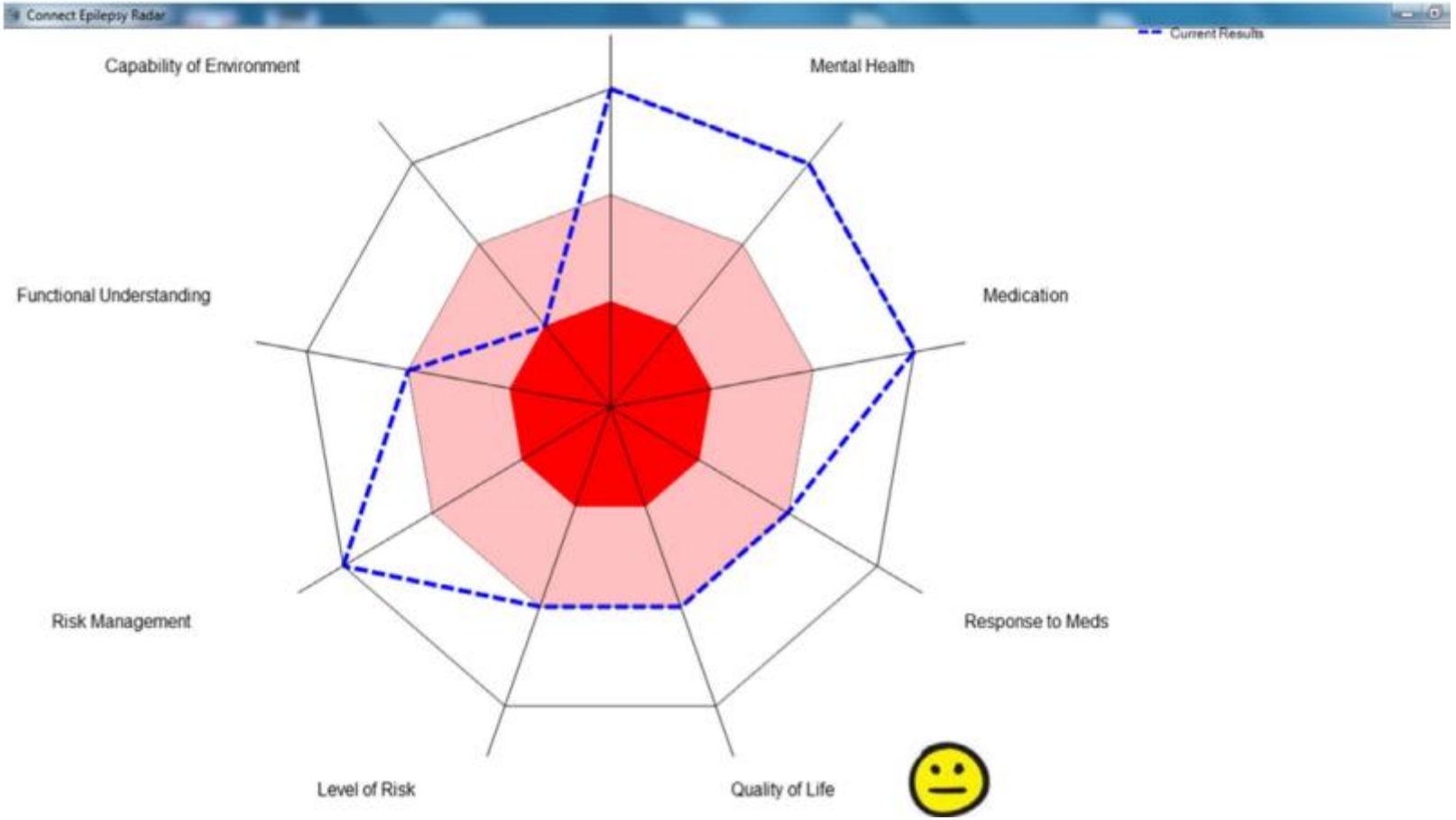
TABLE 2 E-connect algorithm

	Green	Amber	Red
Physical health	Physical health needs fully identified, understood and supported through health action plan within 6 months of referral to Service	Health needs assessment underway within 6 months of referral	Health needs not identified, understood or supported - no health action plan – within 6 months of referral
Mental health	Documented diagnosis and recorded multi-disciplinary formulation – within 6 months of referral	Documented diagnosis or multi-disciplinary formulation – within 6 months of referral	No documented diagnosis or multi-disciplinary formulation – within 6 months of referral
Medication	Appropriate prescribing i.e. to treat a recorded diagnosis	Non-antipsychotic psychotropic without recorded diagnosis	Antipsychotic without recorded mental illness diagnosis, or 2 antipsychotics in absence of documented valid rationale
Response to medication (CGI score)	≥+2 change	No or +1 change	≤−1 change
Quality of life • Has person-centred plan • Has active and effective communication plan • Has personalized daily activities/routine • Has friends/is not lonely • Generally happy/content • Able to effectively access required mainstream services.	4 + indicators	2–4 indicators	<2 indicators

Level of risk (guided by BPI-S)	More than monthly and not severe (does not inflict significant damage)	Weekly – monthly and/or moderate	Daily-weekly and/or severe
Risk management to include reactive risk management such as "As required medication," restraint, environmental restriction, lack of privacy etc	Risk management plans are in place that are legal, proportionate, effective, reviewed and part of a wider plan	Risk management plans are in place but have not been reviewed using MCA and effectiveness	Risk management plans are not in place, or are not legal, proportionate, and effective, reviewed and part of a wider plan
Functional understanding (by everybody involved in person's care e.g. staff/support team, clinical team)	Function of BtC fully understood and needs effectively met, i.e. no longer or rarely needing to resort to E-Connect to communicate unmet need File review to support understanding of history of previous needs/support strategies	Function of BtC is partially understood (some MDT assessments taken place and advice provided) but had partial impact on E-Connect or not yet reviewed Partial file review	Function of BtC not understood at all MDT assessment work thus far has had no impact on E-Connect risk No file review to support understanding of history of previous need/support strategies
Capability of environment (guided by PBS competency framework audit tool)	Fully met	Partially met and working on meeting	Does not meet

Abbreviations: BtC, Behaviour that concerns (challenging/problem behaviour); MDT, Multi-disciplinary Team; MCA, Mental Capacity Act; PBS, Positive Behaviour Support; BPI-S, Behavior Problems Inventory-Short Form (Rojahn et al., 2012).

Visual representation of E-Connect summary findings.



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Cornwall Partnership NHS
NHS Foundation Trust

5. STOMP STAMP

1. Successful withdrawal with no evidence of a mental illness
2. Identified appropriate mental illness **Purple Book**

1. Partial withdrawal of antipsychotic
2. Changes in personality
3. Some psychiatric symptoms
4. **STOMP LD Toolkit – Connect**
5. Patient choice – BI meeting
6. Revisit as appropriate **Purple Book**

1. **inability to withdraw antipsychotic**
2. **Identified social/ provider need <u>outside</u> the remit of health commissioned role**
3. **Evidence provided to commissioner – Connect/toolkit/meeting/ safeguarding etc.**
4. **Re –referral on resolution Purple Book**

Step 5: Assessment of Patients for Withdrawal

Utilizing the Risk Assessment Pyramid (RAP)

Purpose

Assess all referrals for withdrawing antipsychotic medication using RAP.

Patient Prioritization

Prioritize patients for withdrawal based on the RAP evaluation.

Discussion

Full discussion about risk assessment and management with patients and carers.

Dose Changes

Typical dose reductions were 10%-25% of the baseline dose every 6-8 weeks.

Step 6: Follow-up and Contingency Plan

Follow-up

Appropriate arrangements for patient follow-up during and after gradual withdrawal.

Contingency Plan

A detailed plan to address patient and carer anxiety about withdrawal, discussing potential concerns like placement loss, behavior worsening, or hospital admission.

Discussion and Involvement

Contingency plan discussed thoroughly with people with intellectual disabilities and their carers.

Primary Care: Findings

Step 1 Results

GP Participation

44 GPs attended the tutorial (73%) and 42 the follow-up meeting (70%).

Questionnaire Responses

90% completed it; Over 80% correct responses for 16 questions, below 80% for 5 questions.

Medication Management

Most GPs felt psychotropic medication management in intellectual disabilities should be specialist-led.

Audit Findings

243 adults with intellectual disabilities on antipsychotics without a psychiatric diagnosis recorded. 60% had no rationale for use; Blood test rates varied (60%-90%); Only 50% had a satisfactory review after discharge to secondary care.

Step 2

Patient/Carer Involvement: Findings

STOMP Forum Development

A forum was created with patients who successfully withdrew from antipsychotics (experts by experience) to advise professionals and engage with other service users.

Tool Co-Design

Experts by experience co-designed tools like the Purple Book and BtC connect (E-Connect), selecting photos and designs.

Personalization

Focused on ensuring each person with intellectual disabilities has unique needs, influencing the Purple Book's framework for carers.

Step 3: Secondary Care Findings

Audit Insights on Antipsychotic Management

Audit of Electronic Records

Identified 106 people with intellectual disabilities open to the CLDT for problem behavior management. Among them, 61 were on antipsychotic medication.

Nursing and Physical Health Assessments

66% had no nursing/physical health assessment in the past year. 72% did not receive an initial behavioral assessment/functional analysis.

MDT Assessments

Only 3% received all 5 expected MDT assessments. 13% received none, 31% received one, 16% two, 23% three, and 13% four assessments.

Refined Template for Clinic Letters

New template incorporates alternatives to prescribing antipsychotics, diagnosis, rationale for medication use, and a possible formulation.

Outcome of Antipsychotic Withdrawal

Over a ten-month period between April 2018 and January 2019, 71 adults with intellectual disabilities who were on antipsychotics without a psychiatric diagnosis were assessed for withdrawal.

Of them, 33 (46.5%) achieved complete withdrawal, and 8 (11.3%) had over 50% dose reduction but not total withdrawal.

Withdrawal attempts failed in 7 (9.8%) people where antipsychotic doses had to be increased after initial reduction.
However, none needed reinstatement of antipsychotics at three months follow-up.

Using the STOMP STAMP, authors identified 5 (7%) adults in inappropriate placements needing appropriate relocation before considering antipsychotic withdrawal.

Discussion: Feasibility and Success Factors for Antipsychotic Withdrawal

The Cornwall experience shows the feasibility of discontinuing antipsychotic medication in adults with intellectual disabilities, achieving a 46.5% success rate of complete withdrawal.
Previous UK community-based studies reported success rates of 25% (Branford, 1996) and 33% (Ahmed et al., 2000), while Netherlands studies reported 44% (de Kuijper et al., 2014) and 46%-40% at 28-40 weeks (de Kuijper & Hoekstra, 2018).

The failure rate in Cornwall was low (9.8%), with ongoing dose reductions for some patients.

Key factors for success included the involvement of stakeholders from the outset, a structured withdrawal pathway, and continuous support.
Concerns about withdrawal were alleviated through open discussions highlighting previous success rates and having contingency plans.
Structured programs and stakeholder engagement proved vital, showcasing no placement breakdowns or hospital admissions during withdrawal.

Involving Local GPs and Tools for Effective Antipsychotic Withdrawal

Involving local GPs has been beneficial in raising awareness about antipsychotic withdrawal and the use of psychotropics.

Although GPs preferred not to withdraw antipsychotics themselves, they supported the process and were instrumental in gaining access to GP registers for meaningful medication reviews.

Future efforts may involve senior nurse practitioners or community pharmacists working with primary care to initiate withdrawal.

This approach found 60% of patients on antipsychotics without a clear rationale, which is consistent with previous reports.

Involving Local GPs and Tools for Effective Antipsychotic Withdrawal

The full involvement of Community Learning Disability Team (CLDT) members and regular reviews by the multidisciplinary team (MDT), including community pharmacists, are crucial.

Setting up specific medication review clinics, using tools like the RAP, is recommended to prioritize patients for withdrawal.

Utilizing resources like E-connect and the Purple Book can empower patients and carers while facilitating the monitoring process.

National Guideline (Unwin & Deb, 2010) provides draft information sheets to assist this endeavor.

Despite initial challenges with E-connect, it proved beneficial when explained through case examples, improving stakeholder understanding and engagement.

Challenges and Future Directions for Antipsychotic Withdrawal

Field Testing Needed

Pathway and tools need proper field testing to evaluate psychometric properties.

Control Group Absence

Study lacked control group; can't compare with the treatment as usual (TAU).

Geographic Limitation

Findings restricted to one area; unsure if results generalize across the country.

Cost and Resource Implications

Time-consuming program with added NHS costs; potential long-term savings with more resources.

Cornwall Antipsychotic Withdrawal Assessment

Cornwall Population Details

Total population: 538,000
Adults with intellectual disabilities (GP registers): 2,620
Adults known to social services: 1,700

Psychotropic Medication Estimates

Expected on psychotropic medication: 833
Expected on antipsychotic medication: 357

Assessment and Withdrawal Outcomes

Adults assessed (Apr 2018-Jan 2019): 71
Complete withdrawal: 33 (46.5%)
>50% dose reduction: 8 (11.3%)

Additional Findings

Antipsychotic-free at 3 months: 33 (46.5%)
Withdrawal attempts failed: 7 (9.8%)
Need appropriate placement: 5 (7%)

Conclusion

The Cornwall experience has shown that successful withdrawal and dose reduction of antipsychotics prescribed without a specific relevant indication is possible in a large number of adults with intellectual disabilities if a concerted effort is made using a structured approach and involving all stakeholders, particularly people with intellectual disabilities and their carers from the very beginning.

Certain tools may facilitate this process as well.

In the future, an appropriately designed randomized controlled trial (RCT) is needed to formalize the pathway and assess its clinical and economic effectiveness.

Discussion