

Accessible Communication and Monitoring of Clozapine Adverse Effects for People with Intellectual Disability and/or Autism: A Scoping Review

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Accessible information needs an integrated monitoring pathway

The review identified no validated tool combining clozapine-specific monitoring with adaptation for intellectual disability.

Introduction

Differences in communication, cognition, sensory processing and interoception can complicate recognition and reporting of clozapine adverse effects. Routine monitoring may assume that the person can identify, describe and escalate symptoms.

Aim: Map the evidence and identify components for an accessible clozapine adverse-effect monitoring pathway.

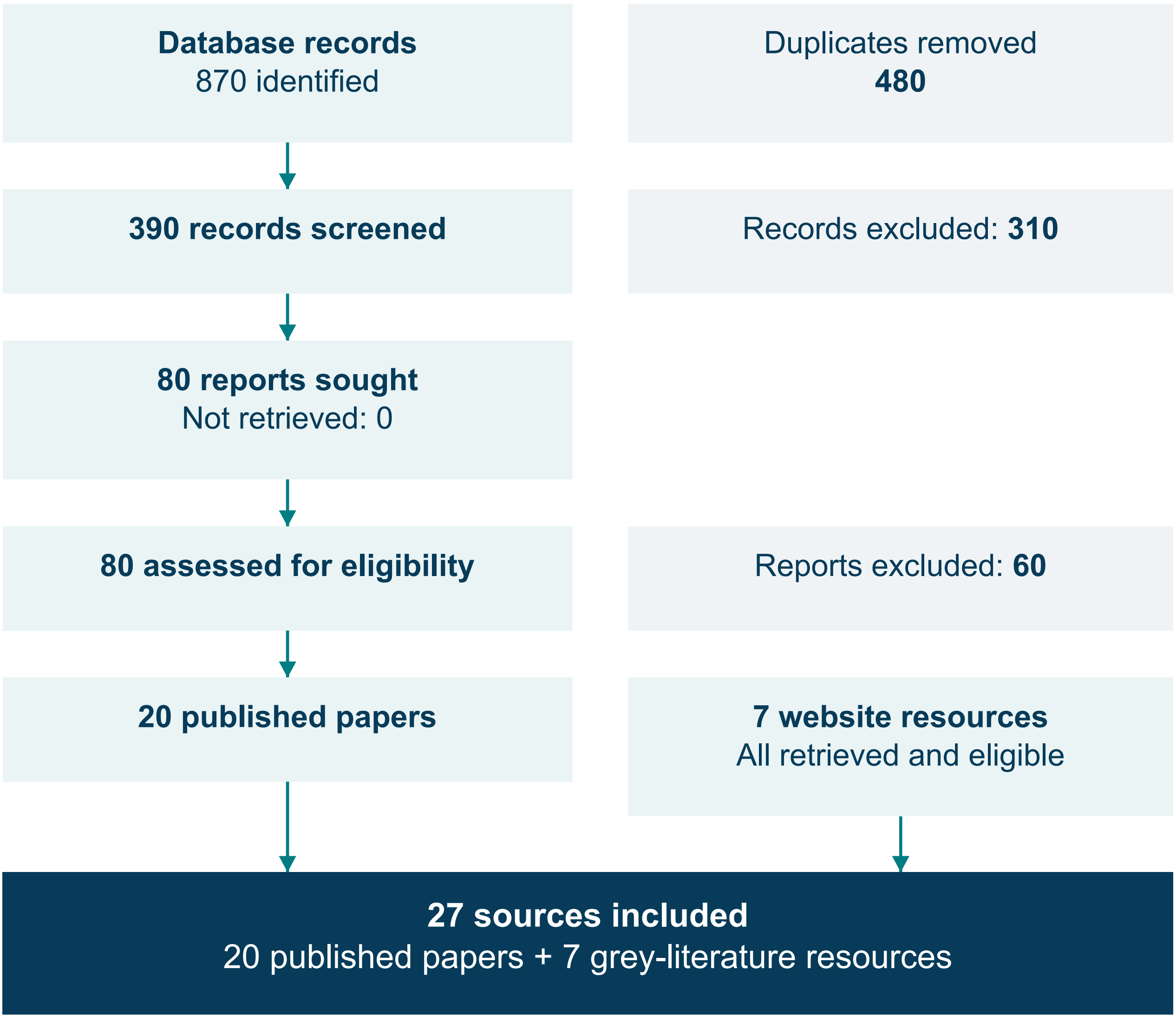
Methods

Scoping review reported using PRISMA-ScR. Six evidence-search outputs from AWP Library and Knowledge Services covered June-July 2026.

Sources included MEDLINE, Embase, PsycINFO, CINAHL, the Cochrane Library and targeted grey literature. Five questions addressed clozapine evidence, accessible information, communication, staff education and monitoring tools, alongside a UK guidance search.

Eligible evidence concerned adults with intellectual disability and/or autism, or transferable psychotropic medication evidence. Sources were charted and synthesised narratively. No formal critical appraisal was undertaken.

Study selection



Condensed from the manuscript PRISMA flow diagram.

Selected references

1. Ayub et al. Cochrane Database Syst Rev. 2015. doi:10.1002/14651858.CD010625.pub2
2. Hynes et al. Schizophr Res. 2015;168:505-513. doi:10.1016/j.schres.2015.07.052
3. Tveter et al. Adv Ment Health Intellect Disabil. 2016. doi:10.1108/AMHID-10-2015-0051

Results

Limited population-specific evidence

Direct evidence was sparse and largely observational. The 2015 Cochrane review found no eligible randomised controlled trials in adults with intellectual disability and psychosis. [1]

A gap in tailored guidance

The search identified no UK national clozapine guideline specifically for people with intellectual disability.

Information exists, integration is missing

Several easy-read resources were available. Communication evidence favoured individualised, co-produced approaches within supportive systems.

Training needs a monitoring system

Staff education should accompany clear monitoring responsibilities, routine documentation and explicit escalation pathways.

Two complementary tools, neither meets both needs

GASS-C: Clozapine-specific self-report scale, validated in 110 clozapine outpatients. Not designed specifically for intellectual disability or autism. [2]

UKU-SERS-ID: Adapted for adults with intellectual disability, but not specific to clozapine. [3]

Discussion and next steps

Co-design and test a pathway that combines:

- Accessible, individualised medicines information.
- Structured symptom enquiry, with supporter observations where appropriate.
- Clear red-flag escalation and named staff responsibilities.
- Brief, recurrent education embedded in routine monitoring.

Evaluate completeness of adverse-effect assessment, actions taken, acceptability and consultation burden.

Limitations: Heterogeneous, mainly observational evidence, no prospective protocol registration and no formal critical appraisal. Proposed components require feasibility testing and do not replace blood tests, physical-health monitoring or clinical assessment.

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Conclusions

The priority is to connect accessible communication with systematic adverse-effect monitoring. Co-designed quality-improvement work should test whether an integrated pathway improves the completeness and clinical usefulness of clozapine monitoring.