

## **Plain language summary of the CERSI-PGx guideline for *ACKR1* genotyping and clozapine**

This summary has been co-written with experts by experience from the Side-By-Side Network.

### **About clozapine**

Clozapine is a medicine that can help people with schizophrenia when other medicines haven't worked.

Everyone taking clozapine must have regular blood tests to check their number of white blood cells. This number can drop for some people, which could affect their ability to fight infections. Regular blood tests ensure that a person's white blood cell count stays above the minimum threshold level. Otherwise, clozapine may have to be stopped.

### **About ADAN**

ADAN is a condition caused by a difference in a gene called *ACKR1*. This can affect anyone, but particularly people with African or Middle Eastern ancestry. People with ADAN have naturally low numbers of white blood cells, but they can fight infections normally.

If a person taking clozapine is found to have ADAN, they are monitored on a different scale with a lower minimum threshold level for white blood cells. This usually means they can continue taking clozapine.

However, ADAN is not always detected. This means that people with undetected ADAN are often unable to take clozapine because their white blood cell level appears too low.

### **What is included in the guideline?**

In the guideline, we explain how to test for the genetic difference that causes ADAN in people taking clozapine. It has been designed so that it can be used in the UK's NHS.

### **Who should be offered this pharmacogenetic test?**

The test can be done by taking a single blood sample and only needs to be performed once. The following should be prioritised for the test. People who:

- are about to start taking clozapine.
- have had clozapine stopped in the past because their number of white blood cells became too low.
- are currently taking clozapine and have a low number of white blood cells.

### **What should happen when we know the result of the test?**

The test result should be communicated to the person by their doctor.

If the person has the genetic profile for ADAN, the minimum threshold level for white blood cells should be lowered. This will ensure that people with ADAN can safely take clozapine without having it unnecessarily stopped. Following this, the normal monitoring frequency will continue.

If the person does not have the genetic profile for ADAN, they should continue to be monitored on the normal scale for number of white blood cells.