

Clozapine Consultation 2023

Summary of responses

June 2024

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Overview of Clozapine Consultation 2023



About the consultation

From 7 August 2023 to 6 October 2023, Medsafe, the Medicines and Medical Devices Regulatory Authority of New Zealand, welcomed participants to take part in an online voluntary survey/consultation about clozapine.

Medsafe would like to thank all those who participated.

Why did we consult about clozapine?

Medsafe carried out this online voluntary survey/consultation to gather information about people's experiences with clozapine in New Zealand.

This was not a scientific investigation or a study, rather an information gathering exercise to understand local real-life experiences with clozapine use to inform the Medicines Adverse Reaction Committee's review of clozapine safety and monitoring requirements.

The Medicines Adverse Reaction Committee (MARC) is an expert committee which discusses the safety of medicines.

Read more information about the consultation [here](#).

Why are we interested in clozapine safety?

Many people experience significant benefits from taking clozapine. However, clozapine can also cause some significant side effects. There are a number of monitoring requirements for clozapine to manage the risk of these side effects.

People who take clozapine and the healthcare professionals who support them may experience challenges with clozapine side effects and the monitoring requirements.

Who could take part?

Anyone taking clozapine, whānau, family and/or caregivers of people who take clozapine, and healthcare professionals supporting people who take clozapine could participate.

The survey was open to people living in New Zealand only. Participation was voluntary.

New Zealand healthcare professional groups/organisations and patient support groups were notified via email. Information was also published on Medsafe's website.

Since this was a consultation only, and not scientific research, participation could only happen through the online tool administered on the Ministry of Health's Citizen Space platform. However, anyone who had difficulties accessing the online platform was encouraged to contact us for alternative options to complete the survey.

Medsafe engaged with relevant Ministry of Health directorates, MARC members and the pharmaceutical companies marketing clozapine for assistance in designing and publicising the consultation.

What did we ask the participants?

We asked questions about clozapine use, side effects and challenges in managing the risks of clozapine treatment. There were a variety of multi choice and open-ended questions. Completion of each question was optional.

What were the responses?

This report outlines the information provided from the responses, which has been grouped into 3 sections.

- [Summary of participants](#) (page 9): the number, type and ethnicity of participants.
- [Consumer experiences](#) (pages 10 to 23): information from individuals who take clozapine and whānau, family and/or caregivers of individuals who take clozapine.
- [Healthcare professional experiences](#) (pages 24 to 46): information from medical doctors, pharmacists, nurses and other healthcare professionals.

The information gathered and presented in this report is not representative of all clozapine experiences in New Zealand.

Not all people who take clozapine or healthcare professionals who look after people who take clozapine participated in this consultation. Information gathered is only the experiences of those who participated.

Responses from people who gave us permission to publish their response can be viewed [here](#).

What next?

This report will be presented to the MARC alongside other information as part of a review of clozapine safety and monitoring requirements.

While the information gathered and summarised in this report was not intended to inform clinical practice, healthcare professionals may find the information useful when reflecting on their own practice.

Clozapine in New Zealand

What is clozapine? Clozapine is an antipsychotic medicine used in treatment-resistant schizophrenia.¹

Why does clozapine have provisional consent? So that legal restrictions can be in place for clozapine use in New Zealand.

Only certain practitioners can prescribe clozapine, and prescribing and dispensing must follow local guidelines. Pharmaceutical companies supplying clozapine in New Zealand must also have an appropriate patient monitoring system in place (described below).

See the Medsafe website for further information ([Product/Application search](#)).

Which clozapine products are approved? There are currently three clozapine products approved in New Zealand: Clozaril (tablet), Clopine (tablet) and Versacloz (oral suspension).

For more information about these products, see the pharmaceutical companies' data sheets and consumer medicine information leaflets (CMI) on the Medsafe website ([Data Sheets and Consumer Medicine Information search](#)).

What are some possible side effects of clozapine and the monitoring requirements?

Blood problems: clozapine can lower the numbers of neutrophils (white blood cells) in the blood. If you have low numbers of white blood cells you are at risk of severe infections. Regular blood tests (haematological monitoring), along with checking for signs or symptoms of infection help monitor this.

Constipation: Clozapine can cause slow movement of the bowels and other bowel related side effects. Medicines that ease constipation (laxatives) and regular monitoring of bowel movements are often necessary.

Heart problems: Clozapine can cause inflammation of the heart muscle (myocarditis) and other heart related side effects. Cardiac (heart) monitoring and checking for signs or symptoms related to the heart help monitor this.

For more information on other clozapine side effects and monitoring, see the data sheets and CMI.

What are 'clozapine patient monitoring systems'? Due to the risk of clozapine-induced blood problems (agranulocytosis - very low number of neutrophils in the blood), regular monitoring of white blood cells (WBC) and neutrophil cells (ANC) is mandatory with clozapine use around the world.¹

Blood tests must be done before starting treatment, weekly for the first 18 weeks and then every 4 weeks during treatment. A blood test (or tests depending on duration of treatment) is also taken after discontinuation of clozapine.¹

There are two clozapine patient monitoring systems in New Zealand: CareLink Plus, managed by Viatris (for Clozaril), and ClopineCentral, managed by Douglas (for Clopine and Versacloz). All patients must be registered on a clozapine patient monitoring system.

¹ Viatris. 2023. *Clozaril New Zealand Data Sheet* 13 March 2023. URL: <https://www.medsafe.govt.nz/profs/Datasheet/c/Clozariltab.pdf> (accessed 5 March 2024).

A traffic light system for blood test results helps determine if clozapine treatment can be safely continued. Clozapine may be continued ('green'), continued with blood testing frequency increased ('amber') or stopped ('red').²

See the clozapine data sheets for further information about monitoring requirements.

How is clozapine dispensed? Before clozapine can be dispensed from a pharmacy, a blood test is taken to measure white blood cell (WBC) and neutrophil cell (ANC) levels, and the results are checked by a pharmacist.²

For more information about clozapine – talk to your usual healthcare professional.

² Viatrix. 2020. *Clozaril Resources for psychiatrists, mental health staff, general practitioners and pharmacists* November 2020 (accessed 5 March 2024).

Summary of Participants



Number of responses

A total of 189 responses were received via the consultation tool.

Two of these were invalid and therefore removed from the analysis. One because it did not provide information on clozapine, and one was a follow-up to a previous response.

There were **187** valid responses.

Who participated

Table 1 outlines the type of people who took part.

Table 1: Types of people who participated

Category	Type of person	Number (%)
Consumer experiences	Individual who takes clozapine	11 (5.9)
	Whānau, family and/or caregiver of an individual who takes clozapine	16 (8.6)
Healthcare professional experiences	Medical doctor	61 (32.6)
	Pharmacist	34 (18.2)
	Nurse	49 (26.2)
	Other healthcare professional	16 (8.6)
Total		187

Ethnicity

There were 156/187 people (83.4%) who reported their ethnicity (Table 2).

Table 2: Reported ethnicity, by type of person

Ethnicity ^a	Consumer ^b (n=11)	Whānau, family and/or caregiver (n=16)	Healthcare professional (n=160)
Māori	4	1	10
Pacific Peoples	-	-	1
Asian	1	1	17
European/Other	6	12	103
Residual categories (not stated, response unidentifiable)	-	2	29

- a. Ethnicity was aggregated at Level 0.³ If more than one ethnicity was reported, prioritisation was used.
b. Consumer = individual who takes clozapine.

³ Source: Ministry of Health. 2017. Ethnicity Data Protocols – HISO 10001:2017, Version 1.1. URL: https://www.tewhātuora.govt.nz/assets/Our-health-system/Digital-health/Health-information-standards/hiso_10001-2017_ethnicity_data_protocols_21_apr.pdf (accessed 12 December 2023).

Consumer Experiences



Overview

This section (pages 10 to 23) presents the information provided by individuals who take clozapine (referred to as consumers) and whānau, family and caregivers of individuals who take clozapine.

Whānau, family and caregivers were asked to answer the questions based on experiences of the person they know who takes clozapine. Therefore, the information provided from this group has been presented within consumer experiences.

Responses have been grouped as follows:

- [Part 1: Clozapine use](#)
- [Part 2: Interactions with healthcare professionals](#)
- [Part 3: Clozapine side effects](#)
- [Part 4: Constipation and clozapine](#)
- [Part 5: Blood tests and clozapine](#)
- [Part 6: Other feedback.](#)

For multichoice and single answer questions, results are grouped by type of person.

For open ended questions or where more information was provided, a summary is given.

Where applicable, quotes from individual responses have been incorporated (*in italics*).

These people have given permission for their response to be published.

Part 1: Clozapine use

We asked general questions about clozapine use.

1. Which best describes you and how you take your medicines, including clozapine?

Table 3 outlines information provided about medicine use.

Table 3: How medicines including clozapine are taken

Routine of taking medicines ^a	Consumer (n=11)	Whānau, family, caregivers (n=16)
Self-managed	8	2
Whānau, family and/or caregivers help	-	8
Mental health team helps	2	2
The person is in hospital and has help from nurses or other healthcare professionals	1	-
None of the above	1	4

a. More than one answer could be selected.

Some people provided further information about how they were the whānau, family or caregiver of someone who takes clozapine and how medicines are taken.

Four people said that clozapine was used previously.

2. Approximately, how long have you been taking clozapine regularly (ie, without stopping)?

Table 4 outlines information provided about duration of clozapine treatment.

Table 4: Duration of clozapine treatment

Duration	Consumer (n=11)	Whānau, family, caregiver (n=16)
Less than 3 months	-	2
Between 3 months and 12 months	2	-
Between 1 and 5 years	3	5
More than 5 years	4	6
I am not sure	2	1
Did not answer	-	2

Part 2: Interactions with healthcare professionals

We asked questions about interactions with healthcare professional.

3. Which healthcare professional(s) do you see while taking clozapine?

Table 5 outlines information provided about interactions with healthcare professionals.

Table 5: Interactions with healthcare professionals

Healthcare professional ^a	Consumer (n=11)	Whānau, family, caregiver (n=16)
Doctor	7	9
Nurse	3	1
Pharmacist	2	3
Mental health team	5	12
Support worker	3	7
Social worker	1	1
Other healthcare professional	2	2
Did not answer	-	1

a. More than one answer could be selected.

Other healthcare professionals interacted with included aged residential care facility staff, staff at supported accommodation, pathways staff, keyworker from community mental health, psychiatrist and specialist neuropsychiatrist.

4. When do you see your doctor about clozapine?

Table 6 outlines information provided about seeing a doctor.

Table 6: How often do people see a doctor about clozapine

Frequency	Consumer (n=11)	Whānau, family, caregiver (n=16)
Every week	-	-
Every 4 weeks or monthly	2	3
Every 3 months	7	4
I am not sure	-	5
Other	2	3
Did not answer	-	1

Some people provided further information about seeing healthcare professionals:

- see their case manager for review regularly
- see doctor every 3 – 6 months or by appointment if required
- see mental health team every 6 – 8 weeks
- see both doctors every 3 – 6 months and also social worker every 2 – 3 months

It was mentioned that the doctor looks at blood tests and contacts pharmacy about the results.

5. When do you see a pharmacist to collect clozapine?

Table 7 outlines information provided about seeing a pharmacist to collect clozapine.

Table 7: How often do people see a pharmacist to collect clozapine

Frequency	Consumer (n=11)	Whānau, family, caregivers (n=16)
Every week	3	-
Every 4 weeks	4	5
Every 3 months	-	1
Someone else collects my medicines for me or my medicines are delivered	3	4
I am not sure	-	2
Other	1	2
Did not answer	-	2

Further information provided included:

- medicines are delivered to aged residential care home
- staff at supported accommodation pick up the medicines
- monthly blister pack medicines given by mental health team
- medicines collected after blood test done.

Part 3: Clozapine side effects

We asked questions about clozapine side effects.

6. Where do you find information about possible clozapine side effects?

Table 8 outlines responses provided about finding information for clozapine side effects.

Table 8: Where people find information about possible side effects of clozapine

Resource ^a	Consumer (n=11)	Whānau, family, caregiver (n=16)
Medicine information leaflet	7	7
Asking whanau, family and/or caregivers	1	5
Asking healthcare professionals	8	10
Social media	2	4
Other	4	3
Not sure	2	1
Did not answer	-	1

a. More than one answer could be selected.

Other sources of information included the Medsafe website, New Zealand Formulary, researching the internet, talking to pharmacist, psychiatrist, general practitioner and reading research from overseas and New Zealand.

7. If you experience a possible side effect from clozapine, who do you usually talk to?

Table 9 outlines information provided about who people would talk to about clozapine side effects.

Table 9: Who people would talk to if they experienced a side effect from clozapine

Person type ^a	Consumer (n=11)	Whānau, family, caregiver (n=16)
Doctor	9	10
Nurse	5	7
Pharmacist	3	3
Social worker	2	-
Whānau, family and/or caregivers	5	6
I am not sure	-	2
Other people	1	1

a. More than one answer could be selected.

Other people that were included in responses as sources of information were pathways staff, family member, mental health team, general practitioner, psychiatrist and neuropsychiatrist.

For this question we also received comments about:

- difficulties contacting the mental health agency
- personal experience of an adverse reaction causing hospitalisation
- how side effects to clozapine are proactively managed.

8. Which side effect of clozapine would you usually tell someone about?

Table 10 outlines information provided about clozapine side effects people would usually tell someone about.

Table 10: Side effects of clozapine that people would usually tell someone about

Side effect ^a	Consumer (n=11)	Whānau, family, caregiver (n=16)
Not able to pass a bowel motion (constipation)	4	10
High temperature or feeling unwell	6	5
An infection	5	4
Feeling sleepy	5	6
Saliva problems	5	9
Heart problems	7	4
Other side effect	4	3
I am not sure	1	1
Did not answer	1	1

a. More than one answer could be selected.

Other side effects mentioned that people would tell someone about were weight gain, extreme fatigue, memory issues, urinary incontinence, dizziness, thermoregulation problems, skin reactions, heart palpitations, stomach pain, impacted bowel, less focused, physical twitches, erectile dysfunction, nausea, anxiety, diabetes, tachycardia, hypotension, tremors, extrapyramidal movements and poor mobility.

One person said they hadn't had any of the side effects listed in the question.

Some people described their experiences with clozapine side effects. Examples of extracts from responses are included below:

'Feeling like a zombie..... Loss of creativity.....Feeling incredibly weighed down. Feeling disconnected and unreal.....'

'.....Restless legs at night....heart issues, feeling dizzy and not swallowing causing panic and loss of breath. Feeling of retardness with no emotions.. dribbling at night....'

'Akathesia..... high anxiety.... neither happy or sad but just flat....'

'Admitted to hospital with heart problems...'

9. Do healthcare professionals ask you about possible side effects of clozapine?

Table 11 outlines information provided about being asked about clozapine side effects.

Table 11: Asked about clozapine side effects

Answer	Consumer (n=11)	Whānau, family, caregiver (n=16)
Yes	6	11
No	3	1
I am not sure	2	3
Did not answer	-	1

10. Have you reported a side effect to the Centre for Adverse Reactions Monitoring (CARM)/Medsafe?

Table 12 outlines information provided about reporting a side effect to the Centre for Adverse Reactions Monitoring (CARM)/Medsafe.

Table 12: Reported a side effect to the Centre for Adverse Reactions Monitoring (CARM)/Medsafe

Answer	Consumer (n=11)	Whānau, family, caregiver (n=16)
Yes	-	1
No	11	12
I am not sure	-	2
Did not answer	-	1

Part 4: Constipation and clozapine

We asked questions about constipation and clozapine.

Constipation (struggle to pass a bowel motion) is a common side effect of clozapine.

11. Have you ever experienced constipation with clozapine?

Table 13 outlines information provided about constipation with clozapine.

Table 13: Experience of constipation with clozapine

Answer	Consumer (n=11)	Whānau, family, caregiver (n=16)
Yes	4	10
No	6	3
I am not sure	1	1
Not answered	-	2

12. Do you take medicines to help with constipation?

Table 14 outlines information provided about medicines to help with constipation from clozapine.

Table 14: Medicine use to help with constipation

Answer	Consumer (n=11)	Whānau family, caregiver (n=16)
Yes	5	10
No	6	2
I am not sure	-	3
Did not answer	-	1

13. If yes to question 12, how often do you take them?

There were 15 responses that selected 'yes' to taking medicines that help with clozapine-associated constipation in question 12.

Table 15 outlines information provided about how medicines to help with constipation are taken.

Table 15: Frequency of medicine(s) use for constipation

Frequency	Consumer (n=5)	Whānau, family, caregiver (n=10)
Every day	2	8
Most days	1	1
1-2 times a week	-	1
Other	2	-

Further information provided is summarised into themes in Table 16 below.

Table 16: Further information about constipation and clozapine

Theme identified	Summary of comments
Laxative use	<ul style="list-style-type: none"> • laxsol regularly and molaxole sachet if required • laxative if don't have bowel motion for more than 3 days • laxatives most days and when needed • laxatives prescribed as a regular medicine • magnesium supplement
Challenges experienced with managing constipation	<ul style="list-style-type: none"> • overeating can make constipation difficult to manage • choice of laxative depends on the individual's preference • hard to monitor bowel motions when the individual does not recognise that stomach pain is related to constipation pain • hard to manage balance between constipation and diarrhoea

14. Have you ever had to interrupt or stop your clozapine treatment due to constipation or bowel problems?

Table 17 outlines information provided about having to interrupt or stop clozapine due to constipation or bowel problems.

Table 17: Has clozapine been interrupted or stopped due to constipation

Answer	Consumer (n=11)	Whānau, family, caregiver (n=16)
Yes	-	1
No	11	11
I am not sure	-	2
Not answered	-	2

Further information provided included:

- people are poorly aware of constipation due to clozapine
- regular review of constipation is needed
- the stigma around constipation needs to be removed.

We also received information about an experience of impacted bowel on 3 occasions causing hospitalisation and an experience of decompensated schizophrenia due to constipation and urinary retention.

Part 5: Blood tests and clozapine

We asked questions about blood tests and clozapine.

As discussed in the overview section, regular blood tests are required throughout treatment to monitor for low levels of white blood cells and neutrophils, which is a side effect of clozapine.

15. How often do you currently have your blood tests for clozapine?

Table 18 outlines information provided about blood tests for clozapine.

Table 18: Frequency of blood tests for clozapine

Answer	Consumer (n=11)	Whānau, family, caregiver (n=16)
Weekly	-	-
Fortnightly	-	-
Every 4 weeks	10	12
I am not sure	1	2
Did not answer	-	2

16. Have you ever had to interrupt or stop your clozapine treatment due to a blood test result?

Table 19 outlines information provided about having to interrupt or stop clozapine due to a blood test result.

Table 19: Has clozapine been stopped or interrupted due to a blood test result

Answer	Consumer (n=11)	Whānau, family, caregiver (n=16)
Yes	1	3
No	10	8
I am not sure	-	2
Did not answer	-	3

Further information provided included:

- interrupted treatment due to neutropenia many years ago
- increased monitoring required but didn't stop treatment
- interrupted treatment when in hospital with Covid-19.

17. Do you experience any difficulties getting a regular blood test?

Table 20 outlines information provided about difficulties getting a regular blood test.

Table 20: Blood test difficulties

Answer	Consumer (n=11)	Whānau, family, caregiver (n=16)
Yes	3	2
No	8	11
I am not sure	-	-
Did not answer	-	3

Further information provided included:

- transportation problems
- difficulty in finding veins
- difficulty to get blood test on the day required
- decline to have a blood test on day required when feeling unwell
- blood form documentation not being available at testing service or is expired when go for test, requiring follow-up and waiting for new form to be sent.

18. Would you like to make any changes to the blood testing requirements for clozapine?

Table 21 outlines information provided about changes to the blood testing requirements for clozapine.

Table 21 : Changes to the blood testing requirements for clozapine

Answer	Consumer (n=11)	Whānau, family, caregiver (n=16)
Yes	1	3
No	7	6
I am not sure	3	4
Did not answer	-	3

Further information provided included:

- likes the security of knowing blood test results
- positive experience getting blood tests and visiting the pharmacy
- good to have blood tests less often
- concerned about scar tissue left behind from having regular blood tests and long-term effects
- helpful to do the test at home.

Part 6: Other feedback

We asked if participants would like to provide any other feedback or information about clozapine.

19. Do you have other feedback or information about clozapine that you would like to tell us?

Twenty people provided further feedback or information about clozapine.

Information provided has been summarised. Where applicable, extracts from some responses are included.

Clozapine use

Some respondents commented about experiences with clozapine use.

'...I have seen them get better in the last year - more engaged with life, people, exercising daily and more motivated generally. It has made a big difference..'

'Clozapine saved my life'

'I hate this med ! I still experience break through symptoms..... I find clozapine DISABLING.....'

'It's a dangerous medication, it never supported me in any way..... Clozapine almost killed me, and has left lasting adverse effects on my health....'

'I was on a higher dose rate of clozapine and then this year a reduction was made and that reduction meant so much lesser of the side effects and suffering of the physical type. Clozapine has not improved my mental health.....'

'Don't take it, not worth it, even if it keeps you well'

Clozapine side effects

Information was provided about experiences related to clozapine side effects and monitoring.

Side effects included in responses were: feeling very sleepy in morning and trouble keeping awake, weight gain, constipation, seizures, effects on cognitive function and ability to provide self-care, heart issues, trouble concentrating, tongue movements, neck twitches, nightmares and psoriasis. Extracts from some responses are noted below.

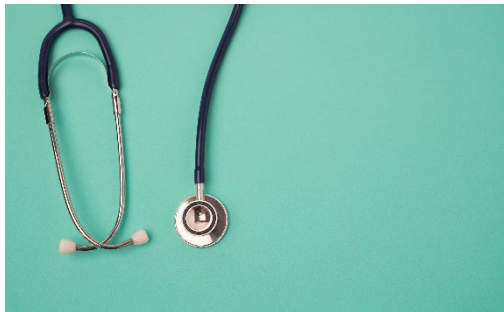
'.....serious sore throat there are a lot of GPs that don't understand the side effects of clozapine and don't understand the necessity to take extra blood tests'

'...There needs to be a proactive support plan for the consumer and the family about all the side effects, what they may be, the effect clozapine has on the body. I get very angry when people, particularly doctors who believed that if you tell the consumer they won't take the drugs. Totally understand that it may not be the right time when put on clozapine, but the family at least needs to be educated then health professionals at follow up need to educate the consumer'

'The information provided at the outset isn't sufficient. The side effects are a real issue.....'

One person mentioned they wanted to swap to another medicine.

Healthcare Professional Experiences



Overview

This section (pages 24 to 46) presents the information provided by medical doctors, pharmacists, nurses and other healthcare professionals.

Responses have been grouped as follows:

- [Part 1: Clozapine use](#)
- [Part 2: Interaction with consumers about clozapine safety](#)
- [Part 3: Clozapine side effects](#)
- [Part 4: Constipation and clozapine](#)
- [Part 5: Blood tests and clozapine](#)
- [Part 6: Other feedback](#)

For multichoice and single answer questions, results are grouped by the type of person.

For open ended questions or where more information was provided, a summary is given.

Where applicable, quotes from individual responses have been incorporated (*in italics*).

These people have given permission for their response to be published.

Part 1: Clozapine use

We asked general questions about clozapine.

1. Please describe your current role and location of practice

Table 22 outlines information about healthcare professional participants' profession, current role and location of practice.

More than one role and more than one location of practice could be chosen.

Table 22: Current role and location of practice

Current role and location of practice ^a	No.	Current role and location of practice ^a	No.
Medical doctor (n=61^b)			
Primary care/community			
General practice	15		
Secondary or tertiary care/hospital			
Outpatient psychiatric service (excluding dedicated clozapine clinic)	31	Inpatient psychiatric unit and/or hospital ward	17
Other outpatient clinical setting	4	Other inpatient clinical setting	5
Dedicated clozapine clinic	3		
Other			
Other role ^c	4		
Pharmacist (n=34)			
Primary care/community			
Community pharmacy	17	General practice	2
Rest home	1		
Secondary or tertiary care/hospital			
Hospital ward	11	Inpatient hospital pharmacy	8
Outpatient clinic	2		
Other			
Other role ^c	6		
Nurse (n=49)			
Primary care/community			
Mental health nurse	23	Nurse practitioner	11
Secondary or tertiary care/hospital			
Mental health nurse	14	Nurse (excluding mental health nurse)	2
Nurse practitioner	5		
Other			
Other role ^c	3		
Other healthcare professional (n=16)			
Primary care/community			
Social worker	2	Support worker	2
Pharmacy technician	1		
Secondary or tertiary care/hospital			
Pharmacy technician	3		
Other			
Other role ^c	8		

a. More than one role and location could be selected.

b. Medical doctor (n=61): psychiatrist or psychiatry registrar (40), general practitioner or general practitioner registrar (17), other medical doctor (4).

c. Other roles included: *Medical doctor*: geriatrician, neurologist, medical officer. *Pharmacist*: community mental health team, manager, pharmacist prescriber, academia. *Nurse*: leadership, physical health nurse. *Other healthcare professional*: Lived Experience Advisor, occupational therapist, recovery facilitator, mental health service, project manager, service manager adult mental health.

2. Approximately, how long have you been looking after people who take clozapine?

Table 23 outlines information provided about duration of looking after people taking clozapine.

Table 23: Approximate duration (years) of looking after people who take clozapine

Healthcare professional type	Duration range (years)	Median (years)
Medical doctor (n=61)	1 – 35	12.5
Pharmacist (n=34)	0.5 – 30	10
Nurse (n=49)	1 – 30	15
Other healthcare professional (n=16)	1 – 30	10

3. Approximately, how many people who are on clozapine are currently under your care?

Table 24 outlines information provided about number of people taking clozapine.

Table 24: Number of people who take clozapine under their care

Number	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professional (n=16)
1–10	38	15	31	6
11–20	11	7	3	3
21–30	3	1	2	3
≥ 31	2	6	5	2
Not applicable/other	7	5	8	2

Further information included:

- not currently looking after people taking clozapine
- intermittently involved in care
- small numbers
- numbers vary depending on service
- non-direct patient-facing roles.

It was mentioned that some people provide information and support to other healthcare professionals who are in patient-facing roles.

4. Of the people who take clozapine under your care, what proportion have been treated with clozapine for over 1 year on a continuous basis?

Table 25 outlines information provided about the proportion of patients taking clozapine for over 1 year.

Table 25: Proportion of patients who have been continuously taking clozapine for over 1 year

Proportion of patients	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professional (n=16)
0–10%	0	2	9	1
11–20%	2	2	2	2
21–50%	5	2	5	1
≥ 51%	50	25	26	9
Not applicable	4	3	7	3

5. Which resources do you use for information about clozapine in your everyday role?

Table 26 outlines information provided about resources used to find information about clozapine.

Table 26: Clozapine resources

Information source ^a	Medical doctor n=61 (%) ^b	Pharmacist n=34 (%) ^b	Nurse n=49 (%) ^b	Other healthcare professional n=16 (%) ^b
Clozapine data sheet	28 (46.0)	27 (79.4)	35 (71.4)	6 (37.5)
Hospital protocols or guidelines	41 (67.2)	15 (44.1)	31 (63.4)	9 (56.3)
National protocols or guidelines	30 (49.2)	25 (73.5)	24 (49.0)	7 (43.8)
International protocols or guidelines	26 (42.6)	6 (17.6)	6 (12.2)	2 (12.5)
Peer-reviewed journal articles	24 (39.3)	11 (32.4)	15 (30.6)	3 (18.8)
Hospital medicine information services	14 (22.9)	2 (5.9)	18 (36.7)	5 (31.3)
Ask colleagues (same profession)	36 (59.1)	25 (73.5)	26 (53.1)	9 (56.3)
Ask colleagues (other profession)	19 (31.1)	14 (41.2)	27 (55.1)	11 (68.8)
Clozapine patient education resources	12 (19.7)	13 (38.2)	30 (61.2)	7 (43.8)
Clozapine Patient Monitoring Services provided by pharmaceutical company	32 (52.5)	25 (73.5)	34 (69.4)	9 (56.3)
Other resources	6 (9.8)	8 (23.5)	5 (10.2)	1 (6.3)

a. More than one answer could be selected.

b. Percentage calculated on total of number of people in each group.

Information provided about additional resources is summarised in Table 27 below.

Table 27: Other resources used for information about clozapine

Information source type	Summary of comments
Clinical resources	New Zealand Formulary, Health Pathways, Primary Health Organisation, continued education, conferences, special interest groups
	Textbooks: Clinical Handbook of Psychotropic Drugs, The Maudsley Prescribing Guidelines, Psychotropic Drug Directory, The Clozapine Handbook.
	Other: coroner's reports, incident reviews and audits
Patient information resources	Consumer medicine information leaflet, accessible format information sheets, information from Choice and Medicines website, self-created patient resources
People-based resources	Patient advocates, peer support groups, speaking with tangata whaiora ⁴ and whānau
Training resources	Pharmaceutical Society of New Zealand (PSNZ) Clozapine Dispensing in Community Pharmacy accreditation course

⁴ Tangata whaiora = a person seeking health, or a person receiving assessment and treatment in mental health, addiction and intellectual disability services.

Part 2: Interactions with consumers about clozapine safety

We asked about interactions with people who take clozapine about clozapine side effects.

6. In general, how often do you ask patients if they are experiencing any potential side effects of clozapine?

Table 28 outlines information provided for asking about clozapine side effects.

Table 28: Asking about clozapine side effects

Frequency ^a	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professional (n=16)
Weekly	6	5	11	5
4-weekly	11	2	11	4
12-weekly	32	5	8	1
Ward rounds/ward visits/work shift	9	8	15	n/a
When medicines collected from pharmacy	n/a	9	n/a	n/a
Not applicable/other	12	11	8	6

a. More than one answer could be selected.

Further information included:

- ask about side effects at every interaction
- frequency of asking is variable
- increased frequency of asking about side effects when starting treatment, at dose changes or in acute issues
- ask other healthcare professionals to ask about side effects
- check monitoring protocols are being followed
- check clinical notes for information about side effects
- give education to other healthcare professionals about which side effects to ask about
- communicate about side effects with other healthcare professionals.

Part 3: Clozapine side effects

We asked about clozapine side effects.

7. Which clozapine side effects do you usually talk about?

Table 29 outlines information provided about specific clozapine side effects that healthcare professionals ask about.

Table 29: Which specific side effects of clozapine do healthcare professionals ask about

Clozapine side effect ^a	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professional (n=16)
Constipation	58	32	48	13
Symptoms of infection	31	16	27	6
Cardiovascular conditions	40	10	32	6
Sedation	47	16	37	9
Hypersalivation	40	17	37	8
Other side effect	8	9	9	3

a. More than one answer could be selected.

Further information provided included additional side effects which healthcare professionals ask about:

- metabolic syndrome including weight gain, appetite stimulation, obesity, diabetes
- falls, postural hypotension, dizziness
- stereotyped behaviours including obsessive compulsive disorders
- movement disorders including tremor, myoclonic jerks, extrapyramidal side effects
- gastric reflux
- sleep related
- fatigue
- jaundice, itching
- urinary incontinence
- headaches
- dry mouth
- restlessness
- confusion
- leg swelling
- shortness of breath
- difficulty breathing
- seizures

Some people said that that they ask about concomitant alcohol use, changes in smoking status, food and diet, and frequency of contact with general practitioner.

The importance of asking open-ended questions about side effects and clozapine tolerance, as opposed to specifying certain side effects was mentioned.

8. In general, how are potential clozapine side effects identified?

Table 30 outlines information provided about how potential side effects of clozapine are identified.

Table 30: Identification of potential clozapine side effects

Identification of side effect ^a	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professional (n=16)
Patients proactively inform	40	21	27	12
Asking patients directly	54	25	42	11
Routine monitoring	51	25	45	11
Not applicable or other	8	2	1	2

a. More than one answer could be selected.

Further information included other methods of identifying side effects:

- other healthcare professionals
- family/ whānau, caregivers and other support people
- monitoring protocols
- observation.

It was noted there were difficulties in the level of engagement and understanding of side effects and the importance of ongoing education about side effects for everyone.

9. If your patients have an adverse reaction to clozapine, do you report it to the Centre for Adverse Reactions Monitoring (CARM)/Medsafe?

Table 31 outlines information provided about reporting of clozapine adverse reactions to CARM/Medsafe.

Table 31: Reporting clozapine adverse reactions to CARM/Medsafe

Answer	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professional (n=16)
Yes	26	17	21	4
No	15	5	12	3
Not applicable or other	19	12	15	8
Did not answer	1	-	1	1

Further information included:

- an adverse reaction would only be reported if it was unexpected and/or serious
- reporting would be dependent on the side effect
- not yet have had to report an adverse reaction
- reporting is generally underutilised.

Part 4: Constipation and clozapine

We asked questions about constipation and clozapine.

10. Approximately, what proportion of your current patients experience constipation with clozapine?

Table 32 outlines information provided about proportion of experiences of constipation with clozapine.

Table 32: Proportion who experience constipation with clozapine

Proportion	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professional (n=16)
0–10%	12	6	12	4
11–20%	3	2	9	1
21–50%	21	5	13	4
≥51%	21	14	10	4
Not applicable or other	4	7	5	3

Further information provided to this question has been incorporated into question 12 below.

11. Do you routinely recommend, prescribe and/or administer laxatives to patients taking clozapine?

Table 33 outlines information provided about laxatives used for clozapine-associated constipation.

Table 33: Recommend, prescribe and/or administer laxatives

Answer	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professionals (n=16)
Yes: regular laxative to be taken at least daily	39	24	35	9
Yes: laxative to be taken if required	13	7	10	1
No	5	2	0	0
Not applicable/other	2	1	4	6
Did not answer	2	-	-	-

Further information provided to this question has been incorporated into question 12 below.

12. Do you have anything you would like to tell us about clozapine associated constipation? (eg, patients needing hospital treatment or had to stop clozapine due to bowel problems, challenges with monitoring or treating constipation)

Seventy-one people responded this question.

Responses are summarised and grouped into themes in Table 34 and Table 35 below.

Additional information from questions 10 and 11 has been incorporated.

Where applicable, extracts from responses have been included.

Table 34: Summary of information about clozapine-associated constipation

Theme identified	Summary of comments with a selection of quotes
Constipation with clozapine	<ul style="list-style-type: none"> • constipation associated with clozapine is common despite use of laxatives and is life-threatening • experiences of hospital admissions due to constipation with clozapine and situations where clozapine was discontinued <p><i>'Constipation is my biggest side effect of concern for patients'</i></p>
Laxative use	<ul style="list-style-type: none"> • high rates of laxative prescriptions among patients taking clozapine • laxatives are prescribed both for regular and if required use • laxatives are started proactively when initiating clozapine • variation of use and frequency of laxative use among patients • individualised treatment <p><i>'Difficulties I have had are trying to get the balance between constipation and then loose bowels due to over-prescription of laxatives'</i></p>
Monitoring constipation	<ul style="list-style-type: none"> • use of protocols (eg, Porirua Protocol) • screening and monitoring tools (eg, Bristol Stool Chart) <p><i>'Constipation protocol for early identification and step wise intervention'</i></p> <p><i>'...trends of poor bowel movement monitoring for clients following discharge from inpatient ward...'</i></p>
Factors that impact constipation with clozapine	<ul style="list-style-type: none"> • other medical conditions and medicines that exacerbate constipation • diet, hydration and exercise <p><i>'It is front of mind when considering prescribing any other medicines, such as analgesics'</i></p>
Awareness and education	<ul style="list-style-type: none"> • importance of awareness and education about constipation and clozapine <p><i>'The seriousness of clozapine associated constipation does not seem to be widely understood in New Zealand'</i></p> <p><i>'All members of the team, most importantly whaiora need to be aware of when medical review and intervention is needed...'</i></p>

Table 35: Challenges experienced with clozapine-associated constipation

Theme identified	Selection of quotes
Adherence to laxatives	<i>'.....find laxatives too much and stop taking them, although they are still prescribed '</i>
Hospital admission due to constipation	<i>'Challenges experienced at emergency department when sending patients for assessment if concerned. The knowledge of clozapine and the seriousness of the problems can be overlooked and are needing strong advocacy, or they are often sent home with laxatives already prescribed without intervention'</i> <i>'Issues encountered are the individuals may come to, or are directed by community services, to attend hospital due to lack of bowel movements for several days or constipation and sometimes the general medicine teams will stop the clozapine immediately rather than reduce dose and/or consult with liaison psychiatry'</i>
Monitoring constipation	<i>'Due to the very nature of the diagnosis, it can be difficult for whaiora to open up honestly about constipation'</i> <i>'....don't present with pain...'</i>

Part 5: Blood tests and clozapine

We asked about haematological adverse reactions of clozapine and related monitoring.

13. Please tell us more about your role in haematological monitoring of clozapine (*pharmacist, nurse, other healthcare professional respondents only*)

The information provided to this question followed several themes.

Responses from pharmacists included checking blood test results before dispensing, receive/follow-up notifications from clozapine patient monitoring systems, ensure blood tests are up to date, organise blood tests, facilitate registration on clozapine patient monitoring systems, liaise with healthcare professionals/mental health teams/patients/family and provide training and education.

Roles provided by nurses included checking blood test results, receive/follow-up notifications from clozapine patient monitoring systems, organise blood tests including transport, take blood tests, provide patient support, ensuring blood tests are up to date and liaise with healthcare professionals/mental health teams/patients/family.

Responses from other healthcare professionals included follow-up of missed blood tests, provide patient support, check blood test results and work closely with clozapine patient monitoring system for patients in region. It was also commented that monitoring is not part of the person's role.

14. Approximately, what proportion of your current clozapine patients are on weekly, fortnightly or 4-weekly haematological monitoring?

Table 36 outlines information provided about haematological monitoring frequency.

Information from responses has been grouped into number of people whose patients are all on weekly monitoring, on 4-weekly monitoring, on weekly or 4-weekly monitoring or on weekly, fortnightly or 4-weekly monitoring.

Table 36: Frequency of haematological monitoring

Frequency of monitoring	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professional (n=16)
All weekly	-	-	1	1
All 4-weekly	34	9	20	4
Either weekly or 4-weekly	15	17	7	6
Either weekly, fortnightly or 4-weekly	2	2	9	-
Not applicable or other	10	6	11	5
Did not answer	-	-	1	-

Further information provided included that the answer to this question is variable week-by-week and hard to quantify. Some people commented they are not in a patient-facing role or have no current patients and were unable to answer the question.

15. Approximately, what proportion of your current patients have had to interrupt or discontinue clozapine due to an abnormal blood test result?

Table 37 outlines information provided about cases where clozapine was interrupted or stopped due to an abnormal blood test result.

Table 37: Proportion of patients who have interrupted or stopped clozapine due to an abnormal blood test result

Proportion	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=49)	Other healthcare professional (n=16)
0–10%	49	28	34	8
11–20%	5	2	5	3
21–50%	1	-	1	-
≥51%	-	-	1	-
Not applicable or other	5	3	8	4
Did not answer	1	1	-	1

Further information about particular cases was provided, which included a case related to benign ethnic neutropenia and a case following vaccination.

Circumstances where the testing frequency was increased was mentioned.

Some people were unable to answer the question due to not currently looking after people who take clozapine, too few patients, not part of their role or have not experienced this occurring.

16. In patients who have experienced agranulocytosis with clozapine, how was this mostly identified?

Table 38 outlines information provided about how clozapine-associated agranulocytosis is mostly identified.

Table 38: Identification of clozapine-associated agranulocytosis

Answer ^a	Medical doctor (n=61)	Pharmacist (n=34)	Nurse (n=47)	Other healthcare professional (n=18)
Routine blood test	34	19	35	8
Signs or symptoms that may be indicative of neutropenia resulting in an additional test	3	6	13	3
Not applicable or other	26	13	9	6

a. More than one answer could be selected.

Some people commented that agranulocytosis has not happened to patients under their care or that this is not within the scope of their role.

17. Is there anything you would like to tell us about the benefits or challenges around the mandatory haematological testing?

Ninety-nine people responded to this question.

Comments that suggested improvements to the haematological testing requirements are included in question 18 below.

The remaining responses are summarised and grouped into themes below. Where applicable, a selection of extracts from responses have been included.

Benefits of the mandatory haematological testing

A summary of themes relating to the benefits of the mandatory haematological testing from healthcare professional experiences are outlined in Table 39.

Table 39: Benefits of mandatory haematological testing of clozapine

Theme identified	Selection of quotes
Safety of clozapine	<p><i>'Dramatic reduction in neutropenia-induced complications'</i></p> <p><i>'With the current strain on the mental health system, it would be almost impossible to implement a process where staff were required to maintain extra vigilance with whaiora on clozapine (ie closely monitor for signs of infection and ordering a full blood count)'</i></p> <p><i>'In the first few months of clozapine treatment, the benefits of mandatory testing undoubtedly outweigh the challenges'</i></p>
Regular engagement with patient	<p><i>'Provides an opportunity for follow-up of the patient in general'</i></p> <p><i>'The patient is seen by a healthcare professional at least once every 4 weeks'</i></p>
Adherence to treatment	<p><i>'The benefit of the system is that it supports adherence through the engagement it requires of clients, and alerts use when there is an interruption, for any reason'</i></p>
Adaptable when needed	<p><i>'Value that system allows clinicians to adapt to specific situations'</i></p>
Symptoms of neutropenia	<p><i>'...not every Whaiora that has neutropenia shows or recognises the symptoms...'</i></p>

Challenges of the mandatory haematological testing

A summary of the themes relating to the challenges of the mandatory haematological testing from healthcare professional experiences is outlined in Table 40.

Table 40: Challenges of mandatory haematological testing of clozapine

Theme identified	Summary of comments
Requirement of ongoing testing	<ul style="list-style-type: none"> • ongoing haematological monitoring after 1 year with clozapine is a burden for patients and healthcare professionals • discourages clozapine use • recent study reviewed less frequent monitoring • updated thresholds for blood counts have caused unnecessary treatment interruptions and inappropriate cessation of clozapine treatment
Impacts to patients	<ul style="list-style-type: none"> • regular blood tests are disruptive to people's lives, especially if they live in rural areas or travel • difficulties in accessing lab for blood tests • cost • do not like having blood tests and may refuse a blood test • discontinued clozapine due to difficulties with haematological monitoring
Blood tests	<ul style="list-style-type: none"> • delays in blood test results, impact to dispensing and follow-up of results (particularly if are abnormal) • blood test results not available or not copied to clozapine patient monitoring system and difficulties in finding the results • difficulties in blood test being taken on the correct day or when taken close to weekends • delayed alerts from clozapine patient monitoring systems • issues with collecting suitable blood samples • haematologist input required for abnormal blood test results
Clozapine patient monitoring system	<ul style="list-style-type: none"> • inflexibility of clozapine patient monitoring systems; clozapine interrupted due to a one off 'red' blood test, timeframes between blood test dates and dispensing dates • communication issues • new user registrations difficulties • slow transfer of patients between systems • use of an overseas based monitoring system
Activities associated with testing requirements	<ul style="list-style-type: none"> • lack of coordination between services • communication difficulties • increases in workload
Awareness of monitoring requirements	<ul style="list-style-type: none"> • lack of understanding of the importance of timely blood tests
Nurse practitioners	<ul style="list-style-type: none"> • restrictions on nurse practitioners being able to commence clozapine is a major barrier
Recognition of other side effects	<ul style="list-style-type: none"> • importance of other side effects of clozapine such as constipation, cardiac events and seizures

A selection of quotes from responses relating to challenges of mandatory haematological testing is highlighted below.

'Blood testing frequency can be an added barrier to getting people well with clozapine'

'The COVID pandemic and restrictions on what we could do with regards to haematological testing demonstrated that it was safe to continue treatment with less frequent testing regimes, this has also been demonstrated in the medical literature and I believe that there is scope to review or amend the testing requirements'

'Significant stress for patients and family during the holidays as labtest and pharmacies have very limited hours or are closed'

'It can be hard to get results, particularly when the test is done on the day that medicine is needed'

'Extremely impactful on patients when they miss a test for whatever reason'

'The system in New Zealand is not patient centred ie. Having a blood test within 72 hours of dispensing clozapine if on 4-weekly full blood counts and then only supplying a month or less'

'Challenges especially in residential care as requires a well organised and streamlined approach of many services interacting and those involved understanding importance of timely results'

18. How could the current haematological testing requirements for clozapine be improved?

Eighty-eight people provided further information to this question.

Some people said that they did not feel any changes to the testing requirements for clozapine are needed.

Suggestions for improvements in responses have been summarised and grouped into themes in Table 41 below.

Table 41: Suggested improvements of the current testing requirements for clozapine

Themes identified	Summary of comments
Frequency of haematological testing	<ul style="list-style-type: none">• reduce frequency• provide greater flexibility
Thresholds of blood counts	<ul style="list-style-type: none">• return to higher white blood cell counts and neutrophils counts post 18 weeks of treatment
Testing methods	<ul style="list-style-type: none">• point of care testing at pharmacies• home blood tests• access to phlebotomists onsite
Management of blood tests	<ul style="list-style-type: none">• guidance to haematologists• access to haematologists specialising in clozapine• use of clinical judgement
Blood test results	<ul style="list-style-type: none">• faster reporting including availability in clozapine patient monitoring systems
Follow-up of blood test results	<ul style="list-style-type: none">• same day follow-up• faster reporting of overdue blood tests
Reminders about blood test	<ul style="list-style-type: none">• text reminders
Responsibility for follow-up of blood tests	<ul style="list-style-type: none">• clarification of who is responsible
Blood test date and dispensing	<ul style="list-style-type: none">• extend time period between blood test date and dispensing date
Clozapine patient monitoring system	<ul style="list-style-type: none">• register patient prior to having a blood test• one monitoring system• New Zealand based system• increased flexibility within system• nurse practitioners as lead clinician in system
Education and awareness	<ul style="list-style-type: none">• increased education and awareness• communication between services• alerts on medical records
Extending testing parameters	<ul style="list-style-type: none">• myocarditis• metabolic screening

Part 6: Other feedback

We asked if participants would like to provide any other feedback or information about clozapine.

19. Do you have any other feedback or information about clozapine that you would like to tell us?

Eighty-five people provided further information to this question.

Feedback and information provided about clozapine is summarised below into themes.

Where applicable, a selection of extracts from responses have been included.

Clozapine use

Clozapine is an effective medicine and for some people it is a life-saving treatment.

Clozapine requires dedication from everyone involved to be aware of the potential side effects and monitoring.

'It [clozapine] is a very effective drug but it does require dedication on behalf of all parties involved to be aware of potential side effects'

'In my experience as a service provider, I have seen many examples of client's having their quality of life improved by receiving clozapine medication. However, it does seem to be a trade-off between this improvement and managing side effects.'

Regulatory requirements of clozapine

Clozapine is underutilised and people who may benefit from its use are being denied access due to difficulties in implementing its use and maintaining the necessary monitoring.

Clozapine is over-regulated, which leads to an unnecessary burden on patients, families and the healthcare system due to difficulties in access to the medicine.

'almost certainly underutilised to the significant challenges regarding adherence with medication and monitoring requirements'

Tertiary/secondary care and primary care

Inability to discharge patients who are stable on clozapine to primary care from secondary/tertiary care.

Primary care needs more funding and support to facilitate general practice management of clozapine.

Hard to initiate treatment with clozapine in the community and that there is limited acute psychiatric hospital beds throughout New Zealand.

'Many patients on clozapine are doing well and are stable, but remain under tertiary psychiatric care'

'It would be very helpful if there was funding available to primary care..'

'Primary care is ill-equipped to deal with many of the clozapine cases who are being pushed into the community because of inadequate funding/staffing in tertiary care'

'I would like to see GPs [general practitioners] take over the role of prescribing clozapine'

'I do feel that patients on long term clozapine should have an annual review with a psychiatrist. This is not provided in this region where a patient is deemed stable on long term clozapine is discharged to GP care'

Clozapine patient monitoring systems

Several people commented about the clozapine patient monitoring systems and difficulties experienced.

'Having a local monitoring system would increase safety and flexibility in managing clients on clozapine who have been discharged to general practice prescribing'

'Clinical discretion is absentthe lack of flexibility in the system has led to some clients to refuse to take clozapine when confronted with such requirements'

'...Having the 2 brands/services is difficult to monitor and provide care for...'

Blood tests

Clozapine monitoring could take place in pharmacies, with finger prick blood tests and pharmacist input in relation to side effect monitoring.

Mental health nurses could be trained to take bloods.

'...testing, patient education and medication collection from specialised community pharmacies...'

Education, awareness and training

There is a lack of awareness about the two brands of clozapine and how there are two clozapine patient monitoring systems.

Education and training are needed about the importance of avoiding treatment gaps, side effects and monitoring requirements of clozapine, and how to manage these.

'more awareness about the importance of monitoring of clozapine..'

'more study days are required in hospital setting...'

'..it seems that pharmacists are the only health professionals involved that need compulsory training/examination in order to fulfil their role in clozapine..'

'...There does seem to be a lack of knowledge at times in A&E [accident and emergency] at the hospital when presenting a client with concerns around symptoms of clozapine side effects.'

Prescribing restrictions for clozapine

Pharmacist prescribers and nurse practitioners are not able to prescribe clozapine, however this should be considered within the prescribing restrictions.

Clozapine should only be prescribed by a psychiatrist.

'...it would be really useful if Medsafe were to consult about adding this class [pharmacist prescribers] to the restrictions on clozapine..'

'...this restriction is entirely unnecessary as Nurse Practitioners are authorised prescribers and mental health nurse practitioners are very much aware of the challenges that clozapine provide as a prescriber. This barrier to practice needs to be removed as it impacts upon clients...'

'Nurse practitioner should be able to take over clozapine care when patient is stable on clozapine and is discharged from mental health services'

'I am strongly of the opinion that clozapine should be a psychiatrist-only medication'

Clozapine side effects

Experiences with clozapine side effects such as myocarditis, cardiomyopathy, bowel related side effects, hypersalivation and metabolic side effects.

The lack of knowledge about the continual use of clozapine over 20 years and in people over 50 years of age was noted.

Side effects seem to increase with age, and that doses can be usually safely reduced with appropriate monitoring.

A weight management programme should be in place at the start of clozapine treatment. There were concerns about longer term metabolic side effects of clozapine and hopes there will be more funded medicines to address such side effects.

Constipation and hypersalivation are common, while neutropenia and agranulocytosis are less common.

Māori

Information provided included Māori being more likely to be prescribed clozapine, use of high doses and cultural awareness.

'There is a serious equity issues in the use of clozapine with Māori being 2.7 times more likely to be prescribed clozapine.....'

'..The dosage for any Māori is too high...remain on high doses without any titration up or down depending on their presentation....'

Indications for use

The indication of clozapine is limited to treatment-resistant schizophrenia in New Zealand, but there is evidence for use in other mental health disorders.

Dispensing

Relaxing the dispensing quantities would be beneficial for those who are on stable long-term treatment, particularly around holidays or long weekends.

Inconsistency in blood test requirements between pharmacies.

'There does seem to be inconsistent requirements for the blood test requirements depending on which pharmacy is dispensing the medication'

Clozapine specific roles

One person discussed how they work within the community mental health teams looking after people who take clozapine in their region. In their role they work with general practitioners, and support community pharmacies dispensing of clozapine.

Support

People require support and assistance in relation to the monitoring requirements of clozapine.

Monitoring resources

One-person highlighted difficulties in getting a clozapine level in a timely fashion.

Another person noted that access to electrocardiogram (ECG) in secondary care outpatient psychiatry is very poor.

Other

There was a comment about the nationwide availability of clozapine liquid between regions.