

## Information for Patients

# Hydroxychloroquine Screening

You have been invited to attend a clinic at Manchester Royal Eye Hospital to screen for signs of damage to your eyes because you have been prescribed hydroxychloroquine or chloroquine.

### What is hydroxychloroquine retinopathy?

Hydroxychloroquine is a disease-modifying anti-rheumatic drug (DMARD). It is used to treat several conditions including rheumatoid arthritis, systemic lupus erythematosus (SLE) and several skin conditions. It is safe and effective; however, it has a low risk of retinal toxicity.

It is known that some people who take hydroxychloroquine for more than five years and/or in high doses are at increased risk of damage to their retina, the light sensitive layer of cells at the back of the eye. This is known as retinal toxicity or retinopathy.

Hydroxychloroquine retinopathy is rarely seen in the first five years. The risk is much higher in patients with a longer duration of use. Between 20 and 50% of people taking the drug for 20 years or more will develop retinopathy. Overall, around 7 patients out of every 100 taking the drug for more than 5 years may develop retinopathy that can be detected with specialised tests. These risks of toxicity are higher if you are taking chloroquine.

Severe retinopathy, especially in the central area called the macula, causes significant, irreversible sight loss. For this reason, the NHS now offers patients taking hydroxychloroquine regular eye health checks to screen them for signs of retinopathy.

## What is hydroxychloroquine retinopathy screening?

The aim of screening is not to prevent retinopathy but to detect the earliest definitive signs of it causing any problems with your vision. This appointment is aimed at patients that have been taking hydroxychloroquine for more than 5 years (or chloroquine for a year or more).

Some patients may be referred for screening earlier than 5 years if they have one of the risk factors. These risk factors include:

- Taking a high dose of hydroxychloroquine or taking chloroquine
- Taking tamoxifen for breast cancer
- Having poor kidney function

## What do I need to bring to the appointment?

- A list of your current medication which includes the dose of hydroxychloroquine
- Any glasses or contact lenses you wear
- Sunglasses, as your eyes can feel sensitive to the light after having eye drops

## What happens at the hydroxychloroquine retinopathy screening clinic?

A vision test, a short questionnaire and a set of specific ophthalmic images including a scan (OCT) and fundus autofluorescence (FAF) are taken on the day of the assessment clinic. Eye drops will be put in your eyes to temporarily make your pupils larger. You may find the drops sting briefly and your vision will be blurred and more sensitive to light for a few hours. The appointment will last approximately 2 hours.

## What happens next?

You are free to leave the clinic once your imaging has been completed. Your ophthalmic images, vision test and questionnaire will be reviewed by an ophthalmologist or an ophthalmic clinician.

We aim to send a letter to you, your GP and the doctor who referred you for screening within 3 weeks with your results.

## What happens if I have underlying retinal diseases?

Patients with underlying retinal disease may be at higher risk for toxicity, although there are no specific data to confirm this. It seems reasonable not to add a potentially toxic agent to the retina on top of existing retinal disease. The existing abnormalities may also

interfere with the test results; therefore, if we detect any existing retinal diseases, we will write to you, your GP and the doctor who referred you for screening to discuss the results.

## Important

Please do not drive yourself to this appointment, you will have eye drops that cause your vision to be blurred for 5-6 hours.

It is important you attend your appointment, if you need to cancel or have any other questions about your appointment, please call us as soon as possible on (0161) 276 5533 (option1) between 8.30am and 4.30 pm Monday -Friday.

## Note

This clinic can only check retinal conditions related to Hydroxychloroquine/Chloroquine screening. We advise continued routine checks with your community optometrist who will be able to do a general eye check.

If you get a new problem in between appointments, you have the option of either contacting us directly, going to the emergency eye service if it is an emergency or getting advice from a community optometrist or your GP. Do not wait until the next routine appointment.

## MyMFT

We would recommend registering for the MyMFT patient portal to better manage your care/appointments, communications, and experience with the Trust, you can do so by using the following link below:

### Sign up for MyMFT:

1. In your Internet browser, go to <http://my.mft.nhs.uk/MyMFT/>
2. Click the Sign Up Now link in the New User box.
3. Enter your one-time MyMFT Activation Code exactly as it appears below. If you do not sign up before the expiration date, you will need to request a new code.

MyMFT Activation Code: Activation code not generated.

Current MyMFT Status: Active

4. Follow the prompts on the screen to complete your signup.

Our staff are here to help you, if you need the following, please let us know if:

- You would like this information in an alternative format, for example large print, braille, or easy read
- At your appointment if you need an interpreter, including British Sign Language
- You are disabled, and we can support you with reasonable adjustments

## **Travel**

You may be able to access free travel to your appointment or be eligible for your appointment travel costs to be refunded through the national NHS scheme – find out more here: [Transport | Greater Manchester Integrated Care Partnership \(gmintegratedcare.org.uk\)](#)

Depending on your health and mobility, you may be able to access the free NHS Patient Transport Service to help you get to your appointment, find out more here:

<https://www.nwas.nhs.uk/services/patient-transport-service-pts/>