

Crizanlizumab for preventing sickle cell crises in sickle cell disease

Information for the public

Published: 3 November 2021

www.nice.org.uk

Crizanlizumab (Adakveo) is available on the NHS as a possible way to prevent recurrent sickle cell crises in people aged 16 and over.

It will be available to patients by February 2022 at the latest.

Managed access period

You can only have it through something called a [managed access agreement](#). A managed access agreement is used when NICE thinks a treatment is promising but is not sure about its long-term benefits, and wants to collect more evidence before it makes a final decision.

To have crizanlizumab, you need to have had 2 or more confirmed sickle cell crises in the past year.

You'll also be asked if you're happy for your data to be collected so that the NHS can understand how patients benefit from crizanlizumab. This includes things like your age, gender and weight. Every year your healthcare team will record if you had hydroxycarbamide and how many sickle cell crises you had.

What happens at the end of the managed access period

Evidence is being collected on crizanlizumab until January 2025. After this NICE will review the new evidence collected during the managed access period, decide whether or not to recommend it for routine use on the NHS, and update the guidance. It will be available through the managed access agreement until then.

If the evidence shows that crizanlizumab does not work well and is not good value for the NHS, it will no longer be recommended and your treatment with crizanlizumab will stop.

Is this treatment right for me?

Your healthcare professionals should give you clear information, talk with you about your options and listen carefully to your views and concerns. Your family can be involved too, if you wish. Read more about [making decisions about your care](#).

Questions to think about

- Why do you need to collect my data?
- How well does it work compared with other treatments?
- What are the risks or side effects? How likely are they?
- How will the treatment affect my day-to-day life?
- What happens if the treatment does not work?
- What happens if I do not want to have treatment? Are there other treatments available?
- What will happen to my treatment if NICE no longer recommends crizanlizumab?

Information and support

The [NHS website](#) may be a good place to find out more.

These organisations can give you advice and support:

- [Sickle Cell Society](#) 0208 961 7795
- [AOFAC Foundation](#) 0740 455 3898 or info@aofacfoundation.org

You can also get support from your local [Healthwatch](#).

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

ISBN: 978-1-4731-4296-1