

Mylron+ & Alice Al chatbot for the Genetic Haemochromatosis (GH) community

Innovative Use of Technology, Social & Digital Media Patient Experience Network National Awards 2024

> Neil McClements, CEO Haemochromatosis UK

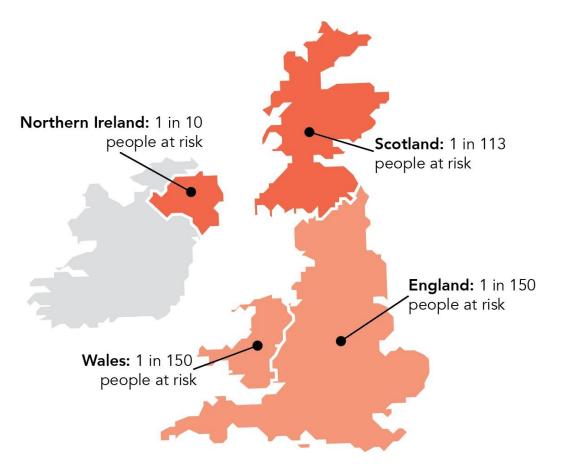
What makes this initiative stand out?

- Genuine co-design and collaboration to address real, unmet patient needs
 - Developed in response to the GH community's unmet needs
 - Designed by the community, for the community
 - Iterative, agile development of clickable then working prototypes for review
- The MyIron+ app was delivered on-time, on-budget
 - Most IT projects over run on cost and are delivered late
 - Mylron+ was delivered on-time and within budget (<£20k)
- The app provides a platform for further patient-advocacy and research
 - App usage generates a unique GH patient registry dataset for clinical research and community advocacy
 - MyIron+ has become the largest patient registry for GH globally within <18 months
- Alice AI chatbot available 24x7 for help & advice
 - Used in over 20 countries by 2,000+ people within 3 months of launch



Why develop an app?

- Genetic haemochromatosis isn't "rare", it's rarely diagnosed
- Clinician awareness is generally low good help & advice is hard to find in NHS
- There is no cure, but treatment is simple & effective very regular blood donation
- For optimal health, patients need to track their blood results, juggle appointments, manage paperwork & advocate for their care
- Demand for the charity's help is doubling annually
-maybe an app could help with this?



1.2 million people at risk nationally

Evaluating the Cost of Illness of Genetic Haemochromatosis in the UK York Health Economics Consortium, January 2022 Source : https://www.haemochromatosis.org.uk/cost-of-illness

Mylron+ The iron overload app

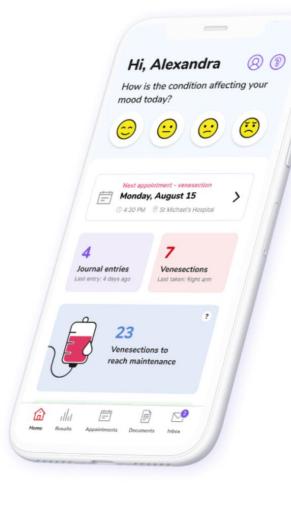
Manage your genetic haemochromatosis with our app. Designed by people with iron overload - for people just like you.

Available today for <u>Apple IOS</u> and <u>Android</u> smartphones & tablets.











Our app was designed by members of the GH community – for the community in

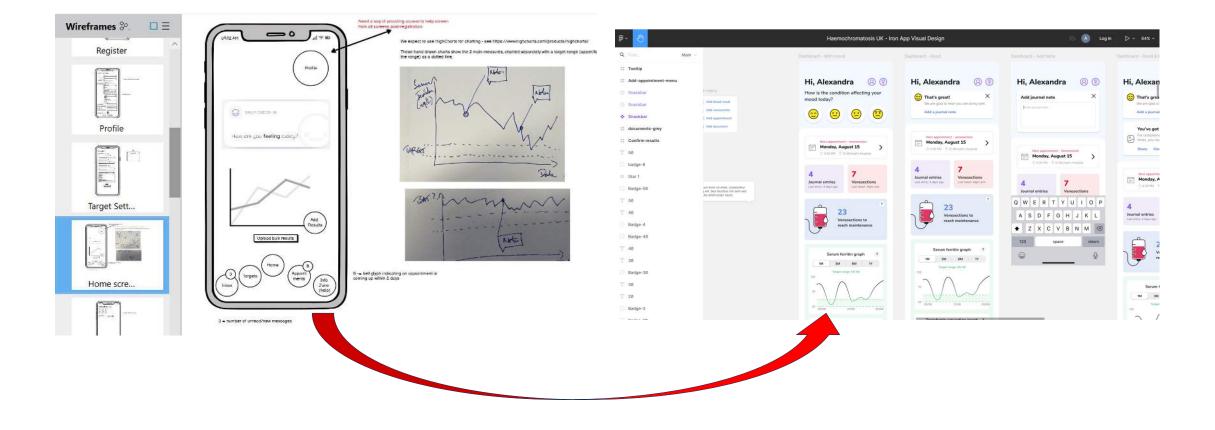
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Haemochromatosis • UK Helping people live with iron overload

Community-led design process

We started with ideas & rough sketches (3 months)...

...transformed to clickable prototype (2 months)





Iterative, agile project delivery

From clickable prototype...

...to working app on IOS/Android phones & tablets (within 5 months)!

How are you feeling today?

(:-)

5

Serum ferritin graph

6M

Venesections

1Y All tim

Latest location: Left arm

<u>..</u>

Journal entries

Latest entry: 427 days a...

Got questions?

Powered by AI, trained by

Ask Alice a question

Haemochromatosis UI

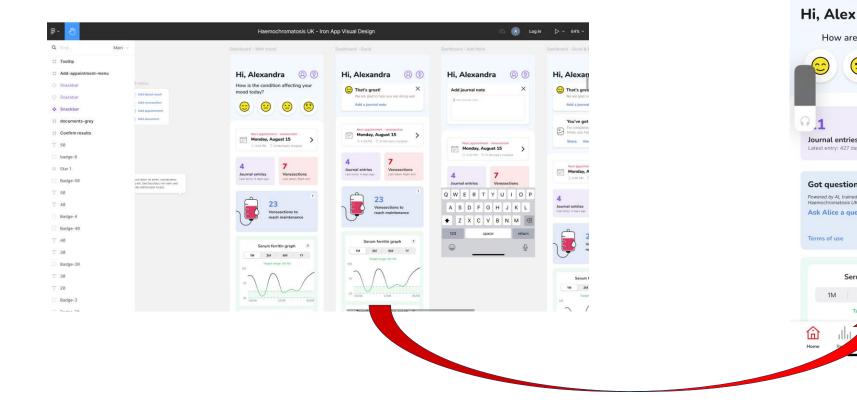
Terms of use

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Alice, the newest member of #TeamIronOverload

Alice is powered by artificial intelligence – trained by Haemochromatosis UK's helpline team in GH care pathways and best practice.

Alice is available 24x7 in Mylron+ app & online.

Alice has helped over 2,000 patients since launch in April 2024 – she compliments the charity's 1-2-1 helpline services, helping the charity scale up its support and provide round-the-clock care.

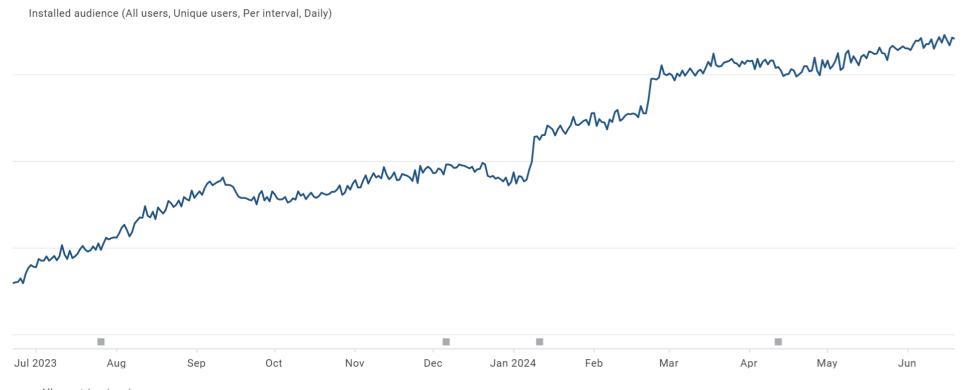
https://www.haemochromatosis.org.uk/alice

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Alice is trained using the charity's clinically approved resources + lots of patient feedback. She is always learning...



Mylron+ usage growing daily, globally



All countries / regions



Mylron+ does just what the community needs...

"Just opened the app and started adding my details. Looks fabulous. It will help me understand and help others understand and move forward. Brilliant."

Prototype triallist patient, March 2023

For further information & download, see : https://www.haemochromatosis.org.uk/app

Mylron+ helps people live well...

- "Essential app for monitoring your iron overload...
- The app is incredibly useful, for planning treatments, documenting your iron levels and being able to reach out to a qualified professional when needed.
- Since diagnosis (through the charity that created the app as my GP was useless), I've been able to track my iron levels, keep note of my appointments, and get to a manageable level now. Thank you!"

Mylron+ app user, June 2024

For further information & download, see : https://www.haemochromatosis.org.uk/app



Mylron+ is inclusive...

"I am autistic, and that makes phone calls a real challenge for me...

I have called up the charity's advice line before and spoke with the nurse who was brilliant, but it is difficult for me to do so.

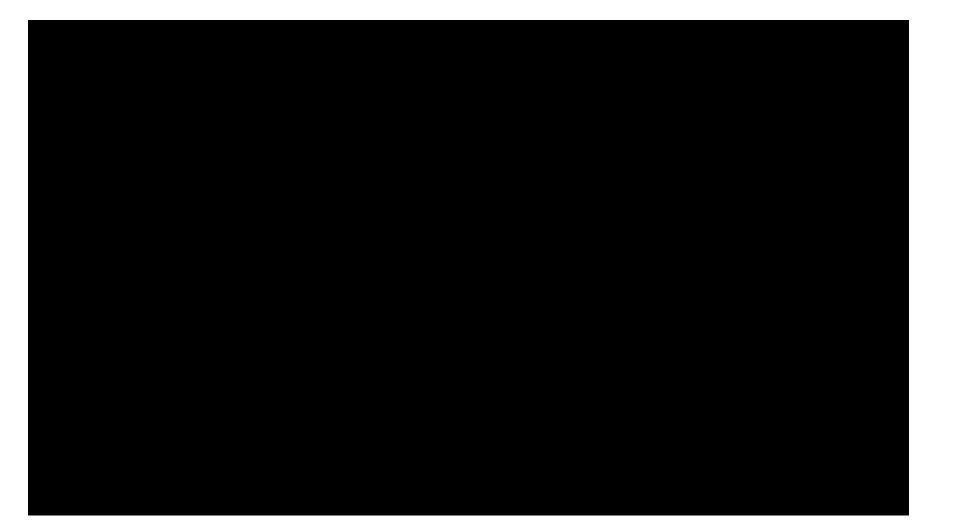
With Alice, I could just quickly fire it up and ask all manner of questions without any anxiety."

Mylron+ app user, January 2024

For further information & download, see : https://www.haemochromatosis.org.uk/app



Apps are not just for "youngsters"...





Try Mylron+ for yourself!





Ap<mark>ple IOS</mark>



Android



Thank you!

Any questions?