Impact
Report

WMuk

Executive Summary

Jane Nicholson, CEO

I am extremely proud to present to you WMUK's first Impact Report. Everything in this report was driven by you – the WM community – to benefit you. At every turn, we've asked patients and families what they need, and you have responded with insightful feedback and enthusiasm.

In a difficult fundraising climate and facing the extra challenges of advocating for a rare disease, we aimed to grow our reach, income and support services. We've learnt a lot along the way, but I think it's clear that we've managed to do just what we set out to do.

A huge thank you for your support – whether that was donating, volunteering time or raising awareness – we could not have done this without you.

At a glance: our impact

WMUK Support Line usage grew by 188%, establishing its position as the only support line of its kind in the world

We published the UK's first WM booklet for anyone affected by the disease

Active Monitoring checklist

for people with

Waldenstrom's macroglobulinaemia

Active monitoring (AM) is when your healthcare team monitor your WM, rather than treating it right away. You may hear it called 'active surveillance' or 'watch and wait'. For more information, visit wmuk.org.uk.

What will AM consist of?

☐ I understand how often I will have monitoring appointments with my healthcare team

☐ I understand and am satisfied with the format of my future appointments (e.g., face-to-face, telephone, virtual)

☐ I understand what tests will need to be performed to monitor my condition and how often these will be performed

☐ I feel that I have been given enough information about what to expect during the active monitoring phase of my treatment

My Waldenstrom's macroglobulinaemia

☐ My current symptoms have been discussed during this consultation

☐ I understand what new symptoms I may experience and when to contact my healthcare team

☐ I understand that WM can affect my immune system and therefo

Made step changes in care pathways by publishing the **Active Monitoring Checklist**

We created the Patient Advisory Group (PAG). Made up of **17 WM patients**, PAG keeps the patient voice at the heart of our organisation

Co-hosted the **first European WM Patient Forum**, attended in person and online by over 200 patients and family members

Supported 124 patients financially, by providing a grant of £200 to help with rising bills and travel costs

About

Waldenstrom's macroglobulinaemia

WMUK is the only charity in the UK focused on supporting people affected by Waldenstrom's macroglobulinaemia (WM).

WM is a rare form of blood cancer, with around 400 people in the UK diagnosed with the disease every year.

It is a slow-growing cancer and doesn't always need treating right away. Symptoms can vary from person to person, from fatigue through to night sweats and numbness or tingling in hands and feet.

Due to the rareness of the disease and lack of treatment options, clinical expertise and reliable information, the experience of people affected by WM can be isolating and confusing. This creates a psychological burden alongside the physical symptoms of the disease.

WMUK exists to change this and help people to live well with WM.

Where we've come from

2012

Charity created and runs as a volunteer organisation.

The Rory Morrison Registry

WMUK

First
UK Waldenström's
Macroglobulinaemia
Registry Report

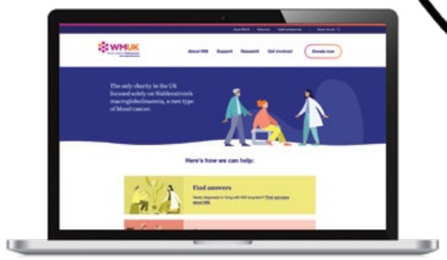
2018

2016

The **Rory Morrison WMUK Registry** is set up in memory of Rory Morrison, who was passionate about using patient data to drive our understanding of the disease and find better treatments.

2019

To reach more patients and give the organisation more strategic purpose, the Board of Trustees reregister the charity and bring on the **first paid member of staff.**



2020

We launch our **first professional website**, with WM-focused information during the global pandemic.

2021

We raise **£124,000** in the 2020–21 financial year, employing three part-time members of staff. The first WM-survey is run, giving valuable insight into the many gaps in services and care faced by the WM community, and focusing the charity's immediate work.

2022

After successful community fundraising campaigns, we launch the **world's first ever nurse-led WM support line**. Initially it's open 2 days a week, but due to need it quickly expands opening hours to four days a week.

2023

The charity raises **£380,000** in charitable income, still with only a skeleton staff of three. By providing services patients are asking for, we engage more people with WM, growing the community by 94%.

How we measure our impact

Our vision is that people affected by WM live longer, good quality lives, being **supported every step of the way by WMUK.**

We published our five-year strategy. Informed by people affected by WM, it lays out how we're going to achieve our vision, focusing on four key areas:

- Be the **expert voice** of WM, the most credible leading-edge source
- **Harness knowledge**, data and evidence to drive equitable access and improve patient outcomes
- **Empower patients** to live well with WM and support them throughout their WM experience
- Be a **financially viable** organisation with a strong foundation for achieving our goal

> I think WMUK are a really excellent charity and I know how lucky I am that I have that support available to me.
>
> Support Line user

Being the expert voice

What we set out to do

- Produce high-quality, up-to-date, trustworthy information.
- Reach more HCPs, outside of the key group of WM experts.
- Provide the community with a wider range of expert- and patient-driven information.

Why it matters

- Patients and families are desperate for more information on physical symptoms and mental health to help them live well with WM.
- More information for under-resourced NHS healthcare teams will help patients get the best care.
- Relationships with other experts will drive meaningful and long-term change.

What we did

Information

We worked collaboratively across the community of patients and HCPs to ensure the expert voice remains throughout our information. Using this approach, we published the UK's first guide aimed directly at people newly diagnosed with WM.

The guide was viewed 333 times in five months, the equivalent of 75% of the UK's approximate newly diagnosed population.

Demonstrating our information is of high quality is vital to earn the community's trust. This year we started the process of applying for PIF TICK accreditation, which will demonstrate that our information is independently certified as being accessible, expert and up to date.

Website

Our website was visited by almost triple the approximate number of people living with WM in the UK.


11,168 unique visitors

Healthcare professional outreach

We kick-started vital healthcare professional outreach and education to help provide better care, improve pathways and create more services, with the ultimate aim of standardising care for all WM patients.

Published the UK's first checklist for Active Monitoring.

Showcasing the importance of collaboration between WMUK, HCPs and the community, we gained consensus on Active Monitoring from 232 patients and 43 HCPs to produce the Checklist, which aims to guide conversations between patients and HCPs, educate HCPs on active monitoring, and empower patients to identify topics which are important to them and their WM. It is a huge step in addressing inequalities in the WM care pathway and ensuring patients receive a more standardised approach to this stage of their care.

> "It was so beneficial hearing first hand from the clinical experts, patient experiences and the great efforts WMUK are doing on our behalf as WMers."
>
> **– Attendee of the European WM Patient Forum**

Harnessing knowledge, data and evidence

What we set out to do

Launch a pilot app for the WM community, to learn how we can support patients in the digital age.

Invest time and funds into the importance of patient-centred data..

Concentrate on internal data capture to better understand the impact we are having.

Why it matters

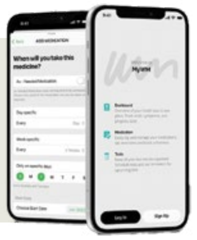
- Data is where true change will come from – the more data and insight we have, the better chance we have of improving outcomes and treatments, and eventually finding a cure.
- In a world of increasing digitalisation, it's our duty to the give the WM community the tools and knowledge they need to navigate in an evolving healthcare system, and better manage their care.

What we did

WM App

We proved there is an appetite from the WM community for an app that helps them to monitor their health and manage their care from home.

104 WM patients signed up to our pilot app, helping us to collect data about their experience and giving us more insight into the reality of living with WM to inform and guide research.



The Rory Morrison WMUK Registry

1,637 patient records, the biggest of its kind in the world.

We further invested in the importance of data, focusing on quality of life and ensuring the data the charity holds remains patient-centred and helps improve outcomes for everyone living with disease.

Data capture to report impact

We worked alongside key stakeholders from across the community to create a Data Strategy to keep patients at the heart of our data programmes, protecting their data and making sure outputs are patient-focused.

Alongside this we developed and implemented internal data capture processes to allow us to report more in depth on our impact, better understand the community's needs and open the possibility of communicating on a more personal basis.

> As a WM patient, there are many things to manage, including medication schedules, symptom tracking, recording of blood tests etc. The new WMUK app will bring all of this information, and more, together in one place via an easy-to-use phone application, helping me to manage my care more effectively."
>
> **– Steve McGraw, WM Patient**

Empowering patients

Empowered patients mean people who have the knowledge and support they need to feel confident having conversations and making decisions about their care. This comes in various forms, from feeling less isolated and less anxious, to understanding how they can make a difference in their own lives, and the lives of others.

WMUK's aim is that every person diagnosed with WM feels empowered to live their life well with WM. This means ensuring all patients find WMUK's information and support services, so that they feel seen and less isolated. We hope that this will in turn encourage them to sign up to our mailing list, where they can find out more about the charity and its impact, contribute financially and give back through sharing data.

What we set out to do

- Grow the WMUK Support Line.
- Grow the annual patient summit by collaborating with the International WM Foundation.
- Grow community engagement through broadening support activities.

Why it matters

- Empowered patients means people who have the knowledge and support they need to feel confident taking an active role in their care, and have better informed conversations with their clinical team about the things which are most important to them and their WM.
- Through support and information we can minimise the psychological burden carried by patients and families.
- An engaged supporter base will allow us to increase and grow our programmes through more funding and a larger voice, meaning we can in turn support more patients and families.

What we did

The WMUK Support Line

188% increase in Support Line usage

We supported 148 individuals over a total of 505 emails and phone calls, showing people use the service more than once. The Support Line is staffed by a haematology nurse, and provides both practical advice and emotional support, helping patients, families and friends to navigate the healthcare system, and understand their diagnosis.

22.5min average phone call

70min longest phone call

We are in a unique position to give everyone the time they need to talk, discuss and be listened to. This helps people affected by WM feel seen and understood, something that's important to help them feel empowered to take an active role in their care.

Through building close relationships with other organisations and services, we are able to signpost patients, families and friends to resources and information that support their wider needs.

The European WM Patient Forum

We co-hosted the first ever European WM Patient Forum, bringing together WM experts and the WM community from across Europe. It was the biggest ever WMUK event with 206 people attending in person and online, all sharing knowledge, expertise and support.

81% of attendees reported feeling more knowledgeable about WM after the Forum.

Engaging the community

We created the Patient Advisory Group (PAG) compromising of 17 patients with a variety of skillsets, backgrounds and experiences. PAG ensures the patient voice remains at the heart of everything we do, and helps steer our core programmes.

124 patients received a one-off grant to help with the rise in the cost of living.

During a cost-of-living crisis, we were able to step in to offer a one-off grant to people with WM or LPL. The majority of the recipients used it to pay for travel costs associated with their treatment, and to cover the rise in household costs, key areas that cause anxiety and stress for our community.

> "I put the money towards the arrears that had built up on my electricity bill over the winter."
>
> **– beneficiary of the Patient Financial Assistance Fund**

We grew our webinar series, broadening the range of information we offer and driven by a need for information in different formats.

Our webinars have now been watched 1,618 times on YouTube.

> Thank you so much for taking the time to talk things through with me, it might not feel like much, but to me it was invaluable in beginning to understand and get to grips with this diagnosis.
>
> **– Support Line User**

Sustainable funding

We're a small charity with big ambitions, but we rely solely on voluntary donations to fund our work. In a difficult fundraising climate, we're proud to have grown our fundraising by 65% this year, meaning we've been able to invest into the WM community more than ever before.

However wonderful income growth is, sustainable funding is our true aim. Without a solid base of reliable income, the charity cannot deliver its services, or plan for the future, meaning it becomes difficult to meet our goals.

Competition for funds was high, and we had limited staff resource to focus on fundraising.

What we set out to do

Diversify our income streams to ensure we weren't relying on one or two 'pots' of money, which is risky for the charity.

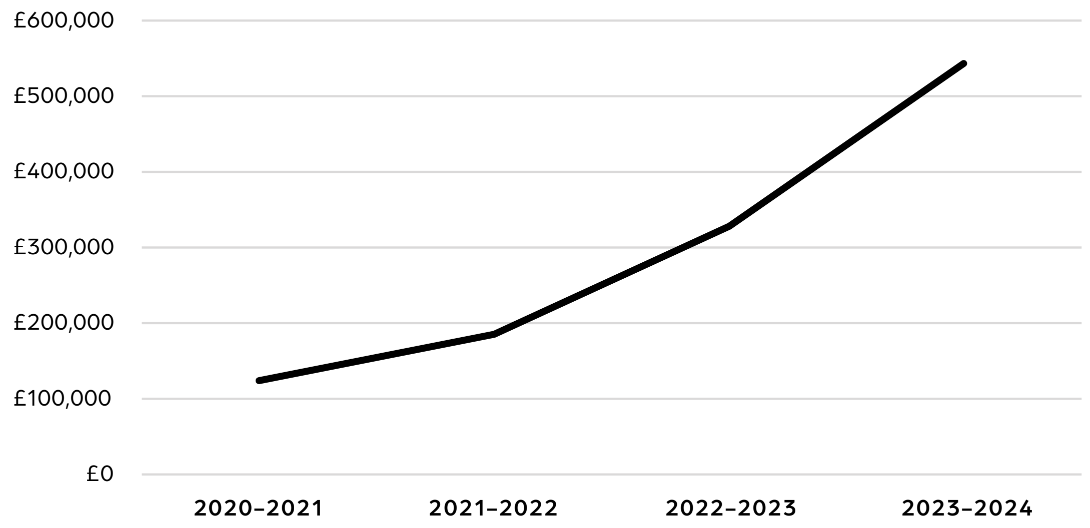
Run two major campaigns.

Ensure we had the processes in place to report back on our impact, to show donors and potential donors how their money is used, thus prompting further investment into our services.

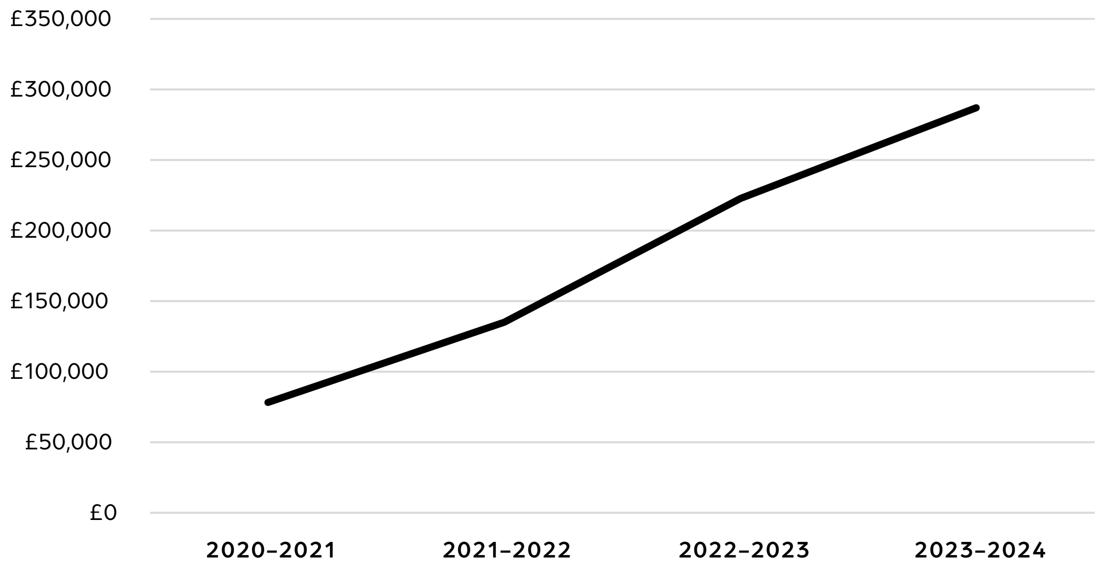
Why it matters

- Sustainable funding ensures the longevity of the charity and its programmes, so that people with WM are supported now and well into the future.
- In a difficult fundraising climate, diverse funding streams helps the charity to weather any significant changes in funding.

Income



Charitable spend



What we did

For the first time, the charity participated in The Big Give for our Christmas campaign. Not only did 247 donors help us raise **£57,164** – smashing our original target of £35,000 – but we were amongst **the top fundraisers for the whole of Big Give**, a phenomenal achievement for a small organisation. This was the charity's biggest ever giving campaign.

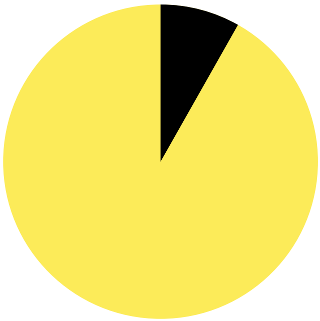
Income and expenditure

Data for financial year ending 31 March 2024

Total income:
£543,580

■	Donations and legacies	£538.58k
🟦	Charitable spend	£0
🟥	Other trading activities	£0
▨	Investments	£0
🟨	Other	£5.00k

Total expenditure:
£312,959*



■	Raising funds	£25.40k
🟨	Charitable activities	£287.56k
▨	Other	£0

*£50K ringfenced for app development in 24/25

Whilst total income for 23/24 was £543k, £121k of this was ring fenced and restricted funds. The available income for charitable spend for 23/24 was £422k of which £287k was spent on charitable activities. The charity always strives to spend two thirds of its available income on charitable spend and one third on core running costs.

WM cyclists pedal for glory

As the rest of us enjoyed our summer bank holiday, a group of 18 cyclists took on a gruelling 3-day cycle to **raise over £56,000 for the WM community.**

One of the team, Rebecca Millburn, whose mum lives with WM, describes the event.

"Nothing quite prepares you for the sight of the Eiffel Tower rising majestically into the Parisian sky. We may have had sore derrieres, but we had huge smiles on our faces.

"The metaphor of a journey is an overused cliché, but so much of the cycle challenge seemed to mirror the daily struggles we all face. It wasn't easy. There are parts of the journey we'd rather forget, and moments we'll remember forever. But what got us through was the team around us.

"The £56,000 we've raised for WMUK will ensure that more people living with Waldenstrom's macroglobulinaemia can get the support they need to live well. As Dr Helen McCarthy, consultant haematologist and cycle team member, said, 'WMUK is such a fantastic charity and it's actually just a great family.'

"My fellow riders and I hope that more people living with and impacted by WM can be part of this fantastic family as a result of our cycling endeavours."

A huge thank you to Rebecca and the team for their enormous efforts – you are all stars.

Thank you

We truly couldn't do what we do without the support of the WM community. Whether it is donating, volunteering time, healthcare professionals spreading the word with colleagues, or giving us feedback, you drive our work.

Our sincere thanks go in particular to:

- Our donors
- Our regular givers, who provide a sustainable and reliable source of income
- Those who gave through the Big Give, many for the first time
- Our Patient Advisory Group
- Our volunteer Support Group Leaders
- Everyone who has taken the time to attend our in-person and online events, and engaged in our community

> "I was so grateful to the WMUK donors for thinking of me and for helping me understand that I really am part of a caring community."
>
> **Beneficiary of Patient Financial Assistance Fund**

General Enquiries: 0300 303 5870

Support Line: 0300 373 8500

Email: info@wmuk.org.uk

wmuk.org.uk