

Impact Report

Wm





Introduction

from our CEO, Jane

Over the past year we have seen an incredible growth in our community. Through our webinars, regular emails, social media, our Patient Summit, and ongoing conversations across the community, we are now reaching more people impacted by WM and LPL than ever before.

But it's not just about numbers. What has been most powerful is the depth of connection we now have with patients, carers and clinicians working in this field. We are listening more closely, learning more deeply, and strengthening the relationships at the heart of our community. These connections are giving us the insight we need to shape our services with purpose and to focus our efforts where they can make the greatest difference.

I often say that we punch above our weight. As you read this impact report and reflect on what has been achieved for the WM community this year, I hope you feel the same pride that I do. We can't wait to see what's next.

Jane Nicholson

CEO
WMUK

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We're here to help those with WM and LPL to live well. Our vision is that people affected by WM and LPL live longer, good quality lives, being supported every step of the way by WMUK.

Our five-year strategy, which is informed by people affected by WM and LPL, lays out how we're going to achieve our vision, focusing on four key areas:



Our Year in Numbers

1000

people received the 2nd edition of our **Newly Diagnosed Booklet**

288

individuals were assisted through our Support Line, a **54% increase** on the previous year

372

patients and carers responded to our WM and LPL patient survey, providing insight to **help shape what we do**

198

delegates took part in the European WM Patient Forum with 95% reporting increased knowledge and two-thirds feeling **more positive about the future**

14%

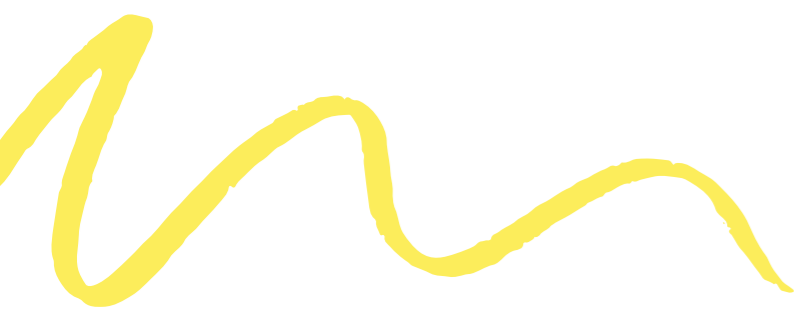
growth in our patient database reflecting **stronger engagement with patients**

100%

increase in visits to the WMUK website

Key Developments

- Launched the UK's first WM and LPL Clinical Trials Hub, giving patients clear access to trials and renewed hope for future treatments.
- Developed an evidence-based advocacy strategy, which shaped our response to the NHS 10 Year Health Plan and National Cancer Plan.
- Through collaboration with Blood Cancer Alliance and Cancer52, the WM and LPL voice is now represented in national cancer conversations.
- Received PIF Tick Accreditation, confirming our health information meets the highest standards of accuracy, accessibility and trust.
- Launched a new WMUK Buddy Service to reduce isolation and connect patients through shared experience.
- Rolled out the Active Monitoring Checklist, presenting the study and Checklist at two major haematology conferences.



Expert Voice

Our Big WM Survey showed 26% of patients received no take-home information whatsoever when diagnosed, whilst a further 40% only received general blood cancer information. Patients tell us they need accurate information to live well with WM and LPL and we strive to provide that as a world-class authority on these cancers.

WM

We set out to:

- Produce high-quality, up-to-date and trustworthy information.
- Reach more healthcare professionals (HCPs), beyond the core group of WM and LPL experts.
- Provide the community with a wider range of expert- and patient-led information.

Why this matters

- Patients and families are desperate for more information on physical symptoms and mental health to help them live well with WM and LPL.
- Better information for under-resourced NHS healthcare teams will help patients receive the best possible care.
- Strong relationships with healthcare professionals across the UK will drive meaningful and long-term change.

What we've achieved

The Trusted Source of Patient Information



A key part of our work is ensuring everyone affected by WM and LPL has information that is specific to their disease, expert led and easy to digest.



- The Patient Information Forum (PIF) awarded us PIF TICK Accreditation, an independent trust mark that is nationally recognised. PIF only award this to organisations that meet their stringent criteria demonstrating accurate, up to date and accessible resources.
- WMUK is the only organisation producing WM and LPL-specific PIF TICK accredited information.
- We published the 2nd edition of the Newly Diagnosed booklet.
- The booklet is the only accredited resource for WM and LPL and was distributed to over 1,000 individuals and multiple healthcare centres.



Search Engine Optimisation



Our Big WM Survey shows 77% of patients rely on the internet for information. We invested in website search engine optimisation to ensure they can find WMUK and the support they need. Since the site relaunched in January 2025 we've seen a significant impact.

- 100% increase in website visitors (2,317 in Jan 2025 vs 1,150 in Dec 2024). This shows that more people are finding expert, accurate and accessible information.
- 54.7% increase in returning visitors (4,200 people returned). This demonstrates that people value the information and are coming back.
- 80% increase in clicks via Google searches means it's easier to find us and people don't need to scroll through pages of search results.
- 14% increase in the number of patients on our database showing that more people are finding accredited information about WM and LPL, engaging with support services and connecting with the WM and LPL community.

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I wish when I had the first initial consultation, they had just pointed me to the WMUK website.

— Hannah, WM patient

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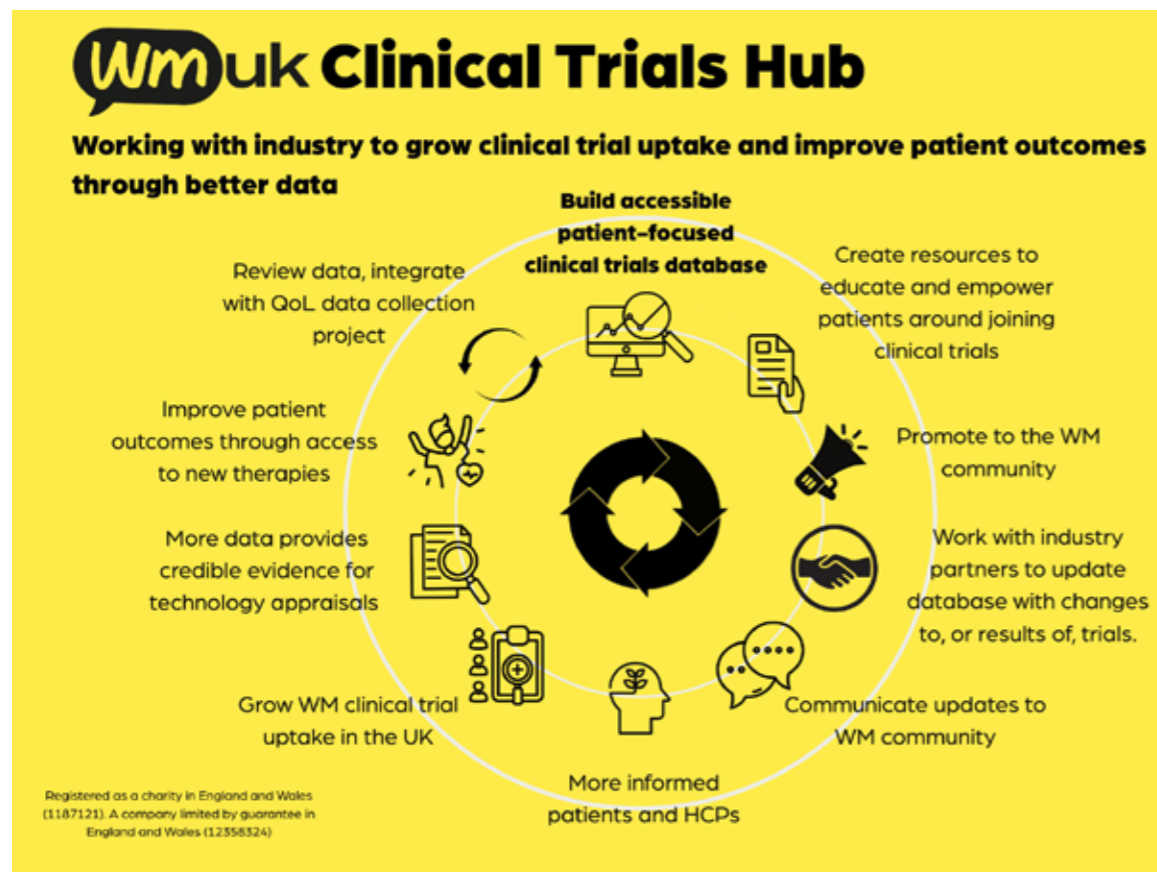
Clinical Trials Hub



We launched the UK's first Clinical Trials Hub to help WM and LPL patients find recruiting trials. Clinical trials offer hope for people with WM and LPL and provide the evidence needed to develop new treatments and secure NHS approval.

Information about clinical trials can be difficult to find and even harder to understand, often buried in highly clinical language that creates unnecessary barriers. The Hub is designed to break these barriers down, offering clear, accessible information through an easy-to-use, searchable database.

- The only database of its kind for the WM and LPL community.
- Patients have already reported using the Hub to inform their conversations around clinical trials with their healthcare teams.
- Visited 1,725 times in the first month, showing the community found immediate value in the resource.
- Users visit pages almost 5 times showing the value they put in the information provided.



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Healthcare Professionals



Our aim is that every person diagnosed with WM and LPL, is referred to WMUK upon diagnosis. We also want to ensure that all healthcare professionals have the most up to date knowledge of caring for people with WM and LPL.

- Strengthened relationships with healthcare professionals through face-to-face meetings and hosting virtual round tables.
- Helped identify and meet patient needs to ensure more equitable care through discussion with healthcare teams.
- Identified core challenges around how WM and LPL is clinically coded, prompting wider discussions about incorporating non-IgM LPL more clearly into our community and charity focus.

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"It is so vital that we, as clinicians, have WMUK as a resource to direct our patients to, so they never feel forgotten or alone.

- Neil Phillips, Consultant Haematologist,
at University Hospitals North Midlands

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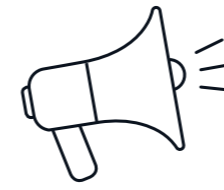


WMUK



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Advocacy



Raising the WM and LPL voice at the highest level is key to attaining long-lasting and meaningful change to WM and LPL care and treatment. For the first time, the charity has been able to focus on advocacy, representing an important milestone for the WM and LPL community.

- Worked with policy advisers, Incisive Health, and the WM and LPL community to develop our first evidence-based advocacy strategy.
- Used results from the Big WM Survey to submit a response to the NHS 10 Year Health Plan and the National Cancer Plan. Through these we called on government to consider the unique needs of those affected by WM and LPL – a first for the charity and WM and LPL community in the UK.
- Strengthened collaborations with the Blood Cancer Alliance and Cancer52 to ensure the WM and LPL voice is represented in national campaigns and discussions.
- Joined best practice sharing meetings with CLL Support and Lymphoma Action to demonstrate collaboration across the sector and ensure excellence in delivering projects for the WM and LPL community.
- Contributed to discussions on the use of AI in genomics for rare diseases, with the help of our WMUK Patient Advisory Group (PAG), which led to greater representation of the WM and LPL community on the national stage.

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WMUK very much
punches above
its weight

– Steve WM Patient

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The style of the [Newly Diagnosed] booklet is perfect. It doesn't speak down to readers, and you don't feel that you need a degree to understand it. It brings all the necessary information together in one place and signposts people to where they can find further information. It's a great blessing to those who are newly diagnosed.

— Michael, WM patient

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Harnessing data

The rarity of WM and LPL means that accurate information about the experiences of the community are scarce. Our aim is to launch real-world data programmes that generate the insights that will drive research, shape services and improve outcomes.

WM

We set out to:

- Test the myWM app as a tool to capture real patient experiences.
- Review the impact of our Active Monitoring Checklist for patients and HCPs.
- Survey our community to better understand the challenges they face.

Why this matters

Data drives change. The more insight we have, the better our chances of improving outcomes, developing treatments and, ultimately, finding a cure.

In an increasingly digital healthcare system, it is our responsibility to give the WM and LPL community the tools and confidence they need to manage their care effectively.

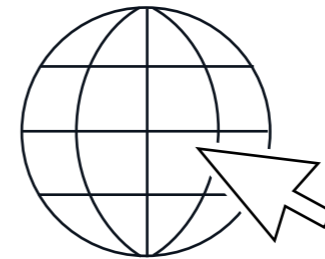
What we've achieved

Big WM Survey

Throughout the year we've been gathering insights from our Patient Advisory Group and wider community. This data is helping to shape the services we provide and contributing toward sector-wide discussions on the future of healthcare.

We conducted the largest WM and LPL patient and family member survey of its kind, exploring the experiences of people living with WM and LPL. The insights have been instrumental in shaping our advocacy priorities and the services and information we provide.

Key findings:



77% of patients rely on online searches for information



20% waited over a year for diagnosis after first visiting their GP



73% wanted to "know everything" about WM/LPL at diagnosis



The majority reported at least one negative mental health impact

Active Monitoring Project

We built on the success of our Active Monitoring Checklist, which supports more meaningful conversations between patients and healthcare professionals by educating clinicians and empowering patients to raise what matters to them.



We presented the checklist poster and consensus study at the International Workshop on Waldenström's macroglobulinaemia (IWWM) in Prague, marking an important step towards reducing inequalities and standardising care.



We convened the first Nurse Advisory Board, bringing together nurses from across the UK to provide feedback on the checklist. Discussions highlighted practical challenges and suggested recommendations for improvement.



A second version of the checklist included the addition of a symptom list and more inclusive language.



The Nurse Advisory Board continues to support the ongoing development and rollout of the Active Monitoring project. The impact of the project will be reviewed in 2025–26.

myWM app

Following a successful pilot of the myWM app, a further 200 patients tested the resource over a period of two months. The app allows patients to track day-to-day experiences, giving us deeper insight into the realities of living with WM and LPL. This project was funded through the Big Give 2023 campaign.



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Everyone's journey is different, but sometimes it just helps to have someone say, 'Yes, I felt that too.'

— Janet, WMUK Buddy

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Empowered patients

We want to make sure that the needs of those living with WM and LPL are put first.

To do this, we work closely with clinicians, researchers, pharmaceutical companies, and the wider WM and LPL community, to ensure patients are involved in research, treatment development, and care pathways to better equip them in making decisions about their care.

WM

We set out to:

- Grow the WMUK Support Line
- Expand the annual Patient Summit in collaboration with the International WM Foundation
- Increase community engagement through broader support activities

Why this matters


When we empower patients we give them the knowledge and support they need to feel confident taking an active role in their care. This means they can have better informed conversations with their clinical team about the things which are most important to them and their WM and LPL.


- 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.

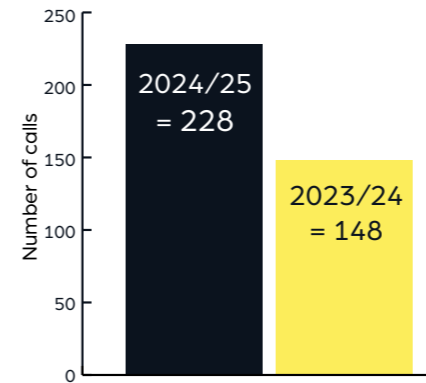
What we've achieved

Support Line

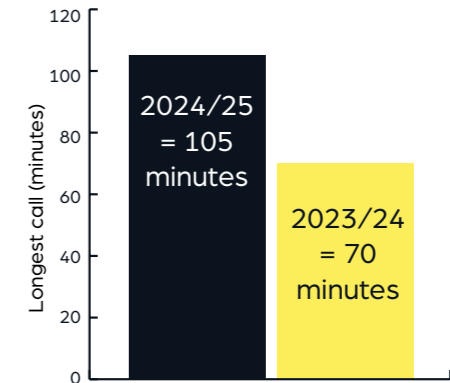
In total, our Support Team spent **7,092 minutes supporting patients and families:**

 **4,045 minutes by phone**

 **3,017 minutes by email**



Number of individuals supported has increased by 58%



The length of calls is increasing, which shows the trust placed in the Support Team.

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Thankfully, I also found WMUK and spoke to Alison on the Support Line, and she was incredible. She explained what was happening to my cells in clear terms and, more importantly, she just got it.

– Rachael, WM Patient

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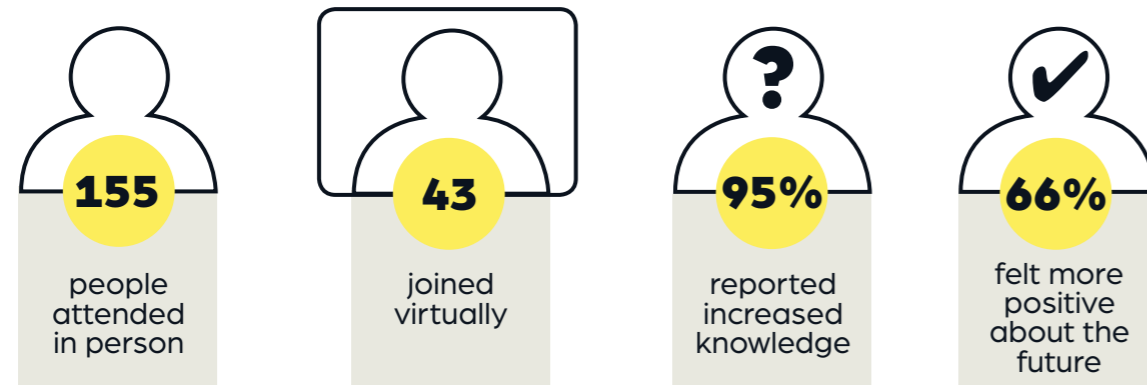
Buddy Service Launch

In March, we recruited our first WM and LPL Buddies with lived experience of WM and LPL to support patients who are newly diagnosed or starting treatment. The six Buddies completed online training with our Support Line Nurse and received an introductory pack. They will get ongoing support as they offer reassurance, encouragement and a listening ear to others living with WM and LPL when the project launches in 2025–26.

European WM Patient Forum

In September, we hosted the European WM Patient Forum in partnership with the International WM Forum (IWFM). The event featured leading experts from the UK and further afield, covering treatments, exercise and diet, and the patient experience.

Feedback highlighted a desire for more regional and holistic content, helping us shape future events.



66 WMUK has been very supportive to me. Basically, it has helped me how to live well with my WM.

– Komal, WM Patient 99



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Sustainable funding

WMUK receives no statutory funding, and our work is funded by the generosity of our community and long-term corporate partnerships. Over the year we've sought to build on relationships and look for new ways to engage our community in our work.

We set out to:

- 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 fundraising 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 this matters

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

What we've achieved

Our WM and LPL community continues to generously support the work of WMUK. This year we have developed additional, creative opportunities to diversify our income and involve our wider community.

Big Give 2024

As demand for services increased, we used the Big Give campaign to help keep the WMUK Support Line running. This was a truly collective effort that has allowed us to grow and sustain the Support Line.

£53,130
RAISED

223
DONORS

26 community pledgers,
enabling matched
funding

Wheels for Waldenstroms

In August a team of 10 intrepid cyclists undertook a 3-day, 200 mile trip from London to the heart of Paris all to raise funds for WMUK. The team was made up of WM and LPL patients and their families and friends. In total, the group raised an astonishing £27,000 to support WMUK.

Fundraising

There have been plenty of other incredible individual fundraising events, including Keely, Nikki and Dot who raised more than £1,500 by completing a 30 mile hike along the Northumbrian coast. WMUK Trustee, Jane Kidd, also inspired a team of 10 cyclists to complete a round trip from Amsterdam to Utrecht to raise money for WMUK.

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We really wanted to do something positive to support WMUK as a thank you for all the amazing support they've given to our little sister (and niece) Melanie since she was first diagnosed.

– Keely, WMUK fundraiser

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- Donations = **£384,464**
- Gift Aid = **£39,353**



- Charitable Activities = **£324,712**
- Raising Funds = **£26,202**

The charity received £423,817 in revenue and finished the financial year with £549,556 in reserves all of which is unrestricted and allows for approximately 17 months of running costs.

The Trustees considered such a buffer above the agreed reserves policy of 12 months was required due to a predicted and significant drop in income from one funding partner in the upcoming year 2025/26. This buffer in the reserves would ensure the charity could continue its activities should the gap in funding not be filled.





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WMUK has offered a sense of community and has been a great resource.

– Kelly, WMUK fundraiser whose mother-in-law is living with WM

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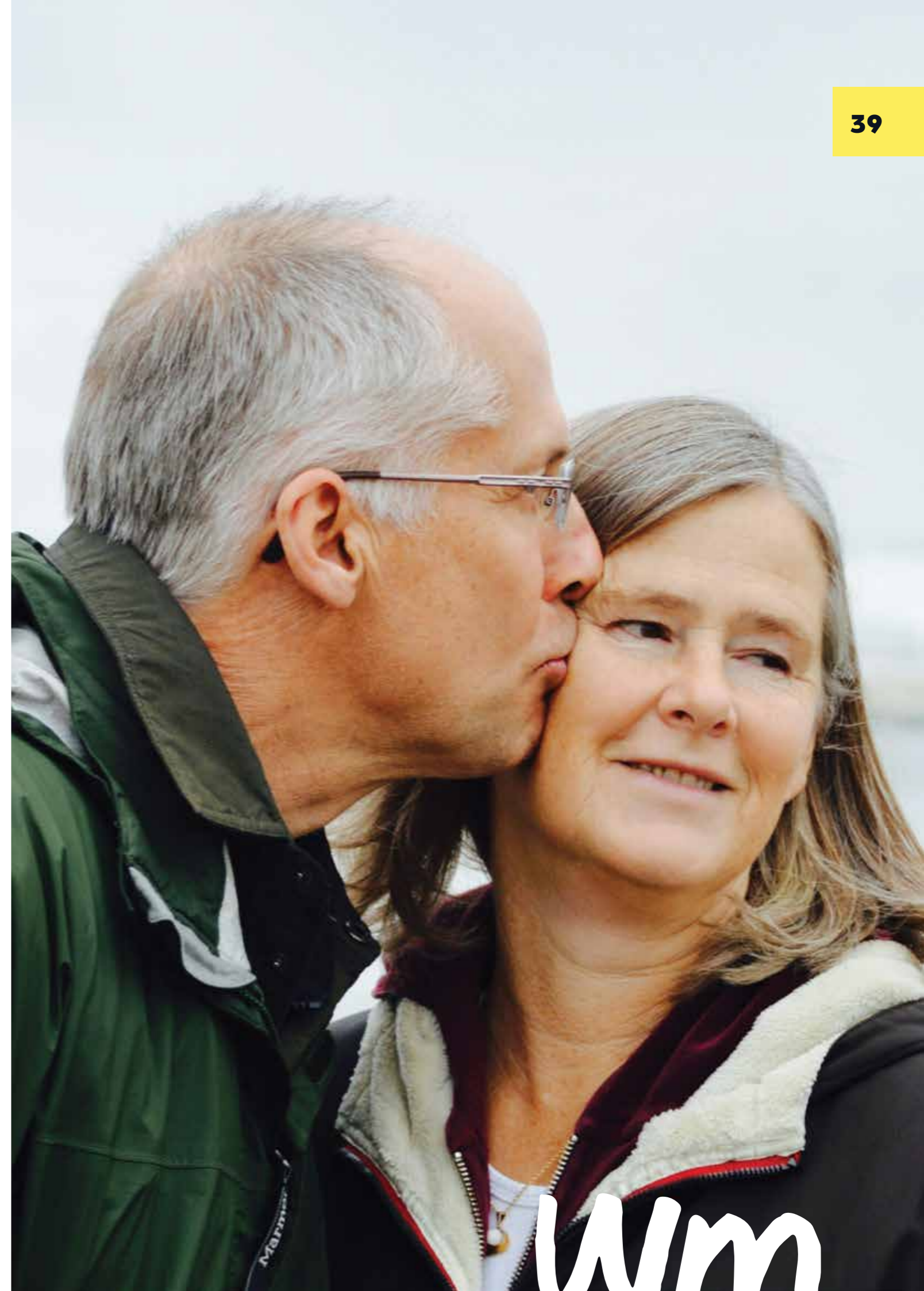
Thank You to Our Wonderful Community

Over the year we've continued to grow with a community that is generous with their time, experience, knowledge and finances.

We are particularly grateful for our

- Regular givers whose generosity helps us to plan and deliver activities throughout the year.
- Patient Advisory Group members who provide critical insight to shape the support and resources for the community.
- Fundraisers who complete extraordinary feats to raise money, awareness and engage their wider networks in our work.
- Big Give pledgers whose donations ensure we can maximise fundraising opportunities at Christmas.
- Support Group Leaders who journey with those living with WM and LPL throughout the year.
- Our WMUK Buddies who provide peer-to-peer support to those newly diagnosed with WM and LPL or who are starting their treatment journey.
- Community of healthcare professionals who review our information and provide wide-ranging and valuable expertise to the support services.

As we look ahead, we are encouraged by what has been achieved so far, and are inspired to keep innovating, collaborating and learning to ensure those with WM and LPL have every opportunity to live well.



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