AUTUMN/WINTER 2024

myeloma Matters

Treatments focus

The new myeloma landscape

Hot topics
Getting drugs from trials to the NHS

Spotlight on
The largest myeloma trial

Policy briefing
Delivering better outcomes for myeloma patients

MyelomaUK

Contents

DEAR READER

Jo Nove
Myeloma Matters Guest Editor

Welcome to the Autumn/Winter 2024 edition of Myeloma Matters.

I am delighted to be the guest editor for the last edition of 2024. As we approach Christmas, we also approach the end of one of the busiest years in getting myeloma treatments approved by the NHS in recent history.

There's a lot to celebrate and to be hopeful for. This year alone our team have worked with volunteer myeloma patients to put the opinions and preferences of myeloma patients into 13 treatment appraisal meetings across the UK. These meetings decide if new drugs will be made available on the NHS and at what point in the myeloma journey they can be used.

The experiences of people who have taken these drugs as part of a clinical trial is an incredibly important part of securing a successful outcome. In this edition we meet Huw, Kathryn, and Nigel who have helped deliver more choices for thousands of myeloma patients through their treatment appraisals volunteering with Myeloma UK. We also welcome Robert, Ross and Sybil, our latest volunteers lending their voices and experiences in these meetings. We are so grateful to all of them for the work they do.

Professor Graham Jackson spotlights Myeloma XI, the largest-ever myeloma clinical trial where teamwork helped secure lenalidomide maintenance treatment after induction therapy and after a stem cell transplant, increasing remission time and overall survival for so many patients. It was such a milestone for patients, and you can read more about how clinical trials work and how new treatments are licensed in this edition, along with a special editorial from our Head of Advocacy, Dr Scott Purdon, as he guides us through the health policy environment and looks ahead at some of the challenges.

Treating myeloma is an important part of our strategy, but so is living well with myeloma and, in this edition, we hear from Dr Romi Carriere on her investigation into why some people experience heart and circulatory problems after being treated for myeloma for a longer period. Understanding how these problems occur can help us stop them happening in the future.

But as we come towards the end of the year, the most important thing to do is to give a heartfelt thank you to everyone for their support of Myeloma UK this year. We couldn't do what we do without you, and you really do make change happen. We wish you all the very best for the festive period.

Visit the **Myeloma UK COVID-19 Information Hub** for the latest information on COVID-19, vaccinations and research.
myeloma.org.uk/covid-19

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MYELOMA RESEARCH NEWS FROM AROUND THE WORLD

Ixazomib could improve remission times for HDT-SCT candidates at first relapse

A phase 3 clinical trial, Myeloma XII (ACCoRD), confirms that consolidation and maintenance treatment using ixazomib (Ninlaro®) is effective in improving outcomes for myeloma patients receiving high-dose therapy and stem cell transplantation (HDT-SCT) after first relapse (known as salvage HDT-SCT).

Ixazomib, a proteasome inhibitor, prevents proteasomes from breaking down proteins, causing toxic protein build-up that kills the cell. Myeloma cells are more dependent on proteosomes than healthy cells, so are more sensitive to ixazomib. In the Myeloma XII clinical trial, 206 participants were randomised into two groups. One group (50% of patients) received HDT-SCT consolidation treatment (ixazomib, thalidomide and dexamethasone) and ixazomib maintenance. The other group received HDT-SCT followed by observational care.

Those receiving ixazomib-based consolidation and maintenance experienced longer-lasting remissions (average: 20 months) compared to those under observation (average: 13 months). Patients generally tolerated maintenance and consolidation treatment well, with most side effects considered manageable. When salvage HDT-SCT is an option for relapsed patients, these results indicate that consolidation and maintenance treatment can effectively extend remissions.

Dose reduction of dexamethasone in newly diagnosed patients

Dexamethasone is a key component of many treatments for myeloma patients, including those newly diagnosed. Current dosages, although effective, are often associated with significant toxic side effects that can affect patients' quality of life. A clinical trial has shown that a dose reduction could have the same positive treatment outcomes without the associated toxicities. Of the 541 newly diagnosed participants, 373 patients (69%) were given a lowered dose as part of their myeloma treatment. No difference in the progression-free survival (PFS) or overall survival (OS) was observed compared to when patients are given the usual dose.

Researchers reported other ongoing trials looking at dexamethasone reduction and encourage more future trials to investigate lowered dose strategies. This could improve patient experience by reducing side effects and improving quality of life.

Innovative lab research hopes to tackle myeloma treatment resistance

Myeloma often becomes increasingly difficult to treat over time because myeloma cells can become resistant to treatments after exposure. New laboratory-based research reveals a novel therapeutic strategy which could prevent, or even reverse, treatment resistance in myeloma.

Macrophages, a type of white blood cell, are part of healthy immune systems. However, in myeloma, a type of macrophage can develop which help myeloma cells to thrive and induce drug resistance. These are called M2-like tumour-associated macrophages (M2 TAMs).

Laboratory researchers discovered that preventing IL10, a chemical messenger, from binding to macrophages can change the macrophages' behaviour. M2 TAMs were reprogrammed, reversing resistance to some drugs such as lenalidomide (Revlimid®), and no longer supported myeloma cell activity.

Whilst in the early stages, this work offers hope that, alongside more and better treatments, clinicians will one day have options to tackle treatment resistance for people living with myeloma.

A new bispecific antibody effective in relapsed and/or refractory myeloma

Linvoseltamab, a new bispecific antibody, shows potential for patients with relapsed and/or refractory (RR) myeloma. Linvoseltamab works like teclistamab (Tecvayli®) and elranatamab (Elrexfio®), two bispecific antibodies recently approved for use on the NHS. Attaching to proteins called CD3 on the surface of T cells, and proteins on myeloma cells' surfaces called BCMA, linvoseltamab brings patient's T cells close to myeloma cells, allowing them to kill the myeloma cells.

This phase 2 clinical trial investigates different dosages for safety and efficacy. Results showed that patients treated with linvoseltamab experienced a higher overall response rate (ORR) of 70.9% compared with teclistamab (63%) and elranatamab (61%). The trial also revealed that linvoseltamab had a lower rate of the side effect cytokine release syndrome (CRS) than teclistamab and elranatamab, offering a more favourable safety profile for patients.

A phase 3 trial is now underway in the UK (LINKER-MM3) comparing linvoseltamab against the combination of elotuzumab (Empliciti®), pomalidomide (Imnovid®) and dexamethasone in RR myeloma. In future, this may result in more treatment options that work better for patients.

OUR LIVES WITH MYELOMA

Meet the selfless band of patients giving up their time to improve access to treatment and rewrite the future for people with myeloma.

NAME: Huw Stiley

LIVES: Hampshire

AGE: 57

I was diagnosed with AL amyloidosis in December 2016, just before my 50th birthday.

My symptoms were minimal, just some swelling in my legs, but with the help of my GP and some superb consultants, I was quickly referred to the National Amyloidosis Centre in London.

My first round of treatment began at the start of 2017. I had a stem cell transplant, which was later followed up with rounds of chemotherapy in 2019 and again in 2020, just as we went into lockdown. December 2024 marks the eighth anniversary of my diagnosis.

Being diagnosed with AL amyloidosis is a tough thing to hear, but as I have found, staying positive and working with your health professionals can result in you maintaining a good quality of life.

Before I was asked to be a patient advocate for the NICE appraisal on DaraCyBorD, the first treatment for AL amyloidosis, I had absolutely no knowledge of what Myeloma UK actually did to get drugs approved. I have been extremely impressed by their professionalism and compassion.

I got to understand how organisations like Myeloma UK work with drugs companies, medical experts and

patients. Without patients becoming involved in these appraisals, the people who make the decisions at NICE would have less knowledge on how new innovative treatments can improve patient experiences and outcomes.

The process for DaraCyBorD started in the summer of 2021. I was initially asked to describe my personal journey, from diagnosis to treatment. This was then included in the submission documents to NICE. The first committee meeting was held in December 2021. After registering with NICE, I was provided various documents from the appraisal submission. This gave me a real understanding of the complex appraisal process which the drug companies have to follow for any approval. My role on the day was to answer any questions the appraisal committee had from a patient perspective. I was also allowed to contribute at certain stages in the meeting.

In January 2022, the committee reached an initial decision not to recommend DaraCyBorD. It was devastating news at the time, but with the subsequent tireless work undertaken by Myeloma UK and the pharmaceutical company behind the treatment, there was a glimmer of hope that they could keep the appraisal process open by appealing the decision.

During the next two years I participated in and contributed at several committee meetings. I vividly recall saying in one Zoom meeting, 'I hope I'm still around the day DaraCyBorD is approved', and I'm pleased to say that in February 2024 I received the formal notification from NICE that DaraCyBorD had finally been approved. It was one of the best days of my life. Whilst it did ultimately take a long time from start to finish, being part of the process was fantastic. I learnt so much and it has been such a fascinating and rewarding experience. Daratumumab has been a game-changer for me. I am currently able to live a fairly normal life although strenuous exercise is sometimes harder than it once was, but then my wife also reminds me how old I am!

I am grateful for being asked and hope that I may have made a tiny contribution to get this fantastic treatment approved in the UK. Contributing as a patient expert in this process has given me an even greater admiration for all the people who work tirelessly to get these new drugs approved. I want to thank everyone involved at Myeloma UK, The National Amyloid Centre and all the wonderful medical teams in the NHS. ■

NAME: Kathryn Oddie

LIVES: Nottinghamshire

AGE: 62

I was diagnosed with myeloma in 2000. I was 38.

I was a practice nurse and I'd had a nosebleed at work. At first my boss thought I was a compulsive nose picker – I wasn't. But he did a blood test which showed I was anaemic. I went to the chemist that Friday to get some iron and when I went to work on the Monday, he came to see me and said, 'You'd better go home'. I didn't know what was wrong, but I knew it was serious. The next day he came knocking at my door. I was diagnosed quickly after that.

I had 11 lines of therapy over the years – daratumumab had worked for about 18 months to two years – but none of them had put me in remission. In 2021, my local hospital said there was nothing else for me but, luckily, my consultant had worked with Dr Rakesh Popat in the trials unit at UCL a few years back so he wrote to him to see if there was anything that could help me. They rang me to say they had this new drug. I was the first to get teclistamab at UCL. Within six months or so it worked.

Now I'm in remission and I can actually get on with my life. It's a miracle drug, to be honest.

It was Dr Popat at UCL who asked me if I'd like to be the patient expert for the appraisal for teclistamab, both with the National Institute for Health and Care Excellence (NICE) for patients in England and Wales and with the Scottish Medicines Consortium (SMC), for patients in Scotland. Teclistamab has worked so well for me, I wanted to help other people get this drug.

Until I got involved, I'd never really thought about the work charities do to get drugs approved. It had not crossed my mind.

For the NICE appraisal, I wrote a statement which was shared with the committee and I then prepared a speech for the meeting. NICE provided support and they had practice sessions, explaining what would happen and what to expect. Caroline Donoghue [Senior Policy Officer] at Myeloma UK also put me in touch with a patient who had done appraisals before, which was very helpful.

The night before the first meeting though, NICE sent over 50 or 60 slides about teclistamab. They were quite complicated, with lots of stats, and way beyond my knowledge of myeloma and I started to worry about memorising things. I thought, 'Better start again', so I rewrote what I'd planned to say. By the end I think I had 10 pages. Of course, it all went out the window during the Zoom meeting because they didn't ask me to read my speech or ask anything technical at all. What surprised me was how basic the questions were: they had nothing to do with the actual drug trial. They only wanted to know about me. They asked how long I'd had myeloma, did I need any supportive drugs…

I quickly realised that I was there to let people know how good the drug was and what it had done for us. You've only got a short length of time to say your bit, so you need to think of three or four key points you want to make. I tried not to repeat myself and get straight to the point.

I found listening to the doctors very interesting, probably because I was a practice nurse.

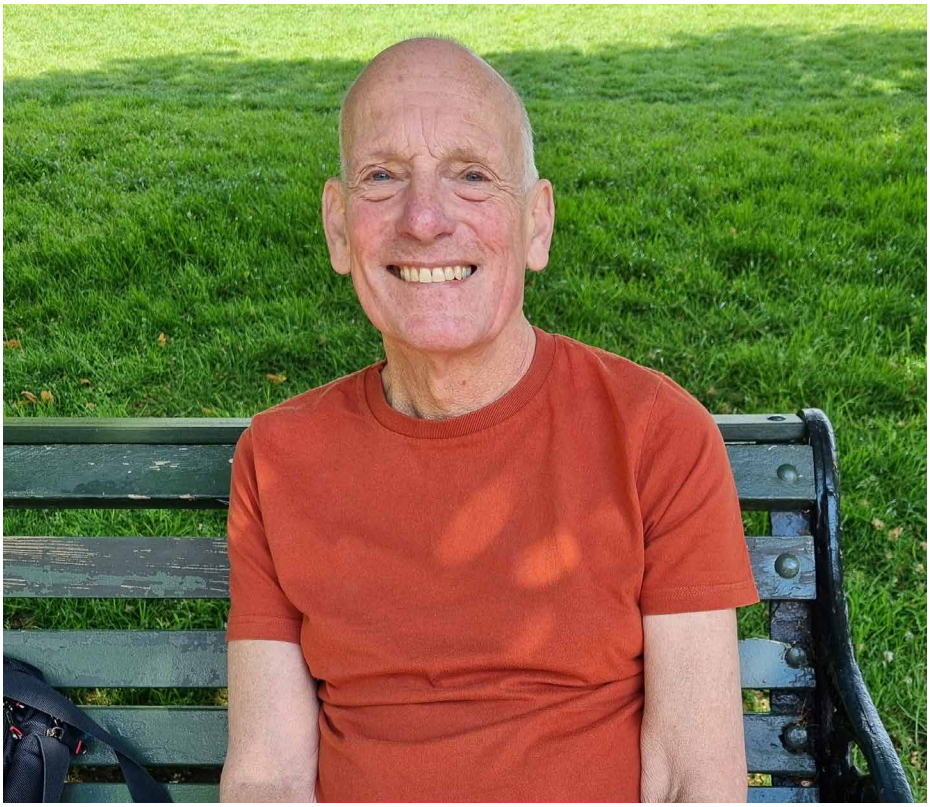
The second NICE meeting was easier. I didn't even bother to go through the slides or all the background information. I knew what to expect and I was probably more myself. I actually made the chair of the meeting laugh at the end when I said I'd had myeloma for 24 years, 11 lines of treatment and quickly added, 'I'm not after the world record or anything'. It made the process feel a bit more human, I think. The process with the SMC was totally different. It was much faster – the meeting lasted an hour on Zoom. It felt a bit more relaxed and less formal.

This process has taught me that the best thing you can do is just be yourself. Just share your experience and say what you think. It's been a positive experience. ■

NAME: Nigel Spencer

LIVES: London

AGE: 65



I was diagnosed with myeloma in July 2018, aged 59.

My symptoms started that February with spasms in my sternum and a number of incidents of similar pain in my back over the next few months. In spite of worsening pain and weight loss my GP didn't seem concerned. In June, he finally referred me to a rheumatologist. I was lucky that he had come across myeloma before and recognised the signs in my scan and blood results and referred me to haematology. It turned out I had been walking around with four wedge fractures and a fractured sternum. My light chains were 12,000 when I started treatment in August. I wore a brace for four months.

I started IsaPD (isatuximab, pomalidomide, dexamethasone) as fourth line treatment in December 2021 and have been in full remission since cycle two. I am feeling really well and leading a pretty normal life.

I completed a questionnaire Myeloma UK posted on Facebook, asking people about their experience with IsaPD and was asked to be part of the appraisal process for the treatment.

It was a no-brainer. I am happy to do anything I can to try and make it available to myeloma patients.

Prior to the appraisal meeting in January this year, I submitted a statement which argued for the continued funding of this treatment.

I knew it would be a very technical and evidence-based process, and it was.

The only thing that surprised me was how granular the discussion was. At times it felt like the NICE committee were not seeing the wood for the trees and I would have liked them to stand back and apply principles like reasonableness.

I don't want to be too hard on the NICE committee as, in this case, they were operating within a very constrained space. It is a good thing that we have an objective and evidence-based process for approving the funding of treatments and so it's crucial that people perform this role. But I saw my role as reminding the NICE committee of the human implications of any decision they made and emphasising my very positive experience of the treatment.

Unfortunately, the decision did not go our way and Myeloma UK had to launch an appeal. In September, I attended the appeal meeting, again by Zoom, and felt that I contributed more to this meeting than the initial review.

> **"Always remember that you know more about myeloma than anyone else in the process. I got excellent support from Myeloma UK as well as the people at NICE who organised this."**

The meeting kicked off with me reading out a statement in which I attempted to reinforce the points Myeloma UK were making in the appeal as well as adding a human, and heartfelt emotional dimension.

There were a number of moments in the appeal when I felt the points we made really hit home. Zoom meetings aren't great for observing body language but there were visual signs from the NICE committee and the panel hearing the appeal that we had made an impact.

Taking part in drug appraisals requires no qualifications. Any experience you can bring is a valuable contribution and is respected by all participants. At no point was I put on the spot and asked challenging questions. Always remember that you know more about myeloma than anyone else in the process. I got excellent support from Myeloma UK as well as the people at NICE who organised this. The only thing for which I had to prepare myself was issues like life expectancy being discussed in a detailed and dispassionate way. I knew what each statistic actually means.

We are still awaiting the results of the appeal and, if it is successful, it will be a huge cause for celebration. ■

SPOTLIGHT ON THE LARGEST-EVER MYELOMA TRIAL

HOW THE LARGEST-EVER MYELOMA TRIAL PAVED THE WAY FOR A BRIGHTER FUTURE

As the Myeloma XI trial comes to an end this year, Chief Investigator and Myeloma UK Chief Clinical and Scientific Officer, Professor Graham Jackson, reflects on how the largest-ever myeloma study radically transformed treatment and paved the way for a brighter future.

What did the Myeloma XI trial set out to investigate?

The Myeloma XI trial was planned as a follow-on from the previous Myeloma IX trial, which had shown that thalidomide used as a maintenance treatment after a stem cell transplant could prolong and deepen remissions but was difficult to tolerate over long periods of time.

At the same time, there was evidence that lenalidomide (Revlimid®) was potentially better tolerated and more effective. Myeloma XI was designed to look at many questions but particularly whether lenalidomide maintenance could prolong remissions and survival. It was also very important to make sure that the adverse effects, both short- and long-term, of such prolonged therapy were acceptable in the context of the effectiveness of this novel therapeutic approach. The trial began in 2009 and was completed this year – 15 years later.

Tell us about your involvement in the trial.

The four chief investigators were initially Dr Faith Davies, Professor Nigel Russell, Professor Gareth Morgan (who led the study until 2013) and myself. I took over as trial lead in 2013 until completion. Chief investigators invest a huge amount of time designing the study, seeking funding to allow the trial to be financed as well as monitoring safety and outcomes throughout.

How has the trial transformed treatment for people with myeloma?

The trial has transformed treatment for myeloma patients in the UK by establishing that long-term maintenance therapy could deepen and prolong remissions for high-dose therapy and stem cell transplant (HDT-SCT) eligible patients. Results from the study were instrumental in leading to NICE approving long-term lenalidomide maintenance treatment after induction therapy and particularly after a stem cell transplant.

What has been the biggest highlight for you, as chief investigator?

The biggest highlight is undoubtedly the NICE approval of lenalidomide maintenance, which would not have been approved in the UK without the Myeloma XI trial.

As it is the largest-ever myeloma study, it has provided a critical foundation and dataset on which other trials have been developed and built – advancing more trials and treatments for patients worldwide.

> **“It is the patients and their families who are critical to the success of any study and without whom Myeloma XI could not have come to fruition.”**

A huge study like Myeloma XI is dependent on great teamwork between doctors, nurses, the pharmaceutical industry and universities across the UK. Ultimately though, it is the patients and their families who are critical to the success of any study and without whom Myeloma XI could not have come to fruition. Our thanks and gratitude go out to every single patient who entered the study and to their families who supported them.

Myeloma UK has been involved in Myeloma XI from the start. What difference did having the charity's support and input make?

Myeloma UK has been critical to the success of Myeloma XI through promotion of the study and support of the trial infrastructure. One of the most important outcomes of the study is a better understanding of how the genetics of the myeloma cell can affect responses to treatment. These groundbreaking outcomes and the subsequent results and collaborations have been critical to developing a better understanding of high-risk myeloma and led to the design of the hugely important follow-on OPTIMUM/MUK nine clinical trial.

"These groundbreaking outcomes and the subsequent results and collaborations have been critical to developing a better understanding of high-risk myeloma."

Why are trials so important for people with myeloma?

All our knowledge of how best to treat our patients comes from clinical trials and each trial builds on the results of previous studies. Trials also allow patients to access novel therapies.

For example, over 2,000 patients were able to receive lenalidomide maintenance through the Myeloma XI trial. This would not have been possible if they had not been on the study.

BRITISH SOCIETY OF HAEMATOLOGY GOOD PRACTICE PAPER **DIAGNOSIS AND INITIAL TREATMENT OF TRANSPLANT-ELIGIBLE HIGH-RISK MYELOMA PATIENTS**

The British Society of Haematology (BSH) published a 'good practice paper' in the summer which outlines key recommendations for the diagnosis and initial treatment of transplant-eligible high-risk myeloma patients.

The paper highlights the critical unmet need of high-risk patients who do not benefit from current standard of care treatment for myeloma.

The evolving landscape in diagnostic testing is also outlined. These novel tests can help inform our understanding and ability to risk stratify individuals using extended cytogenetic tests and gene expression profiling (GEP).

Equitable access to GEP testing, access to advanced imaging (such as whole-body MRI) and the plea that high-risk myeloma patients are considered for enrolment onto appropriate clinical trials are a few of the many recommendations documented within the paper.

What is High-risk and Ultra-high-risk Myeloma?

Myeloma is a very complex and individual cancer. Whilst treatments can work well for the majority of people, there are some people who do not respond well to treatment and may relapse early.

The cohort of people who do not respond well can be defined as 'high-risk' or 'ultra-high-risk'. The definition is based on a number of characteristics, including genetic changes.

What is Myeloma UK doing in this space?

We recognise and welcome the recommendations outlined in the BSH good practice paper, which is a major step forward in highlighting and defining the unmet need and future provisions required for good practice to be achieved. The paper aligns with Myeloma UK's Access Strategy where we call for person-centric treatment approaches and equitable access to new diagnostics for high-risk and ultra-high-risk patients.

Dr Martin Kaiser, the lead author of the good practice paper, is Chief Investigator of the OPTIMUM/MUK nine clinical trial. The MUK nine clinical trial aims to find a better way to treat high-risk patients and is one of the first trials to test treatments specifically for ultra-high-risk patients using novel diagnostic approaches such as genetic profiling.

Dr Kaiser's research is supported by Myeloma UK through the Jaquelin Forbes-Nixon Research Fellowship.

You can read more about the OPTIMUM/MUK nine trial at **myeloma.org.uk/news/trial-identifies-a-better-way-to-treat-ultra-high-risk-myeloma-patients**

> **"The paper aligns with Myeloma UK's Access Strategy where we call for person-centric treatment approaches and equitable access to new diagnostics for high-risk and ultra-high-risk patients."**

Our next steps

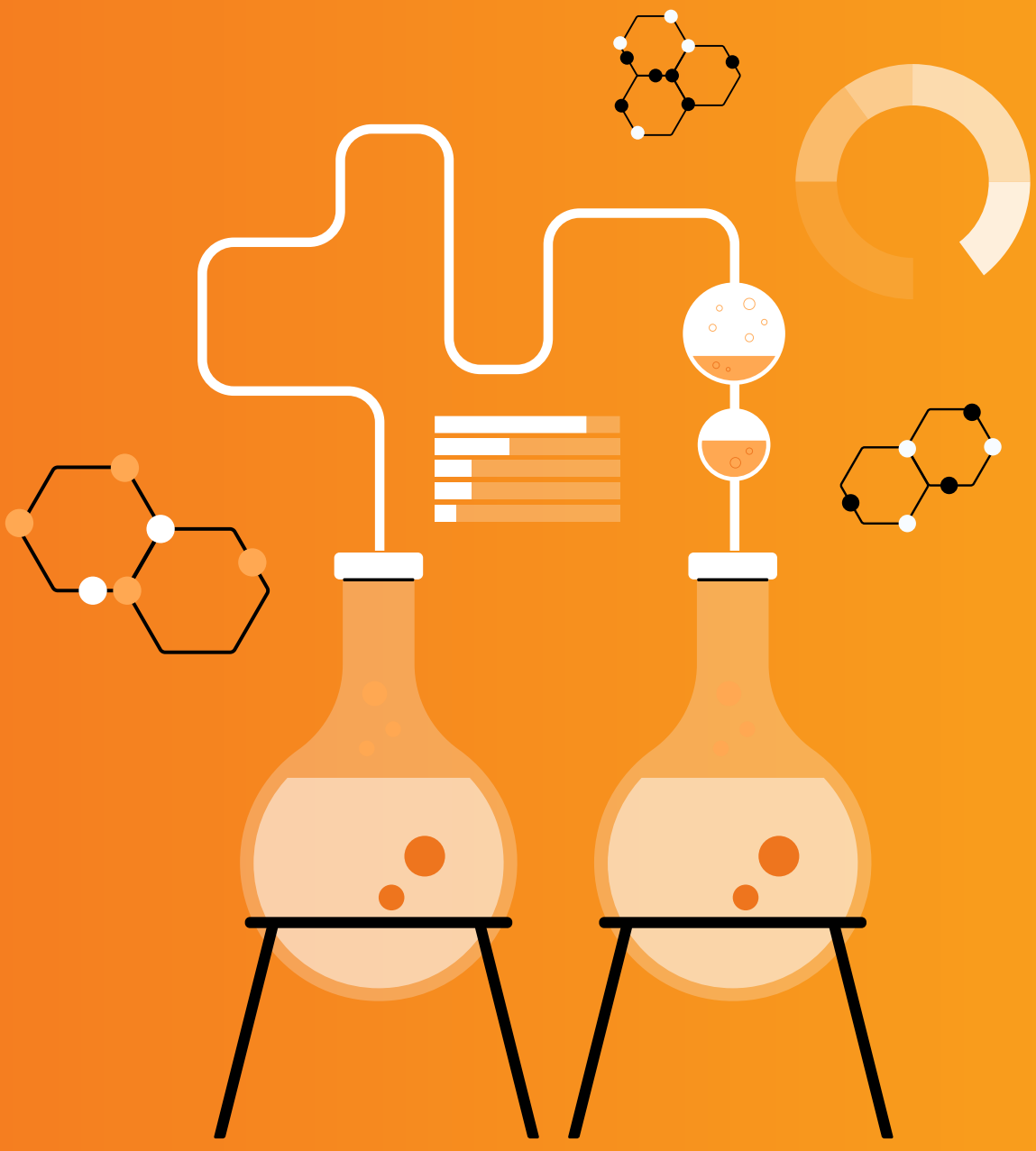
We are currently building on the information and knowledge outlined in the paper to develop an evidence base informed by research as well as engagement with the clinician and patient community.

This programme of work by Myeloma UK will enable us to identify any potential challenges and barriers which could impact future recommendations for best practice in the diagnosis and treatment of high-risk myeloma.

You can read the paper and recommendations in full at **onlinelibrary.wiley.com/doi**

Clinical trials: the future of myeloma treatment

Clinical trials are essential to advancing medical treatment and care and ensuring that there are more treatments in development for myeloma patients. That's why Myeloma UK continues to call for investment and support in myeloma clinical trials across the UK.



Since its inception over 25 years ago, Myeloma UK has invested more than £19 million into myeloma research.

That research has led to new treatments and a better understanding of how myeloma develops. For people living with myeloma, clinical trials can play a crucial role, not only in the development of new treatments, but for those who are running out of approved treatment options.

Clinical trials are research studies that test new treatments to determine how safe and effective they are.

So, what are clinical trials?

Clinical trials are research studies that test new treatments to determine how safe and effective they are. They provide the evidence needed to decide if a treatment should continue development and eventually be assessed for licensing and approval for use in the NHS.

During a clinical trial, patients receive treatment under carefully controlled conditions. They are closely monitored to check how they are tolerating treatment and/or the effectiveness of the treatment.

Sometimes, another group of patients receiving the usual 'standard of care' treatment are monitored in the same way. This helps researchers to compare the new treatment with existing ones.

At the moment, a clinical trial cannot offer a cure for myeloma, but a key benefit of taking part can include access to new treatments. By joining you are also helping create the evidence needed to make effective and safe treatments available to others through the NHS in the future.

Access to clinical trials

Patients can participate in clinical trials if they meet certain eligibility criteria. However, we know that the lack of diversity in clinical trials continues to be a challenge. The barriers to participation can be different for different people but include practical aspects like financial or geographical barriers, lack of support for carers, communication difficulties, or even eligibility criteria.

We need all of those involved in clinical trials – government, pharmaceutical companies, research organisations, healthcare providers and more – to commit to expanding access to clinical trials for people with myeloma.

Here's what we're calling for:

1. Expand trial locations for easier access
2. Improve awareness and education for patients and healthcare providers
3. Streamline regulatory trial approval processes
4. Routinely involve patients or patient organisations as part of the trial design

Setting world-leading standards for trial development

Myeloma UK believes that, long-term, the UK government should capitalise on the opportunity to build a world-leading regulatory framework to accelerate the development and delivery of cutting-edge treatments, making the UK a destination of choice for clinical trials. Such a framework would maximise inclusivity and encourage innovation in patient-centric trial design.

With investment and commitments, the future of myeloma treatment looks promising.

Challenges and Future Directions

Conducting clinical trials comes with challenges, such as regulatory hurdles and funding constraints. However, over the years, we have gone from having no approved treatments to many, thanks to clinical trials.

But we know we need to do more. That's why clinical trials and research investments were key aspects in our open letter to the new Secretary of State for Health and Social Care – signed by more than 4,500 of our supporters in just over a week. With investment and commitments, the future of myeloma treatment looks promising. Through research, we will find new ways to a cure for myeloma.

Find out more about clinical trials currently recruiting in the UK by visiting our **Myeloma Trial Finder** at **trials.myeloma.org.uk**

GAME-CHANGING TREATMENT **OFFERS NEW LIFELINE**

Teclistamab is the very first in a new class of drugs, known as a bispecific antibody, approved on the NHS in England and Wales.

The new drug, which has been hailed as a "miracle" treatment by some patients, has been shown to stop the incurable blood cancer myeloma in its tracks for more than 11 months.

It has even allowed some people who had never fully responded to treatment up to that point to get their first complete remission.

Teclistamab was initially approved on the NHS in England and Wales back in July but the approval came with strict restrictions on who could access the treatment.

The restrictions meant that those who had previously received the treatments known as IsaPD – a combination of isatuximab, pomalidomide and dexamethasone – or pomalidomide plus dexamethasone (PD), were not eligible for teclistamab.

> **Myeloma UK, along with patients, hit back at the move to severely limit the number of people able to receive the treatment and made the case for wider access.**

This was a huge blow to the many people who had pinned their hopes on the new drug, some of whom faced the prospect of end-of-life care without treatment.

Myeloma UK, along with patients, hit back at the move to severely limit the number of people able to receive the treatment and made the case for wider access.

Three months on, NICE has now lifted all previous restrictions.

Teclistamab is now available to anyone who has received at least three rounds of treatment, whose cancer has progressed and who has previously received an immunomodulatory agent such as lenalidomide (Revlimid®), a proteasome inhibitor like bortezomib (Velcade®) and an anti-CD38 antibody like daratumumab (Darzalex®) or isatuximab (Sarclisa®).

> **The approval means that teclistamab is available to eligible myeloma patients as a potential treatment option in England and Wales.**

The approval means that teclistamab is available to eligible myeloma patients as a potential treatment option in England and Wales.

Patients at third relapse (fourth line) and beyond who have previously been treated with an immunomodulatory drug, a proteasome inhibitor and an anti-CD38 monoclonal antibody can now receive teclistamab.

This means patients whose myeloma has become resistant to previous treatments now have access to an innovative treatment which kills the myeloma cells in a new way.

The Scottish Medicines Consortium (SMC) approved teclistamab for use on the NHS in Scotland in September. In Northern Ireland, the Department for Health makes decisions on which treatments to fund through the NHS. It can follow guidance issued by either NICE or the SMC but usually follows the guidance issued by NICE.

Our Senior Policy Officer, **Caroline Donoghue** said:

"This is fantastic news and a hard-earned victory for all involved. Teclistamab is the first of a new class of drugs to be approved on the NHS in England and Wales and could be a lifeline for people who are close to running out of treatment options.

Approvals like this highlight why we continue to fight for treatment, submit evidence on behalf of the myeloma community, attend committee meetings and push for access to pioneering drugs."

MYELOMA

HOT TOPICS

GETTING TREATMENTS FROM CLINICAL TRIALS TO THE NHS

So a new treatment has demonstrated safety and effectiveness in clinical trials – great news! Now what?

How are new treatments licenced?

Before a new treatment can become available on the NHS, it must first be licensed then approved for use. Treatment licensing is the process of deciding if a treatment is safe and effective, based on data from clinical trials and laboratory studies.

A treatment licence allows the treatment to be sold in the UK, and for doctors to prescribe it. However, it does not guarantee it will be funded on the NHS.

The licence specifies the way the treatment is used, for example:

- What it is used to treat
- How the treatment is given
- The recommended dose
- Whether it is given in combination with other treatments

Who licenses treatments in the UK?

The Medicines and Healthcare products Regulatory Agency (MHRA) licenses treatments in the UK. It is able to consider licensing decisions made by the European Commission, which licenses treatments based on recommendations from the European Medicines Agency (EMA).

In Northern Ireland, treatments can be licensed via the MHRA or the EMA. From 2025, only the MHRA can license new treatments for use in Northern Ireland.

How are new treatments approved?

For a treatment to be made available through the NHS, it needs to be appraised by a health approval body. This treatment approval process is called a Health Technology Assessment.

The treatment approval process looks at the benefits of the new treatment and compares these with existing treatments already available on the NHS.

The treatment approval process considers questions such as:

- How well does the new treatment or combination work?
- Is the new treatment or combination good value for money?
- How well does it work in relation to its cost to the NHS?

Who decides what treatments are available on the NHS?

Treatment approval is done by different organisations in different parts of the UK.

In England, the National Institute for Health and Care Excellence (NICE) decides which treatments are available on the NHS.

In Scotland, the Scottish Medicines Consortium (SMC) decides which treatments are available on the NHS. Its decisions are separate from those made by NICE.

In Wales, the All Wales Medicines Strategy Group (AWMSG) decides which treatments are available on the NHS. Generally, they follow NICE decisions.

In Northern Ireland, the Department of Health makes decisions about health and social care. They usually follow NICE decisions.

If a new treatment is approved by one of these organisations then it becomes available on the NHS within that part of the UK.

Your healthcare team can tell you which treatments are available and whether they are suitable for you.

Treatment demonstrates effectiveness in clinical trials

Treatment licencing process
Clinical trials data and laboratory data

New treatment is licensed as safe and effective

Health Technology Assessment (HTA)
Evidence of benefits and costs

Treatment is approved for use in one or more countries of the UK

Find out more about treatment licensing and approval:

Read our Infosheet, **Clinical trials and how treatments are developed**

Read our **Ask the Nurse blog on Treatment options**

Speak to your healthcare team

PATROLLING THE MYELOMA MICROENVIRONMENT: HOW IMMUNOTHERAPIES WORK

If myeloma cells are invaders, writes Edmund Watson, then the tumour microenvironment, made up of surrounding tissues and immune cells, is the neighbourhood they are invading.

Imagine you are the size of an average cell – about two-hundredths of a millimetre tall. That's the equivalent shrinkage of the Empire State Building becoming a grain of rice! Let's go for a tour around this neighbourhood to appreciate it better.

Inside the hollow of the bone

We see islands of cells all around us, perhaps thousands of cells wide, jostling and talking with each other. These are interspersed with fatty spaces and interrupted by arching columns of bone tissue that form a huge lattice across the entire bone's inside. Blood vessels, some as narrow as our now-miniscule bodies, are never far, bringing blood to or from the marrow. The whole neighbourhood is bathed in fluid.

If this were bone marrow at the time of a myeloma diagnosis, somewhere between 10– 60%, occasionally more, of all the cells we see are myeloma cells. The rest are the normal neighbourhood residents, but they are being crowded out by the myeloma cells.

Most of the residents produce different types of blood cells (haematopoietic) – we see immune cells (white blood cells), red cells and platelets. The myeloma invasion reduces production of these healthy cells leading to problems like increased risk of infection, anaemia and thrombocytopenia [low platelet count]. The remaining residents are stromal cells, which create and maintain the structures of the marrow and support the haematopoietic cells. When myeloma disrupts these cells, the bones weaken.

Myeloma invasion does not go unchecked

There is a Neighbourhood Watch in place. Immune cells called lymphocytes attempt to destroy the myeloma cells. They are assisted by other haematopoietic cells – some signpost where the invaders are and activate the lymphocytes; others help by directly attacking myeloma cells.

Sometimes, the Neighbourhood Watch response keeps the invading cell numbers so low that myeloma never actually arises; this could describe monoclonal gammopathy of uncertain significance (MGUS).

When myeloma does arise, it seems that the invading cells hoodwink the immune response; they disable the Neighbourhood Watch.

They communicate with lymphocytes and natural killer cells by direct contact, or through secreted chemicals, to stunt their aggression. They exploit certain immune cells who normally act as moderators to ensure immune responses don't get out of control.

Immunotherapies harness hope

Immunotherapy treatments offer the Neighbourhood Watch an opportunity to take power back. They harness the immune system, helping it gain control again to kill myeloma cells and help the microenvironment repair.

Immunomodulatory agents (IMiDs) like lenalidomide (Revlimid®) help rejuvenate tired lymphocytes and directly kill myeloma cells. New treatments continue to be developed which engage the body's own Neighbourhood Watch to target the invasion of myeloma cells.

Monoclonal antibodies, such as daratumumab (Darzalex®) and antibody-drug conjugates like belantamab mafodotin (Blenrep®), stick to myeloma cell surfaces and act as beacons to help the Neighbourhood Watch attack. Bispecific antibodies like teclistamab (Tecvayli®) and elranatamab (Elrexfio®) activate T cells (a type of immune cell), bringing them very close to the myeloma cells to help the T cell kill the myeloma cells. CAR-T cell treatments deliver a dose of laboratory-modified T cells, primed to seek out and kill myeloma.

Exploring new horizons

In laboratories and clinics across the globe, clinicians and researchers are working hard to hit myeloma hard by giving full support to this industrious Neighbourhood Watch. Invading myeloma cells only survive and thrive whilst they can adapt the microenvironment for their use and their activities go unchecked, but immunotherapies offer a way to take back control – watch this space!

Edmund Watson is a Doctoral Research Fellow at NDORMS, University of Oxford.

THREE NEW MEMBERS LEND THEIR VOICES TO MYELOMA UK'S TREATMENT ACCESS PANEL

This summer, we recruited new members to our Advocacy Panel – a group of patient and family volunteers that help us with our influencing for treatment access and policy work.

The Panel are a vital part of our commitment to put the patient voice at the heart of decision making, and our members help us with NICE and SMC appraisals, surveys, roundtables, education events and campaigns by sharing their personal experiences. Every member helps us to drive positive change for people living with myeloma.

Robert McGaughey from Country Antrim joined in the Panel in July this year and has opened the door to give us insight into the diagnosis, treatment and care of people living with myeloma in Northern Ireland.

Robert was diagnosed seven years ago and is currently in remission, making the most of his time off treatment to help others in any way he can. Alongside his clinical team and a local charity, he helped to set up Northern Ireland's first myeloma support group, as well as doing peer support work and fundraising for Leukaemia & Lymphoma NI. Robert is also a UK athletic performance coach and finds the relationship between coaching and talking to patients very interesting and quite similar, especially on confidence building and promoting quality of life.

Ross Ellice from Kent is a retired GP and lived with MGUS for 30 years before he was diagnosed with myeloma in November 2022.

Ross brings his experience of living with a precursor condition to the Panel, and this is important as we develop our research to understand why MGUS and smouldering myeloma progress into active myeloma. His career as a GP brings together clinical and patient experiences, which is a unique and powerful perspective to share with decision-makers.

Sybil Parris sadly lost her mum to myeloma recently and wanted to join the Panel to help other families caring for people living with myeloma.

Her mum was West Indian and Sybil felt that despite the Black community being more likely to develop myeloma, their voices in important circles weren't well represented. Sybil wants to change that, and her first step is being part of a project in collaboration with the Race Equality Foundation, which aims to increase awareness of myeloma in Black African and Black Caribbean communities across the UK.

INTERVIEW WITH ROMI CARRIERE

CHAPMAN-LIVANOS SURVIVORSHIP FELLOW

As Myeloma UK's Chapman-Livanos Survivorship Fellow, Dr Romi Carriere has spent the past few months investigating whether heart and circulatory problems in people with myeloma are a result of the cancer itself, of intensive treatment, or an unfortunate but random occurrence. Here she sets out how and why this new research project could radically change our understanding of myeloma and improve the quality of life for generations of patients.

What drew you to this research project?

I was interested in challenging myself and returning to my PhD work in cancer research. My main interest was addressing cancer survivorship in lower and middle-income groups and understanding how their cancer journeys differ from others.

On a personal level, one of my mum's friends passed away from hereditary cancer. She unfortunately delayed action even when experiencing symptoms of cancer which, ultimately, led to her death. This deeply motivated me to conduct research that could help people live longer and better with cancer.

How has your experience of cancer research informed, and will continue to inform, your work at Myeloma UK?

My background is in epidemiology, statistics and public health. What that means is, I do research about the whole group of people affected by a disease and seek to find out why their cancer or issues related to it result in particular outcomes.

I have experience of working with different people affected by poorer health and, specifically, cancer and I want to use the skills and expertise I have to improve cancer patients' lives and, in particular, myeloma.

Tell us about the Chapman-Livanos Survivorship Fellowship.

The fellowship aims to understand the source of heart and circulatory (H&C) issues in myeloma. This involves scanning the current evidence for H&C to find out more about what is already known about these challenges and taking the insights from previous research we have carried out – namely, the Unmet and Emerging Needs Research that so many patients and their families were involved in – to begin to look at why these issues arise.

We have collected a lot of information about patients' family health history, the other conditions they have in addition to their myeloma that are associated with H&C disease, the treatments they have taken and a whole range of other things that may help us understand these issues.

> **"The fellowship aims to understand the source of heart and circulatory (H&C) issues in myeloma."**

The first phase of this project is taking place over 18 months, but we are interested in taking this project beyond that timeframe.

We know this area of research is important and there is a lot of potential future research we can carry out on behalf of patients and their families.

How could this research help improve patients' quality of life and our understanding of myeloma generally?

If we know what the challenges are and why these occur, we can begin to think about ways in which we can avoid these issues arising. This first phase helps us to begin to tease out why this may happen, but it is just the first step. We want to develop interventions or new ways of perhaps treating or supporting patients to live well and have the best quality of life they can achieve.

Why is it important for Myeloma UK to focus on survivorship and quality of life?

We know myeloma has some of the longest times to diagnosis of any cancer and this is a complex blood cancer. Treatments often have a lot of side-effects and, taking all of this together, it is challenging for patients to live well. If we can find ways to help them do so and remove some of the challenges, we can ensure they have better outcomes and live well with myeloma.

What has been the highlight of your work so far?

Having the funding approved was obviously a big success and the fact that part of it came from a myeloma patient made it really special. Knowing that I am delivering a patient-centred project it simply amazing and makes it even more significant as we use that support to deliver improvements to patients' lives.

Meeting Sir Frank Chapman, one of our funders, was one of the best introductions to the project. He was very welcoming and enthusiastic about the project. He asked lots of questions and I enjoyed having the opportunity to meet the person who made this fellowship come to life.

We were successful in getting the protocol published for one part of the project and that really set the scene for what I was going to do in the first part of the project. We are now really moving forward with the work, and it has really helped guide everything that comes next.

What is Myeloma UK's biggest asset as a charity?

One of the biggest assets we have is the involvement of people with myeloma. We couldn't do this work without their support, and we always appreciate everything they do to make our work possible. That includes completing our surveys to understand patient/carer experiences and we use that insight to inform our work and the wider clinical community.

> **I am really thrilled to be part of that and to make a difference to patients' lives.**

Additionally, our supporters raise vital funds to help us to ensure that, together, we are the cure. I am really thrilled to be part of that and to make a difference to patients' lives.

> **They gave up everything to give me and my younger brother the opportunities we have had. So, I figure I should pass it on.**

What inspires you, both at work and in life?

Being intentional in anything I do and with my whole heart. My family are a big part of that journey.

They were immigrants to the United States who left everything behind and moved to another country where they had no ties, family or friends. They gave up everything to give me and my younger brother the opportunities we have had. So, I figure I should pass it on.

MEET THE NEW EDITOR
NICOLA LAMB

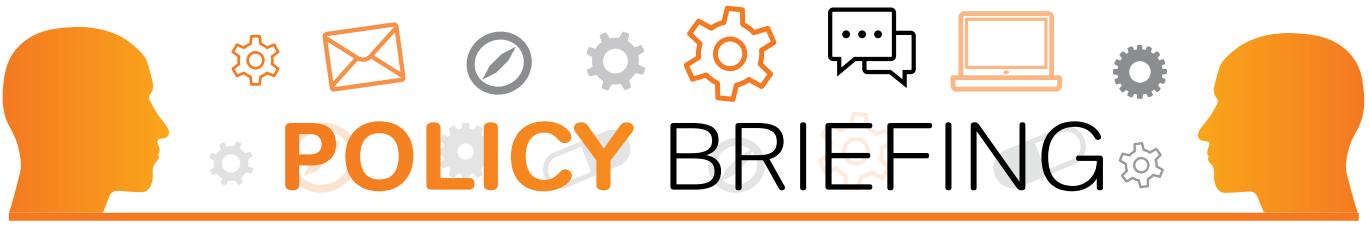
Nicola Lamb joined our Patient Information team at Myeloma UK in May 2023, and has recently stepped into the role of Patient Information Manager.

Since joining the team, she has worked on the full range of our information materials, including booklets, videos and more. She is responsible for ensuring that our patient information goes through a professional and robust production process by trained staff, is based on reliable information and up to date evidence, and is written in plain English.

Coming from a background in medical writing, she understands the positive impact that informative and engaging content can have on patients and families. She believes that people affected by myeloma need more than just information on treating their disease, they also need support on how to live well with their condition. Myeloma is a very individual cancer, and people's needs can be different and can change over time. Nicola believes that every voice matters and aims to create a space where readers can find inspiration, connection, and valuable resources.

When not working on our wonderful patient information, she enjoys baking, reading, language learning and tap dancing! Nicola is excited to take on this meaningful role and looks forward to engaging with the Myeloma Matters community.

Find out more about myeloma and its related conditions, how they are treated, and how to live well with them, as well as advice and stories from the myeloma community on our website at myeloma.org.uk/library



IMPROVING DIAGNOSIS, TREATMENT AND CARE BY ADVOCATING FOR UK HEALTH POLICY THAT DELIVERS BETTER OUTCOMES FOR OUR MYELOMA COMMUNITY

Myeloma UK Head of Advocacy, Dr Scott Purdon, shares his thoughts on working with and informing key health policy decision makers.

We are making amazing progress in the research and treatment of myeloma. However, too many people with myeloma are still impacted by delays in diagnosis and challenges to accessing treatment. We need to go further, faster.

At Myeloma UK, our most important advocacy goal is to provide an evidence-based approach to proposed changes in UK health services, so that people with myeloma can live longer and with a better quality of life. By providing lived experience testimony from our community, we continue to make an impact and strive to improve health service experience and to get access to the best quality of services.

> **We constantly monitor government plans to change the way myeloma health services are provided.**

To influence the UK and devolved nation's respective government policy developments, and ensure commitments are implemented, requires a thorough and expert knowledge of health decision makers and the policy process in the UK.

We constantly monitor government plans to change the way myeloma health services are provided.

> **We keep abreast of multiple governmental departments and institutes whose decision making can impact the lives of our community.**

These can be standalone myeloma issues or requests for information within blood cancer action plans, or wider cancer and general health legislation. Similarly, we keep abreast of multiple governmental departments and institutes whose decision making can impact the lives of our community. For example, the Department for Health and Social Care (DHSC), the National Institute for Health and Care Excellence (NICE), the Scottish Medicine Consortium (SMC), the Medicines and Healthcare products Regulatory Agency (MHRA), and the respective UK National Health Services (NHS).

We also engage actively with parliamentarians, both those in cabinet and opposition parties, to seek political endorsement and action to act on behalf of their constituents and the UK as a leader in life sciences. We meet regularly with MPs from across the UK, in one-to-one meetings, in formal parliamentary inquiries and sessions and with cross-party groups which focus on specific areas of health. This activity is critical to making sure those governing and in opposition hear what is happening at the frontline of myeloma treatment and care.

We strengthen and amplify our advocacy calls for improved care and treatment services through partnerships and coalitions such as Chairing and providing the secretariat for the Charity Medicines Access Coalition (CMAC), and our founding membership of the Blood Cancer Alliance (BCA), and taking part and informing Cancer52, National Voices, and One Cancer Voice (OCV) policy campaigns. We also have leading roles in devolved nations consortia including the Scottish Cancer Coalition, the Wales Cancer Alliance and the Northern Ireland Cancer Charities Coalition.

> **We strengthen and amplify our advocacy calls for improved care and treatment services through partnerships and coalitions.**

Such alliances are critical to mobilising many diverse communities, representing millions of people affected by different diseases and experiences and to provide a unified call to action.

The UK health policy environment

The challenge for all charities seeking to make a meaningful change to improving health outcomes for their communities is the complexity of how health policy decisions are made in the UK. There are myriad governmental departments, arm's-length bodies, and a sea of legislative process that make navigating the policy system difficult. Often there are different viewpoints and opposing views from these respective departments and organisations as to how best to spend UK taxpayers' money to improve health outcomes.

> **In times of austerity, in what can appear as government indecision, it is even more important to ensure that the voice and experience of our myeloma community are heard.**

Furthermore, they often disagree who to spend the money on. For example, different policy decision-makers are keen to champion either childhood diseases, chronic conditions, rare diseases, respiratory, cardiology, neurological or cancer. In times of austerity, in what can appear as government indecision, it is even more important to ensure that the voice and experience of our myeloma community are heard, and changes are made to improve lives. The new Labour government has committed to a ten-year health plan and action to half the gap in healthy life expectancy, but, has not provided any breakdown by disease focus including myeloma.

We believe that policymakers and regulators, nearly always responsible for different parts of the health system, do not communicate with each other as effectively as they could.

This means that we need to engage and influence across many different policy institutions which requires different evidence and messaging.

> **There are competing and conflicting voices in the provision of health services in the UK.**

We also need to consider which policy organisations to prioritise and how to ensure that our advocacy to improve myeloma health outcomes is acted on at multiple levels of government.

There are competing and conflicting voices in the provision of health services in the UK. Government says it has no more funding for the NHS, and the NHS states it needs more people, state of the art equipment and facilities and financing. The pharmaceutical industry argues that the UK is becoming less attractive, and that the UK is no longer their priority to make available next-generation treatments.

All this discord and lack of clarity on who ultimately aligns cohesive policy means we need to be determined and resilient and noisy. We must adapt to fast-moving and contradictory policy changes. We do this by acting together to increase the pace of change to deliver world-class myeloma health outcomes.

Making lived experience heard

We make it possible to live longer and better lives with myeloma. We do this by delivering meaningful health policy change and responding to government consultations which oversee the way health is provided and funded in the UK. These consultations can be general and broad-ranging, or they can be highly technical and deal with the drug regulatory and NHS approval processes. We also provide our experience in NHS development and implementation of diagnosis and care pathways and advocate for improved holistic support services such as provision of psychological wellbeing, dietary and physiotherapy services.

At the core of our policy advocacy is the voice and experience of our community. Through our lived experiences panels such as the Advocacy Partner Panel, the Patient and Carer Research Panel and the Patient Information Panel, we seek, collate, and amplify our community voice to deliver impactful health policy regulations.

> **This year has been the busiest in terms of new drug approvals in the history of Myeloma UK.**

Ongoing policy consultations

This year has been the busiest in terms of new drug approvals in the history of Myeloma UK. This reflects the success of the pharmaceutical industry's myeloma pipeline, delivering new medicines to be considered for use in the NHS.

The number of industry submissions to NICE and SMC for approval of new drugs is very positive. However, each drug submitted has faced significant challenges including quality of data, efficacy outcomes, side effect profiles and cost to the NHS. This has involved a huge volume of technical consultations as we fought to overcome restricted access and decisions not to fund new treatments.

We have a senior-level engagement programme with key UK access policy decision makers across government, industry and health providers. This year alone, responding as Myeloma UK, CMAC, and BCA, we have submitted lived experience evidence to five major NICE consultations and two key NHSE consultations.

- **NICE: A public consultation on our new approach to prioritising guidance**
- **NICE: Public consultation on updates to health technology evaluations manual**
- **NICE: Building an integrated, rules-based medical technology (medtech) pathway**
- **NICE: Interim methods and processes statement for including NICE technology appraisal recommendations in guideline topic areas**
- **NICE: Working alongside people and communities at NICE: a strategy**
- **NHSE: Commercial Framework for New Medicines**
- **NHSE: Budget Impact Test threshold consultation**

Each of these consultations involved a large amount of work to analyse the proposals, to consider the impact on current systems and possible positive and negative outcomes of the consultations if they were implemented unchanged. Working together with our lived experience community and with other charities we can provide robust and impactful insights, in the language of policy and health economic decision makers. Each of these consultations are, on average, open for six weeks, and are preceded by weeks to months of meetings.

The impact of not responding to such consultations cannot be understated. The NICE consultations will determine when and how new drugs and new diagnostic tests will be made available to UK patients. The NHS consultations will greatly impact how pharmaceutical companies and the NHS may reach agreement on the price of drugs and therefore a direct consequence if or when UK drugs will be available to patients.

Each of these consultations has the potential to have a significant impact, positive and negative, on access to medicines and diagnostic services for UK patients. As such, we continue to inform, challenge and monitor the outcomes, implementation and impact of all these key health legislation proposals to ensure that we deliver the best outcomes for our myeloma community.

Looking ahead at what's coming next

The immediate prospect for improving health outcomes for the UK has a political commitment largely focussed on prevention and reducing the burden of illness that the NHS must manage. We are fully committed to research for myeloma precursor conditions such as monoclonal gammopathy of undetermined significance (MGUS) and smouldering myeloma, and for everyone with myeloma to be diagnosed as early as possible and receive the best possible treatments. We have identified the need to ensure that forthcoming health policy consultations are fit for purpose before they are sent out for public consultation. Our experience is that often consultations for consideration are already ninety nine percent finalised with minimal input from those with lived experience.

> **We are determined that our community expertise is heard and included into the forming of new health policies.**

We are determined that our community expertise is heard and included into the forming of new health policies. We use our senior level relationships at high level government decision making; including the regulators of medicine approvals and the people that decide how much and who to spend the NHS drug budgets on, to communicate our insights.

We are a leading catalyst for joint working and partnerships that seek to deliver cohesive UK health policy. This is challenging but we are committed to ensuring that everyone living with and affected by myeloma gets the best chance to live well.

> **Almost a third of patients now live for more than 10 years after diagnosis – and many for much longer.**

We are a trusted partner, we are effective advocates for change, and we are seen as an organisation who understands the financial realities that the UK government faces. We do not shy away from difficult conversations, however, everything we do is based on lived experience, our healthcare policy expertise and we will continue to ensure that our voice makes a difference.

Our impact

We have transformed treatment and care for people living with and affected by myeloma. From no myeloma-specific cancer treatments 25 years ago to a range of treatments that can be given in multiple combinations by the NHS, today. The average life expectancy for a person with myeloma has quadrupled during this time. Almost a third of patients now live for more than 10 years after diagnosis – and many for much longer.

Together with our myeloma community we have had considerable success in directing health policy in the UK. We welcome all the advances to date and are optimistic that our work can make ongoing progress until the day we have a cure.

ASK THE NURSE

Rebecca Huntley and Ellen Watters **Myeloma Information Specialists**

My granddaughter has just had the live nasal spray flu vaccine, is it safe for me to have contact with her?

Unfortunately, myeloma patients are always at an increased risk of infection due to both the myeloma itself, and as a potential side effect of myeloma treatment. When someone has a live vaccine, they can shed small amounts of the live virus via their bodily fluids. It is thought that viral shedding is possible for anywhere between a few days up to a number of weeks following vaccination. This means that there is a small chance that myeloma patients can have the virus passed onto them by a child who has had the nasal flu vaccine.

The amount of virus shed is normally below the levels needed to pass on infection to others, and the weakened virus does not survive for long outside of the body when compared to natural viral infection, which can spread very easily. So, the risk of viral shedding to myeloma patients is low and will be reduced further if they have received their flu vaccine. (The injected flu vaccine is non-live and is therefore safe for myeloma patients to receive.)

To reduce infection risk, people with weakened immune systems, such as myeloma patients, should avoid close contact with people who have had the nasal flu vaccine for two weeks. However, as it may not be possible to avoid all contact with a child following the nasal flu vaccine, it is advised to avoid very close physical contact such as kisses and hugs, whilst practising regular handwashing.

I'm due to start on a bispecific antibody treatment and I've been told it can cause Cytokine Release Syndrome, what is it?

Cytokine Release Syndrome (CRS) occurs when the immune system responds more aggressively than it should. Cytokines are 'chemical messengers' released by the body, which normally send signals for the immune system to respond in a certain way. CRS happens when too many cytokines are released at once. CRS can be triggered by certain drugs, for example bispecific antibody drugs like teclistamab (Tecvayli®) or elranatamab (Elrexfio®).

CRS can be mild but can sometimes be very serious. CRS commonly causes symptoms such as fever, shortness of breath, and changes in blood pressure. CRS is more likely to occur when you are first treated with a drug like a bispecific antibody. To reduce the risk of CRS occurring, bispecific antibody drugs are often started at a lower dose at first, before being "stepped up" to a higher dose if they are tolerated well enough.

When you are receiving bispecific antibody drugs, you also will be given supportive treatments alongside these, to reduce the risk of developing CRS. You will also be carefully monitored for signs of CRS, and you would be given additional treatment should a reaction occur. Your medical team will also tell you what signs to look out for, and who you should contact if you become unwell when you go home after having your treatment.

I am feeling tired and breathless and have been told that I am anaemic. Would taking iron supplements help to improve my symptoms?

Unless your medical team (haematologist and/or clinical nurse specialist) has told you that you should take specific supplements or vitamins, these are not recommended for myeloma patients. This is because supplements that have not been prescribed or approved by your haematologist could have the potential to cause problems when taken alongside your prescribed treatment.

It is important to speak to your medical team before taking any kind of supplement or treatment that they have not prescribed, including herbal, traditional or natural medicines and remedies, and vitamins or wellbeing supplements. This is to ensure they are safe and will not have any harmful effects or interactions with your prescribed treatment.

It is also worth noting that iron supplements would only be likely to help with tiredness and breathlessness if you were diagnosed with iron deficiency anaemia. Your medical team will be monitoring you with regular blood tests to identify any potential anaemia.

If you have a questions for our Myeloma Information Specialists, call the **Myeloma Infoline** on **0800 980 3332**, use our online form at **myeloma.org.uk/AskTheNurse** or email **AskTheNurse@myeloma.org.uk**

SUPPORTER STORIES

What would you like to be remembered for?

Franko Kowalczuk recently shared his story, highlighting the importance of writing a will and leaving your legacy to a cause that matters to you.

Franko, a librarian who lives in Buckinghamshire was diagnosed with myeloma in 2018. After having a successful stem cell transplant, he went into remission, but two years ago Franko relapsed. He had chemotherapy last year and is now on the second line treatment of carfilzomib. Initially this treatment didn't react very well with Franko, but he is now back to living life to the full. He has been on a recent holiday to Portugal to see friends and earlier this year fundraised for Myeloma UK by completing the Chiltern 50 Ultra Challenge.

As well as going through the ups and downs that a myeloma diagnosis brings, sadly Franko also faced family bereavements when he lost two of his siblings in a short space of time. All of this made Franko realise that he wanted to get his affairs in order and write a will. **He wanted everything to be clear about what his wishes were so that there was no room for confusion or misunderstanding.**

"It is a simple process writing your will and it does not even take much effort. It's not as complicated as you might think. Just a few simple steps and a conversation with a solicitor will enable your wishes to be captured."

It was important to Franko to make sure that he left a gift in his will to Myeloma UK. He felt that lots of people leave gifts in their wills to larger charities, but often smaller charities get forgotten.

Franko was the face and voice of the Myeloma UK Legacy campaign this year because he wanted to encourage others to remember charities that are meaningful to them in their will.

> **"Make sure that you leave money in your will to a charity that is close to your heart and that your loved ones know that these are your wishes."**

Franko is a great believer in the efficiency of getting two things done at once – get your affairs in order and leave money to a cause that means something to you. You can decide how you want to be remembered and the legacy that you will leave. For Franko it's clear to him why he's left a gift in his will to Myeloma UK.

> **"I hope my legacy will be towards finding further treatments to help control myeloma and ultimately to find a cure."**

Gifts in wills are so important to Myeloma UK. They help us provide support for people living with myeloma so that no one faces myeloma alone.

And they help us invest in ground-breaking research and innovative treatments, to find new ways to a cure.

Myeloma UK Free Will Writing Service

We've partnered with National Free Wills Network who can help you write your simple will or a joint will for you and your partner for free. Contact our Gifts In Wills team who will organise for you to be sent a free will writing information pack. You can then choose a solicitor who is local to you, book an appointment, and start writing your will for free, ensuring your family and friends know exactly what's important to you.

This is a free service provided by Myeloma UK. You are not obliged to leave a gift in your will to Myeloma UK.

To find out more, scan the QR code or go to **myeloma.org.uk/gifts-in-wills** or get in touch, by emailing **giftsinwills@myeloma.org.uk** or phoning **0131 230 0429**.

My Coffee Morning

It's beginning to look a *latte* like Christmas...

Sign up and host your own Christmas Coffee Morning at **coffee.myeloma.org.uk**

Or get in touch to tell us about your other Christmas fundraising plans by emailing the team at **fundraising@myeloma.org.uk**

Myeloma UK is a registered charity, number SC026116.

Help families make more joyful moments this Christmas

"I'm so glad I found Myeloma UK. I don't think I could've faced myeloma alone. The support I received means I can concentrate on making the most of every moment with my son Alfie."
– Jodie Hill

Can you give this Christmas, so that families like Jodie's can have **more days defined by family, fun and joy**, and not by myeloma?

Donate today at **christmas.myeloma.org.uk** or scan the QR code

MyelomaUK

Myeloma UK is a registered charity, number SC026116.

MyelomaUK

We're here for everything a diagnosis of myeloma brings

Call our **Myeloma Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.

Get answers to your questions by emailing our Myeloma Information Specialists on **AskTheNurse@myeloma.org.uk**

Learn about myeloma from experts and meet other patients at our **Infodays and Digital Infoday Sessions**.

Order or download our **information publications**, which cover all aspects of myeloma – call **0800 980 3332** or visit **myeloma.org.uk**

Join your nearest **Myeloma Support Group** to meet other people living with myeloma face to face or online.

Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; from news on the latest research and drug discovery to articles on support, treatment and care.

Get matched up with a trained **Peer Buddy** for one-to-one support from someone with experience of myeloma.

Chat and share experiences with others affected by myeloma, including our peer volunteers, on the **Discussion Forum**.

Help make myeloma history by **fundraising and donating**. Email **fundraising@myeloma.org.uk** or call **0131 230 0429** to find out ways you can help.

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