Myeloma UK is the only organisation in the UK dealing exclusively with myeloma. We understand its complexities, and the impact living with a diagnosis of myeloma can have on patients, families and carers.

At Myeloma UK patients come first in everything we do.
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One of the key aspects of my role as Chairman, and the role of all our Trustees, is to ensure that our work is aligned with the most urgent as well as future needs of patients.

As an organisation, we are acutely aware that while progress has been made in both length and quality of life for myeloma patients in the UK, there is still much work to do and many hurdles to overcome.

Treatments are improving but there is still no cure and only 47 per cent of patients are alive after five years. Patients continue to drive our sense of urgency and desire to accelerate the delivery of improved care, effective treatments and ultimately to find a cure for myeloma.

We have recognised the increasing need for earlier diagnosis and for more patients to be reached, particularly in more communities and where we have previously not been well connected. We are building bridges to these under-represented groups while at the same time strengthening and deepening our offering to patients, carers and healthcare professionals.

By engaging with stakeholders and requesting regular feedback we have been able to validate and develop our strategy for the next five years. This consultation has ensured that our plans meet the needs of our stakeholders so we can be as effective as possible.

A shared vision ensures unity across patients, family members and friends as well as our supporters, researchers, clinicians, our board and staff. We believe that this approach ensures that we succeed and that we are able to continue to invest in crucial areas of research to achieve our goals for patients.

We are in awe of the courage that patients and carers display, who are on this journey with us and the journey continues until we find a cure.

As you will see from this report, progress continues and our incredible supporters fuel our drive to make a better future for more myeloma patients. I’m proud to be a part of it.

**Judy Dewinter**  
Chairman, Myeloma UK
It is with immense pride and gratitude that I present you with our impact report, showcasing the progress and major achievements of Myeloma UK. Our continued success would not have been possible without the generosity of our donors, fundraisers, and supporters. As well as the dedication of our staff, board, and volunteers.

Myeloma UK, its staff and partners are committed to exploring every avenue to understand myeloma better, and ensure that all patients get access to the best possible treatment, care, information and support.

It is this unity that has allowed us to strive toward our mission to find a cure. The increased reach and impact of our work, aligned with structured and engaging information for support services have seen us enhance our profile, grow as an organisation, and make significant impacts into myeloma research.

Over the past 21 years the generous donations we have received have funded vital myeloma research and supported patients and families with the experiences a myeloma diagnosis brings. Funds have also allowed us to do work to help raise awareness of myeloma among healthcare professionals, and champion the cause of patients by appealing to policy makers to improve access to treatment and care.

However, the work will not stop until we find a cure and we need further funding and support to help us achieve our goal.

On behalf of everyone at Myeloma UK, I say thank you to all who have helped us in our mission and look forward to continuing to work with our staff, partners and supporters to make myeloma history.

Rosemarie Finley
Chief Executive, Myeloma UK
Helping patients and their families

Our support services can be tailored to the individual needs of patients and their families. We understand people are affected by myeloma differently and it is important that anyone living with a myeloma diagnosis can get the help they need, when they need it.

Although we focus on myeloma we also provide a range of information and support on related conditions, such as smouldering myeloma, monoclonal gammopathy of undetermined significance (MGUS), AL amyloidosis, POEMS and plasma cell leukaemia.

“\textit{We understand the importance of information and support in helping people deal with each stage of myeloma, make informed decisions about treatment and care, and find practical ways to live well with myeloma.}”

– Dr Ira Laketic-Ljubojevic, Director of Healthcare Advocacy Services, Myeloma UK

At any one time there are around 17,500 people living with myeloma in the UK.

Every year 5,700 new cases of myeloma are diagnosed in the UK – that’s 15 cases every day.
Infoline

The Myeloma Infoline is a quality accredited, freephone service which provides information, practical advice and emotional support to anyone affected by a myeloma diagnosis. The calls have no time limit and we stay on the line for as long as necessary, with all conversations kept completely confidential.

3,249 Infoline calls in 2017

711 information publications sent out following calls in 2017

“It was a very positive experience and I would urge anyone to use the Infoline both for the excellent information but also for the way it is given.”

“Very positive, informative and far and above my expectations. Very caring, supportive staff.”
Patient and Family Services

Ask the Nurse Email

For those who prefer typing to talking about myeloma, our team of Myeloma Information Specialists will provide answers to any myeloma-related questions over email.

Case Study: Mary*

Mary was suffering from diarrhoea as a side effect of her myeloma treatment. Her situation had become so bad that she was considering giving up on all myeloma treatment. Mary reached out for help and emailed us at Ask the Nurse.

Our Nurse Information Specialist, Ellen Watters, told Mary about Bile Acid Malabsorption (BAM), which has been identified as a potential cause of diarrhoea in some patients taking lenalidomide (Revlimid®) for their myeloma, and sent her a paper on the topic.

Mary passed the research to her haematologist, who had never heard of BAM caused by lenalidomide. Because of the information we sent, the haematologist added BAM treatment to Mary’s myeloma treatment and her diarrhoea was drastically reduced after a few days of this treatment.

Mary got back in touch to say that her life had been turned around. She had been ready to give up on all myeloma treatment, but now could continue to take lenalidomide which had been treating her myeloma. Furthermore, the haematologist was so impressed that they decided to present the research at a multi-disciplinary meeting.

This example highlights the expertise of the staff at Myeloma UK and how vital our services are for patients.

* Identities have been changed to protect the privacy of the individual.
Website

From an initial diagnosis of myeloma through to common complications, our website provides all the information patients and carers need to help anyone affected better understand myeloma.

The ten most visited web pages on myeloma.org.uk visited between July 2017–July 2018:

1. What is myeloma?
2. Homepage
3. Symptoms and complications
4. Discussion Forum
5. How is myeloma treated?
6. Frequently Asked Questions
7. I am newly diagnosed
8. Shop
9. Initial treatment
10. Facts and figures

The most popular pages on the website refer to early stage myeloma questions that patients might have. We can also see that many people (89,555) visited the Discussion Forum, hopefully finding others to talk to and answers to any questions they might have.
Infodays

The Myeloma UK Infodays allow patients and family members the opportunity to learn more about myeloma and share experiences with one another.

Our Infodays run across the UK and are relaxed, yet informative. They’re interactive full-day events, featuring presentations, discussions, and breakout sessions. We always make sure information is delivered in a way that is easy for everyone to understand and there’s something for all levels of knowledge and stages of myeloma.

Our Infodays allow people to:
- Learn from experts
- Ask questions
- Take part in group sessions
- Meet people

“...especially if you are nervous or anxious about any aspects of myeloma. Everyone was friendly and willing to talk to others, so being on my own was fine.”

“I would recommend that they attend an Infoday it is an excellent day very informative and friendly”

“It was a worthwhile event, good opportunity to meet MUK staff, hear of the developments in research, feel part of a determined organised group”

“I do not think the day could have gone any better. My wife and I were very impressed.”

11 Myeloma Infodays in 2017 + An AL amyloidosis Infoday

Our first Carers Infoday

1,217 attendees at our Myeloma Infodays in 2017
“All the people from Myeloma UK were very friendly and informative and meeting people with myeloma makes your condition seem less singular to you so not so overwhelming.”
Patient and Family Services

Support Groups

There are currently around 100 Myeloma Support Groups in the UK and Ireland. Most of these are myeloma-specific, but there are also a number of general haematology groups that welcome those affected by myeloma. Some groups are run by patients, carers or family members, others by healthcare professionals, such as nurses or counsellors, and they vary in size, frequency and format. We provide support, information and resources to the group leaders, to make sure everyone who attends gets the best level of support.

The annual Support Group Leaders Weekend Workshop was a cause for celebration in 2017 as we increased our number of Myeloma Support Groups in the UK and Ireland. To help us reach even more groups, we plan to hold Regional Events in the latter months of 2018. These events will cover Edinburgh, Manchester and Cardiff. We will connect with Group Leaders across the country, with an aim to inform and enable more specific support to a greater number of Support Group Leaders.

“I have found that a Support Group can help and indeed through one I’ve simply increased my circle of friends.”
– Myeloma patient
Visits to Support Groups

We have increased our engagement with Support Groups and our presence at their meetings over recent months. These have included visits to the Edinburgh, Cornwall, Slough, Liverpool, the West Pennines, Aberdeen, Worcestershire, Hereford, Perth, Cardiff and Stoke-on-Trent Support Groups. This has improved our relationships with Support Groups and increased the attendance to our upcoming Regional Events.

“The main thing was you got information from other people who’d had the transplant or the treatment you had. You also get great role models who have survived myeloma for quite some years.”

– Denis, myeloma patient and Support Group Leader
Patient and Family Services

Patient Information

Our patient information covers all aspects of myeloma and related conditions. We provide information in variety of formats, both online and in print, to help patients and carers live well with myeloma right from their diagnosis.

Myeloma Matters

Our free quarterly myeloma-specific magazine keeps people up to date on the latest developments in myeloma as well as providing hints and tips to help people live well with myeloma. The personal stories from patients and family members inspire others and help them to see that they are not alone.

AL amyloidosis Matters

Our free twice yearly AL amyloidosis-specific newsletter provides information on the latest developments in research and shares peoples’ experiences of living with AL amyloidosis.
“Just a little feedback on the re-vamped magazine and website. Both are excellent – I find that the insight, honesty and detail are first class! If there is anything I need to know I feel that it is covered by the website or magazine. Praise indeed as a former portfolio publisher for IPC magazines, I well know what goes into the day to day decisions that go towards producing excellence – well done. I am currently recovering from a stem cell transplant and find the personal experiences particularly useful. 10 out of 10.”
– Myeloma patient

“The sex and intimacy section [in the new Infopack for living well with myeloma] is well written and very helpful. It’s something that nurses and doctors don’t talk about unless prompted to, great that it’s included in such depth.”
– Myeloma patient

“The information you provide (specifically printed publications) is brilliant – the best available. Your information is clear and accurate and provides me with plenty of information and enough detail to be able to make decisions.”
– Myeloma patient

97% of respondents to our Patient Information survey said the information made them feel better equipped to make decisions.

98% of respondents to our Patient Information survey said the information told them what they needed to know.

Over 5,000 Infopacks for newly diagnosed patients sent out or downloaded in 2017.

97%

98%

5,000+

Patient Information survey
We recognise the importance of working with healthcare professionals to ensure patients are diagnosed as soon as possible, and receive the best treatment and care. We provide resources and tailored information for those involved in diagnosis, treatment and care of myeloma patients.

Early Diagnosis

The Myeloma UK Early Diagnosis Steering Committee was established in 2017, with the aim to identify routes to achieve reductions in the time to diagnose myeloma. In 2018 the work of the Committee has gathered momentum. Current workstreams include:

- Identifying barriers to diagnosis in primary care. In 2018, this has included a five-minute online myeloma education module (partnered with the Royal College of General Practitioners), the further distribution of the Myeloma Diagnosis Pathway and two education events for GPs
- Addressing delays in secondary care, including our 2018 campaign to encourage haematology teams to run an education session for their colleagues in other hospital departments
- Producing a myeloma best practice guide for laboratories, with the aim to improving the consistency of testing and reporting of abnormal results
- An early mortality audit to identify whether the outcome for this group of patients could have been improved, or whether early mortality is primarily due to the aggressive nature of myeloma in a subset of patients

More recently, the Early Diagnosis Steering Committee gathered together experts in primary oncology care. The view was that GPs don’t suspect myeloma - tests results indicate myeloma. Recently published research has indicated that GPs could combine the results of two standard blood tests to rule out myeloma. If abnormalities are detected in this test, it should lead to urgent further tests. Professor Willie Hamilton (Professor of Primary Care Diagnostics, University of Exeter) commented “We report a simple way a GP can check patients presenting symptoms such as back, rib and chest pain, or recurrent chest infections, and determine whether they have myeloma or not.” The Steering Committee are now looking at how to rapidly progress this work to speed up diagnosis for all myeloma patients.
Case Study: Education Events for GPs

The Support Group Leader of the West Lancs and Merseyside Support Group lobbied his local Clinical Commissioning Group (CCG) to hold an event to educate GPs on myeloma. The outcome was a collaboration between Myeloma UK and Liverpool CCG to hold a “Haematological malignancies and problem blood counts” event. The programme covered lymphoma as well as myeloma – so we invited Lymphoma Action to join us.

Sixty GPs and staff attended the event, which Liverpool CCG viewed as excellent for this hard-to-engage group. Afterwards a video of the myeloma presentation and slides from the event, together with links to the online myeloma education module, Myeloma Academy and the Myeloma Diagnosis Pathway, were emailed to all GP practices in the area. Thanks to this support group, we are now exploring the possibility of running a similar event with West Lancashire CCG in 2019.
Resources and Services for Healthcare Professionals

Early Diagnosis: Grand Round

One of our 21st Year events inspired a Grand Round. A Grand Round is a hospital-wide event, where a specialist presents information about a particular condition to other doctors, nurses etc. They are an excellent way to educate healthcare professionals in areas that are outside their usual practice.

“Following our Grand Round, two patients with kidney problems were identified as myeloma patients and started treatment within a few days. We are grateful to our colleagues in other departments for their assistance in identifying patients with suspected myeloma.”
– Dr Neil Rabin

Case Study: Myeloma Grand Round in Hospitals

A Grand Round on myeloma held at North Middlesex University Hospital NHS Trust saw two patients with kidney problems diagnosed with myeloma after non-haematology professionals recognised the symptoms.

Dr Neil Rabin (Consultant Haematologist) and Dr Kushani Ediriwickrema (Haematology Registrar) supported by Millicent Blake-McCoy (Clinical Nurse Specialist) held a Grand Round using slides provided by Myeloma UK, as well as case studies, to illustrate delays they have seen in patient diagnosis.

The presentation was well received and encouraged a lot of discussion about how the hospital could do better in identifying myeloma symptoms in patients.

CSEP: Clinical Service Excellence Programme

The Clinical Service Excellence Programme (CSEP) is a Myeloma UK accredited programme, developed in partnership with patients, family members and healthcare professionals. The programme is designed to support hospitals to deliver optimum care, celebrate success and identify areas for improvement.

A CSEP accreditation demonstrates a hospital’s application of Myeloma UK best practice standards and commitment to providing quality, patient-focused care to all myeloma patients.

“Following our Grand Round, two patients with kidney problems were identified as myeloma patients and started treatment within a few days. We are grateful to our colleagues in other departments for their assistance in identifying patients with suspected myeloma.”
– Dr Neil Rabin
CSEP Case Study

Hospitals throughout the United Kingdom have been presented with the Myeloma UK Clinical Service Excellence Programme Award (Myeloma UK CSEP), in recognition of their commitment to providing outstanding treatment and care to their patients and their families.

The award programme was established in 2015 to recognise when superior care is given to myeloma patients, share best practice initiatives and to benchmark optimum standards in myeloma treatment. Participation brings about positive change by helping frontline staff define, drive and share service improvements.

Dr Kamaraj Karunanithi, Consultant Haematologist at Royal Stoke University Hospital, who leads the myeloma service in University Hospitals of North Midlands (UHNM), said:

“The work we are doing here at UHNM ensures local myeloma patients can access top-quality care and ground-breaking research. I am delighted we have been given this award.”

The Future

Through continued support and dedicated staff we will build upon recent success and look to increase reach and engagement across all services. We also strive to increase the remit of our offerings for both myeloma and its related conditions.

“Myeloma is often difficult to diagnose, as symptoms may be non-specific. In the last 10 years, with improvements in treatment and care, survival rates are increasing faster than most other cancers. Despite this, the diagnosis is often delayed.”
We help myeloma patients, their family and carers, by using donations and funding to develop new approaches to myeloma treatment, through our programme of translational research and Clinical Trial Network. We also use our Health Services Research Programme and patient advocacy to get patients the highest quality of care and access to the best treatments.

Our Research

Our Approach

Our research focuses on three programmes:

- Translational Research
- The Myeloma UK Clinical Trial Network (CTN)
- Health Services Research (HSR)

Translational Research

Our Translational research aims to increase our understanding of the underlying disease mechanisms and apply this knowledge towards patient benefit.

The Myeloma UK-funded research programme at the Institute of Cancer Research (ICR) in London is focused on the complex genetic changes which give rise to myeloma and which drive the disease. Our research continued to make progress with publications in peer-reviewed journals representing the principle ‘currency’ of our research output. In the past year, five research papers were published in prestigious journals citing Myeloma UK. In addition, new findings from the ICR were presented at influential international conferences. These outputs represent new knowledge and insight to drive further discoveries.
The Myeloma UK Clinical Trial Network (CTN)

Our Clinical Trial Network (CTN) links patients to a portfolio of early phase myeloma trials through a UK-wide network of hospitals as trial centres. The CTN trials are designed and led by leading academic clinicians with the Myeloma UK Clinical Trials Coordinating Unit in Leeds, in partnership with Pharma companies. The past year has seen two new trials open in the CTN, and presentations at international conferences on CTN trials.

“Over 600 patients have taken part in Myeloma UK CTN trials so far. In addition to any benefits to individual participants, the data generated from the trials will guide the development of new drugs and new treatment combinations.”

– Dr Simon Ridley, Director of Research, Myeloma UK

Health Services Research (HSR)

The Health Services Research (HSR) Programme provides insight into the needs, experiences and preferences of people with myeloma and related diseases and uses this insight as evidence to influence, inform and effect change. Over the last 12 months we have:

- Published guidance and recommendations on the use of patient-reported outcomes measures (PROMS) in myeloma; see Case Study overleaf
- Published a stated preference study into individual trade-offs between possible benefits and risks of myeloma treatments in the Oncologist journal, in collaboration with the European Medicines agency (EMA) and University of Groningen. This type of research is important because the best way to address patient need is to understand what patients need and value
- Presented findings from our patient preference study (in collaboration with Community and Patient Preference Research, CaPPRe) at the European Haematological Association (EHA) and Health Technology Assessment International (HTAi) conferences in Rome and Madrid

- Received funding from Myeloma Patients Europe (MPE) to develop and deliver research capacity building workshops for patients on our Patient and Carer Research Panel

“Myeloma Patients Europe is committed to supporting projects that benefit the myeloma community through our Scholarship and Capacity Building Programme. Funding we have provided to Myeloma UK for two capacity building workshops, will help them to build upon their excellent Patient and Carer Research Panel – improving patient and carer knowledge of what good research looks like and developing their ability to advise researchers on what matters to patients and carers. We are really looking forward to seeing the results of this innovative programme.”

– Ananda Plate, Chief Executive Officer, Myeloma Patients Europe
Case Study – Patient-reported outcome measures in myeloma (PROMS)

Treatment advances in myeloma have significantly increased survival for many patients. However, while myeloma patients are living longer, they are also living with symptoms and treatment side effects and concerns about their future. Research suggests that myeloma patients have significant unmet supportive care needs and a higher burden of disease than many other cancers. There is therefore a critical need to understand the impact that myeloma has on individuals so that their needs can be addressed and for such data to drive improvement in outcomes that matter to patients. One way to achieve this is for healthcare professionals and researchers to use questionnaire-based tools called patient reported outcome measures (PROMs).

Industry representatives from across the myeloma community. Our aim was to generate discussion about the landscape of PROMs in myeloma and, together, consider how the future use of PROMs can be enhanced to benefit patients.

Our findings suggest that the principle of collecting and using patient-reported outcome data through PROMs is highly valued. However, in practice using, scoring, interpreting, and recording such data is complex. In our interviews with a broad range of healthcare professionals and researchers we learnt that PROMs are infrequently used in myeloma clinical practice, partly due to a lack of training and support for PROM use.

Using PROMS, Myeloma UK conducted a research project to collate the published literature and present new findings based on the perspectives and experiences of patients, clinicians, researchers, and pharmaceutical industry representatives from across the myeloma community. Our aim was to generate discussion about the landscape of PROMs in myeloma and, together, consider how the future use of PROMs can be enhanced to benefit patients.

Our findings suggest that the principle of collecting and using patient-reported outcome data through PROMs is highly valued. However, in practice using, scoring, interpreting, and recording such data is complex. In our interviews with a broad range of healthcare professionals and researchers we learnt that PROMs are infrequently used in myeloma clinical practice, partly due to a lack of training and support for PROM use.

“In publishing our research reports we hope to provide all those working with myeloma patients – in research and in the clinic – with up to date insight on the current PROMs landscape. We encourage all stakeholders to work with Myeloma UK on delivering these recommendations which we believe are necessary to deliver on the potential of PROMs to benefit myeloma patients.”

– Dr Jayne Galinsky, Health Services Research Manager, Myeloma UK
Our Research

Partners/Collaborations

- Amgen
- Celgene
- Community and Patient Preference Research (CaPPRe)
- European Medicines Agency (EMA)
- Institute of Cancer Research (ICR)
- Jansen
- Manchester Royal Infirmary and Institute of Cancer Science
- National Institute for Health and Care Excellence (NICE)
- Novartis
- Oncolytics
- Structural Genomics Consortium
- Takeda
- University College London (UCL)
- University of Birmingham
- University of Groningen
- University of Leeds

“Our latest research project with Myeloma UK has been very successful in exploring the potential value of quantitative patient preference data for health technology appraisal processes. We have also worked on raising awareness of these values, both internally here at NICE and externally among a wide range of interested stakeholders. Whether through assisting us in connecting with patients, or providing feedback on our research outputs, Myeloma UK have been keen to engage with and support our progress on a regular basis. Research partnerships such as this are a relatively new experience for NICE, and the positive experience of this project has contributed to ensuring that such collaborative efforts will continue in the future.”

– Luke Cowie, NICE

Myeloma UK Clinical Trial Network 2017–2018

- Seven trials
- At over 30 trial centres

Research 2017–2018

- Seven academic institutions involved
- Five research papers published
The Future

With an ambitious new strategy to drive progress we will:

• Continue our translational research programmes at the ICR and Structural Genomics Consortium, Oxford

• Continue to support the development and delivery of innovative, patient-centred early phase clinical trials through our Clinical Trial Network

• Scope the development of a Myeloma Patient Registry to bring together powerful data on clinical, quality of life measures and treatments, identify variations and inequalities. This can then be highlighted in our patient advocacy and policy work

• Develop and deliver capacity building workshops for patients and their families. This will enable them to better understand, engage with, and benefit from research into myeloma

• Increase the reach of our organisation and extend our work with hard-to-reach patient communities who may not know about or use Myeloma UK services
Our aim is to ensure that decision making is driven by patient need and priorities. We have campaigned for access to the best new drug treatments and helped shape government policy to meet the needs of people affected by myeloma. By using our knowledge and expertise in talking to Government, to the NHS and to industry, we have given a voice to myeloma patients and their families.

**New treatment approval**

Throughout the course of the year our work has influenced the approval of three key new myeloma treatments: carfilzomib (Kyprolis®) in England, Scotland and Wales; daratumumab (Darzalex®) in Scotland; and ixazomib (Ninlaro®) in England and Wales, via the Cancer Drugs Fund.

“Our success, working with charity partners, in securing a commitment to having patients at the table in NICE committee meetings is an example of the impact we can have in make sure the needs and priorities of patients are front and centre in decision making.”

– Shelagh McKinlay, Head of Patient Advocacy, Myeloma UK
“For me, ixazomib was a gift of time. It can extend life expectancy and as an oral treatment, it means patients do not need to spend time travelling to hospital. This is a huge morale booster for patient and carer alike. Drug approvals like this are so encouraging: they advance the fight against myeloma and give clinicians an ever increasing armoury from which to construct patient-specific treatment regimes. I was glad to be able to work with Myeloma UK to help deliver approval of this important treatment option.”

– John, myeloma patient
Patient Advocacy

Policy reform
Throughout the course of the year we ensured that the patient voice was heard in significant policy reforms. In particular, the introduction of a budget impact threshold for new medicines and changes to the National Institute for Health and Care Excellence (NICE) technology appraisal process, which decides whether new treatments should be made routinely available on the NHS.

Furthermore, as part of a coalition of charities we were successful in prompting NICE to rethink proposals to reduce patient representation at NICE committee meetings.

Collaborative working
We worked with the Blood Cancer Alliance and myeloma patients to spearhead the first blood cancer awareness campaign to be supported by all key blood cancer charities. The ‘Make Blood Cancer Visible’ campaign was launched at a special art installation in central London and raised the profile of the challenges facing blood cancer patients across social and mainstream media.

We also continued to raise the profile of myeloma by presenting and participating in influential policy summits and workshops such as Janssen, Celgene, Novartis and Takeda Patient Group Summits, ‘Keep Up with Cancer’ initiative roundtable, Westminster Health Forum on the future of NICE, and the Scottish Medicines Consortium Public Partner Event.

The Future
We will continue to press for access to the best new treatments, so that the UK keeps pace with best practice in Europe and the rest of the world. We will also lobby for improvements in diagnosis and for personalised care to be made a reality. In doing so we will work even more closely with patients to make sure that the diversity of their needs and experience underpins the development of treatment and care.
Fundraising

Our work is only possible because of our generous supporters. From patients, family and friends to doctors, nurses and industry, a wealth of people are joining forces to raise funds to help us make myeloma history. This essential support allows us to invest in research and to ensure that patients get access to the best possible information, support, treatment and care. We thank everyone who has donated to us over the past year or who has helped support myeloma by raising funds.

How are our funds invested?

We receive no government funding and rely on voluntary donations and fundraising activities. Our key objective is to ensure that all funding is invested to maximum effect to support core activities such as:

- Supporting patients and their families to help them cope with everything a myeloma diagnosis brings
- Funding our world-leading genetics research programme at the ICR to support new ‘tailored’ treatments for precision medicine
- Funding the Myeloma UK Clinical Trial Network that gives patients access to the most promising new drugs
- Delivering unique resources and tailored information for doctors, nurses and other healthcare professionals to ensure patients receive the best treatment and care
- Working in partnership with decision-makers to ensure the speedy approval of drugs and the delivery of innovative policy solutions to the benefit of the myeloma community

£5.50
Excluding support and governance costs allocated to the cost of raising funds, for every £1 spent on raising funds in 2017, we raised £5.50

88p
From every £1 of expenditure in 2017, 88p was spent on improving the lives of people with myeloma
“I have two friends who are going through treatment for myeloma at the moment. It is hard, but inspiring to see them cope and deal with the myeloma and the treatment.

I wanted to do something to help make the future slightly easier for others if not them. I hope that the work of Myeloma UK will be part of that.”

– Myeloma UK donor
Inspiring others: Case study – Carmen Lester

In 2014 and at the age of 54, Carmen Lester was diagnosed with Free Light Chain myeloma. Carmen had been experiencing chronic bone pain and fatigue but as an active and healthy person, she didn’t think much of it.

Carmen said, “At diagnosis, 95% of my marrow was populated with myeloma. The consultant was amazed I even made it to the appointment, never mind driving there and working full time.

“I was put on three months of aggressive chemo as I was young and ‘fit’ and by December 2014, the myeloma was down to 3%. Unfortunately, nine months after my stem cell transplant in May 2015, I relapsed.

“I have had a few different treatments, but I am currently on low dose maintenance tablets to keep the myeloma under control. As of May this year I am in regression.”

As a way to help mark Myeloma UK’s 21st Year and to raise money for the charity, as well as to keep active, she decided to take on the 21 Miles for Myeloma Challenge.

“My husband Tony and my brother Rafer will walk with me in case I have a wobble. My family will walk part of the way (21 minutes minimum) to cheer us on throughout the walk. It will hurt, it will be fun, the scenery will be inspiring and it will hopefully raise awareness about this debilitating cancer.”

The trio started their walk in Portland Bill, Dorset walking through the Portland peninsula, along Weymouth Harbour and the coastal path, to finish in Lulworth Cove. The rest of the family joined them 15 miles in at Smuggler’s Inn in Osmington Mills, with another crowd waiting for them at the pub. Carmen raised over £5,800 for her 21 mile walk.
The Future

By producing inspirational, engaging and innovative fundraising campaigns we will continue to deliver patient centred care and support, which is based on understanding the core needs of everyone living with myeloma.

Building on solid fundraising foundations, we will increase our national reach, engage with new audiences and explore new avenues for income generation. We will also utilise existing income platforms such as social media, creating engaging content to show our growing followers, how their fundraising can, and is, helping.

The funds that we receive will continue to be invested in research and support for everyone affected by a myeloma diagnosis.

We recognise the invaluable role that support groups and Infodays have in contributing to the care of all patients. Which is why we will extend our services offering, providing as much support through patient and carer focussed events as possible.

We play an important role in developing myeloma research but we cannot achieve our ultimate goal of finding a cure alone. By continuing to engage with existing corporate supporters, and identifying new sponsors, we will work toward delivering our vision to make myeloma history.
RHS Chelsea Flower Show

The Myeloma UK Garden debuted at the RHS Chelsea Flower Show 2018, winning a silver-gilt medal. Designed by John Everiss and Francesca Murrell, the garden was one of the major events marking our 21st Year.

The Myeloma UK Garden was inspired by Peter King, a Myeloma UK supporter from Hertfordshire whose wife Gill and brother Graham both passed away in 2016 shortly after being diagnosed with myeloma.

The garden gave a positive message that patients can live well with myeloma. The large-scale head and shoulder sculpture at the centre of the garden was modelled on Peter and Gill King’s daughter, Gemma Peace, and represented the role of the carer, a crucial figure in supporting the patient throughout their care.

Gemma’s left hand was pushing away boulders. These were physical representations of plasma cells, from which the cancer arises, as well as symbols of the barriers and the obstacles people face in care when they are living with myeloma.

Gemma’s right hand was cupped and appeared to be gently blowing seeds and plants onto fertile soil below, to represent new treatment and as a sign of hope and growth.

There was no defined path through the garden, purposefully mirroring the situation many myeloma patients face. Up to 60 different plants and trees featured across the garden including: *Taxus* balls, *Prunus* and *Malus*, *Anthriscus sylvestris*, *Matteuccia struthiopteris* and *Melica nutans*.

“When Myeloma UK contacted me about doing this garden, I didn’t have a second thought about it. It’s been an amazing process and particularly enjoyable working with people that really believe in what they are doing.”

– John Everiss, designer of The Myeloma UK Garden at RHS Chelsea Flower Show 2018

Coverage

The Myeloma UK Garden received 111 pieces of coverage through 80 outlets, both online, in print and through broadcast media.

This included high profile outlets such as BBC Two, *The Telegraph*, *The Times* and BBC Radio 2.

The coverage gained was powerful reaching a potential audience of over 1.8 billion people.
**Digital Engagement**

Over 10,000 users visited the website during the Chelsea Flower Show 2018, with an increase of 2,000 more users than an average week, meaning more people were exposed to what myeloma is and who we are. We managed to convert these visits to boost our newsletter audience by 10%.

71% of visitors to the website during the show were new to the website.

<table>
<thead>
<tr>
<th>Channel</th>
<th>Follower Increase</th>
<th>Engagements</th>
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<tbody>
<tr>
<td>@MyelomaUK</td>
<td>0.51%</td>
<td>3,486</td>
</tr>
<tr>
<td>myelomauk</td>
<td>1.32%</td>
<td>6,488</td>
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<tr>
<td>@myelomauk</td>
<td>2.93%</td>
<td>658</td>
</tr>
</tbody>
</table>

Our increase in followers means that we have a new audience to educate about myeloma and Myeloma UK. By creating engaging and innovative content, we can show them what we are doing to make myeloma history and how important their donations are.
Case study: MyelomaStars.com

The objectives for the campaign were to conceive and implement an innovative digital proposition that would inspire audiences and raise awareness of myeloma. As part of this, we wanted to communicate early diagnosis information to an audience currently unaware of the disease.

As well as increasing engagement with existing supporters, the campaign aimed to create an impact lasting beyond Myeloma Awareness Week. This focus allowed us to also set the target of achieving the highest social media engagement levels ever during Myeloma Awareness Week.

MyelomaStars.com was the answer; a digital experience to highlight the impact of research into myeloma and open up the conversation about a brighter tomorrow.

Visitors to a dedicated microsite were invited to add star messages to a night sky, in the form of messages of hope or care. These could be shared via social media to reach out and spread knowledge of myeloma and of the work of Myeloma UK.

Our activity reached 2,240,000 individuals, resulting in 98,000 engagements and delivering 22,000 visitors to MyelomaStars.com to learn about myeloma. With 1,058 of those individuals taking the desired action and posting, our conversion rate was a solid 4.8%. People viewed our content in over 135 countries (see map below) and audience growth across our platforms was 8.8% during the campaign. 40% of messages posted were from new contacts – showing how we engaged new audiences.
A message of Hope
Paul Watts

April '17 - a twinge in my back and then pain. Diagnosed July '17. Treatment followed by stem cell transplant Christmas '17. Six months on and back to 90% of my former self; hill-walking, yoga, camping and overseas holidays. My message? Trust the NHS and always try to think positive.

A message of Care
Hannah Gammons

Over a year ago our beautiful Mum passed to myeloma. Mum you showed strength and determination through your battle. Wherever a beautiful soul has been there is a trail of beautiful memories. Your love continues to shine bright just like your star. X

A message of Care
Briana Canty

Thank you so much to Myeloma UK, especially for the amazing digital work, for caring for so many people. We’d be lost without you.
Thank You

We are extremely grateful to everyone who supported us throughout the past year and the many individuals who have given up their time and energy to take part in an event, raise money or make a donation.

Thank you to all of our patrons, benefactors and friends, and to the Trusts and Foundations who have supported our work this year. A special thank you to our Board of Directors, partners and all the staff at Myeloma UK who make our work possible.

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We are very grateful for legacies left to Myeloma UK by our generous donors.

Anonymous Donors
We also wish to thank our Guardians, Benefactors, Patrons and Friends who chose to remain anonymous.

If you would like to support our work visit: myeloma.org.uk/get-involved