

METUPUK STRATEGY 2026



OUR VISION

We want everyone living with Metastatic Breast Cancer (MBC) in the UK to have equitable access to excellent care, timely treatment, research opportunities and the support needed to live as well as possible. We want to see more people living longer with MBC and work towards the day when MBC becomes a manageable long term condition.

The harsh reality of MBC requires more than just awareness - it requires urgent systemic change. We exist to change the narrative and demand accountability from policymakers, charities, and government bodies. We ensure MBC is no longer an afterthought. We advocate for the funding, research, innovation and support that this community deserves.

OUR PRIORITIES

This refreshed strategy document sets out our priorities across three main areas:

Awareness and Education METUPUK aims to be a trusted voice on MBC, challenging existing narratives about MBC, and building greater understanding among health professionals and the public and lasting change in levels of awareness.

Research and Access to Drugs and Treatments METUPUK champions fairness and urgency in MBC research and access to treatment. We will use our influence to convene partners, advocate for more choice and better treatments, and ensure that patients' needs and experiences remain central to research, policy and practice.

Care Quality and Living Well with MBC METUPUK calls for equitable care across the UK and advocates for better quality of care rooted in lived experience. We strive to ensure everyone affected by MBC feels supported and informed and has a good quality of life.

1. AWARENESS AND EDUCATION

Our awareness and education work aims to improve understanding of MBC, challenge misconceptions, and help patients, professionals, decision-makers and the public understand the realities of living with the disease.

- **Understanding Metastatic Breast Cancer**

MBC is often misunderstood. People, including health professionals, the media and the general public, may confuse it with primary breast cancer, see only positive 'survivor' stories, and rarely hear from people living long term with MBC. METUPUK will raise awareness of the disease in a way that is honest, inclusive and based on lived experience.

- **Reframing breast cancer narratives**

Breast cancer messaging often leaves out metastatic disease and focuses only on cure. METUPUK will promote language that reflects MBC as an incurable but treatable long-term condition.

- **Education for patients and the public**

Everyone affected by MBC needs clear, accessible information about MBC at different stages of the patient journey. METUPUK will support people to access information on symptoms, progression and long-term management so they can have informed conversations and recognise metastatic disease earlier.

- **Professional and system-level education**

We know there are gaps in awareness and access to information across healthcare and support settings. METUPUK will work with NHS and other partners to promote shared resources, consistent messaging and better understanding of MBC as a complex, currently incurable, lifelong condition.

- **Educating policymakers and decision makers**

We aim to build awareness of MBC among policymakers and funders. METUPUK will help decision-makers recognise MBC as a priority in policy, funding and strategy, and

ensure lived experience shapes service design and delivery.

- **Inclusive and accessible awareness and education**

People living with MBC and their families face unequal access to information because of age, geographic location and systemic inequalities. METUPUK will make sure its awareness and education work is inclusive, accessible and shaped by diverse lived experience.

2. RESEARCH AND ACCESS TO DRUGS AND TREATMENTS

METUPUK is committed to improving outcomes for people living with MBC by presenting the patient perspective to research funders, improving access to clinical trials, speeding up access to effective treatments, and making better use of data and technology. The charity will use its influence, partnerships and advocacy to address the barriers patients face now, while helping to shape a fairer and more responsive system for the future.

- **Research that reflects need**

We will advocate for research priorities that are driven by patients' needs and their lived experiences. This includes campaigning for greater investment in MBC research, improving transparency in how research funding is allocated, and working with charities, researchers and industry to ensure that research activity reflects the scale and urgency of unmet need.

We also campaign for funding for MBC research to reflect the number of people it affects, and the proportion of breast cancer deaths caused by metastatic disease.

- **Improving access to clinical trials**

We will work to make clinical trials easier to access and more equitable for people living with MBC. We will collaborate with partner organisations to improve awareness of available trials, support more inclusive and transparent trial design, challenge unnecessary restrictions, and enable patients to identify and pursue relevant opportunities regardless of where they live.

- **Better data, diagnostics and decision-making**

We will champion better use of data, diagnostics and technology to improve treatment decisions and long-term outcomes. This includes supporting stronger data

collection and analysis, encouraging the use of evidence to guide clinical and policy decisions, and advocating for access to diagnostics and personalised approaches that can help ensure patients receive the most appropriate care and treatment.

- **Accelerating access to effective treatments**

We will campaign to reduce delays in the approval and availability of new drug treatments for MBC on the NHS. We will submit evidence to technology appraisals and guidelines for the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC), as well as working with regulators, health systems and pharmaceutical companies to call for clearer and faster access routes so patients can benefit from innovation as quickly and fairly as possible.

- **Tackling inequality in access and outcomes**

We will highlight and challenge inequalities that affect access to trials, diagnostics, specialist advice and treatments. Our work will focus on reducing postcode variation, promoting consistency across systems and ensuring that all people living with MBC have a fair opportunity to benefit from advances in research and care.

- **Driving change through collaboration and patient voice**

We will work in partnership with patients, charities, clinicians, researchers, policymakers and industry to drive systemic change in the way research is designed and carried out, and how it reflects patients' priorities. We will place patient voice at the centre of our work, strengthen collaboration across the sector, and turn insight into practical action and measurable impact.

3. CARE QUALITY AND LIVING WELL WITH MBC

METUPUK's approach to care quality and living well with MBC is centred on improving outcomes and quality of life for people living with MBC across the UK. Although the charity does not deliver clinical treatment, we play a vital role in advocacy, information, signposting, enablement and support.

METUPUK will work alongside patients, families, clinicians, charities and wider stakeholders to reduce inequity in services, strengthen access to evidence-based care, and ensure that lived experience informs every aspect of our work.

- **Improving access to appropriate treatment and care**

METUPUK will work to improve access

to timely, appropriate and equitable treatment for people living with MBC. The charity will support patients to better understand treatment pathways, navigate complex systems and access the services and support they need. Through collaboration and advocacy, we will also challenge regional variation in care, delays in specialist support and barriers to accessing services.

- **Clear, trusted information and signposting**

METUPUK will provide clear, trusted and evidence-based information to help patients make informed decisions about treatment and care. We will signpost to high quality resources via our website, digital channels and partnerships, reduce confusion caused by conflicting information, and promote understanding of evidence-based treatment options, support services and steps in the patient journey.

- **Psychological and emotional support**

METUPUK recognises that emotional and psychological wellbeing is a fundamental part of living with MBC. The charity will work to ensure patients can access appropriate emotional and peer support. By reducing isolation and promoting resilience, METUPUK aims to support the whole person as well as their treatment journey.

- **Complementary support and quality of life**

METUPUK will promote complementary support that enhances wellbeing and quality of life, while making clear that such approaches should sit alongside, not replace, clinical treatment. The charity will encourage safe, supportive interventions such as exercise, wellbeing activities and practical coping strategies that help people live as well as possible alongside MBC.

- **Advocacy for consistent, high-quality care**

METUPUK will use the voices and experiences of patients to advocate for consistent, high-quality care across the UK. The charity will campaign to address inequities in access to clinical nurse specialists, hospice care,

supportive services and other key elements of care. We will work in partnership with others to influence health systems and improve quality of care to meet the needs of the MBC community.

- **Empowering patients through lived experience**

Lived experience remains at the heart of METUPUK's strategy. The charity will ensure that its resources and priorities are shaped by the voices of people affected by MBC. We will ensure people can access relevant and compassionate support that empowers them and informs their decision-making without adding to the burden they already face.

- **Addressing practical barriers**

We recognise that financial pressure, employment issues and caring responsibilities can have a direct impact on treatment and wellbeing. The charity will take a holistic approach by signposting patients and families to practical, financial and welfare support, helping to remove non-clinical barriers that affect quality of life and access to care.

METUPUK (Metastatic Exchange to Unleash Power UK)

METUPUK is a UK-wide patient advocacy charity for people with Metastatic Breast Cancer (MBC) campaigning to increase public awareness and education about MBC. We work to see better care, access to drugs and trials as well as representation of MBC patients within NHS UK, the national regulators and drug companies.

Structure

METUPUK is a Foundation Charitable Incorporated Organisation registered with the Charity Commission of England and Wales (1196494), registration date 9 November 2021, and with the Office of the Scottish Charity Regulator (SC055472), registration date 27 June 2024.

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