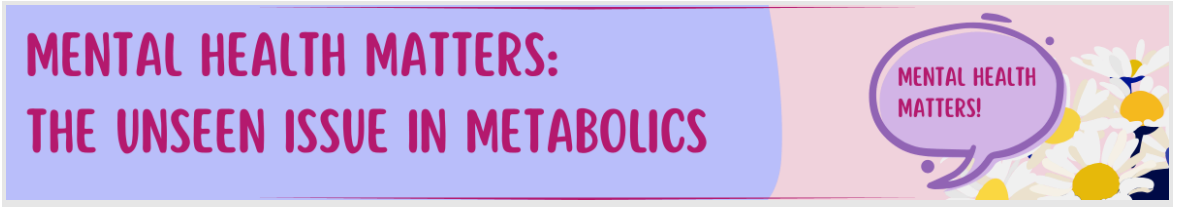

More than 15 million people (30% of the UK population) live with one or more long-term conditions, and more than 4 million of these people live with mental health problems. These statistics are especially important when considering that Inherited Metabolic Disorders (IMDs) are a collection of over 500 lifelong conditions that affect over 20,000 people in the UK alone. The impact on the mental health of our communities is clearly visible through the work we do, with an average of 23 mental health related individual enquiries received per month.

Mental health is complex and is influenced by our genes, life experiences, upbringing, and environment. Considering this wide range of factors, living with a rare disease often magnifies mental health issues due to the associated pressures. This relationship was highlighted in the **Mental health care for rare disease in the UK** paper, published in 2022 which was informed by 1231 rare disease patients and 564 carers. More than 90% of responders stated that they have felt worried/anxious; stressed; and /or low/depressed and 36% of patients and 19% of carers stating that they'd had suicidal thoughts. The study revealed that the emotional impact of living with rare disease was caused by multiple factors and the statistics from people's responses are displayed in an infographic we have put together below.

Interactions with healthcare professionals and services

Information from Spencer-Tansley, R., Meade, N., Ali, F. et al. Mental health care for rare disease in the UK – recommendations from a quantitative survey and multi-stakeholder workshop. BMC Health Serv Res 22, 648 (2022). https://doi.org/10.1186/s12913-022-08060-9

Factors influencing mental health	Proportion of respondents affected
Lack of awareness of the condition among healthcare professionals.	88%
Not being believed or taken seriously.	80%
Being treated as a medical curiosity.	50%
Trying to access health services or treatments.	80%
The way care is coordinated or organised between different departments or services.	79%
Accessing financial support such as disability living allowance.	76%
Accessing other support such as social care or respite care.	72%
Feeling socially isolated.	76%
Financial pressures and worries.	80%
Major life events.	86%
Lack of available information about the condition.	76%
Having to explain the condition to other people.	81%
Feeling uncertain about what the future holds.	87%
Lack of understanding about the condition among the public.	90%

MENTAL HEALTH MATTERS!

MENTAL HEALTH MATTERS!

Everyday living with a rare condition

Factors influencing mental health | Proportion of respondents affected

Through our conversations with people living with IMDs and their families, we recognise that these issues impact the mental health and wellbeing of our communities. Additionally, it has been identified that some IMDs are a rare but significant cause of psychiatric disorders in adolescents and adults with these conditions being linked to psychotic disorders, depression, and anxiety. This impact is not, however, isolated to the person affected. The families of persons living with IMDs are also psychologically impacted due to poor coordination of care leaving the family to effectively coordinate with multiple systems, worries about the future, disease acceptance and a low quality of life. Further to this, many IMDs require careful measures to avoid triggers which can cause life-threatening metabolic crises, this places an enormous degree of anxiety on families. This burden of worry is also carried by adults with IMDs who often struggle to determine which symptoms are early signs of metabolic crises, leading to high levels of anxiety that can affect an individual's quality of life.

To reduce this impact, mental health support must be offered. However, people living with IMDs struggle to access mental health services due to a lack of understanding amongst healthcare professionals, meaning when individuals are referred to mental health services, they aren't able to access the support they need. This means the responsibility of care falls to patient organisations to facilitate access to counsellors and/or expensive mental health services via external organisations. Even if persons living with these conditions can access mental health services specifically for their conditions, a 2019 review of these services by Lynne Aikenhead (a clinical psychologist and honorary lecturer at the Department of Neuromuscular Diseases, UCL Institute of Neurology) states that they are unable to meet international guidelines. This is then further worsened due to the services having high levels of provision inequality as demonstrated across adult services with some offering no mental health services and those that do varying in their employment of full-time equivalent (FTE) psychologists with a ratio of 1 FTE psychologist per 400 patients to 1 FTE psychologist per 3000 patients.

The England Rare Disease Action Plan (ERDAP) sets out priorities and actions to achieve the national vision laid out in the UK Rare Diseases Framework to improve the lives of the 3.5 million people living in the UK with a rare disease. As part of the 2023 ERDAP iteration, mental health was highlighted as a focus area under action 21 which requires all new and revised service specifications for patients with rare diseases to consider user's psychosocial needs and ensure coordinated pathways for access to mental health. This is underpinned by action 19 which aims to support the healthcare workforce to ensure patients are well informed and well cared for during their diagnostic and management journey and action 20 which includes commissioning research to provide the evidence needed to operationalise better coordination of care in the NHS.

To achieve these, provisions must first be put into place to refer people to facilities and systems offering mental health support.In steps to address this gap, the NHS Long Term Plan has committed an additional £2.3 billion a year for mental health services in England by the 2023 to 2024 financial year. This will serve two important purposes: supporting an additional 2 million people in accessing NHS-funded mental health support and growing the mental health workforce by an additional 27,000 staff to provide these services.

Despite these steps, just 1 in 8 adults affected by mental health problems are receiving treatment and according to the Centre for Mental Health it is estimated that up to 10 million people in England may need support for their mental health. As a result, the NHS Long Term Plan still leaves many without access which is compounded by the chronic shortage of qualified mental health nurses. This has led to services seeking other solutions, such as employing ward managers and other

professionals to substitute for nursing cover which raises concerns about safety and wellbeing due to staff taking on responsibilities they may not be qualified for.

Awareness is key:
To make referrals to mental health services for those living with IMDs as part of ERDAP's action 21, healthcare professionals first need to understand the significant need amongst our communities. As such, the Department of Health and Social Care must ensure this focus is integrated into the training of the healthcare workforce as part of action 19 of the ERDAP and must work with patient organisations when commissioning research into this area to ensure the patient voice is captured in action 20.

Prevention is better than treatment:
To reduce the pressures on an underfunded, understaffed mental health system, focus must be placed upon improving people's quality of life through addressing people's basic needs such as improving their financial situation, increasing access to respite and social care, and through supporting people through counselling. This will assist in achieving the goal of the UK Rare Diseases Framework through improving the lives of the 3.5 million people living in the UK with a rare disease.

Provision, provision, provision:
To ensure mental health support is available for those living with IMDs, there must be a push to improve services available to ensure they meet international guidelines and to reduce the inequities in provision. Further to this, these centres for mental health should take steps to increase employment of mental health practitioners including clinical psychologists that receive special training on inherited metabolic disorders, this may be achieved through ring-fencing a proportion of some of the investments being made into mental health services to make improvements to IMD mental health services.

We offer individual support:
We support our communities and their wider networks via individual support, offering advice and practical help to ensure our community feels supported, empowered and happy. For individual support enquiries, fill in the contact form on our website or call 08452 412 173 between 10am-4pm, Monday to Friday.

We build communities:
Having a rare condition can be isolating, that's why we connect people that have been affected by the same condition to discuss their experience, to offer peer-to-peer support and to share tips on how best to manage their condition. This sense of community reduces feelings of isolation and can

be extremely beneficial to improving mental health. For more information on our communities, please contact our Community Engagement Manager, Toni Mees via toni@metabolicsupportuk.org

We share our insight into the mental health of our communities:
We are focusing on mental health as a key area in our **Thoughts into Action** report that will be launched in Parliament in September with attendance from a wide range of people including the government, healthcare professionals, partner organisations and our community.

We've produced resources:
We have produced a wide range of resources that can be found in our advice hub: These range from mental health specific resources to others that may help improve our community's quality of life, ranging in topics from benefits and money management to family and relationships.

We amplify our community's voice:
We use our voice and unique position to ensure that the mental health and wellbeing of our community is placed at the forefront of the development of any new services, policies, and treatment appraisals and that conversations are prioritised about the psychosocial impact of living with an IMD.

We're conducting an IMD service review:
We plan to conduct an IMD service review, which aims to evaluate if IMD services are meeting the needs of our communities to identify service delivery improvements that may be implemented to ensure the support of people living with IMDs. This review will consider the phycological support offered to our communities in order to improve the support offered.