MEDICALLY UNEXPLAINED SYMPTOMS

A Multidisciplinary Conference Addressing the Challenges of Medically Unexplained Symptoms

Hosted by
The Forgotten Patients, Overlooked Diseases Charity
and
Members of the General Practice and Primary Care Section at the Royal Society of Medicine

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Meeting Chairs

Dr Jay Verma (President, Royal Society of Medicine, GP and Primary Care Section)
Dr Jeshni Amblum-Almer (Past President, GP Section RSM)
Dr Adrian Tookman (Chair, Forgotten Patients, Overlooked Diseases Charity)

The inaugural Forgotten Patients, Overlooked Diseases (FPOD) meeting, held in conjunction with members of the Royal Society of Medicine, was a thought-provoking and inspiring event. The comprehensive agenda provided insights into the challenges, hopes, and potential solutions concerning the identification and diagnosis of people with medically unexplained symptoms (MUS).

Over 100 delegates attended the meeting both in London and online from all over the world. Twelve presentations were delivered by a range of experts – including people with MUS, general practitioners (GPs), and secondary care specialists – offering broad perspectives on the issue of MUS.

The overarching tone was one of pragmatism mixed with optimism, with a sense that this meeting marks the beginning of a long journey to improve support for people with MUS, along with the healthcare professionals (HCPs) who care for them.

Executive Summary

Several themes emerged throughout the day:

- **The in-person consultation is the key.** There are limited opportunities for patients and HCPs to meet in person, but the conversations that happen in those precious minutes are fundamental for identifying and diagnosing MUS. Presenters explored what happens when consultations are effective, and the factors that allow trustful and open discussions to take place. There was also an exploration of how consultations can go wrong, with lack of rapport between HCP and patient being a significant barrier.

- **Patients and HCPs are limited by constraints within their healthcare systems.** Two aspects of the National Health Service (NHS) are barriers to effective management of MUS:
  - GPs and other HCPs are extremely time-poor. Consultation times are constantly being eroded and despite good intentions, GPs find it difficult to devote the time needed to explore the causes of MUS. HCPs are encouraged to make quick decisions and delay in the hope of resolution, discharge or referral. Time pressure also affects the quality of the GP–patient relationship within consultations, with empathy and listening skills being the first casualties of a rushed consultation.
  - Healthcare systems encourage 'working in silos', such that a person with MUS may be seen by multiple specialists without one HCP ever taking a holistic view of their condition. The current focus on diagnosing patients based on set medical codes can be unhelpful when a diagnosis is not clear, and many of the meeting attendees expressed dissatisfaction with the term MUS itself.

- **Better education is needed about MUS and possible causes.** HCPs need support in 1) identifying MUS, 2) 'joining the dots' to investigate possible causes of MUS, and 3) getting the right information to inform a medical diagnosis. More knowledge is needed, particularly in primary care, to ensure that people with MUS receive adequate medical care.

The Problem of MUS

The patient's experience

Christianne Forrest and **Katia Chrysostomou,** two patient advocates, gave the meeting's opening presentation, setting the scene for the day.

Both speakers provided personal and heartfelt insights into the difficulties of receiving a diagnosis for less-known medical conditions. Katia and Christianne became involved in the Forgotten Patients and Overlooked Diseases charity as patient representatives due to struggles within their families in getting Ehlers-Danlos syndrome (EDS) diagnosed. They were aware of the relief and validation that receiving a diagnosis can bring, as well as the access it provides to appropriate treatment and support.

Christianne contrasted the long and difficult journey undertaken to get her own and her family members' EDS diagnosed with the straightforward pathway to diagnosis she followed for her breast cancer. She described a clear, doctor-led pathway for her breast cancer diagnosis, guided by a multi-disciplinary team which ultimately led to a definitive diagnosis and subsequent treatment. In contrast, for those with MUS, the absence of a standard diagnostic pathway creates challenges for both HCPs and patients.

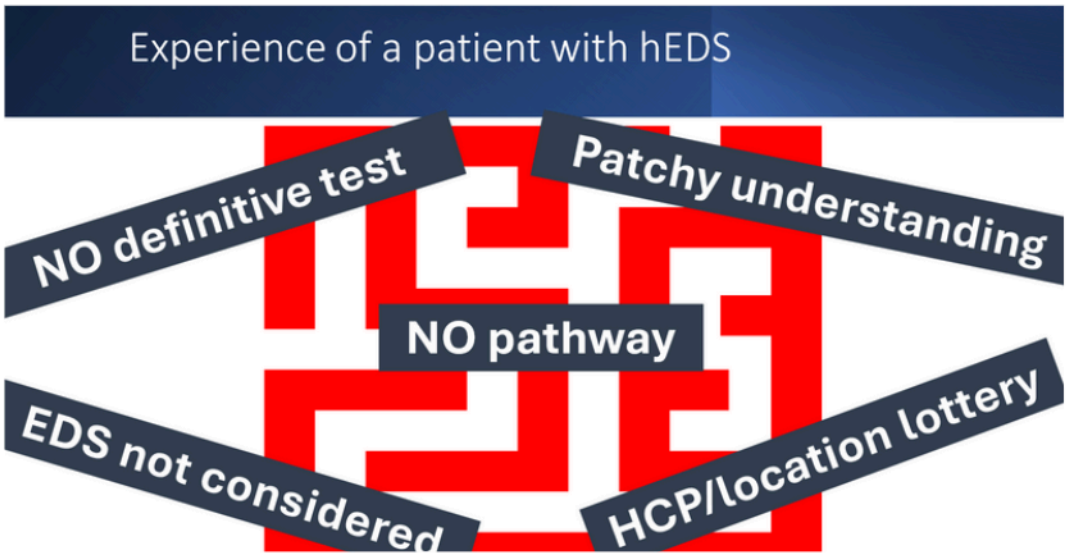
Both accounts highlighted the struggles faced by people with MUS. Katia and Christianne acknowledged the difficulty in capturing the diverse experiences of patients with MUS. They explained that these vary depending on individual differences among patients, including their geographical location within the UK, financial circumstances, and past interactions with HCPs.

The Problem of MUS

The patient's experience

Katia and Christianne emphasised that getting the right diagnosis is crucial for patients even if there is no 'cure' because it gives them validation, access to support (both emotional and financial), and effective care. Without a clear path to diagnosis, patients either present repeatedly to the healthcare system, which often leads them to be labelled as 'pushy' or anxious, or they can become disillusioned and give up altogether, living with debilitating symptoms without medical input. This means that patients must be resilient and persistent in the face of ongoing and often painful symptoms. In conclusion, Katia and Christianne suggested some ways that HCPs can improve the journey for patients with MUS, including:

- Listening to patients without preconceptions and avoiding judgement based on an individual's ability to articulate and communicate symptoms.
- Collaborating across healthcare teams to diagnose and treat patients with MUS holistically.
- Receiving better training to identify possible causes of MUS.

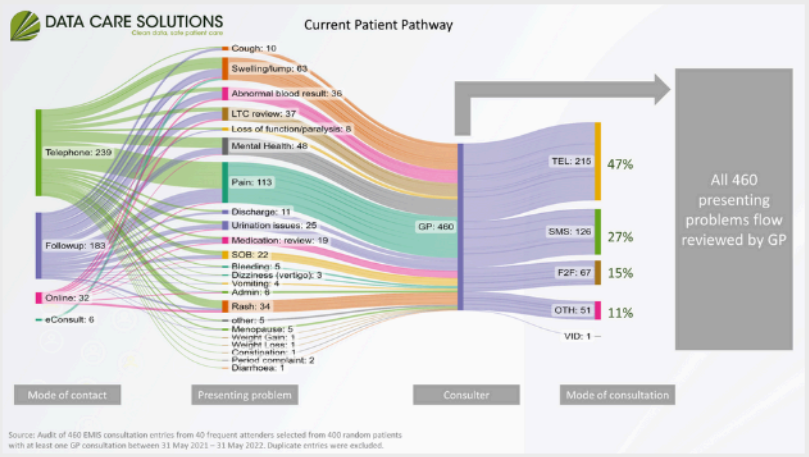


hEDS (hypermobile Ehler's Danlos syndrome)

The Problem of MUS

The doctor's experience of MUS

Dr Jay Verma described the pressures on GPs that contribute to the lack of diagnosis – and therefore inadequate care – for people with MUS.



> "The main challenge for GPs when diagnosing patients with MUS is lack of time."

Lack of time is a major challenge for GPs, especially when dealing with complex medical conditions. Before COVID, GPs in the UK saw around 25 patients daily, but post-COVID, the number of consultations has increased to 80–90 daily. This has further limited the time available for patient consultations, and made it increasingly difficult for doctors to investigate and manage people with MUS[1].

Electronic management systems offer potential solutions; however, data is currently stored in separate systems, hindering the exchange of patient information between primary and secondary care. Better sharing of patient data may help HCPs to identify patients with ongoing and undiagnosed symptoms, allowing them to spot patterns that can lead to a medical diagnosis[2].

A potential way forward suggested by Dr Verma involves tagging patients with uncertain diagnoses to aid future consultations and educate other HCPs. Dr Verma proposed the concept of a 'digital twin' in which a patient's data is readily available in the healthcare system, allowing doctors to connect information and identify patterns that facilitate diagnosis.

Dr Verma concluded that correct diagnoses can save both patient and GP time, highlighting the importance of addressing these challenges collaboratively.

The Problem of MUS

MUS in A&E – is the picture different from primary care?

Dr Jon Matthews highlighted the challenges faced by Accident and Emergency (A&E) departments in diagnosing and treating people with MUS.

He pointed out that in the UK, 4.5% of patients leave A&E departments without a diagnosis, despite investigations being carried out. From a financial point of view, these unproductive investigations and resource usage account for an estimated 10% of his A&E department's budget.

Currently, the A&E system puts pressure on doctors to fit patients' symptoms into predetermined categories so they can be discharged quickly. If patients with complex symptoms do not fit into one of these categories, they are often discharged without a diagnosis or follow-up plan[3], and may be labelled as 'making up' their physical symptoms. This leads to a pattern of repeated visits that can have a significant impact on patients, who often feel let down, frustrated, distressed, or isolated.

Clinicians often share these feelings of frustration and can also feel challenged when they are unable to provide patients with answers to their symptoms. They may become overwhelmed by the number of follow-up visits and investigations when patients keep returning with the same symptoms.

There is a clear need to change the way that frequent A&E attenders are managed, and at Imperial College London, a newly formed Health Improvement Unit aims to identify patients with recurrent A&E visits. These patients are allocated a caseworker to provide tailored support with a view to reaching a medical diagnosis for their symptoms. Dr Matthews proposed the introduction of agreed care plans through collaboration within A&E departments and between primary and secondary care. This will ensure that MUS patients receive equitable treatment when they attend A&E and facilitate effective coordination between healthcare organisations.

Keynote Presentation:

Where does the consultation go wrong?

The keynote presentation focused on the patient–GP consultation. This short but important interaction is pivotal, providing the opportunity for patients to tell their stories, and for GPs to get the information needed to work towards a medical diagnosis.

Prof. Graham Easton presented research on patient–GP communications, first focusing on consultations that 'go right'. He proposed that the consultation is a powerful narrative of a story that can take three forms:

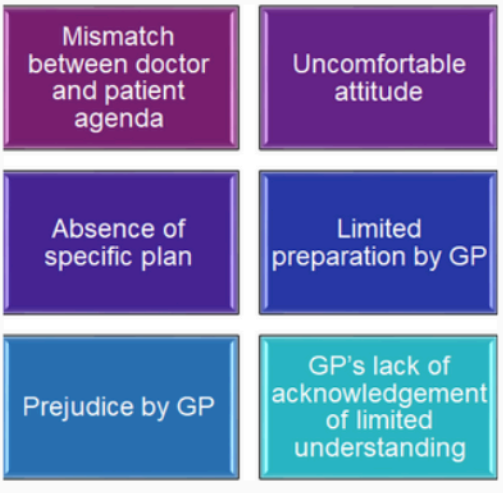
1. **Illness story:** This is the patient's lived experience that captures 'what matters' to them.
2. **Disease story:** The HCP's story, centred on a medical perspective, with a prescribed structure for history taking, physical examination, investigation, and diagnosis.
3. **Shared story:** This is the goal, a story co-constructed by the patient and the doctor, producing an agreed working diagnosis and shared management plan.

This type of consultation relies on a range of social skills, including compassionate curiosity, co-identification of agenda, explanation through information sharing, and planning of next steps.

Unfortunately, patient consultations in the real world often 'go wrong'. Prof. Easton noted that GPs faced with limited consultation times, and high workloads may understandably lack empathy and listening skills.

In this section, he discussed a study on patients' views of consultation[4]. The study identifies six themes from the patient's perspective regarding why consultations go wrong:

1. A mismatch between the doctor and patient agendas.
2. Uncomfortable attitude of the doctor.
3. Absence of a specific care plan.
4. Display of limited preparation by the doctor.
5. Prejudice (diagnostic bias).
6. Failure to acknowledge lack of certainty (for the GP to acknowledge 'I don't know').



Keynote Presentation:

Where does the consultation go wrong?

A further study on language and interactions was discussed[5]. This involved a systematic review of 18 publications, which identified linguistic and interactional features that are problematic in consultations with people with MUS:

1. **Symptom recognition:** When doctors cannot validate and legitimize the patients' symptoms.
2. **Double trouble potential:** When the doctor and the patient differ in their knowledge domain.
3. **Failed negotiation and persuasion:** Disagreement about the problem and management plan.

Summarising the issue, Prof. Easton said: "Patients want a patient-centred approach, taking into account the patient's preferences, thinking of them as a whole person and not a body part or a condition, and asking them to get involved in decisions and management plans."

In summary:

- Consultations relating to MUS can be challenging for both the doctor and the patient.
- A mismatched agenda can occur when the doctor does not consider the patient's ideas, concerns, and expectations.
- A successful consultation involves co-creating a mutually acceptable account by trusting adults.

> "When a biomedical approach doesn't seem to have all the answers, communication in the consultation becomes absolutely vital to relationship management."

Exploring Solutions

Ethical considerations in MUS and equity of access; what needs to change?

Dr Kiran Jani reported a scoping exercise performed by the Office for Life Sciences[6], which aims to develop strong and consistent ethical standards in genomic healthcare and research. This aim is especially relevant to people with MUS as many difficult-to-diagnose medical conditions have a genetic basis. The report found knowledge gaps within the current ethical guidelines concerning the use of genomics. These gaps relate to the issue of consent in genetic testing, familial disclosure of genetic conditions, and diversity in genomics. A lack of research on diversity needs to be addressed urgently as failure to do so will perpetuate inequalities of access to healthcare. Other issues that need to be addressed include the cost of genomic testing and whole-genome sequencing of newborns. For these gaps in guidelines to be addressed, patient and research participant input is needed to determine what best practice looks like.

Chantal Patel discussed how ethical considerations lead us to look at the way the physician and the patient with MUS interact with one another. This is especially important as it has been reported that patients with MUS may account for up to 45% of GP consultations[7]; because there is no diagnosis, people lack the necessary support that allows them to manage the condition and get back to work. Nor do they have access to benefits that they would have otherwise had if it had been possible to reach a diagnosis. In addition, while some GPs adopt a patient-centred approach, others take a tick-box approach, leaving some patients with MUS feeling that they are not being properly cared for.

When looking at patient-doctor interactions through an ethical lens, patient experience falls into three main categories:

- Patients' symptoms are dismissed as 'all in the head'.
- Patients are referred to several specialists.
- Some of the symptoms are treated, temporarily getting patients' hopes up, only for the symptoms to return, leaving them disappointed.

The following changes are needed to overcome these ethical and moral challenges:

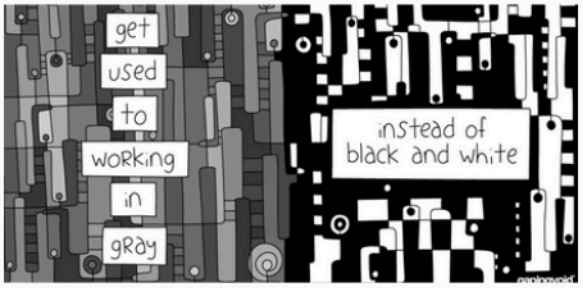
- Developing mutual respect between the doctor and patient, this is likely to improve trust.
- Respecting the autonomy of the patient – listening to and understanding what the patient is saying and working collaboratively to find a way forward.
- Recognising the moral tension when dealing with people with MUS:
  - Uncertainty relating to a lack of diagnosis – patient may feel concerned that there is no diagnosis and feel the physician has not taken action. Therefore, clear communication is needed to highlight the absence of a diagnosis, the reasons why there is no diagnosis and the plan going forward.
  - Disregard of patients' previous experience and past accounts of living with their symptoms.
- Adopting a holistic model in which to explore doubts and uncertainties, based on what the patient says.
- Emphasising the importance of patient-centred care and patient empowerment.
- Equipping HCPs with skills that go beyond standardisation and guidelines, so as to improve patient communication.

Exploring Solutions

Importance of clinicians exploring doubt in people with MUS

Dr Adrian Tookman spoke about the limitations within our current healthcare system which restrict the exploration of doubt. The current system:

- Encourages physicians to make a diagnosis quickly.
- Labels people and illnesses.
- Operates in silos.
- Has strict rules on appointment times and funding – the more consultations that are completed, the more money is received by the healthcare system.
- Takes a tick-box approach.
- May not acknowledge that HCPs are there because they love the work they do.



Within such operational constraints, people with MUS often feel BITTEN[8]:

- **B**etrayal – institutional betrayal.
- **I**ndicators – tick-box exercise.
- **T**rauma symptoms – emotional as well as physical symptoms.
- **T**rust – patient loses trust in healthcare.
- **E**xpectations – become negative and patients become angry in subsequent appointments.
- **N**eeds are unmet.

Once patients are BITTEN, they can project a negative persona and attitude, which can lead the physician to have negative perceptions about their interactions with the patient. When this happens, physicians are more likely to view the patient's symptoms as medically unexplained and 'all in their head'[9].

HCPs must therefore acknowledge the impact of the patient experience and their persona in the consultation. Several changes are needed in order to move forward:

- Clinicians must acknowledge their limitations and where there is doubt, explore it.
- A system is needed for cross-functional communication between specialists.
- Avoid making diagnoses in the first minute of meeting a patient.
- Only label people when it is clear that the label fits – incorrect labels are dangerous.
- MUS is not a sufficient diagnosis for patients with persistent physical symptoms.
- Physical diagnosis is important.
- People with MUS must be listened to.
- HCPs need to understand and support all patients, including the challenging ones.
- Think 'out of the box' when creating solutions.

Exploring Solutions

But, is it all in the mind? Views of a specialist psychiatrist

Dr Muj Husain acknowledged that MUS can be both physical and mental, and the lack of a medical diagnosis does not mean they are simply imagined or fabricated by the patient. A challenge in managing MUS is that there is a considerable overlap between different symptoms, and that diagnoses are built around medical specialties rather than problems. For this reason, Dr Husain prefers to use the same language used by patients.

There are five key facts about MUS, or a term generally preferred by patients and healthy populations, namely persistent physical symptoms (PPS)[10]:

- Unexplained symptoms are common.
- Patient symptoms are real and their distress is real.
- There is no greater risk of missing an underlying organic pathology.
- MUS can and do get better, and treatments are often available.
- Overlap with pre-existing physical health conditions is common.

In Dr Husain's clinic, the model used to understand and manage PPS adopts a holistic approach: looking at family history, triggers for PPS, impact on the patient, and treatment through cognitive behavioural therapy (CBT)[11]. Most importantly, the model emphasises the need for a positive explanation for the diagnosis in which doctors state clearly what they know and are honest about what they don't know. The model also proposes that physicians stress to patients that their symptoms are real and reassure them that PPS are treatable. This involves a shared collaborative approach to diagnosis between doctor and patient.

Patients should be considered for referral to a PPS service when they do not respond to first line treatment, get referred to multiple specialists, and are at risk of self-harm. Patients are also often referred if they exhibit multiple physical symptoms, co-morbid depression and anxiety.

Exploring Solutions

Is genetic testing the answer? Should everyone with MUS undergo genetic testing?

Prof. Julian Barwell discussed how to determine whether a disease has a genetic basis, and what developments are occurring in the genetic space that could be relevant to people with MUS.

The genetics field has moved towards whole-genome sequencing. Clinical genetics informs the past and present in that it identifies genetic abnormalities that already exist. However, it cannot always predict abnormalities that might develop in future. Therefore, clinicians need to use a combination of family history and phenotypic data to facilitate diagnosis.

Once patients present in a primary care setting, physicians need to start to think about how to determine if a disease is genetic. This is achieved by looking for clues such as an unusual presentation, conditions known to run in the family, and the age of onset of the disease or symptoms. HCPs can also look up symptoms to identify a series of genes that are associated with a particular condition through the Online Mendelian Inheritance in Man (OMIM) website.

More recently, whole-genome sequencing in combination with phenotypic data is playing an important role in obtaining difficult diagnoses. One example is the 100,000 Genomes Project, which can trace conditions or symptoms to specific gene changes in individuals, that are not found in other family members. Diagnoses of this type can help to explain medical conditions, but also reassure family members that they are at low risk of developing the same condition without the genetic mutation.

Genetic testing is now capable of analysing several thousand genes, which raises issues relating to consent. Often, patients only want to look for genetics that explain one set of symptoms and analysing several other genes may reveal genetic mutations that they may not want to know about. Therefore, it is important to ask patients for their consent before conducting genetic tests. If genetic testing reveals abnormalities that have wider implications, physicians need to explore the diagnosis sensitively, asking the patient whether they would like to act on it and letting them decide if they want support.

A range of genomic testing is available including the National Genomic Test Directory. However, the directory needs to be expanded to include genomic tests for people with MUS.

Exploring Solutions

AI and MUS – Dr GPT will see you now

Dr Keith Grimes began his talk by defining generative artificial intelligence (AI) and how it has evolved into a powerful general purpose tool that can answer questions, summarise information, infer, and reason. With these capabilities in mind, generative AI can potentially help solve a number of challenges faced by people with MUS:

- Limited time available for patients to tell their story and for physicians to collate and understand the story.
- A lack of understanding on the part of the clinician concerning the patient and their families.
- The time and effort devoted by patients in researching their symptoms which is then dismissed by the clinician.

Generative AI can solve these problems by transcribing, summarising, and making sense of what the patient and physician are saying during a consultation. This will enable the doctor to focus on the patient and actively listen to their story.

Generative AI can summarise the information in a way that patients want, in any language and in a form they can share with their family, as well as summarising medical information in a way that a lay person, i.e., the patient, can easily understand. These summaries can then be used by patients with MUS to reflect on what's going on in a way that makes best use of their time with the clinicians. Patients can also ask generative AI to explain complicated scientific terms.

However, it is important to be aware of the risks of using generative AI. Large language models tend to 'hallucinate', giving seemingly plausible answers that are incorrect. Generative AI can also produce biased results if they are not trained on representative medical data. Therefore, it is crucial to use the best possible AI model and keep the human in the loop.

Learning from Others

Good medicine has much to offer – Practical tips for individuals, families, and HCPs

Returning to the issue of limited time for patient consultations in primary care, **Dr Jay Verma** addressed the problem of patients being faced with a process that is stressful and anxiety-provoking, and being forced to fit into a reactive, inefficient system that is not timely, comprehensive, or appropriate. Looking at a primary care practice's monthly performance, he talked about in-house research demonstrating that 16% of their frequently attending patient accounted for 80% of the practice workload. This must be seen against a finding that most patients did not visit the practice at all during the period under review[12]. This inevitably creates a huge inequality in healthcare. Dr Verma suggested that primary care should undergo forward planning for the next 100 years to overcome the lack of time and a shortage of GPs[13]. The focus needs to be on the following:

- **Optimising the appointment system:** Could we capture medical questions before the appointment? Can tools help patients better illustrate their symptoms?
- **Using and re-evaluating data:** To optimise internal processes, can data from previous years be used and re-evaluated to drive changes and improve future processes?
- **Building a co-joined story with the patient:** Can we improve the outcome of the consultation by letting the patient drive it?

Learning from Others

Explaining persistent physical symptoms

Prof. Chris Burton talked about the importance of viewing PPS, such as chronic pain, as an independent entity rather than an indicator of an underlying problem. Symptoms are physical sensations that indicate actual or potential disease. These sensations are caused by signals in the body that are sent to the brain through a complex network. In the case of persistent symptoms, the symptoms can become worse due to a neurological feedback loop that reinforces the symptoms experienced by the patient. One of the key points in Prof. Burton's presentation was that explanations of symptoms can help people make sense of them, adapt to them, and learn to control and manage them. This was shown in a multi-symptom study, in which GPs had four sessions over a period of three months with patients who were experiencing PPS[14,15]. The four sessions focused on:

1. Actively listening to the patient and validating the symptoms.
2. Giving the patient personalised explanations based on symptom science.
3. Teaching the patient symptom management techniques, such as specific breathing and techniques to override or distract from symptoms.
4. Consolidating new knowledge and skills.

After just the first step, patients felt valued and encouraged to believe that the follow-up sessions could have a positive effect. Following an explanation of their symptoms, patients were more likely to comply with suggestions regarding how best to manage their symptoms.

> "Illness typically stops you from being the person you are or want to be and gets in the way. If that illness remains medically unexplained, there is no way to get moving again. But what we found... is that the explanation (of the illness) has allowed people to get moving again."

Learning from Others

Supportive strategies, innovative approaches and thinking out of the box

Through her mantra "You are more than your illness", **Dr Minha Rajput-Ray** emphasised the importance of seeing patients beyond their disease. Dr Rajput-Ray practices integrative medicine, which addresses the physical, emotional, mental, and spiritual aspects of health[16]. Together with colleagues from various disciplines, she works to treat patients with MUS, who often suffer from pain, fatigue, and chronic conditions that are resistant to conventional therapies. Key elements of her integrative medicine 'toolbox' include:

- Review the patient's medical history.
- Understand concerns about pain and function.
- Consider unconventional tests if necessary.
- Analyse and interpret results.
- Integrate different treatment options.
- Discuss the case with other healthcare professionals.
- Empower patients to take control of their health journey.

As an example, Dr Rajput-Ray highlighted the importance of testing amino acid levels and ensuring that the body gets the right nutrition to produce its own amino acids[17]. She discussed how amino acid deficiencies can cause conventional tests to fail to detect certain diseases and therefore fail to explain ongoing symptoms.

"Let's be kind to each other, learn from each other and let's know that the patient is our biggest teacher."

Learning from Others

Medically unexplained symptoms (a practical toolkit from a rheumatologist's perspective)

Dr Francis Kynaston-Pearson spoke from a pragmatic perspective, sharing approaches to MUS based on his own experience as a rheumatologist. He typically works with patients who are experiencing symptoms such as pain, fatigue, or cognitive dysfunction. He summarised the following steps:

- **Patient validation:** Acknowledge and affirm symptoms and concerns - an important first step.
- **Screening:** Categorise the complaints, e.g. inflammatory symptoms (IA screen), tissue disease (CTD screen) or red flags.
- **Look for triggers:** These may include past infections such as COVID-19, physical or psychological trauma, chronic life stressors such as a busy lifestyle or pressure from lack of social support.
- **Look at functional characteristics:** Key features include pain, fatigue, or cognitive issues.

While medical treatment is important, Dr Kynaston-Pearson pointed out that other methods of support have a role:

- Providing education and resources, e.g. information about groups such as the British Society of Lifestyle Medicine or the Hypermobility Spectrum Associations. Various support groups and patient forums can play an important role.
- Psychological support, e.g. counselling and CBT can help, as can mindfulness apps such as Waking up or Headspace. Some individuals might benefit from a psychiatric referral.
- Reminding the patient of important steps to healthy living and lifestyle improvement, including diet, exercise, and the importance of relaxation and hobbies.
- Emphasising the importance of sleep quality, which can be improved by avoiding coffee and alcohol in the afternoon and evening, as well as physical activity and modifications inside the bedroom.

His take-home message was to believe in and empower patients, do the basics well, recognise the limitations of modern medicine, and be cautiously open to new, innovative approaches.

> "The HOW of what we do in medicine is as important, if not more important, than the WHAT and WHY of what we do."

Learning from Others

All the light we cannot see

Dr Sanjay Gupta is a cardiologist with an interest in a condition called POTS (postural orthostatic tachycardia syndrome). He provided a personal story of how a chance meeting with a patient with POTS transformed the way he practices medicine. To date, Dr Gupta has seen 2,000 patients with POTS. To improve their quality of life, he developed the following:

- **Pre-treatment videos:** Videos that patients can watch before an in-person consultation, which allow patients to check whether their symptoms fit the usual presentation of POTS and learn about lifestyle changes that could improve their symptoms before treatment begins.
- **Meetings with physiotherapists:** Patients are offered the opportunity of a free consultation with a physiotherapist specialising in POTS symptoms.
- **Tailored medication based on patient feedback:** Because experience is limited and supporting evidence for different medications generally lacking, Dr Gupta has started offering tailored treatments based on small studies and patient feedback in an effort to improve quality of life. This means that medications can vary from patient to patient.
- **Advocacy support**: Patients are given advocacy support to help them with issues such as tribunals or finding accommodation.

He explained that a series of small steps together can make a big difference to patients' quality of life. Dr Gupta ended his presentation with a quote from one of his patients: "To think that two years ago at this time I was trying to take my own life, and now I want to be here to see my girls grow up."

> “Medicine is becoming a little bit of an impersonal science. We are experts in conditions but rarely experts in people who have these conditions.”

Conclusion

The most inspiring moments of the day came from data, experiences, and stories about how a diagnosis for an underlying condition, which resolves the uncertainty of MUS, can be truly life-changing for patients and their families. Despite many significant challenges, attendees left the meeting feeling hopeful. The discussion of potential solutions and strategies provided a sense of optimism and possibility for improved patient care and outcomes.

A Dutch delegation from the organisation the Witte Raven attended the first "Medically Unexplained Symptoms - Forgotten Patients and Overlooked Diseases" conference in London. The Witte Raven specializes in cases involving Unbearable Unexplained Complaints (UUC), exploring rare diseases or unusual phenomena. During the event, Dr Tonnie van Kessel and medical student Bibiana van der Helm presented their work, discussing Witte Raven's referral process, research efforts, and database strategies. For more information, please visit www.witteraven.org.

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For more information, please visit www.forgottenpatients.org

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