



## Draft outline of a proposed service model for those very severely affected by ME/CFS

### 1. Issues to address

- Documented concerns about patient safety and preventable deaths  
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- Extended periods of in-patient stays for a few patients
- Inappropriate detention under the mental health act of severe patients due lack of health care professional education and misinterpretation of severe illness.
- Lack of data on prevalence and need
- Continued delays in the implementation of commissioned services for very severe ME, a key commitment within the Department of Health and Social Care Final Delivery Plan.

There are currently no commissioned NHS services for people with severe ME. This absence represents a significant system gap, highlighted in the Prevention of Future Deaths report concerning Maeve Boothby-O'Neill. As a result, patients remain at risk of deterioration and harm, with an ongoing risk of preventable deaths. This applies to both adult patients and children and young people. This is disproportionately affecting young women.

To help address this, the patient community, including Forward-ME, would welcome the opportunity to work collaboratively with Department of Health and Social Care and NHS England to explore and develop service options that could be implemented at pace.

### 2. Key elements of a proposed model

A medium-term (five-year) pilot to centralise specialist advice and guidance for those most severely affected, ensuring equitable access to expert support irrespective of postcode. The pilot would support consistent implementation of National Institute for Health and Care Excellence guidelines and provide structured support to local clinicians managing complex cases in areas without a commissioned ME service. This would be achieved by implementation of:

**2.1 National response multi-disciplinary clinical team** consisting of a small number of specialist physicians with significant expertise in ME/CFS to be available to support hospital in-patients and provide clear advice on treatment in line with NG206 and evidence-based best practice. The team would support hospital clinicians in managing

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<sup>1</sup> Prevention of Future Deaths Report for Maeve Boothby O'Neill  
<https://www.judiciary.uk/prevention-of-future-death-reports/maeve-boothby-oneill-prevention-of-future-deaths-report/>

complex cases and enable the centralised collection of data to inform the development of a national registry.

2.2 Development of **minimum safe standards of care** for in-patients with very severe ME, in line with MICE guidelines'.

2.3 Development of an **ME Clinical Reference Group (CRG)**, with a view to establishing commissioned hub-and-spoke virtual ward services for the most severely affected patients'.

2.4 **Specialist nurses** in each ICB would provide the home visiting service where needed and would be part of the PCB service specification template.. (Role description to be defined).

2.5 A review of definitions and coding to allow more accurate data collection on prevalence.

<https://www.dialogues-mecfs.co.uk/films/severeme/>

### 3. Proposed benefits of the above model:

- Significant improvement on patient safety
- Potential reduction in length of hospital stay
- Fit with maximising use of technology
- Fit with NHS 10 year plan of supporting more patients in the community
- Flexibility of the model to respond to need
- Built-in data collection, where insufficient data exists to argue for a highly specialised service
- Achievable in the short-term whereas the process for pursuing a specialised service commissioned by the Secretary of State will be very lengthy and may not succeed. Expert clinicians currently exist who could form the basis of a national response team in a short time.  
Appointing experienced specialist nurses will require a workforce training programme so will take a little longer.
- A model of a virtual ward for people with ME/CFS currently exists - learning could be sought from existing models.

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