

## THEMES FOR ME ENGAGEMENT EVENTS

### **SPEAK UP Events**

We welcome feedback in your own words. You can choose whether to anonymise your written feedback.

Below you will find some headings for you to use as a guide to your feedback but don't feel restricted in what you want to say as part of this exercise.

It is important that you include comments on any aspects of your treatment and support that you feel have worked well as well as aspects that have caused you difficulties.

#### 1. IMPACT OF ME

Describe the impact ME has had on your life?

And how do you rate the severity of your condition - whether mild, moderate, severe or very severe?

#### 2. DIAGNOSIS: early and accurate diagnosis is critical in delivering appropriate treatment and other help and support.

What has been your experience of getting a formal diagnosis? How long did it take, and what examinations and tests were undertaken by your doctor? And what information and advice was given to you on how to best manage your symptoms?

#### 3. TREATMENT & SUPPORT: accessing ME specialist support is needed whether to advise on diagnosis where this is in doubt, and/or to develop an individualised care and support plan.

What has been your experience of being referred to ME specialist support, not just in relation to ME but also addressing other symptoms and medical conditions, for example pain and/or sleep management, PoTS? How supported have you been during any ME flare ups and relapses? And please comment on the extent to which you have had ongoing and regular support after initial diagnosis.

#### 4. SOCIAL CARE

Comment on the extent to which your doctor or other health care professional has helped you to access suitable social care and other support, for example in relation to issues related to accessing benefits, or dealing with problems related to your employment, education, or training (as applicable)?

## 5. DOCTOR/PATIENT RELATIONSHIPS

This theme is intended to cover your experience of dealing with doctors and other NHS staff. How confident have you felt that you were being heard and taken seriously by doctors etc who understood ME? What worked well for you? What did you find unsatisfactory? How have relationship issues impacted how you regard, and engage with, the NHS. What obstacles have you faced whilst trying to move forward?

## 6. What HAS WORKED WELL AND WHAT CHANGES WOULD YOU LIKE TO SEE?

What has worked well so we can learn and build on this? Please outline any and all changes you would like to see from a dedicated ME service that would make a big difference to how you manage your ME. What aspects/symptoms would you like more support with?