**Notes of “NICE Scoping Workshop on Future ME/CFS Guideline” held in London, 25 May 2018**

*Sue Waddle attended the NICE Scoping Workshop on the Future ME/CFS Guideline on behalf of ME Research UK and was delighted to see many friends of our charity there, from supporters to medical colleagues and researchers that we work with. Her feedback of the workshop is noted, below.*

About 60 people attended the workshop and were arranged around tables in groups of about 8 to facilitate discussion of the Draft Scope document generated by NICE.

The attendees were introduced to the Chairman of the Guideline Development Group [GDG], Dr Peter Barry, a Paediatrician, and the Vice Chairman, Baroness Iilora Finlay, a consultant specialising in Palliative Care.

Delighted as I was to catch up with friends, supporters and colleagues, the real reason for being there was to talk about the Draft Scoping Guideline on ME/CFS, to discuss what was covered (and what wasn’t) and to offer opinions on what should and shouldn’t be in the final Scope. The discussions are important because when the new Guidelines are developed only those issues included in the Scope will be considered, so it is really important that nothing be missed out at this stage.

A new Guideline Development Committee will be formed consisting of doctors and healthcare professionals as well as lay people - including patients and carers. At this stage, it is not proposed to include a Psychiatrist in the committee membership. Applications for membership can be made between 21 June and 19 July 2018, so if anybody is interested please consider applying so that your voice can be heard.

After introductions were made and the purpose of the meeting explained, all the groups discussed the Draft Scoping Document.

There was some opposition to the Draft Scoping Document and a member of our group suggested that the Scoping document relating to Multiple Sclerosis be considered because it was well-written Another member of my group was concerned that other conditions relating to ME might not be covered by the Guideline and she explained how important it was for her that some conditions relating to ME should be included. I wanted to stress the importance and difficulty of the severely affected being considered as a priority. One way to ensure that the severely affected are included, might be to use a novel approach, such as receiving short video clips, or having short Skype meetings with people who are severely affected, or their carers. The group facilitator promised to feed back all the comments raised.

My overriding concern, one that I have raised numerous times with NICE over the last 2 years, is that CBT and GET are still being recommended by the existing ME/CFS Guideline that is not “fit for purpose” and as a consequence, it could make sufferers worse - and especially children and young people remain at risk of being taken from their parents or being subjected to treatment that can make them worse. I asked that a Warning Notice be issued as soon as possible because the current Guideline will not be replaced until 2020! The facilitator responded that she would submit feedback to the “appropriate person”.

There were too many issues raised to cover here and, also there were a lot of topics that were needed to be covered, but could not be, as we ran out of time. However, my overriding sense was of positivity and of a genuine desire to try to get the NICE Guideline for ME/CFS right next time.