

## The “London” criteria: 1990 versus 1993

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It seems that confusion still exists about the involvement of Miss Ellen Goudsmit PhD with the “London” criteria and about the various and disparate claims she has made in relation to them, so for convenience some examples are once again provided and further clarification supplied:

Miss Goudsmit has previously stated about the “London” criteria:

- (i) “The London criteria were devised for MEAction, now AFME, for use in all studies funded by them” (“The London criteria: correction and clarification”: 7<sup>th</sup> May 2005, Co-Cure)
- (ii) “The LC were devised so researchers could identify the ‘real patients’ and they did. The abnormalities they found **using the LC** were found in ALL patients who met the criteria. Costa et al was one of the most important studies to date” (8<sup>th</sup> May 2005, cfs research)
- (iii) “Costa et al did not refer to the London criteria but to the ‘MEAction’ criteria. **The MEAction criteria are the London criteria**”(8<sup>th</sup> May 2005, IMEGA)
- (iv) “They (the LC) were first published in the National Task Force report **i.e. they are operationalised criteria. They were used in all studies funded by AfME from 1993 to 1997, e.g. Costa, who discovered hypoperfusion in the brainstem, and Scholey et al, who found cognitive impairment consistent with organic brain disease. Paul et al also used them**” (7<sup>th</sup> June 2004)
- (v) “I not only thought of the idea (of the “London” criteria) but was involved in writing and disseminating them” (21<sup>st</sup> October 2001)
- (vi) “The London criteria are research criteria, for use in research, e.g. Costa et al, Scholey et al, Paul et al. I know this as I was one of the co-authors” (9<sup>th</sup> January 2002)
- (vii) “As I noted before, I did not write any of the text of the LC” (12<sup>th</sup> June 2004)
- (viii) “They (the LC) were initially used by Costa et al” (10<sup>th</sup> September 2004)
- (ix) “e.g. wrong reference to the London criteria, cited as 1990, but I didn’t think of them until 1993, let alone compile them with colleagues” (January 2002, letter to the Chief Medical Officer)

- (x) “The LC were formulated for in-house use (by MEAction, now AfME) as opposed to general use” (10<sup>th</sup> May 2005, IMEGA)
- (xi) “One has to fulfil a number of criteria to be cited as author. I did not actually write a word of the LC but I was sufficiently involved to merit inclusion as author” (10<sup>th</sup> May 2005, IMEGA)
- (xii) “The London criteria were developed for MEAction and Costa refers to the criteria as those from ME Action” (10<sup>th</sup> May 2005, IMEGA).

These statements by Miss Goudsmit are unequivocal, but not only are they inconsistent, they are also misleading and have led to considerable confusion and even distress.

Those who take the trouble to inform themselves of the facts as distinct from the fiction will be aware that attempts to demystify the whole issue of the “London” criteria do not constitute a “personal” attack upon Miss Goudsmit as they are the reproduction of her own words, together with relevant referenced facts.

Importantly, it has been shown that whilst Costa et al do indeed refer to ‘MEAction’ criteria, those criteria are **not** the “London” criteria as asserted by Miss Goudsmit, but criteria suggested by Dr William Weir that were based on the Holmes et al 1988 criteria and were referenced in a textbook that was published in 1991 ie. before Miss Goudsmit claims she had even thought of the “London” criteria; see:

[http://www.meactionuk.org.uk/The\\_LC\\_-\\_QED.htm](http://www.meactionuk.org.uk/The_LC_-_QED.htm)

[http://www.meactionuk.org.uk/Observations\\_on\\_Ellens\\_response\\_re\\_the\\_London\\_criteria.htm](http://www.meactionuk.org.uk/Observations_on_Ellens_response_re_the_London_criteria.htm)

[http://www.meactionuk.org.uk/Ellen\\_and\\_the\\_London\\_criteria.htm](http://www.meactionuk.org.uk/Ellen_and_the_London_criteria.htm)

Another key point is that in [her letter of January 2002 to the UK Chief Medical Officer](#), Miss Goudsmit asserted that the Report of the CMO’s Working Group was wrong to have referred to the “London” criteria as having been formulated in 1990 (claiming that she had not thought of them until three years later, ie. 1993).

The National Task Force Report states that the “London” criteria were proposed by the UK Patient Organisations (Action for ME; the ME Association and The International Federation of ME Associations) in **1993** (page 96). This ascription would undoubtedly include Miss Goudsmit since she referred to her activities as The International Federation of ME Associations but significantly, no mention is made of any input by Dr Melvin Ramsay or Dr Betty Dowsett (see below).

In contrast, the CMO’s Working Group Report states the following (Appendix II, page 76): **“London, 1990 (ME); Derived from Dowsett and Ramsay)**

“Complaint of general or local muscular fatigue following minimal exertion with prolonged recovery time; neurological disturbance, especially of cognitive, autonomic and sensory functions; variable involvement of cardiac and other systems; a prolonged relapsing course; syndrome commonly initiated by respiratory and/or

gastrointestinal infection but an insidious or more dramatic onset after neurological, cardiac or endocrine disability”.

No mention is made in the Working Group Report of Miss Goudsmit’s involvement in the formulation of the “London” criteria, nor of Drs Macintyre or Shepherd, and nor is there any mention of the “London” criteria having been developed only for in-house use by MEAction as claimed by Miss Goudsmit.

As credited in the CMO’s Working Group Report, the first so-called “London” clinical criteria originate from Drs Ramsay and Dowsett, as can be seen from their paper entitled “Myalgic encephalomyelitis – a persistent enteroviral infection?” (Postgrad Med J 1990;66:526-530) which states:

“Conventional technology is limited in demonstrating abnormalities and this has hitherto permitted misinterpretation of the symptoms as psychogenic. We adopted the following **clinical criteria** for investigation of ME: a syndrome commonly initiated by respiratory and/or gastrointestinal infection but an insidious or more dramatic onset following neurological, cardiac or endocrine disability occurs. The pathognomonic features are: a complaint of general or local muscular fatigue following minimal exertion with prolonged recovery time; neurological disturbance, especially of cognitive, autonomic and sensory functions; variable involvement of cardiac and other systems; a prolonged relapsing course”.

It is clear from the wording that the “London” criteria to which the CMO’s Working Group Report refers are those formulated for clinical investigation of ME patients by Drs Ramsay and Dowset et al.

The Ramsay/Dowsett criteria are not, however, designated research criteria. This being so, since the Medical Research Council states that researchers involved in the PACE trials are unable to use the Canadian Clinical Working Case Definition (Carruthers et al, JCFS 2003;11:1:7-115) because they are clinical (not research) criteria, it is logical that the MRC PACE trials cannot use the Ramsay/Dowsett “London” clinical criteria either.

It is indisputable that Miss Goudsmit had nothing whatever to do with the formulation of the Ramsay/Dowsett clinical criteria by whatever name they may be known.

It can only be interpreted from Miss Goudsmit’s own words (illustrations above) as to why she wrote to the CMO complaining that the Working Group Report of January 2002 was in error about the “London” criteria since it was she who had thought of the “London” criteria in 1993, thereby implying that no such criteria existed in 1990.

It remains the case that no “London” research criteria have ever been defined or published in a medical or scientific journal.