

REPLIES RECEIVED IN RESPONSE TO PHASE I OF THE POLICY CHANGE NOW CAMPAIGN

Response on behalf of Rt Hon. Andrew Lansley:

Thank you for your recent emails to Andrew Lansley about xenotropic murine leukaemia virus-related virus (XMRV) and chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). I have been asked to reply on Mr Lansley's behalf.

Whilst the Department of Health agrees with the World Health Organization's classification of CFS/ME as a neurological condition of unknown cause, it has many different potential causal factors, including those of a neurological, endocrinal, immunological, genetic, psychiatric and infectious nature, which have been investigated, but the diverse nature of the symptoms cannot yet be fully explained.

More research into the causative factors of CFS/ME is needed. The Medical Research Council (MRC) has recently identified and prioritised research topics where high-quality proposals should be encouraged. This exercise involved both experts in the field of CFS/ME and research leaders in aligned areas. Further information on this work can be found on the MRC website at: www.mrc.ac.uk/Ourresearch/ResearchInitiatives/CFSME/index.htm.

Regarding the recent interest around the role of XMRV, its precise role in the causation of CFS/ME remains a source of debate within the scientific community. A recent study in the USA reported that XMRV has been detected in a number of CFS/ME sufferers. The results of this study have not been replicated in Europe. An ongoing research programme characterising XMRV at the MRC's National Institute for Medical Research recently investigated the basis for this finding. The study, which was funded jointly by the MRC, the Wellcome Trust and the CFS Research Foundation, failed to replicate the findings of other studies in this area and found no association between XMRV and CFS/ME.

In addition, an expert subgroup of the National Expert Panel for New and Emerging Infections (NEPNEI) met in May 2010 to consider all available evidence about XMRV and conduct a risk assessment. The subgroup concluded that XMRV can infect humans but there is currently no evidence that it causes human disease and that, on the evidence before the group, no public health action is required at this time. Since the subgroup meeting in May there has been no new scientific evidence that would change these conclusions. In July, the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO), similarly decided not to recommend further measures at present. Both groups will continue to monitor the situation.

Both NHS Blood and Transplant (NHSBT) and Health Protection Agency (HPA) experts concur with the views expressed by NEPNEI and SaBTO and also recognise the need for further research on the prevalence of XMRV in the UK. In a recent unpublished pilot study conducted by NHSBT/HPA, a

series of 540 randomly selected English blood donors were screened for XMRV and none were found to be infected.

The UK Blood Service's decision to exclude people with CFS/ME from donating blood is to protect the patient, not because of any potential infection risk. CFS/ME is a relapsing condition and blood donation may be detrimental to the affected person. This decision is in line with practice for other conditions where individuals are permanently excluded from blood donation to protect their health.

I hope this reply is helpful.

Yours sincerely,

Paul Larkin

Customer Service Centre

Response received on behalf of Dame Sally Davies:

Thank you for your recent emails about xenotropic murine leukaemia virus-related virus (XMRV) and chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). I have been asked to reply.

Whilst the Department of Health agrees with the World Health Organization's classification of CFS/ME as a neurological condition of unknown cause, it has many different potential causal factors, including those of a neurological, endocrinal, immunological, genetic, psychiatric and infectious nature, which have been investigated, but the diverse nature of the symptoms cannot yet be fully explained.

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I hope this reply is helpful.

Yours sincerely, Jonathan Tringham

Customer Service Centre

Department of Health

Response on behalf of Sir John Savill:

Thank you for your recent messages to Sir John Savill, I have been asked to reply on his behalf.

The MRC is a publicly funded organisation dedicated to improving human health and we support research across the entire spectrum of medical sciences, from fundamental laboratory based science to clinical trials, in all major disease areas.

We recognise that Chronic Fatigue Syndrome/Myalgic Encephalomyelitis is a complex and debilitating condition with a diverse range of symptoms which have a profound impact on the lives of those who suffer from the condition, their families and carers.

Support for high-quality research on CFS/ME has been a priority for the MRC for a number of years and more research is needed into all aspects of the condition, including causative factors. The MRC's funding for scientific projects, including those on CFS/ME, is based on an assessment of scientific quality and likely impact, and is provided in response-mode to proposals from the research community.

In 2008 the MRC set up a new group, the CFS/ME Expert Group, to consider how to encourage high-quality research proposals, focusing on the potential for partnerships between researchers already working on CFS/ME and those in associated areas. The Expert Group, which was chaired by Professor Stephen Holgate, chair of the MRC Population and Systems Medicine Board, has now identified and prioritised research topics where the MRC might target our efforts to high-quality proposals. This exercise involved both experts in the field of CFS/ME and research leaders in aligned areas. Further information on the work of the group, including the recommendations for research topics and priorities can be found on our website at www.mrc.ac.uk/Ourresearch/ResearchInitiatives/CFSME/index.htm. The MRC is currently considering how these recommendations might be taken forward.

Regarding the recent interest around the role of XMRV, its precise role in the causation of CFS/ME remains a source of debate within the scientific community. The MRC is supporting research relating to XMRV and an ongoing programme on the characterising XMRV at the MRC National Institute for Medical Research has recently investigated the basis for this finding. The study, which was funded jointly by the MRC, the Wellcome Trust and the CFS Research Foundation, failed to replicate the findings of other studies in this area and found no association between XMRV and CFS/ME.

Dr Declan Mulkeen

Director of Research Programmes