

# Vector-Borne Infection Research-Analysis-Strategy

November 7th 2017



***Discrimination against chronic Lyme Disease patients in the UK has parallels with one of the most notorious medical experiments ever conducted.***

**Unthinkable? Read this - it will change your mind**

**The full title of the notorious Tuskegee Experiment was: ‘Tuskegee Study of Untreated Syphilis in the Negro Male’. The title reveals the most appalling aspect of the experiment – it was *RACIST*.**

The [Tuskegee Experiment](#) tricked black men into being unwitting subjects in a long-term study of syphilis. The men were told that they had ‘bad blood’ when they actually had untreated syphilis. Nearly 400 men were deceived so that researchers could observe the effects of the illness. This went on for 40 years until 1972. In 1997 President Bill Clinton [publicly apologised](#) to survivors and families of the victims.

**The Tuskegee Experiment was shocking because the victims were denied a true diagnosis of their illness and the treatment they needed for the infection.**

It might seem unthinkable that such despicable treatment of people could happen in the UK today, where patients with a potentially dangerous infection could be misled about their illness and denied treatment. But this is what is being done to possibly tens of thousands of patients with chronic Lyme disease. This abuse of patients with a dangerous infection is not coming from some extremist group. It originates from the UK health authority, Public Health England (PHE) and is being condoned and actualised by the National Institute for Health and Care Excellence – commonly known as ‘NICE’.

It is not easy to look beyond the racism of the Tuskegee experiment, but when one does, it can be seen that there are clear parallels with NICE’s development of their guidelines for Lyme disease. NICE published their [draft guideline](#) for Lyme disease in September 2017. When this was [analysed](#) by the patient campaign group [VIRAS](#), it was found to discriminate against large numbers of UK patients in ways shockingly similar to what was done to the victims of the Tuskegee experiment.

NICE specifically excluded patients diagnosed with Myalgic Encephalomyelitis (M.E.) or Chronic Fatigue Syndrome (CFS) from consideration in their guideline for Lyme disease. They did this while fully aware that M.E. and CFS are common misdiagnoses of Lyme disease. This denial of a true diagnosis and necessary treatment must predictably result in serious harm and even manslaughter.

- Syphilis is caused by infection with *Treponema Pallidum*, a spirochaete bacteria which in long-term infection can cause serious and complex symptoms. Sir William Osler (known as ‘the Father of Modern Medicine’), remarked that, “he who knows syphilis,

knows medicine”, because patients with syphilis can have symptoms affecting any organ or system of the body. The variability of syphilis symptoms led to it being described as ‘the Great Imitator’, due to the infection mimicking many other diseases.

- Lyme disease is also caused by infection with spirochaete bacteria in the family of *Borrelia*. The first official Lyme spirochaete, *Borrelia burgdorferi*, was identified in 1982 by Dr Willy Burgdorfer. Lyme disease is generally transmitted to humans by the bite of an infected tick. Lyme disease can produce equally widespread and complex symptoms in long-term infection, which can be devastating or even fatal.
- Dr Willy Burgdorfer, who discovered *Borrelia burgdorferi* in 1982, stated ([Under Our Skin, 2007](#)): “I am a believer in persistent infections because people suffering with Lyme disease, ten or fifteen or twenty years later, get sick [again]. Because it appears that this organism has the ability to be sequestered in tissues and [it] is possible that it could reappear, bringing back the clinical manifestations it caused in the first place.”
- And in reply to the question: what are the similarities between *Borrelia burgdorferi* and syphilis? Dr. Burgdorfer stated: “The similarities that I know of are associated with the infection of the brain, the nervous system. The syphilis spirochete, *Treponema pallidum* has an affinity for nerve tissues. The *Borrelia burgdorferi* spirochete very likely has that too. Children are especially sensitive to *Borrelia burgdorferi*. The Lyme disease spirochete is far more virulent than syphilis.”

NICE develop a new guideline by first defining its Scope, this determines all the aspects that their guideline will include. The NICE [Scope](#) document for Lyme disease states: **“Areas that will not be covered: Managing chronic fatigue syndrome”**. **The NICE draft short-guideline makes no mention at all of M.E. or CFS.** Therefore NICE specifically excluded patients with the most likely and common misdiagnoses of unrecognised Lyme disease. An unknown number of patients diagnosed with these illnesses will certainly have Lyme disease, but most have never even been investigated, let alone diagnosed and treated.

It is estimated that there are between [150,000 to 250,000](#) people in the UK diagnosed with M.E. or CFS. Tens of thousands of these patients could be misdiagnosed cases of Lyme disease, because the symptoms of chronic Lyme, M.E. and severe CFS are identical. Due to their misdiagnosis, these patients have often suffered for years and decades from an infection which could have been treated quite easily had it been recognised early. Without a timely diagnosis and proper treatment, Lyme disease can lead to severe and debilitating chronic illness. Research has repeatedly shown that patients diagnosed with M.E. or CFS, are more impaired and have a [worse quality-of-life](#) than most other chronic illnesses. Later research into chronic Lyme disease has shown similarly [severe incapacity and poor quality-of-life](#).

It is claimed that there is no known cause for M.E. and CFS so once diagnosed, patients get minimal investigations. There are no valid treatments for the illnesses and patients are only treated for their symptoms. This is why some patients refer to these as being ‘waste-basket’ diagnoses, because once a person has one of these labels, the patient’s medical providers can consign them into a cheap and convenient medical black-hole. This is what NICE did to M.E. and CFS patients when they published their “CFS/ME” guidelines in 2007 (CG53, see below).

In 2014, VIRAS conducted a [survey](#) of 120 Lyme disease patients which showed that 62% had previously been diagnosed with M.E. or CFS. Other diagnoses included fibromyalgia (31%), arthritis (31%), sleep disorder (29%), migraine (24%) and thyroid disease (17%). It can be seen that some patients have multiple diagnoses. Some of these might be valid co-diagnoses, e.g., Lyme+sleep disorder, or Lyme+migraine. However, M.E. or CFS would generally be misdiagnoses if the patient actually has Lyme disease. An exception to this would be where Lyme disease caused inflammation of the spinal chord or brain-stem, in which case M.E. could be a legitimate co-diagnosis with Lyme disease.

In 2016, VIRAS conducted a survey of 44 patients. Eight of these were diagnosed with Lyme, 16 with Lyme previously diagnosed as M.E. and 20 diagnosed with M.E. The survey used the [Isabel Symptom Checker](#), a sophisticated online programme which produces an ordered list of possible diagnoses based on a set of symptoms. The top three diagnoses produced were Lyme disease (34), M.E. (32) and Fibromyalgia (25). The three top categories of diagnoses taken from the top ten suggestions for each respondent were: Neurological (87), Infectious Disease (82), Rheumatologic (57).

It is notable that while Lyme disease is an infectious disease caused by a spiral bacteria related to *borrelia burgdorferi*, arthritis or painful joints are frequent symptoms, which can lead to patients being referred to rheumatologists. As a main symptom, arthritis is more common in North America. In Europe, neurological symptoms are common and patients are often referred to a neurologist. These factors suggest that the Isabel Symptom Checker was accurate in categorising patient's as having an infectious disease with symptoms being predominantly neurological or rheumatic.

Common sense dictates that the striking match between the symptom profiles of Lyme disease and M.E. and CFS, mean that patients with Lyme disease are at serious and predictable risk of being misdiagnosed with those illnesses. There is abundant evidence that this has been happening in the UK for decades and that it affects many patients. The tests used by the NHS to aid in the diagnosis of Lyme disease are so poor, that they would be unacceptable in many other serious infections. One [analysis](#) found that the NHS test methods for Lyme produce around 500 times more false-negatives than testing for HIV. [American researchers](#) found that the type of tests used for Lyme disease in the UK, have a sensitivity of only 56%. If true, this would mean that for every 56 positive test results, another 44 patients would get a false-negative result, leaving large numbers of patients without laboratory confirmation of their infection. This serious problem applies to patients who **actually get tested for Lyme**, whereas the vast majority have never even been tested because neither they nor their doctor, knew enough about Lyme disease to realise it was a possibility.

It could be argued that the victims of Tuskegee were deliberately deceived so that their illness could be studied, and this is different to what is happening to M.E. and CFS patients in the UK. But that is looking at the Tuskegee experiment from the **researcher's** point of view. That might be bad enough, but surely it is the perspective of the individual **victims** of the experiment which is most important, and that is shockingly simple.

**The victims were knowingly deceived about their illness with a misdiagnosis and deprived of the treatment they needed for the infection.**

This is precisely what is being done to the thousands of UK Lyme disease patients misdiagnosed with M.E. or CFS. VIRAS know that these patients exist because it actually happened to some of us, and we consider it unacceptable. NICE knows that

these patients exist because several [stakeholder responses](#) to the NICE draft Scope raised the issue of M.E. and CFS actually being misdiagnosed Lyme disease. But they have flatly refused to address the problem, preferring to leave patients misdiagnosed and deprived of treatment. E.g.:

[Lyme Disease UK](#), which has over 8,000 members, stated in their Stakeholder comments to the NICE draft Scope: "Even if the risk of Lyme disease is properly investigated before diagnosing CFS (which does not always appear to be happening based on shared patient experience), weaknesses of current tests mean that some might nevertheless, actually have Lyme disease."

VIRAS remarked in our response to the draft Scope: "VIRAS will argue that those patients [Lyme misdiagnosed as M.E. or CFS], some of whom by now have been infected for decades, deserve proper investigation and a correct diagnosis. Even if some believe that patients with chronic LB [Lyme borreliosis] infections may suffer the same fate as Tertiary Syphilis patients, who can have intractable infection and symptoms, it would be unethical to leave these patients misdiagnosed with CFS."

VIRAS added: "Dr Hugh Derham (2014) in Australia tested 300 of his ME, CFS and FM patients and found that 95% were positive for Lyme. Dr Samuel Shor (2011) in the USA reviewed 210 patients and found that a "potentially substantial proportion of patients with what would otherwise be consistent with internationally case defined CFS [...] actually have a perpetuation of their symptoms driven by a persistent infection by *Borrelia burgdorferi*." Dr. Kenny De Meirleir (2014) in a presentation to the Belgium Senate, observed that 95% of Chronic Fatigue Syndrome and ME (Fukuda & Canadian criteria) were cases of Late Stage Lyme Disease. 95% having had positive *Borrelia burgdorferi* LTT tests."

The Royal College of General Practitioners (RCGP) asked about CFS in their Stakeholder response to the Scope: "There is clearly a link being made between chronic fatigue syndrome and Lyme disease by the support groups for sufferers (sic) of chronic fatigue. Some GPs have seen a few patients who are desperate to pursue a diagnosis of Lyme disease to explain their fatigue symptoms. The RCGP feels that it would be invaluable if this guideline helped to differentiate on clinical grounds those fatigue sufferers who need further investigation and those that we can reassure without recourse to blood tests, investigations and/or referrals."

**To which NICE replied:**

**"Thank you for your comment. This guideline only covers Lyme disease. We acknowledge that the clinical presentations of Lyme disease and chronic fatigue syndrome (CFS) can be very similar and that it can be difficult to make a definitive diagnosis of one or the other." And added: "[CFS] will not be covered by this Lyme disease guideline."**

Stakeholder responses to the draft Scope ensured that NICE were fully aware of the matching symptoms found with chronic Lyme, M.E. and CFS. NICE acknowledge that they understand this, writing: "it can be difficult to make a definitive diagnosis of one or the other". The RCGP asked for help to distinguish between these diagnoses but were told in no uncertain terms, that though NICE recognise the difficulty in making a differential diagnosis, they were not going to do anything about it. It appears that from the outset, it was the intention of NICE to leave Lyme disease patients misdiagnosed with M.E. or CFS exactly where they are - misdiagnosed and with no treatment for their infection.

There might be a non-medical reason for leaving Lyme disease patients misdiagnosed with M.E. or CFS – that is because this wholesale misdiagnosis is actually part of a plan initiated by the Health Protection Agency (HPA, incorporated into PHE in April 2013). This plan determined that patients who did not have positive NHS serology (even though said serology is so insensitive as to be practically useless), and could not provide proof that they had Lyme, should be given a diagnosis of CFS. This was clearly intended to be a one-way-street. Chronic Lyme patients could be 're-diagnosed' as CFS, but patients could not be re-diagnosed the other way around.

In a [document](#) prepared by the Health Protection Agency in 2012, and submitted to the Health and Safety Executive (HSE) from the HPA are the following remarks: (note: Lyme disease testing for England was transferred to 'RIPL', the Rare and Imported Pathogens Laboratory at Porton Down in June 2012. Public Health England (PHE) took over the roles of the Health Protection Agency (HPA) in April 2013.

"As a significant proportion of self-acclaimed Lyme sufferers are self diagnosed, with no objective evidence of infection, it is essential to develop protocols that identify true cases, and refer those with other conditions sympathetically but firmly to appropriate practitioners for their problems." (p.3)

"RIPL and HPA staff will discuss with Simon Wesseley's (sic) group and other interested parties the development of guidance for clinicians on dealing with the disaffected group with unprovable Lyme disease. This will cover the therapeutic approach, investigation of cases and "disengagement" strategies when further investigation is counter-productive." (p.24)

'Simon Wessely's group' has been responsible for psychologising M.E. and CFS for three decades. Their conduct eventually resulted in the useless NICE Guideline ([CG53](#)) for M.E. and CFS as well as the notorious '[PACE Trial](#)' of 'rehabilitation' treatments for the illnesses. In the PACE Trial the 'treatments' [failed](#), but this has not discouraged PHE from pursuing a cheap option for difficult to treat Lyme disease patients, even if it means unethical practice and endangering patient's health. But it is not only patients that will suffer from the anti-science and anti-patient strategies of PHE and NICE. Doctors inveigled into this plan, could become unwitting participants into the abuse of their patients.

Lyme disease patients misdiagnosed with 'CFS', cannot give Informed Consent for treatment with CBT or GET, because the diagnosis of their illness is wrong and therefore so are these treatment prescriptions. If this mistreatment took place in genuine ignorance then it would be an accident. But as PHE and NICE are aware that these mistreatments will inevitably occur, any injuries which result will constitute medical negligence.

Contrary to the assertions of PHE, many of the patients that they plan to 'disengage' from their doctor, actually do have 'objective evidence' of Lyme disease. This evidence comes from top-class laboratories, some of which meet operating standards superior to that of RIPL. Other patients have been clinically diagnosed by highly experienced practicing physicians with years of study and experience of Lyme disease. It is notable that 'no objective evidence' is precisely what PHE have – no objective evidence that these patients do NOT have Lyme disease and they do not even have any means of testing patients that would meet the requirements to show that the infection is absent. Yet without ever seeing or examining them, they still intend to give these patients a remote null-diagnosis and eject them from the healthcare system, by touting 'evidence' when it suits them but ignoring 'evidence' when it does not.

PHE's underhand stratagem to dispose of tens of thousands of patients, has moved a step closer to realisation with the draft NICE guideline. Those familiar with PHE's plans to get rid of chronic Lyme disease patients by 'disengaging' them from their healthcare providers are aware of this. We are also aware that an author of the quoted HSE document is employed by PHE as head of the RIPL testing laboratory at Porton Down and is also a member of the NICE Guideline Development Committee (GDC) for Lyme disease. It is also apparent that for years, PHE/HPA policies have ensured that they have had a virtual monopoly for testing for Lyme disease in England and that that monopoly is protected and enforced within the NICE draft guideline.

The hypocrisy of PHE is glaring. PHE will not recognise patients with chronic Lyme disease because according to them, it is 'unprovable', and the only 'proof' they will accept is NHS serology which is known to be so inefficient that it would be unacceptable for diagnosing most other serious infections. Yet PHE and NICE evidently intend that the re-diagnosis of patients should be a one-way-street, regardless of any evidence, logic or whether or not the patient has been thoroughly examined or tested.

The Lyme disease testing laboratory at RIPL, Porton Down has a monopoly on testing for Lyme disease in England and Wales. This monopoly which PHE/HPA have maintained for Lyme disease testing in England may help to keep the costs of testing down. But this is done at the expense of patients and doctors who are forced into only one choice of test, and a second-rate test at that.

PHE's monopoly also allows them to keep control over the diagnosis of Lyme disease and the number of patients getting treatment. This can be easily manipulated by using tests with low sensitivity (which fail to detect many cases) and by applying inconsistent 'interpretation' of the results.

Another financial motive would be the costs of care and treatment for patients with different diagnoses. Patients with chronic Lyme disease may require long-term and complex treatment which might include intravenous antibiotics which is relatively expensive. However, when these patients are misdiagnosed with 'CFS', they might receive some rehabilitation therapy (CBT or GET) after which medical care is limited to treating individual symptoms (painkillers, sleep medication, etc). Re-diagnosis with 'CFS' has the added bonus for insurance companies that most long-term medical policies for this diagnosis are limited to two years, whereas payments for disability resulting from chronic Lyme disease could continue until retirement.

Another significant cost to the NHS associated with misdiagnosis would relate to medical negligence claims. UK solicitors remark on the 3 main types of misdiagnosis:

1. Failure to diagnose – where a condition is simply missed altogether and so receives no treatment
2. Late diagnosis – this could mean that as well as suffering from your health condition for longer, both your survival chances and recovery time could be affected
3. Incorrect diagnosis – where you are misdiagnosed with the wrong illness, this could lead to the wrong treatment which could be even more harmful.

All three of these apply to patients with Lyme disease, with numbers 2 and 3 being highly relevant to chronic Lyme disease patients misdiagnosed with M.E. or 'CFS'. All medical authorities recognise the importance of early diagnosis and treatment for Lyme disease. Delaying the diagnosis can result in serious and possibly permanent injury and the unchecked infection may be much more difficult to treat. E.g., England rugby player Matt Dawson needed multiple heart operations and 18 months of treatment after a

“very, very long story, but to cut it short I came back positive for Lyme but it had got into my heart and created some scar tissue”.

A misdiagnosis of M.E. or ‘CFS’ could leave Lyme disease patients untreated for years or even decades. This could result in unnecessary physical and mental injury and suffering as well as huge personal costs. Loss of income/career/studies, loss of property and relationships including marriage and other family connections, enforced dependency and loss of independence, all these could occur with misdiagnosis. If delays or misdiagnosis resulted from incompetence then the NHS would be liable for compensation for these costs. Failure to diagnose and misdiagnosis cost the NHS [£185 million](#) in compensation claims in 2014/15. With tens of thousands of Lyme disease patients misdiagnosed with M.E. or CFS, it is not really surprising that neither PHE or the NHS want to recognise these cases and have a compelling motive to just ignore their existence.

Jenna Luché-Thayer, is a human rights expert with 32 years of experience in 42 nations. In an [article](#) titled: ***Human Rights Violations of Relapsing Fever and Lyme Disease Patients Under International Investigation***, Jenna remarks:

“Borreliosis infections are pandemic – these include relapsing fever and Lyme borreliosis. The WHO diagnostic codes do not recognize many of the disabling conditions caused by these infections. Across the globe, medical systems use these codes to diagnose illness and determine treatments. The outdated codes result in very sick people being denied treatment —even when treatment options meet the internationally accepted gold standard for guidelines set by the Institute of Medicine (IOM).” And added:

“Can you imagine health insurance companies telling Lyme patients they will not cover such treatments but [will pay for their euthanasia](#)? According to Dutch researcher Huib Kraaijeveld, this is happening in Europe. These are shameful and predatory actions, and appear to be largely driven by outdated science, outdated codes and skewed financial motivations”.

The UK ***Criminal Justice and Courts Act 2015*** applies to individuals such as doctors, dentists and nurses as well as **corporate** healthcare providers. [Section 21](#) of the Act relates to ***‘ill-treatment or wilful neglect: care provider offence’***.

The 2015 Act makes those providing healthcare, whether directly as an individual, or as part of a ‘body corporate’ or ‘unincorporated association’, which ‘provides or arranges for the provision’ of healthcare, accountable for wilful neglect or ill-treatment of those receiving care. This includes **“a duty owed under the law of negligence”**.

It will be interesting to see whether members of PHE and NICE can be successfully prosecuted under the 2015 Act. Their obvious negligence and ill-treatment of chronic Lyme patients appears to meet all the requirements of the Act, and perhaps worst of all, is actually incorporated into their policies.

In a further disturbing twist, the Health and Social Care Act of 2012, actually names NICE as the ‘authoritative source’ for healthcare information. Therefore it could be argued that NICE are ultimately responsible for any and all harms inflicted on end-users (patients) ***resulting from providers following NICE guidance***. The Act states:

“9. The National Institute for Health and Care Excellence will continue to provide independent advice and guidance to the NHS, and will extend its role to social care. The Information Centre will continue to act as the central, authoritative source of health and social care information.”

**The evidence provided above suggests that the discrimination of PHE and NICE against Lyme disease patients misdiagnosed with M.E. or CFS, is a selective act of ill-treatment and wilful neglect. It will predictably and inevitably prolong the misdiagnosis, deprive patients of an accurate diagnosis and obstruct proper treatment and management of their illness. It will predictably result in these patients being recommended inappropriate and harmful treatments.**

The NICE Guideline for 'CFS/ME' (CG53) published in 2007, specifies only two treatments for these conditions: Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET). These therapies encourage the patient to rationalise that their symptoms are simply the product of deconditioning (lack of exercise) and/or misperceptions (hypochondria). Patients are encouraged to ignore worsening symptoms and to push their physical limits, which they are told will improve their fitness and functioning. The aforementioned PACE Trial proved that both of these treatments are ineffective even for patients with M.E. or CFS. Their effect on patients with Lyme disease have never been evaluated.

In the case of patients misdiagnosed with M.E. or CFS but who actually have Lyme disease, there can be no question but that the serious and potentially fatal infection CANNOT be treated by either of these therapies. Furthermore, both of these treatments are potentially dangerous and could result in mental or physical harm to the patient.

Knowingly allowing patients to be prescribed the wrong treatments because the patient is misdiagnosed risks causing injury through medical negligence. Recommending GET or CBT to undiagnosed Lyme disease patients and telling them that these are 'treatments' which can improve their health is negligent and possibly criminal. [Lyme carditis](#) can cause serious injury to the heart and can even be fatal. [Lyme arthritis](#) is painful and can result in complete destruction of a joint. [Neurological and neuropsychiatric](#) Lyme disease can cause loss of coordination, disorientation, memory loss, vertigo and other balance problems. Persuading patients with these complications to disregard their symptoms by prescribing "[Just get out and exercise](#)" is negligent.

In May 2015 the M.E. Association [reported](#) the findings of its ***ME/CFS Illness Management Survey Results***. Which showed that:

"3:3:2 Effect of Courses on Illness Severity – GET There was significant movement between categories of severity of ME/CFS in GET:

- Before GET courses, 62% of respondents were mild to moderate sufferers and 38% were severe to very severe sufferers
- After GET courses, 41% of respondents were mild to moderate sufferers and 59% were severe to very severe sufferers

"This suggests to us that substantial harm was done to many GET participants."

The survey figures show that following Graded Exercise Therapy, an additional 21% of respondents met the Chief Medical Officer's Working Group [Criteria](#) for 'Severe ME/CFS'. This was in contrast to the reported effect of Pacing therapy, in which 'Severe ME/CFS' was reduced by 6%.

Chronic Lyme disease patients who are misdiagnosed with M.E. or CFS and who are injured as a result of being prescribed these useless and potentially harmful 'treatments', will be entitled to report their doctor to the GMC and to sue the NHS for compensation.

In another comparison between the management of Lyme and the Tuskegee Experiment, Dr Kenneth B. Liegner, M.D. [remarked](#):

“In the fullness of time, the mainstream handling of chronic Lyme disease will be viewed as one of the most shameful episodes in the history of medicine because elements of academic medicine, elements of government and virtually the entire insurance industry have colluded to deny a disease.

“This has resulted in needless suffering of many individuals who deteriorate and sometimes die for lack of timely application of treatment or denial of treatment beyond some arbitrary duration.”

For decades, patients diagnosed with M.E. and CFS have been neglected and discriminated against by UK medical authorities. Now it seems that PHE and NICE intend the same fate for patients with complicated and chronic Lyme disease who they plainly intend should be re-diagnosed with M.E. or CFS. NICE have actualised this unethical intent within the production process of their guideline ng10007, and this appears to be in collaboration with PHE. And so a modern-day abuse of patient rights, disturbingly similar to that imposed on the victims of the Tuskegee Experiment goes on, right here in the UK - and PHE and NICE are part of it.

**VIRAS campaign for better diagnosis and treatment of Lyme disease in the UK.  
Our members have expertise in Science and Research, Management, Psychology,  
Psychotherapy, Teaching, Publicity and Journalism.  
<http://counsellingme.com/VIRAS/VIRAS.html>**