

Freedom of Information Act 2000 (FOIA) Decision notice

Date: 29 March 2016

Public Authority: The Governing Body of Queen Mary University

of London

Address: Queen Mary University of London

Mile End Road

London E1 4NS

Decision (including any steps ordered)

- 1. The complainant requested from Queen Mary University of London ("QMUL") data connected with a published article about chronic fatigue syndrome. QMUL refused the request as vexatious under section 14(1) of FOIA.
- 2. The Commissioner's decision is that QMUL has correctly applied section 14(1) to the request. He does not therefore require it to take any further steps to ensure compliance with the legislation.

Request and response

3. On 29 June 2015 the complainant requested from QMUL the following information under FOIA:

"I am writing to request the fitness data for the PACE Trial (on Chronic Fatigue Syndrome).

That is to say the
(i) mean
and
(ii) standard deviation

for each of the four arms of the trial i.e. (a) CBT (b) GET (c) APT and (d) SMC-alone at (I) baseline



(II) 12 weeks (III) 24 weeks (IV) 52 weeks.

This data was presented in Figure 2 in the following paper that was published earlier this year:

Chalder T, Goldsmith KA, White PD, Sharpe M, Pickles A. Rehabilitative therapies for chronic fatigue syndrome: a secondary mediation analysis of the PACE trial. Lancet Psychiatry 2015; published online Jan 14.

http://dx.doi.org/10.1016/S2215-0366(14)00069-8

However, the figure is too small to extract the exact data."

- 4. QMUL responded on 23 July 2015 and refused to provide the requested information. It cited section 14(1) as its basis for doing so.
- 5. The complainant requested an internal review on 28 July 2015. QMUL sent the outcome of its internal review on 26 August 2015. It upheld its original position.

Scope of the case

- 6. The complainant contacted the Commissioner 22 September 2015 to complain about the way his request for information had been handled, in particular QMUL's application of section 14(1) to his request.
- 7. The Commissioner considered whether QMUL correctly applied section 14(1) to the complainant's request.

Reasons for decision

Section 14 – Vexatious request

- 8. QMUL argued that section 14(1) applied to the complainant's request.
- 9. Section 14(1) provides that:

"Section 1(1) does not oblige a public authority to comply with a request for information if the request is vexatious"

10. The Commissioner has set out below the arguments provided by QMUL in support of its application of section 14(1) to the request and following those the arguments provided by the complainant as to why he did not believe that it applied.



11. As part of its submissions to the Commissioner and in support of its arguments, QMUL provided numerous links to information available on the internet which are not included in this notice.

QMUL's arguments in support of its application of section 14(1)

12. QMUL argued that the complainant's request should be viewed in the context of a campaign of opposition to the PACE trial, its investigators and its findings.

Background

- 13. QMUL informed the Commissioner that since February 2011 it had received a stream of Freedom of Information Act requests (and other correspondence) about the PACE trial, either to its dedicated FOI inbox or to members of staff connected with PACE, which have all been logged. It had considered each of the requests individually on its own merits. In total it had refused 16 requests; supplied information in response to 13 requests and in 7 cases the information had not been held. In one other case some information was supplied where held and the rest refused under s.22. Altogether there had been over 160 individual requests for information within the FOIA requests. These 37 requests covered information such as minutes from the trial management/steering groups, to raw data from the trial, to enquiries about whether and when certain data or results would be published.
- 14. QMUL explained that the PACE trial, of which it was the main sponsor, was a large-scale, randomised clinical trial testing treatments for chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME). CFS/ME is a condition of as yet unknown cause affecting a small percentage of the population and it is a contentious area of both science and medicine.
- 15. The Commissioner was informed by QMUL that the trial had been subjected to extreme and unprecedented scrutiny for a clinical trial and that there existed a community whose members were driven to challenge the outcomes of studies with results which did not comport with their beliefs as to the causes and treatment of CFS/ME.
- 16. QMUL went on to explain to the Commissioner that CFS/ME was a divisive area of research and the PACE trial was no exception. There had been debates in the House of Lords mentioning PACE; there had been complaints to The Lancet, where the main trial results were first published, and to the Medical Research Council (one of the funders of the trial). These had all been dismissed.
- 17. The Commissioner understands from QMUL that the Medical Research Council has also received FOI requests about PACE, one of which was



from a requester who had sent three requests to QMUL and the nature of which - asking for the accounts of a sponsored clinical trial - it had told QMUL was unprecedented. In QMUL's view, this suggested an 'anything and everything' approach to making requests related to PACE.

18. QMUL informed the Commissioner that it started to receive FOI requests in the run up to the publication of the results in The Lancet in March 2011 and that it has never experienced such quantities of requests on any one subject before or since, especially over such a prolonged period of time. It did not appear to QMUL that they would stop any time soon, even though the frequency had slowed.

The Specific Request

- 19. Whilst it recognised that there was a public interest in this research and the PACE trial generally, QMUL explained that it firmly believed that the intent of these requests was not always a true seeking of information, but an attempt to find out information that the requesters believed would discredit the trial and those who undertook it. QMUL informed the Commissioner that, after five years, the PACE team now felt harassed by these requests and believed that they were vexatious. The trial team had made sure that all papers were free for any member of the public to read, which has cost the team, their funders and sponsors some £15,000 in fees to publishers. They had also provided a website giving the latest information about the trial, including 56 frequently asked questions.
- 20. QMUL stated that, in May 2014, it refused a PACE-related request under s.14(1) for the first time. This was upheld at internal review and by the Commissioner in March 2015 under case reference number FS50558352. QMUL relied on that decision in support of its refusal of the current request.
- 21. With regards to the complainant's present request, QMUL acknowledged that information had already been published in graphical form (although this was mean and confidence intervals rather than standard deviation) and that it might not be difficult to produce the requested information. However, it believed that it was the requester and the context of the request which justified its refusal under section14(1). It was of the view that, although the current request was the first since August 2014, if it should start to respond to PACE-related requests again, it could encourage more when it had effectively tried to draw a line. It noted that, a new request had been received on 1 November 2015.
- 22. QMUL stated that there was always a flurry of activity on social media when a Decision Notice or a new research paper was published. Even though the complainant had never submitted an FOI request to QMUL, it



believed that his assumption "my scepticism of the conclusions of the PACE trial, and my wish to analyse the data for myself has played a part here," said a lot about his view of PACE.

- 23. QMUL also noted that the complainant had recently written a parody of a defence of PACE by Sir Simon Wessely and that he is a contributor to the MEAnalysis YouTube channel and websites which are designed to challenge PACE. QMUL took issue with his accusation that its refusal should be regarded as 'vexatious' since it believed that he must be aware of other FOI requests made to QMUL and the responses given. It pointed out that he had contributed to discussions on these and used WhatDoTheyKnow.com himself for the present request.
- 24. It was contended by QMUL that, proportionally, this request was adding to the burden of a long period of requests on this topic from different individuals, it believed largely acting in concert. It noted that Decision Notice FS50546642 (later upheld by the Information Tribunal) recognised the drain on resources this can have for public authorities, even if a single request alone may not be.

1. Motive - Evidence of a campaign

- 25. QMUL informed the Commissioner that there was evidence of a campaign against the PACE trial of which it was the sponsor. Moreover, it could be shown that certain individuals had encouraged correspondence and the making of FOI requests as part of an effort hostile to the trial. It was of the view that there was a belief amongst these individuals that QMUL was trying to withhold information which the requesters imagined might discredit the trial and it believed that there was a campaign to attempt to do this, despite the fact that the results from PACE had been and continued to be published and had been independently verified. Its belief was that certain individuals simply did not accept this.
- 26. It was acknowledged by QMUL that the area of research which the PACE trial concerned was one which elicited strong and opposing views and was seen by some as controversial. However, it believed that there were a number of 'activists' who were vociferous in their opposition and criticism, for example the Phoenix Rising website which had over 2600 posts since May 2010 and the petitions to the government against Professor White.
- 27. QMUL contended that much could be read in to the post from the thread on the Phoenix Rising Forum by one of the Lead Moderators which stated "Let's have some more FOI requests please... I always thought FOI requests were our best weapon and we need to play that card much more strongly in all areas". It argued that the ICO said in its guidance



'Dealing with vexatious requests' that this could be taken in to account as evidence of a campaign.

- 28. QMUL also pointed to a hashtag on Twitter, #PACEtrial, which individuals and even patient organisations used to promote attacks on the trial. It informed the Commissioner that the tweets using this hashtag used language such as "rubbish", "fraudulent", "sleight-of-hand", and "unscientific claims" and that it was not used to promote or support PACE in any way. It believed that hostility would not be too strong a word as it included mocking of QMUL's refusals of requests. It noted that #PACEgate was also used to criticise the trial. QMUL contended that the complainant was a regular contributor to these fora.
- 29. As part of its evidence, QMUL pointed to a series of videos directed by the complainant "illustrating some of the absurdities of the PACE trial and its subsequent series of papers". These were available on the Phoenix Rising website. QMUL noted that the names of the contributors, along with their world views, were all in the public domain.
- 30. The Commissioner was informed by QMUL that there was even an online wiki, which it seemed was solely aimed at complaining about and attempting to demean the PACE trial, and that certain individuals clearly dedicated a lot of time to authoring negative and arguably offensive pieces about researchers and PACE, for example information on the Phoenix Rising website. QMUL believed that whenever anything was published about PACE, and now also about ICO or Information Tribunal decisions relating to PACE, there was a concerted effort by a small number of people to write replies in an attempt it seemed, to dispute all issues and introduce counter arguments. This could be witnessed by comments made on WhatDoTheyKnow.com, on the British Medical Journal rapid responses and on the *Information Rights and Wrongs* blog, among others.
- 31. In light of the above, QMUL explained that most, if not all, of the requests received had, therefore, been deemed part of a campaign. It believed that it was possible to show links between the requesters in many cases, although up to this point it had not been deemed relevant. As it had previously stated, all requests have been treated on a case-by-case basis. QMUL noted that the individuals denied that there was any campaign or activism on their part. It pointed to the fact that the complainant was one of the main authors of the Evaluating PACE web site and linked to a number of other campaigners by that web site and the Phoenix Rising Forum.
- 32. QMUL stated that, as noted in the decision of the Information Tribunal in *John Mitchell Jr. vs. IC and QMUL (EA/2013/0019)*, when results were published in The Lancet, such was the volume of critical letters it



received that it concluded there was an active campaign to discredit the research. Further at para. 27 the Tribunal recognised itself that a campaign existed. QMUL believed that the evidence it had presented supported this.

33. QMUL noted that The Lancet's editors commented that

"one cannot help but wonder whether the sheer anger and coordination of the response to this trial has been born not only from the frustration many feel about a disabling condition, but also from an active campaign to discredit the research".

34. While in response to another paper in 2013, the editor of Psychological Medicine stated,

"unusually for Psychological Medicine, we publish below six letters concerning the paper by White et al. (2013) on the PACE Trial. The UK Office of the Journal received 15 letters criticizing aspects of this paper, but it seemed unlikely that all of these letters originated entirely independently since a number arrived on successive days and reiterated the same points".

35. QMUL explained that its strategic aims were to create and disseminate knowledge and that it believed that its staff had a right to be able to carry out the research on which they decided and their peers review. If staff were required to carry out unplanned analysis on data at the whim of any external party, it took those staff away from their core duties and impacted on the primary purpose of the institution. QMUL did not believe that it was the intention of the legislation for this to occur to such an extent.

2. Burden on QMUL and its staff

- 36. The Commissioner was informed by QMUL that, although the quantity of requests alone could not be said to have been overwhelming, the persistence and the aggregated burden on staff, especially when requests were escalated to the ICO and Information Tribunal, had been of growing concern and has had a detrimental effect on it. It pointed to the fact that in IC v Dransfield ([2012] UKUT 440 (AAC) (28 January 2013)) at para 30 it was acknowledged that, "Volume, alone ... may not be decisive".
- 37. QMUL stated that overall there had been 37 distinct requests to date, plus follow-ups. Due to the subject matter and the nature of the requests, these need to be interpreted and dealt with mainly by one person, the Lead Co-Principal Investigator of the PACE trial, Professor Peter White. QMUL explained that Professor White had many other important responsibilities from which he was taken away by the



continuing flow of information requests and analysis that must be undertaken to evaluate whether or not the information could be released. While he recognised fully that it was his legal obligation to respond, this - in addition to such things as providing responses to Parliamentary Questions from members of both Houses of Parliament on the research - had a serious impact on his time to finalise the publications that remained, oversee the current trial of a self-help treatment for patients with CFS, oversee his other research into the causes of CFS, and all of his other academic duties which included teaching, research into helping patients who had survived cancer, and his clinical responsibilities, which included running a clinic for CFS patients, and overseeing psychiatric assessment and care of hospital patients for other health problems, such as cancer.

38. QMUL informed the Commissioner that Professor White has been personally targeted in the past. Papers which were published were analysed in minute detail, for example on the Phoenix Rising website where one poster comments among other things,

"This part is complete trash, resulting from their insistence in using questionnaires which are grossly inappropriate for patients with physical disability. Apparently not being capable of doing things we used to do, even if we want to do them, means we're depressed. Whoops! Or it just means they're a bunch of idiots. I favor the "idiot" theory - it's much better supported by the available data."

39. QMUL noted that Professor White had stated that:

"These serial requests have caused my colleagues [who are external to QMUL] and me annoyance and frustration, and in my opinion they are clearly part of a campaign to discredit the trial, and are not in the public interest."

- 40. It emphasised that he was the one at QMUL with the knowledge and expertise, meaning he had to bear the brunt of such requests with correspondence that could be lengthy and complex and which took him away from his other work.
- 41. QMUL stated that PACE-related FOI requests also took up a disproportionate amount of the Records & Information Compliance Manager's time. It explained that notwithstanding the requests drawing staff away from other duties and functions, as with many public authorities at this time, resources were stretched with no one else to deal with them. Its Records & Information Compliance Manager dealt with all FOI requests, this being only part of the role, with no other 'team' or help.



- 42. QMUL believed that the history of requests suggested that further requests would follow even if, on the face, any one request standing alone might not be judged vexatious. In some cases requesters had acknowledged that the request they were making had been made previously. It also pointed out that from 1 January 2012 to date, the ICO had contacted it 13 times about FOI-related concerns. All but 3 of these had been about PACE.
- 43. The Commissioner understands from QMUL that previous requests had been generally for data, although there had also been requests for the minutes of the Trial Steering Committee and Trial Management Group. However, it believed that the FOI requests and other complaints to other parties would suggest that these individuals were looking for anything and everything to somehow find fault with the PACE trial and persist with new requests over time despite the publication of papers from the trial and in spite of refusals and Decision Notices. It was in this wider context that QMUL argued that the present request might be seen as vexatious at this point in time and that at least part of the motive was to create a burden to QMUL and in particular Professor White.
- 44. QMUL contended that the ICO's Decision Notice FS50592450 surrounded comparable circumstances where the requester concerned had created an aggregated burden on Wigan Metropolitan Borough Council and did not seem to accept or believe that public authority's explanations. His requests diverted resources from core duties and the disruption was found to be disproportionate.
- 45. It was argued by QMUL that the importance of defending academic freedom in universities, whose raison d'être was to carry out research and advance science, could not be underestimated and that this had been acknowledged in a previous ruling in QMUL's favour at the Information Tribunal. It pointed to paragraph 31 et seg of the judgement from that Tribunal (EA/2013/0019) which recognised in robust terms the necessity of defending academic freedom and the wasting of time created by diversion of resources by such requests. It also noted that it included a reference to Article 13 of the Charter of Fundamental Rights of the European Community and the Education Reform Act 1988. QMUL explained that, overall, considerable time and effort had been expended in dealing with these requests and it looked as though there would be no end to them. It believed that if it supplied some data, a requester might come back for more and that it was not unreasonable that it should seek at this juncture to reduce the burden on it and its staff.



3. Harassment

46. QMUL stated that harassment was in many ways linked to the burden on staff. In this particular case it was possible that the ultimate aim of some of the requesters might be to prevent Professor White from continuing his research by constantly questioning and criticising it, looking for any slight inconsistency and taking him away from his other duties and present clinical trial. It was also the case that the requests were likely to continue given the wider context and history. QMUL noted that a recent comment directed at Professor White and colleagues on the Phoenix Rising website read,

"Our PACE authors have 2 years before their careers are over and they face justice. They will come out fighting I am sure but don't worry, every day is one day closer to the end for these fraudsters. In the meantime we can enjoy turning the screw on them".

- 47. The Commissioner was informed by QMUL that this was but one example. It did not matter that the preceding quote was not about FOIA, it believed that it demonstrated the animosity and the use of any means to put pressure on Professor White and his colleagues.
- 48. QMUL explained that Professor White had previously been harassed by certain individuals who did not agree with his research and, for instance, often received emails asking his opinions or to defend a position, examples of which had been previously provided to the Information Tribunal. As mentioned above, he had also been the subject of petitions to government, at least one of which was set up by one of the FOI requesters to OMUL.
- 49. It informed the Commissioner that it was Professor White's view that, after the time that this correspondence had continued, the requests were having the effect of harassing him personally. Moreover he considered that researchers would be put off from entering or staying in this area of research by such actions and the generally adversarial nature of this area of medicine. QMUL noted that it had supplied the Commissioner previously with an article demonstrating the concerns in this area and that the Guardian Newspaper had also published a similar article.
- 50. QMUL pointed to Decision Notice FS50568116 which found that the online presence of the requester criticising the public authority contributed to the verdict that the request was vexatious. It explained that the latest campaign against PACE could be found at ehttp://www.meaction.net/pace-trial which included another petition, which was entitled 'Misleading PACE claims should be retracted.'



4. Unreasonableness

- 51. QMUL argued that there appeared to be an unwillingness on the part of requesters about PACE to accept refusals of any type, which could be deemed unreasonable or irrational. It believed that the complainant was being disingenuous if he were to claim that he could not understand why a request about PACE would be considered vexatious by QMUL.
- 52. QMUL submitted that, for example, any refusals were usually quickly, sometimes immediately, appealed; one review request included language like 'elaborate excuses', 'preposterous', 'motivated by an attempt to suppress information' and the refusals were discussed with scepticism online on the Phoenix Rising website. It was very rare that a requester actually presented an argument based on a point of law, rather than their own opinions on perceived 'weaknesses' with the trial and the amount it cost.
- 53. QMUL noted that, as of November 2015, nine of the requests related to PACE had been appealed to the ICO, not including this one, and four of these were further considered by the Information Tribunal, in one case following QMUL's instigation. All but one of these cases had resulted in rulings in QMUL's favour, though one was withdrawn at a late stage by the appellant. These appeals had created a tremendous amount of work for QMUL. It also noted that in one decision, the Information Tribunal recognised three important points: firstly the "profound importance" of academic freedom, secondly that these types of requests were essentially vexatious due to their polemical nature and thirdly, that they were part of a campaign. It pointed to paragraph 34 of that decision in which the Tribunal stated:

"All too often such requests are likely to be motivated by a desire not to have information but a desire to divert and improperly undermine the research and publication process – in football terminology – playing the man and not the ball. This is especially true where information is being sought as part of a campaign – it is not sought in an open-minded search for the truth – rather to impose the views and values of the requester on the researcher. This is a subversion of Academic Freedom under the guise of FOIA and the Commissioner, under his Article 13 duty must be robust in protecting the freedom of academics from time-wasting diversions through the use of FOIA".

- 54. And at paragraph 36, "The tribunal has no doubt that properly viewed in its context, this request should have been seen as vexatious."
- 55. QMUL stated that it fully endorsed these views. It explained that following that decision on 22 August 2013, what had been a 3.5 month



hiatus from requests being received, came to an end. It provided the Commissioner with details of a number of actions that it believed appeared to have been triggered by the publication of this ruling. These included comments on the British Medical Journal website and new discussion threads set up on the Phoenix Rising Forum including one specifically about the IT decision which contained comments effectively disparaging the judge. It argued that one only had to look at some of the hostile language on the fora and in comments posted on related websites to see the level of opposition and the apparent disbelief that the decision was correct.

- 56. The Commissioner was informed by QMUL that following Decision Notice FS50558352, the requester wrote a response of more than 3000 words linked from the Whatdotheyknow website in which he was critical of the ICO and, in its view, simply did not appreciate the background to his request at all, supporting QMUL's view of the unreasonableness and obsessiveness of such requesters. The thread from Phoenix Rising resulting from this included the comment, "The Commissioner's entire decision notice is a shockingly unreasonable, defamatory, and partisan response".
- 57. In addition, QMUL explained that, where data had been requested which could potentially be extracted from the raw data held, the requesters often claimed that the information could be supplied by carrying out some simple calculations as though this would take a few minutes to perform. This was not the case and such claims were based on speculation and wishful thinking. It informed the Commissioner that the PACE trial collected significant amounts of medical data and that the processes necessary to produce measures and results were not straightforward but would include the work of a statistician to perform the various programming and data file operations as well as the calculations to produce accurate data and check it. Moreover, as there was no longer a statistician employed by the PACE trial, one would need to be recruited for this operation and trained. QMUL submitted that it was not reasonable that such recruitment or calculations could be done for FOI and certain requests had been refused using section 12 on this basis or stating that the information was not held.
- 58. QMUL also noted that the data collected from the PACE trial was confidential as it was disclosed in a clinician-patient relationship under a clear obligation of confidence. It explained that since a disclosure under FOIA is a disclosure to the world at large, it was not feasible to release swathes of data where individuals might be identifiable. Though it acknowledged that it was the right of any individual to make a request for information (and to appeal), it believed that the inability to accept this premise supported the view that these requesters did not take a reasonable approach to the refusals and were perhaps unrealistic about



the likelihood that information would be released or wanted to depict refusals as evidence that QMUL was trying to conceal different results.

59. QMUL also argued that the length and complexity of certain correspondence indicated a degree of obsessiveness from requesters. If a refusal was received the immediate conclusion drawn seemed to be that QMUL had something the hide.

5. Value and serious purpose

- 60. QMUL informed the Commissioner that the PACE trial demonstrated that certain treatments might have positive effects for some patients suffering from CFS/ME. Ultimately the activists believed that the results from PACE had been 'spun'. They claimed that the data they requested via FOI was necessary to show that either different results were manipulated from the data or because the treatments could be dangerous to certain patients and should be released on those grounds, or simply because they believe QMUL was trying to hide something.
- 61. QMUL acknowledged that all of these requesters no doubt believed that there was a serious purpose to their requests and were it the case that there was indeed some possibility that results had been engineered or that there was some danger posed by the recommended treatments, then QMUL would have to agree. However, it contended that, in reality, from their base of mistrust, it was the requesters who were deciding the value on behalf of the community rather than there being a genuine wide public interest in the release of such information in most cases. Indeed, the arguments about whether release of much of the information requested was in the public interest, rather than the private interests of a few, were also pertinent. OMUL argued that the PACE trial had enhanced rather than threatened public health and there was no overriding public outcry that CFS/ME research or treatments should be subjected to such scrutiny. There was, however, a vocal minority who were likely to never be happy with certain research and look for any chance to smear or otherwise harm it. They did not believe in it and therefore they attacked it, often with obsessional attention to detail and a refusal to accept the integrity of the science.
- 62. QMUL noted that in the *Dransfield* decision it was stated that "the proper application of section 14 cannot side-step the question of the underlying rationale or justification for the request" (para 34). It stated that if required to produce data or perform other unplanned analysis at the whim of any requester when there was no statistician in place, the intended analysis, other research and the wider duties of staff were all impacted. It noted that some requesters had pointed to both the fact that the trial was publicly funded and that there was a general shift towards open data i.e. making research and other data available to all



through data repositories. It also noted that QMUL's own Research Data Management and Access Policy avowed this principle. However, it believed that there was a fundamental difference where research data had been collected from a clinical trial and consisted of personally identifiable information. The PACE trial data consisted of substantial quantities of sensitive personal data. Privacy, consent and participants' reasonable expectations must be taken in to account when considering its use, storage and release. QMUL was of the view that there was no justification to disclose such information where the individuals were likely to be identifiable, even if the present request did not fall in to this category. As such, the aforementioned Policy specifically did not apply to trials involving medical information.

- 63. QMUL explained that it also took in to account that some of the requests had been repeated, on one occasion where the requester stated that the sole purpose for this was so that it could be escalated to the ICO because of "timing issues". Though it accepted that this was a valid reason for resubmitting a request, it believed that the motivation was not to obtain information, but to create more work by appealing to the ICO as he expected it to be refused.
- 64. QMUL advised the Commissioner that it was also not the case that it only refused PACE-related requests under section 14(1). In 2015, it had refused four other requests under this section that had nothing to do with the PACE trial or research.
- 65. QMUL acknowledged that the current request was not necessarily lacking serious purpose. It stated that it had provided explanations and data wherever possible when previous PACE-related requests had been received in the past. As it had indicated above, it was not onerous to supply the data, but it considered that in the end that the refusal was justified at this point in time given the context and history. QMUL submitted that the information itself would not reveal any "truth" that the complainant supposed to either "supporters [or] sceptics". It believed that starting to respond to certain of these requests could encourage more requests and the burden that this had imposed on QMUL had reached a tipping point.

The complainant's arguments

66. The complainant explained that he believed that the issue was quite simple. He was asking for the actual plotted values shown in a small graph in a recently published study. In his view, this was important because, when the PACE trial was being set up, emphasis was placed on the fact that both subjective and objective data would be used to assess the effectiveness of the therapies. Instead, the use of the actometer was dropped, and the results of the 6-minute walking test showed minimal



change: the value of these results were then downplayed on the grounds that the tests had not been conducted appropriately. The complainant informed the Commissioner that the position on health benefits claimed and patients in full or part-time work actually worsened a little over the course of the trial, which was blamed on the financial situation and the fact that patients had been out of work for a while. As objective measures, that only left the results of the step test, which were initially held to be important measures of the deconditioning hypothesis. These have not been included in any analysis of recovery or improvement, but simply as a minor graph in the appendix of a complex, statistical analysis of mediation, where they will have been missed by many. The complainant argued that, as a patient, he believed that he had a right to accurate information about treatments that could affect him, and this data was important.

- 67. The complainant informed the Commissioner about his previous experience as a teacher of mathematics and his history in relation to ME/CFS. He explained that his analysis of previous studies of CBT as a treatment for ME/CFS had led him to believe that the evidence for it was very weak and his analysis of the PACE trial, as far as could be managed, suggested that, with the improvements on subjective assessments being small, the potential for peer pressure influencing the responses was large. He went on to explain that this last set of objective data was an important part of the results for this major study.
- 68. The complainant submitted that the trial was funded by public money, and the desire was to discover the truth. If there was an improvement due to these therapies, then the data would reflect that: it would be difficult to misrepresent such a small set of data. He stated that he had never made any secret of his scepticism of the claims that CBT or GET is effective for ME/CFS, but scepticism was an essential quality of any scientist wanting to get at the truth.
- 69. In response to the arguments presented by QMUL, the complainant commented that, first of all, he was not responsible for the behaviour of others, although it was pretty clear to him that if the PACE authors had released results for the outcomes that they had chosen and published in their protocol, or had tried to come to a negotiated agreement over the release of some of their data, they would not have been subjected to repeat requests, which they have chosen to refuse. He accepted that he was sceptical of many of their claims but argued that this was the duty of any scientist. The complainant asserted that he quality of the analysis presented had been poor, and that he had clearly said so.



70. The complainant stated that:

"When the first paper was published in The Lancet, a group of us got together to pool our expertise to study it. That is no different from there being a group of doctors and researchers pooling their expertise to produce the paper in the first place. It is called teamwork. We tried to engage in a discussion with both The Lancet and Prof. White. In both cases we were ignored. We repeated our attempts to engage in discussion, and again were ignored. The Countess of Mar intervened on our behalf, but still we were ignored. With a record like that, obviously I am critical of PACE's refusal to participate in discussion."

- 71. The complainant informed the Commissioner that it was interesting to note though that there was now an open letter to The Lancet, with 42 signatures from respected researchers and doctors calling on PACE to release its data. There were calls from all the ME charities for PACE to release data. There were concerns expressed by doctors, researchers and medical journalists from around the world. He wondered if that was also to be seen as part of "his" campaign.
- 72. The complainant stated that he had no idea why comments on Twitter had been brought into the discussion as he had never been part of Twitter. He confirmed that all of his online comments were clearly set out under his name. He believed that it was clear that a large number of patients (many of whom had significant scientific and research backgrounds) had grave misgivings about the secrecy around the PACE trial and queries whether he was being held responsible for their actions.
- 73. The Commissioner was informed by the complainant that it was true that, in response to many people asking him, he had produced a number of videos covering both the lack of public funding of biomedical research into the illness, and explaining to a more general audience the nature of the disquiet over the way that the PACE data had been analysed. He contended that it was also true that those specific concerns had yet to be answered.
- 74. The complainant explained that his blog had also tried to explain other matters, including the recent one about an important error in the interpretation of statistical measures from an entirely different 2007 study into ME and prior psychological problems. He pointed out that he was, after all, a maths teacher by profession. He believed that knowledge and information must be shared and communicated in such a way that it was accessible to as many as possible. The complainant stated that he found it strange that, in replying to Sir Simon Wesley's cruise-ship foray into the debate, his contribution was seen as evidence



of being part of a campaign to have the PACE data released, whereas Sir Simon's part was not considered part of a campaign to prevent it.

- 75. The complainant provided an example of an individual that he knew with ME, who attended a health-insurance related interview. He explained that this started with the representative asking why she wasn't on anti-depressants, because "everyone with CFS should be", then went on to assure her that anyone who had done CBT properly would be cured. He argued that it was just as inappropriate to try to tie this in with the attitude of the PACE authors, as it was for them to tie the actions of large numbers of other people to him.
- 76. The complainant informed the Commissioner that he could quote many unpleasant and inappropriate remarks made to patients by doctors about this illness, but that too would be inappropriate. He queried why so many of the arguments from QMUL related to comments and issues that had nothing to do with him. He explained that he had tried to be critical, analytical, and open and had tried hard to adhere to the principles that he had as a teacher, which were to criticize any wrong actions, but not to make personal attacks.
- 77. The complainant submitted that, according to PACE, prior to posting their first paper, the required results showed whether there was any evidence to support their prime hypothesis of deconditioning. He stated that, if the data were to show that CBT or GET was effective, then he would be amongst the first to say so. Much more than that, if he found anything that was truly effective, not only would he publicize it, but he would be first in line to be treated as he did not believe that anyone wanted to continue to be affected by the illness from which he was suffering.

The Commissioner's view

- 78. Section 14(1) does not require a public authority to comply with a request if it is vexatious.
- 79. The term "vexatious" is not defined in FOIA. However, the Upper Tribunal in *The Information Commissioner v Devon CC and Dransfield [2012] UKUT 440(AAC), (28 January 2013)* took the view that the ordinary dictionary definition of the word 'vexatious' is only of limited use, because the question of whether a request is vexatious ultimately depends on the circumstances surrounding that request.
- 80. The Upper Tribunal's decision establishes the concepts of 'proportionality' and 'justification' as central to any consideration of whether a request is vexatious. The Commissioner's guidance on section 14 confirms that the key question to ask when weighing up whether a



- request is vexatious is whether the request is likely to cause a disproportionate or unjustified level of disruption, irritation or distress.
- 81. In its decision, the Upper Tribunal emphasised the need to protect public authorities' resources from unreasonable requests when it defined the purpose of section 14 as follows:

"Section 14...is concerned with the nature of the request and has the effect of disapplying the citizen's right under Section 1(1)...The purpose of Section 14...must be to protect the resources (in the broadest sense of that word) of the public authority from being squandered on disproportionate use of FOIA..." (paragraph 10).

82. QMUL argued that the request should be seen in the context of opposition to the PACE trial and a campaign to discredit its findings. The Commissioner therefore initially considered whether the request should be considered in the context of a campaign in relation to QMUL.

(i) Whether the request was made as part of a campaign

83. As regards the issue of linking requests to campaigns, the Commissioner's guidance on section 14 states that:

"If a public authority has reason to believe that several different requesters are acting in concert as part of a campaign to disrupt the organisation by virtue of the sheer weight of FOIA requests being submitted, then it may take this into account when determining whether any of those requests are vexatious." (paragraph 89)

84. The guidance goes on to state that:

"The authority will need to have sufficient evidence to substantiate any claim of a link between the requests before it can go on to consider whether section 14(1) applies on these grounds." (paragraph 90)

- 85. It is QMUL's position that this request should be viewed in the context of a campaign of opposition to the PACE trial, its investigators and its findings. It explained that the requests concerning the trial have generally been for data, although there have also been requests for minutes from the Trial Steering Committee and Trial Management Group.
- 86. QMUL has argued that correspondence and the submitting of FOI requests has been encouraged as part of an effort which is hostile to the trial. It has submitted that these requests, coupled with PACE related



correspondence to other parties, including the Lancet and the British Medical Journal (the "BMJ"), demonstrate that the individuals involved are looking for any way to discredit the trial.

- 87. It has identified, as already mentioned, one particular forum, the Phoenix Rising Forum, as actively promoting the use of requests under FOIA as a means of opposing the PACE trial and its outcomes. Furthermore, QMUL has explained that there is even a hashtag on Twitter #PACEtrial which individuals use to promote attacks on the trial in critical and hostile language.
- 88. QMUL has also argued that The Lancet's editors have noted there appears to be an active campaign to discredit the research and that the editor of the Journal Psychological Medicine also considered that a series of 15 letters it had received concerning the trial appeared to be related.
- 89. The Commissioner also notes that in 2013, in the appeal proceedings considering an earlier request for information related to the PACE trial (EA/2013/0019), the Information Tribunal in that case (the "2013 Tribunal") noted that the request was:

"part of a campaign which has now extended to the use of FOIA as a means of advancing an argument which in essence has roots in clinical medicine and in a black and white view of the mind/body problem. There is a view among some members of the CFS/ME community that the distressing disorder which they suffer from has a simple and straightforward physical cause which if properly researched will lead to a cure. They view any diversion from that as wasteful and indeed duplicitous."

- 90. QMUL has argued that the complainant's request should be seen as part of the campaign which is opposed to the PACE trial. The Commissioner has considered the evidence submitted by QMUL and is satisfied that a number of requesters do appear to be linked by their activity on Twitter, the Phoenix Rising Forum and their posts on various websites including the Whatdotheyknow website. He is satisfied that QMUL has provided sufficient evidence to demonstrate the existence of a campaign of opposition to the trial and that the complainant is part of that campaign.
- 91. The Commissioner accepts that the complainant has genuine reasons for wanting to obtain the information that he requested in order to carry out his own analysis of it, with a view to highlighting what he perceives to be weaknesses in the work that has been done. In addition, the Commissioner notes that the complainant has stated his scepticism as to some of the results from the PACE trial and also as to the motives of the team involved in the trial.



- 92. In his submission to the Commissioner, the complainant explained that he had been working with others after the first paper was published in the Lancet in order to engage in discussion with the Lancet and Professor White about the PACE trial. He also acknowledged that he had made information available on the internet, including the Phoenix Rising Forum, which highlighted what he believed to be concerns about PACE trial.
- 93. In light of the above, the Commissioner considers that QMUL was entitled to consider the complainant's request in the context of the other requests that it had received as part of a campaign in opposition to the PACE trial. Consequently, it was justified in assessing this request in the context of those other requests in determining whether it was vexatious.

(ii) Whether the request was vexatious

94. The Commissioner's guidance on section 14(1) indicates that the key question that a public authority should consider is whether the request is likely to cause a disproportionate or unjustified level of disruption, irritation or distress. Where this is not clear, the Commissioner considers that public authorities should weigh the impact on the authority and balance this against the purpose and value of the request.

Burden of the requests and disruption to QMUL

- 95. QMUL has acknowledged that although the quantity of requests that it had received on its own could not be described as overwhelming, the persistent and aggregated burden on staff had caused growing concern and had a detrimental impact. Given the very specific nature of the subject matter, it informed the Commissioner that the requests needed to be handled mainly by one person, Professor White, the lead Co-Principal Investigator of the trial.
- 96. QMUL explained that responding to requests had taken Professor White away from other important responsibilities. They had also taken up a disproportionate amount of the Records and Information Compliance Manager's time. QMUL explained that this represented a further burden, especially when the history of requests suggested that they would continue.
- 97. The Commissioner accepts that, as QMUL has acknowledged, responding to this particular request on its own would not necessarily impose a significant burden. However, he is satisfied that the aggregated burden of all of the requests that QMUL has received that are linked to the campaign in opposition to the PACE trial has had a detrimental impact upon it.



98. The Commissioner is also of the view that had QMUL responded to the complainant through the Whatdotheyknow website and provided the information requested, given the public nature of the website, it is likely that this would have led to further requests, not necessarily from the complainant, but from others involved in the campaign.

Disproportionate irritation and distress

- 99. QMUL explained that Professor White had made it clear that after five years, the requests that had been received were causing annoyance and frustration to both his colleagues and himself, as the people who had to deal with them. QMUL advised that the effect of these requests had been that those involved in the PACE trial, and in particular Professor White, felt harassed and believed that the requests were vexatious in nature.
- 100. The Commissioner is also aware that the 2013 Tribunal stated that:

"There has been a storm of comments about this study. There had been deeply wounding personal criticisms of individuals concerned and over the years individuals in this field of research and treatment have withdrawn from research in the face of hostile irrational criticism and threats".

- 101. The Commissioner notes this case took place approximately three years ago, yet the requests and criticism have continued. It is apparent to him that the pressure of continuing requests placed upon QMUL would undoubtedly cause ongoing irritation and distress.
- 102. With respect to this case, QMUL is of the view that there is a belief amongst those involved in the opposition campaign that the PACE data itself might discredit the trial and that this is the reason that QMUL is trying to withhold it. However, QMUL has explained that the results of the PACE trial have been (and continue to be) published and that these results have been independently verified. It therefore considers that this counters any argument that it is trying to withhold information which, if disclosed, might discredit the trial. Furthermore, in terms of the papers relating to the trial, QMUL has explained that the PACE team has made sure that all papers are available free to the public.
- 103.In such circumstances the Commissioner considers the ongoing opposition to the trial and repeated requests for data would undoubtedly cause disproportionate irritation and distress to Professor White and his colleagues.



Purpose and value of the requests

- 104.QMUL is of the view that the requests made as part of the campaign do not represent a true seeking of information in the public interest, but are an attempt to find out information which it is believed will discredit the trial and those involved.
- 105. As noted above, the Information Tribunal in 2013 acknowledged that the request in that case was part of a campaign and it went on to say it had no doubt that, properly viewed in context, the request should have been seen as vexatious and did not constitute a true request for information. The Commissioner considers that the same argument applies to the request in this case.
- 106.QMUL has explained that its strategic aims are to create and disseminate knowledge and that staff have a right to be able to carry out the research they decide upon, which is reviewed by their peers. Handling requests for information takes staff away from their core duties and impacts on the primary purpose of the institution. Furthermore, the Commissioner is satisfied that QMUL has in place appropriate processes for review and dissemination of information relating to the PACE trial.
- 107. Whilst the Commissioner accepts that the PACE trial and its results are of significant interest to the ME/CFS community, he also accepts the argument that there is a campaign focussed on attacking and attempting to discredit the trial rather than on obtaining useful information about this topic.
- 108. The Commissioner therefore accepts the argument that this request has been submitted as part of an opposition campaign which refuses to accept the integrity of the science behind the PACE trial. He therefore considers the nature of this campaign has an effect on the purpose and value of the request.

Conclusion

- 109. In considering the background to this case, the Commissioner accepts QMUL's arguments that the request, combined with other requests made as part of the campaign against the PACE trial, has had the effect of harassing the public authority and its staff. He considers that the judgement of the Information Tribunal from 2013 has particular relevance to this case.
- 110.In its consideration, the Tribunal placed significant weight on the profound importance of academic freedom, particularly in the area of scientific research. It went on to state that the Commissioner has a duty to give effect to Article 13 of The Charter of Fundamental Rights of the



European Community [European Union] in his decisions and guidance.

- 111. The Tribunal commented further that the primary purpose of universities is the dissemination and generation of knowledge through teaching and research. It went on to question the value of a parallel process of dissemination through FOIA.
- 112. The Tribunal was of the view that all too often such requests are likely to be motivated by a desire to divert and improperly undermine the research and publication process. It observed that this was particularly true when information was being sought as part of a campaign.
- 113. The Tribunal also observed that the Commissioner must, in accordance with his Article 13 duty,

"be robust in protecting the freedom of academics from timewasting diversions through the use of FOIA".

- 114.In terms of academic freedom, the Commissioner notes that Professor White has sought to publish a lot of information about the trial. Irrespective of this he has been put in a position of handling FOIA requests about his research. There is no question that the number of FOIA requests indicates an attempt to discredit the trial. This in turn undermines the ability of Professor White and his colleagues to retain that academic freedom.
- 115.In reaching his conclusion, the Commissioner would note that he is aware that this is a particularly contentious and controversial area of research. He has no doubt that the PACE trial is of significant interest within the ME/CFS community.
- 116. Although the complainant has argued the request has a serious purpose and value, the Commissioner finds that in all the circumstances, the request, when combined with other requests made as part of the campaign, has caused a disproportionate amount of distress, irritation and disruption to QMUL. He is also satisfied that the request has been submitted as part of a campaign to discredit the trial and therefore considers that this undermines the possible motivation and purpose behind the request. Finally, he has concluded that responding to the requests made as part of this campaign has placed an unreasonable burden on QMUL and, in particular, Professor White.
- 117. The Commissioner therefore considers QMUL is correct to apply section 14(1) to this request.



Right of appeal

118. Either party has the right to appeal against this decision notice to the First-tier Tribunal (Information Rights). Information about the appeals process may be obtained from:

First-tier Tribunal (Information Rights) GRC & GRP Tribunals, PO Box 9300, LEICESTER, LE1 8DJ

Tel: 0300 1234504 Fax: 0870 739 5836

Email: GRC@hmcts.gsi.gov.uk

Website: www.justice.gov.uk/tribunals/general-regulatory-

chamber

- 119. If you wish to appeal against a decision notice, you can obtain information on how to appeal along with the relevant forms from the Information Tribunal website.
- 120. Any Notice of Appeal should be served on the Tribunal within 28 (calendar) days of the date on which this decision notice is sent.

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