

## Freedom of Information Act 2000 (FOIA)

### Decision notice

**Date:** 9 March 2016

**Public Authority:** Queen Mary University of London

**Address:** Mile End Road  
London  
E1 4NS

#### Decision (including any steps ordered)

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1. The complainant has requested information related to a clinical trial concerning treatments for chronic fatigue syndrome carried out by Queen Mary University of London ("QMUL"). QMUL has refused the request as vexatious under section 14(1) of the FOIA.
2. The Commissioner's decision is that QMUL has correctly applied section 14(1) to this request. There are no further steps to be taken.

#### Request and response

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3. On 1 November 2015, the complainant wrote to QMUL and requested the following information:

*'I would like to request, for each of the 4 treatment arms of the PACE trial, the 6 min walking test data*

- a) before treatment and*
- b) (where available) at follow-up (52 weeks)*

*I appreciate that my previous request was denied due to it being deemed to require the creation of new data. This request has been carefully chosen to avoid that problem, consisting of a request to supply a list of numbers for each of the 4 treatment arms of the trial.'*

4. On 27 November 2015 QMUL responded to this request. It applied section 14(1) of the FOIA as it considered the request to be vexatious.
5. The complainant requested an internal review on the same date. She explained that it was not her intention to submit a vexatious request and argued that in response to a previous request, QMUL had confirmed that it holds a list of numbers for each of the 4 treatment arms of the trial.
6. On 1 December 2015 QMUL informed the complainant that it would not be conducting an internal review of this matter as it had recently carried out an internal review on similar lines and did not wish to conduct another.

### **Scope of the case**

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7. The complainant contacted the Commissioner on 11 December 2015 to complain about the way her request for information had been handled. She does not consider that QMUL is correct to refuse her request as vexatious.
8. The Commissioner considers to scope of this case to be concerned with QMUL's application of section 14(1) of the FOIA to this request.

### **Background**

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9. The PACE (Pacing, graded Activity and Cognitive behaviour therapy: a randomised Evaluation) trial was a clinical trial carried out by QMUL which commenced in 2002. It was a large scale trial to test and compare the effectiveness of four of the main treatments available for people suffering from chronic fatigue syndrome ("CFS"), also known as myalgic encephalomyelitis ("ME").
10. Results from the PACE trial were published in The Lancet in March 2011. QMUL's website (<http://www.pacetrials.org/>) provides further information and details about the trial.
11. The Commissioner notes that the PACE trial has resulted in some public debate, with some organisations and individuals being opposed to the treatment methods used. QMUL has described CFS/ME as a contentious area of "both science and medicine" and acknowledges that the research into this area is divisive. It has explained that the PACE trial has been subjected to extreme and unprecedented scrutiny for a clinical trial.

12. Since February 2011, QMUL has received 39 requests for information about the trial. These requests have asked for over 160 pieces of information. QMUL has explained that it has never experienced such quantities of requests on any one subject previously or since and cannot see an end to these requests.
13. QMUL has explained that up to the end of December 2015, it has refused 16 requests in whole, supplied information in response to 13 requests and in 7 cases the information has not been held.
14. In May 2014 QMUL refused a PACE-related request under section 14 for the first time. This was considered by the Commissioner in a decision notice for case reference FS50558352 and the request was found to be vexatious. Many of the arguments submitted in that case are repeated in this decision notice, as although the complainant in that case was a different individual, the issues are the same.

### **Background to this complainant's request**

15. On 28 March 2013 the complainant made a request for information concerning the 6 minute walking test (as reported in the original PACE paper), asking for mean and standard deviation results. QMUL responded that the information was not held.
16. On 3 September 2013 the complainant made a similar request for information concerning the trial (follow-up data for the 6 minute walking test including mean test times and standard deviations). QMUL initially applied section 14(2) of the FOIA as it considered the request was a repeat of the earlier one. However, following the Commissioner's intervention, QMUL again confirmed it did not hold the requested information and the case was closed (case reference FS50533053).
17. In its internal review for this case, QMUL explained that the requested data does not exist and that it would require significant analysis in order to produce.
18. QMUL explained that although it did hold the raw data from the PACE trial from which it might be possible to derive the information, no such analysis has been undertaken. It was therefore being asked to create new information that it did not hold when the request was made.
19. On 30 May 2014, the complainant again requested information concerning the 6 minute walking test results, both before treatment and at follow-up, and broken down into treatment type.
20. QMUL refused this request as vexatious and applied section 14(1) of the FOIA. However during the course of the Commissioner's investigation QMUL confirmed that it did not hold the requested information.

21. In that case, the Commissioner found that QMUL holds the 'building blocks' to generate the requested information but that the action required to produce it would equate to creating new information in order to respond to the request. The Commissioner noted that public authorities are not required by the FOIA to create information.
22. QMUL confirmed to the Commissioner that although it holds all the raw data from the PACE trial, the requested information itself was not held as raw data. The Commissioner therefore found that the information was not held (case reference FS50557646).
23. The complainant is now asking for the raw data from this 6 minute walking test.

### Reasons for decision

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24. Section 14(1) of the FOIA says that a public authority does not have to comply with a request for information if the request is vexatious.
25. The Commissioner's guidance<sup>1</sup>, published in May 2013, refers to an Upper Tribunal decision that establishes the concepts of 'proportionality' and 'justification' as central to any consideration of whether a request is vexatious.
26. The guidance suggests that the key question the public authority must ask itself is whether the request is likely to cause 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.
27. Where relevant, public authorities also need to take into account wider factors such as the background and history of the request. QMUL has argued the request should be viewed in the context of opposition to the PACE trial and a campaign to discredit its findings. The Commissioner considers that these factors are of particular significance in this case and has therefore considered the request in the context of this campaign and other FOIA requests received by QMUL.

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<sup>1</sup> <https://ico.org.uk/media/for-organisations/documents/1198/dealing-with-vexatious-requests.pdf>

28. He has considered factors such as the overall burden of the total requests received, the continued disruption to QMUL which the requests impose, the distress and irritation caused by the requests and the question of their purpose and value.

**Context to the request: campaign of opposition to the PACE trial**

29. 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. 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.
30. QMUL has asserted that correspondence and the submitting of FOI requests have been encouraged as part of an effort which is hostile to the trial. QMUL 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.
31. It has explained that one particular forum (the Phoenix Rising Forum) actively promotes the use of FOIA stating:  
  
*"Let's have some more FOI requests please...I always thought FOI requests were our best weapon and we need to play that card more strongly in all areas."*
32. Furthermore, QMUL has argued that one only has to have a token browse of the complainant's Twitter feed to see her opposition to PACE and promotion of this. It has also explained that there is even a hashtag on Twitter *#PACEtrial* which individuals use to promote attacks on the trial in critical and hostile language.
33. QMUL has identified a number of 'activists' who are vociferous in the opposition to and criticism of the PACE trial. It has demonstrated that there are links between this particular identifiable group of requesters who are responsible for two-thirds of all PACE-related freedom of information requests. This includes the complainant.
34. Although QMUL has explained it treats every request on a case by case basis, it considers that the spacing of the requests it receives seem likely to have been coordinated in such a way as to prevent aggregation.

It has also noticed that once the Information Tribunal has ruled against an individual, that person will no longer make requests, but others do.

35. QMUL has also argued that The Lancet's editors<sup>2</sup> have noted there appears to be an active campaign to discredit the research and that the editor of the Journal Psychological Medicine<sup>3</sup> also considered that a series of 15 letters it had received concerning the trial appeared to be related.
36. The individuals all deny there is any campaign or activism on their part. For example, the complainant has explained she was unaware of the status of a case concerning a request from another individual (which includes a request for the same data she requires) until she noticed it on the Whatdotheyknow website. This was after she had submitted her current request.
37. However QMUL has argued it is inconceivable that the complainant did not know of the status of this other request as it was immediately adjacent to hers on the Whatdotheyknow website. It considers this current request to be part of a new strategy to request discrete data piecemeal thereby avoiding cost limits and potential personal data refusals.
38. The Commissioner has considered the evidence submitted by QMUL and is satisfied that the 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.
39. 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.*

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<sup>2</sup> [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60696-X/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60696-X/fulltext) (accessed 01/12/15)

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<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8955884&fulltextType=LT&fileId=S0033291713001256> (accessed 02/12/15)

*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."*

40. The Commissioner considers the 2013 Tribunal finding also applies to this request and he is satisfied that QMUL has provided sufficient evidence to demonstrate the existence of a campaign of opposition to the trial.

### **Burden of the requests and disruption to QMUL**

41. QMUL has acknowledged that although the quantity of requests alone (39) could not be described as overwhelming, the persistent and aggregated burden on staff has caused growing concern and has had a detrimental impact.
42. Given the very specific nature of the subject matter, QMUL has explained that the requests need to be handled mainly by one person, Professor Peter White who is the lead Co-Principal Investigator of the trial.
43. Whilst Professor White acknowledges the legal responsibility he has to respond to requests, QMUL has argued these take him away from other important responsibilities. These include: providing responses to Parliamentary Questions from both Houses; finalising the publications which remain; oversight of the current trial of a self-help treatment for patients suffering from CFS/ME; oversight of his research into the causes of this condition; and undertaking all of his other academic and clinical duties.
44. In addition to Professor White's input, the requests take up a disproportionate amount of the Records & Information Compliance Manager's time. Handling FOI requests is only part of the role, and with already stretched resources, QMUL has explained that this represents a further burden especially when the history of requests suggest that these will continue.
45. Although responding to the current request on its own would not necessarily impose a burden on QMUL, the Commissioner nevertheless accepts that the aggregated burden of all the requests has had a detrimental impact upon the public authority.



## **Disproportionate irritation and distress**

46. Professor White has made it clear that after five years, the requests are causing annoyance and frustration both to his colleagues and himself who have to deal with the requests.
47. QMUL has advised that the effect of these requests has been that the team involved in the PACE trial, and in particular the professor involved, now feel harassed and believe that the requests are vexatious in nature.
48. The Commissioner also notes 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”.*
49. The Commissioner notes this was approximately three years ago yet the requests and criticism have not stopped. It is apparent that the pressure of continuing requests placed upon QMUL will undoubtedly cause ongoing irritation and distress.
50. With respect to this case, QMUL has argued there is a belief amongst those involved in the opposition campaign that the PACE data itself might discredit the trial and therefore that QMUL is trying to withhold it.
51. 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 this invalidates any argument that QMUL is trying to withhold information which, if disclosed, might discredit the trial.
52. Furthermore, in terms of the papers relating to the trial, QMUL has asserted that the PACE team has made sure that all papers are available free to the public. This is something that has cost the team, its funders and sponsors in the region of £15,000 in fees to publishers.
53. The team has also established a website to provide the latest trial information. The website includes 56 frequently asked questions.
54. 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**

55. QMUL has explained that the professor involved in the trial firmly believes the requests 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.
56. As explained above, the 2013 Tribunal 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 current request in this case.
57. 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 and 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.
58. Furthermore, the Commissioner is content that QMUL has in place processes for review and dissemination of the information relating to the PACE trial and that Professor White has put in place mechanisms to ensure that as much information as possible is in the public domain.
59. The complainant has argued she is not trying to be vexatious and that this is a genuine attempt to find a way to get a better understanding of the 6 minute walking test data in a way that is acceptable to QMUL. She has explained that she has a genuine interest in this data, as both a scientist and as a patient.
60. She has acknowledged that her previous request was considered to require the creation of new data and she explained that this new request was carefully defined 'in the hope that it would be not be too time-consuming or onerous' for QMUL to fulfil.
61. The Commissioner accepts that the PACE trial and its results are of significant interest to the ME/CFS community. However 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.
62. The Commissioner therefore accepts the argument that this request has been submitted as part of a hostile campaign which refuses to accept the integrity of the science behind the PACE trial. He therefore considers the nature of this campaign brings into question the purpose and value of the request.

## Conclusion

63. In considering the background to this case, the Commissioner accepts QMUL's arguments that the request has had the effect of harassing the public authority. Viewed in the context of the other requests received, online posts and complaints to the Lancet and BMJ, the Commissioner accepts that QMUL is correct to view the request as part of a campaign.
64. In reaching his conclusion, the Commissioner has also considered the 2013 Tribunal judgement. He considers that this has considerable relevance to this case.
65. 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.
66. 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.
67. The Tribunal argued 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.
68. The Tribunal also observed that the Commissioner must, in accordance with his Article 13 duty,  
  
*"be robust in protecting the freedom of academics from time-wasting diversions through the use of FOIA".*
69. In terms of academic freedom the Commissioner notes that Professor White has sought to publish as much information as possible regarding 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.
70. 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.

71. Although the complainant has argued the request has a serious purpose and value, the Commissioner finds that in all the circumstances, the request has caused a disproportionate amount of distress, irritation and disruption to the public authority. He is satisfied that the request has been submitted as part of a campaign to discredit the trial and therefore considers that this undermines any other possible motivation and purpose behind the request.
72. The Commissioner therefore considers QMUL is correct to apply section 14(1) to this request.

## Right of Appeal

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73. 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](mailto:GRC@hmcts.gsi.gov.uk)

Website: [www.justice.gov.uk/tribunals/general-regulatory-chamber](http://www.justice.gov.uk/tribunals/general-regulatory-chamber)

74. 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.

75. Any Notice of Appeal should be served on the Tribunal within 28 (calendar) days of the date on which this decision notice is sent.

Signed .....

**Rachael Cragg**  
**Group Manager**  
**Information Commissioner's Office**  
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