

Freedom of Information Act 2000 (FOIA)

Decision notice

Date: 12 July 2018

Public Authority: Queen Mary University London
Address: Mile End Road
London
E1 4NS

Decision (including any steps ordered)

1. The complainant has requested information relating to Queen Mary University London's (QMUL) role as an employer with regard to harassment of researchers. The Commissioner's decision is that QMUL has correctly applied section 14(1) (vexatious request) to the requested information. The Commissioner does not require the public authority to take any steps as a result of this decision notice.

Request and response

2. On 7 November 2017, the complainant wrote to QMUL and requested information in the following terms:

"These questions relate to the university's role as an employer and its responsibilities under Health and Safety legislation.

These requests refer to harassment of researchers working in the field of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) only. Please do not include any incidents other than those specifically related to work on ME/CFS.

The requests are only for incidents involving harassment from outside parties. Please do not include any possible internal staff disputes.

Please provide the following:

1. *The number of incidents of harassment recorded by the university in*

the period 2000-2017 (inclusive). Please give the total number and the number of incidents per year.

2. The number of occasions when the police were involved in cases of harassment at the university in the period 2000-2017 (inclusive). Please give the total number and the number for each year.

3. The number of occasions when the police issued a crime reference number for cases of harassment at the university in the period 2000-2017 (inclusive). Please give the total number and the number of incidents per year.

4. The number of assessments carried out by the university about the risks to staff welfare posed by such harassment in the period of 2000-2017. Please give the total number and the number for each year. Please do not include routine assessments or any general assessments, but give only the number conducted specifically as a result of incidents of ME/CFS-related harassment.

These requests concern FOI requests received by Queen Mary University of London (QMUL) regarding work related to myalgic encephalomyelitis/chronic fatigue syndrome only, from 2000 onwards (including 2000 and the current year, 2017).

Please provide the following, giving the total number and the number each year, where appropriate:

1. The number of requests received by QMUL. Where a communication makes multiple requests, please give the number of communications and the number of requests.

2. The number of requests refused by QMUL as deemed vexatious.

3. The number of requests rejected by QMUL as deemed otherwise exempt.

4. The number of requests where information was provided.

5. Please also give in each of the four instances (total numbers; numbers deemed vexatious; numbers deemed otherwise exempt; numbers where information was provided), the numbers of requests relating to the PACE trial (Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial).

I am happy to receive this information in electronic format."

3. QMUL responded on 5 December 2017 and refused to provide the requested information. It cited section 14(1) as its basis for doing so.
4. Following an internal review QMUL maintained that section 14(1) was applicable in this case.

Scope of the case

5. The complainant contacted the Commissioner on 26 January 2018 to complain about the way his request for information had been handled.
6. The Commissioner considers the scope of this case to be to determine if QMUL has correctly applied section 14(1) of the FOIA to the request.

Background

7. The university was the main sponsor of the PACE trial. It was funded by the Medical Research Council, the Department of Health, the Department of Work and Pensions and the Scottish Chief Scientist's Office. The trial compared how effective different treatments for chronic fatigue syndrome were. It involved over 600 patients who were split into four groups, each group received different treatments for the condition.
8. The initial planning for the trial commenced in 2002 after which patients were recruited between 2005 and 2010. Following peer review the findings were published in the Lancet in March 2011. The trial found that cognitive behaviour therapy and graded exercise therapy were more effective treatments for chronic fatigue syndrome than either specialist medical care or pacing therapy.
9. The causes, and therefore the treatment, of chronic fatigue syndrome is a contentious area of science. The Commissioner understands that there are those who believe it has a physical cause and therefore should be treated as such, while another school of thought approaches its treatment from a psychiatric perspective. The two treatments found by the trial to be most effective were psychiatric therapies. Some patients and patient groups maintain that by ignoring the physical cause of the condition, these two therapies can result in patients suffering adverse effects. The rigour of the methodology employed in the trial and its results were therefore challenged, the validity of those challenges is debated as is the extent to which trial's findings are generally accepted within the scientific and medical community. It is fair to say however that the trial attracted some controversy.

Reasons for decision

Section 14(1) – vexatious requests

10. Section 14(1) of the FOIA states that a public authority is not obliged to respond to a request for information if the request is vexatious.
11. The term 'vexatious' is not defined in the FOIA. The Commissioner has identified a number of 'indicators' which may be useful in identifying vexatious requests. These are set out in her published guidance on vexatious requests. In short they include:
 - Abusive or aggressive language
 - Burden on the authority
 - Personal grudges
 - Unreasonable persistence
 - Unfounded accusations
 - Intransigence
 - Frequent or overlapping requests
 - Deliberate intention to cause annoyance
12. The fact that a request contains one or more of these indicators will not necessarily mean that it must be vexatious. All the circumstances of a case will need to be considered in reaching a judgement as to whether a request is vexatious.
13. The Commissioner's guidance suggests that if a request is not patently vexatious the key question the public authority must ask itself is whether the request is likely to cause a disproportionate or unjustified level of disruption, irritation or distress. In doing this the Commissioner considers that a public authority should weigh the impact of the request on it and balance this against the purpose and value of the request.
14. Where relevant, public authorities may also need to take into account wider factors such as the background and history of the request.

The complainant's position

15. The complainant referred to a previous decision notice¹ (FS50687719) and has argued that QMUL continues to use the allegations of harassment and that they played a role in the ICO's decision. The Commissioner found that partly because of these allegations it was 'not unreasonable for the qualified person to consider the risk of a hostile response'. Furthermore, although the Commissioner found the minutes should be released, she did consider these allegations as part of her weighing up of the public interest.
16. He further argued, that this 'opened the door' to his request to know the extent of the harassment at QMUL. QMUL has made this issue one of public interest and cannot now prevent proper scrutiny.
17. The complainant further pointed out that QMUL only provided two examples; an article in *The BMJ* of 2011 and a reference to a discussion on a patient forum a few years ago. In *Matthees*, it was agreed no threats have been made either to researchers or to participants. The only example given of activist behaviour was that an individual at a seminar had heckled Professor Chalder.
18. The complainant referred to the Commissioner's statement about the patient forum discussion: 'although anyone unaccustomed to facing a disgruntled audience is likely to find some of the comments unpleasant, the dissatisfaction is not expressed in such strong terms that it would cause those against who it is directed at any real concern'.
19. The Commissioner notes here that the forum referred to was an online forum.
20. The complainant also argued that the report in *The BMJ* was a second-hand account of what was told to the journalist. There have been no reports ever of anyone having been charged, cautioned or arrested for offences related to ME. As far is known, no one has ever faced any official sanction of any kind for this alleged harassment.
21. He maintained that nothing untoward has happened after the release of data ordered by the FTT in *Matthees* or since the Trial Steering Committee (TSC) or the Trial Management (TMG) minutes were made available. The complainant considers that the more QMUL predicts such

¹ <https://ico.org.uk/media/action-weve-taken/decision-notice/2018/2258289/fs50687719.pdf>

behaviour and it does not happen, the more the suspicion grows that it is unreasonable to treat information relating to ME/CFS any different from any other kind. The complainant believes his request would shed light on this question.

QMUL's position

22. QMUL believes that this request should be viewed in the context of a campaign of opposition to the PACE trial, its investigators and its findings. Some of the evidence below has been presented to the Commissioner previously, in relation to previous cases.
23. This request only specifically mentions the PACE trial at point 5 of the second part. However, given the identity of the requester and his other requests and since the request is all about research in to chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), it is inextricably linked to the stream of FOI requests (and other correspondence) about the PACE trial received since February 2011.
24. These have either come to the dedicated FOI inbox or to members of staff connected with PACE, which have all been logged. QMUL stated it had considered each of the requests individually on its own merits. Up to the end of April 2018, in total, it has refused 28 requests in whole; supplied information in response to 20 requests and in 10 cases the information has not been held.
25. One request was withdrawn and in three other cases some information was supplied where held and the rest refused. (Altogether QMUL estimates there have been over 200 individual requests for information within the FOIA requests).
26. It provided the Commissioner with an appendix of these requests, which have covered information such as minutes from the TMG/TSC groups, to raw data from the trial, to enquiries about whether and when certain data or results will be published, etc.
27. QMUL explained that PACE was the largest clinical trial concerning CFS/ME to date and the Co-Principal Investigator, who was employed by QMUL but is now retired, was Professor Peter White. Professor White had spent much of his career treating and researching this condition. This request is mainly targeted at him as there has not been much other work or very many colleagues working in this field at QMUL.
28. Furthermore, QMUL stated the ICO has now issued 14 Decision Notices out of 19 involving QMUL; a further one is pending:
 - i. 26/09/2012 - FS50451416* (deterioration rates for each therapy group).

- ii. 09/01/2013 - FS50463661* (minutes from Trial Steering Committee, Trial Management Group and Data Monitoring and Ethics committee)
- iii. 09/01/2013 - FS50458231 (as above)
- iv. 01/08/2013 - FS50484575 (all trial raw data before analysis)
- v. 23/01/2014 - FS50514995 (primary outcome measure scores for SF-36 and CFQ)
- vi. 17/03/2015 - FS50557646 (6-minute walking test data)
- vii. 18/03/2015 - FS50558352 (dates and confirmation or denial of various factors in trial)
- viii. 28/10/2015 - FS50565190* (11 scores of individual trial participants)
- ix. 09/03/2016 - FS50609018 (6-minute walking test data)
- x. 29/03/2016 - FS50600710 (mean and standard deviation fitness data)
- xi. 01/02/2018 - FS50673373 (patient-level data, various scores at baseline, 24 and 52 weeks)
- xii. 20/02/2018 - FS50687719 (minutes from TSC and TMG)
- xiii. 14/03/2018 - FS50696884 (conflict of interest statements)
- xiv. 23/05/2018 - FS50721768 (objective measures raw data of individual trial participants)

29. In addition, the Information Tribunal has subsequently issued three decisions; two further appeals FS50484575 and FS50557646 were also withdrawn by the requester/appellant):

ICO decision notice	Tribunal ref	Outcome
FS50451416	EA/2012/0229	Allowed
FS50463661	EA/2013/0019	Dismissed
FS50565190	EA/2015/0269	Dismissed
FS50673373	EA/2018/0034	Pending

30. QMUL went on to explain that the PACE trial, of which QMUL was the main sponsor, was a large-scale, randomised clinical trial testing treatments for CFS/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. The trial has been subjected to extreme and unprecedented scrutiny for a clinical trial. Unfortunately, there exists a community whose members are driven to challenge the outcomes of studies with results, which do not comport with their beliefs as to the causes and treatment of CFS/ME. This single trial has generated a disproportionate amount of work for QMUL, over a long period.
31. QMUL stated CFS/ME is a divisive area of research and the PACE trial is no exception. There have been debates in the House of Lords mentioning PACE; there have 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 have all been dismissed. The Medical Research Council has also received FOI requests about PACE, one of which was from a requester who has sent three requests to QMUL, and the nature of which, it has told QMUL is unprecedented. This would suggest an 'anything and everything' approach to making requests related to PACE. FOI requests to QMUL started in the run up to the publication of the results in The Lancet in March 2011. QMUL has never experienced such quantities of requests on any one subject before or since, especially over such a prolonged period of time and it does not seem likely that they will stop any time soon even though the frequency has slowed.
32. QMUL further explained that the trial generated a lot of clinical data and this and other information have been repeatedly requested under FOI, refusals of which have been upheld by the Commissioner in decision notices when appealed. Some individuals are unwilling to accept the trial's findings. This is despite the release of peer-reviewed papers and the results having been independently verified by other trials and by a re-analysis by a Cochrane Collaboration research centre.
33. Furthermore, it is important to note that the PACE trial is not controversial among the majority of scientists in the field or indeed experts in clinical trials. The findings of the trial were consistent with and reinforced the pre-existing NICE guidance (the body that recommends treatment for use in the NHS for the treatment of CFS) and supported, rather than changed, the existing evidence for these. It is NICE, not the trial authors, that makes recommendations for treatment.
34. The results from PACE have been published in a number of journal articles. The research found that cognitive behaviour therapy (CBT) and

graded exercise therapy (GET) were better than specialist medical care and pacing therapy as treatments for CFS.

35. QMUL recognised that there is a public interest in this research and the PACE trial generally, it believes that the intent of these requests is not always a true seeking of information, but an attempt to find out information that these requesters believe will discredit the trial and those who did it.
36. After seven years, the PACE team and QMUL feel harassed by these requests and believe some of them are vexatious. The trial team have made sure that all papers are 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 have also provided a website with information about the trial, including 56 frequently asked questions.
37. In May 2014 QMUL refused a PACE-related request under section 14(1) for the first time. This was upheld at internal review and by the Commissioner in March 2015. Subsequently, the Commissioner has upheld two further refusals under section 14(1) in FS50600710 and FS50609018. QMUL is relying on these decisions in support of its refusal of the current request.

The current request

38. With regards to the present request, QMUL believe that it is motivated by a desire to smear the researchers; an effort to dig for information to use to attack or discredit them.
39. However, it is the requester and the context of the request that it believes justifies its refusal under section 14(1). Proportionally, this request is adding to the burden of a long period of requests on this topic from different individuals, it believes largely acting in concert. 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.

Evidence of a campaign

40. QMUL consider that there is an explicit campaign to discredit the trial and its authors by individuals who are unwilling to accept the results and believe these have been 'spun'. Moreover, it can be shown that certain individuals have encouraged correspondence and the making of FOI requests as part of an effort hostile to the trial. QMUL further considers that there is a belief amongst these individuals that QMUL is trying to withhold information which the requesters imagine might discredit the trial and it is QMUL's belief that there is a campaign to attempt to do this. This is despite the fact that the results from PACE have been and

continue to be published and have been independently verified. Certain individuals simply do not accept this.

41. The area of research that the PACE trial concerns is one that elicits strong and opposing views and is seen by some as controversial. There are a number of 'activists' who are vociferous in their opposition and criticism, see for example <https://forums.phoenixrising.me/index.php?threads/pace-trial-and-pace-trial-protocol.3928/> which has had over 3000 posts since May 2010 and the petitions to the government against Professor White.

42. QMUL stated that much can be read in to this post from the above thread on the Phoenix Rising Forum by one of the Lead Moderators:

"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".

The ICO says in its guidance² that this can be taken in to account as evidence of any campaign. There are even two hashtags on Twitter, #PACEtrial and #PACEgate, which individuals and even patient organisations use to promote attacks on the trial. The tweets using these hashtags use language such as "rubbish", "fraudulent", "sleight-of-hand", "travesty" and "unscientific claims". They are not used to promote or support PACE in any way. Hostility would not be too strong a word as it includes mocking of QMUL's refusals of requests.

43. Five FOI requesters have all been regular contributors to these fora. Dr Sheridan has also posted to Phoenix Rising. QMUL also referred to other individuals who had made complaints or been critical of PACE and also a separately advocated campaign in Twitter comments. These individuals have written to, or made comments on, the British Medical Journal's website, as well as others, on correspondence related to PACE. One has directed a series of videos "illustrating some of the absurdities of the PACE trial and its subsequent series of papers", and one maintains a blog which is critical of the type of CFS/ME research that PACE tested and also posts to the forum Science for ME. These names, along with their views, are all in the public domain.

44. QMUL further stated that there is an online wiki, which it seems is solely aimed at complaining about and attempting to demean the PACE trial,

² <https://ico.org.uk/media/for-organisations/documents/1198/dealing-with-vexatious-requests.pdf>

and certain individuals clearly dedicate a lot of time to authoring negative and arguably offensive pieces about researchers, PACE and generally approaches to CFS/ME with which they do not agree see for example <http://forums.phoenixrising.me/index.php?threads/uk-bristol-talk-on-april-2-by-peter-white-lessons-from-the-pace-trial.29345/> and <https://forums.phoenixrising.me/index.php?threads/psychiatric-theory-in-practice-liverpool-cf-cfs-clinic-patient-handout.3066/>.

45. QMUL explained that whenever anything was published about PACE, and 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 seems, to dispute all issues and introduce counter arguments. This can be witnessed by comments made on WhatDoTheyKnow.com (WDTK), on the British Medical Journal rapid responses and on the Information Rights and Wrongs blog, among others. On WDTK many of the annotations are not related to the request or FOI process but unrelated comments about ME/CFS or 'flawed' research.
46. QMUL stated that most, if not all, of the requests received by it have, therefore, been deemed part of a campaign: it is possible to show links between the requesters in many cases, although up to this point it has not been deemed relevant. As previously stated, all requests have been treated on a case-by-case basis. The individuals deny that there is any campaign or activism on their part even though there are often references to "our case" or similar.
47. QMUL then provided the Commissioner with details of the individuals it believes are linked. It stated that these individuals are responsible for well over half of all PACE-related FOI requests.
48. QMUL also argued that the spacing of the requests seems likely to have been co-ordinated in such a way as to prevent their aggregation so that they may be refused on that basis. It also stated that once a Tribunal has ruled against them, that individual no longer makes requests, but others do. QMUL does not believe this is a coincidence. Nevertheless, up to now they have been treated on a case-by-case basis and QMUL has disclosed information in response wherever possible. In other cases exemptions have been used where it was felt appropriate. Where it has refused a vexatious request and these have been appealed, the Commissioner has agreed.
49. QMUL stated that as noted in the Decision of the Information Tribunal of 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 paragraph 27 the Tribunal recognised itself that a campaign exists. QMUL believe that the evidence presented herewith

supports this. It also believes that the complainant is demonstrably part of this.

50. QMUL stated that the Lancet's editors made this comment, *"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"*. 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"*.
51. Within a few days of each other in February 2016 QMUL said that a number of letters were received from different patient organisations. Even though these made no reference to each other, they had identical subject lines and were copied to the Principal's office. This clearly shows that the campaign is co-ordinated.
52. As mentioned above, recently, the complainant has posted information he has received from the DWP online. This is clearly done to allow others to scour the material; one of the responses in this thread is a suggestion of names that have been redacted in one of the documents released.
53. QMUL believe that the evidence it has presented in the past, which the Commissioner has even detailed, for example in decision notice FS50600710, is still valid and relevant.

Burden on the public authority

54. QMUL stated that although the quantity of requests alone cannot be said to have been overwhelming, the persistence and the aggregated burden on staff, especially when requests are escalated to the ICO and Information Tribunal, has been of growing concern and has had a detrimental effect on QMUL as expanded below. In Dransfield it was acknowledged that, *"Volume, alone ... may not be decisive"*. The complainant has made eight FOI requests to QMUL to date.
55. Due to the subject matter and the nature of the requests, these need to be interpreted and dealt with by individuals familiar with the trial. Professor Peter White was the Lead Co-Principal Investigator, however, he retired from QMUL on 31 December 2016. As such, when requests have been received since then, QMUL has to contact the other Principal Investigators who are based at the University of Oxford and King's College London (Professors Sharpe and Chalder). Papers which are

published are analysed in minute detail, for example at <http://forums.phoenixrising.me/index.php?threads/adverse-events-and-deterioration-reported-by-participants-in-the-pace-trial-of-therapies-for-cfs.29882/> (accessed 11/06/18) 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 favour the "idiot" theory - it's much better supported by the available data."* Where this leads to more requests, the burden grows further.

56. In order to deal with this particular request, for the first section QMUL stated it would have to contact:
- the Chief Operating Officer of the School of Medicine and Dentistry,
 - the Institute Manager and possibly other colleagues of the Institute where Professor White worked
 - Human Resources
 - Security
 - Health and Safety
 - The Co-Principal Investigators at KCL and Oxford
57. For the second section about FOI requests, QMUL had some data from logs. However, in order to determine the 'number of communications and the number of requests...where a communication makes multiple requests' it would be very time-consuming. This is because each request would need to be consulted individually. Therefore, this is not a straightforward request to complete.
58. QMUL further stated that PACE-related FOI requests take up a disproportionate amount of time. Notwithstanding the requests drawing staff away from other duties and functions, as with many public authorities at this time, resources are stretched. There is only one individual that deals with all FOI requests, this being only part of the role. There is no other 'team' or help. In addition GDPR compliance work has taken up a huge amount of time in the last 12 months or more. The history of requests suggests that further requests will follow even if, on the face, any one request standing alone may not be judged vexatious. In some cases requesters have acknowledged that the request they are making has been made previously. Decision notice FS50557646 was escalated to the Information Tribunal only for the appeal to be later withdrawn. However, this was after QMUL had spent a tremendous

amount of time responding. The threads on Phoenix Rising discussing this includes "What a horrible man Peter White is" and "Queen Mary's [sic] must be a pretty shite university, if no one working there knows how to easily retrieve data from a spreadsheet or similar" .

59. Professor White stated in the past: "These serial requests have caused my colleagues [who are mostly 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." When he was still at QMUL, he was the one who had to bear the brunt of such requests as the only person with the knowledge and expertise, which took him away from his other work. Now it is more complicated.
60. Many requests to QMUL have been for data, although there have been requests also for the minutes of the Trial Steering Committee and Trial Management Group. However, the FOI requests and other complaints to other parties would suggest that these individuals are looking for anything and everything to somehow find fault with the PACE trial and similar research, and persist with new requests over time despite the publication of papers from the trial and in spite of refusals and decision notices. It is in this wider context that QMUL argues that the present request may be seen as vexatious at this point in time and that at least part of the motive may be to create a burden to QMUL.
61. Decision notice FS50592450 surrounds 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.

Harassment

62. Harassment is in many ways linked to the burden on staff. In this particular case, QMUL argued in the past to the Commissioner that it was possible that the ultimate aim of some of the requesters may have been 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. Now that he has retired, QMUL still believe that requests are made at least partly for the purpose of attempting to discredit him and his collaborators.

"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"

is an example of the type of comments aimed at them, though there are many others.

63. QMUL argued that although the preceding quote is not about FOIA, it demonstrates the animosity and the use of any means to put pressure on colleagues who conduct this type of research. It would actually seem that these people want this type of research to be stopped.
64. QMUL also stated that the Co-Principal Investigators have all previously experienced degrees of harassment by certain individuals who do not agree with such research. This questions their academic freedom, which is protected in law and by the institutions they work for. For example, Professor Chalder believes that pages such as this [http://media.org/wiki/Trudie Chalder](http://media.org/wiki/Trudie_Chalder) are an attempt to smear her. The complainant has used information previously released to him to harass Professor Sharpe on Twitter. Professor White would often receive emails asking him opinions or to defend a position, examples of which have been previously provided to the Information Tribunal. As mentioned above, he has also been the subject of petitions to government, at least one of which was set up by one of the FOI requesters to QMUL. He expressed the view that, after such time as this correspondence has continued, the requests had the effect of harassing him personally. Moreover he considers that researchers will 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. We have supplied the Commissioner previously with an article demonstrating the concerns in this area. The Guardian has also published a similar article.
65. QMUL also referred 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. Another campaign against PACE can be found at <http://www.meaction.net/pace-trial/> which includes another petition.
66. QMUL also stated that the complainant made what the Co-Principal Investigators have described as potentially libellous remarks in previous correspondence with it, as well.

Unreasonableness

67. QMUL argued that there appears to be an unwillingness to accept refusals of any type, which could be deemed unreasonable or irrational.
68. For example, any refusals are usually quickly, sometimes immediately, appealed; one review request included language like 'elaborate excuses', 'preposterous', 'motivated by an attempt to suppress information' and the refusals (and even responses where information is supplied) are

discussed with scepticism online. It is very rare that a requester actually presents an argument based on a point of law, rather than their own opinions on perceived 'weaknesses' with the trial and the amount it cost.

69. QMUL have outlined above the number of PACE-related requests that have been appealed to the ICO and Information Tribunal over the years. All but three of these cases have resulted in rulings in QMUL's favour, though one was withdrawn at a late stage by the appellant. These appeals have created a tremendous amount of work for QMUL. 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 these are part of a campaign. From paragraph 34 of that decision:

"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".

And at para. 36, *"The tribunal has no doubt that properly viewed in its context, this request should have been seen as vexatious."*

70. QMUL fully endorses these views. Following that decision made on 22 August 2013, what had been a 3.5 month hiatus from requests being received, came to an end. A number of actions appear to have been triggered by the publication of this ruling.
- On 26 August 2013 one requester requested an internal review on the last possible day, which we do not imagine was a coincidence. [In line with best practice, all responses to FOI requests from QMUL include a paragraph about the applicant's right to request an internal review and/or complain to the ICO if s/he is dissatisfied with the response. They are advised that contact must be made within 40 working days to set out what aspect of the response they find unsatisfactory.]
 - On 24 August 2013 a new discussion thread was set up on the Phoenix Rising Forum specifically about the IT decision. This includes comments effectively disparaging the judge. One only has 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.

- On 2 September 2013 another new discussion thread was set up on the Phoenix Rising Forum re-opening a request QMUL had refused in April 2013. This includes the accusation that QMUL has “played a disingenuous game to say the least”. Through Twitter, where comments included “a misleading reply from QMUL”, the requester was encouraged to re-submit the request, which she did on 3 September 2013 and QMUL subsequently refused under section 14(2). The reaction, behaviour and opinion of opponents of the trial can be seen from comments on online fora and social network sites.
 - There have been a number of comment pieces, such as on the respected Information Rights and Wrongs blog and by the British Medical Journal. On 24 August and 28 August comments were made on the Information Rights and Wrongs website, again criticising the decision and comments on the BMJ website are all from those opposed to PACE.
71. This demonstrates that there is a collective action being waged by sections of the CFS/ME community against QMUL – through FOI and also through wider channels – and its decisions about what should be released, with the requesters unwilling to accept that a refusal has been legitimately applied and keen to keep the pressure on QMUL by, for example, repeating requests or asking for similar data. Of course, the requesters would deny that any community exists or that there is anything ‘extremist’ about the behaviour.
72. QMUL further stated that following decision notice FS50558352, the requester wrote a 3000+ word response linked from https://www.whatdotheyknow.com/request/timing_of_changes_to_pace_trial#comment-59096 in which he is critical of the ICO and simply does 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 includes the comment, *“The Commissioner’s entire decision notice is a shockingly unreasonable, defamatory, and partisan response”*.
73. In addition, where data has been requested which could potentially be extracted from the raw data held, the requesters often claim that the information could be supplied by carrying out some simple calculations as though this would take a few minutes to perform. This is not the case and such claims are based on speculation and wishful thinking. The PACE trial collected significant amounts of medical data. This includes actigraphy recordings in binary format and a great deal of numerical, textual and audio information in databases, spreadsheets and on CDs,

some held in proprietary formats. The processes necessary to produce measures and results are not straightforward which anyone can do 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 is no longer a statistician employed by the PACE trial, one would need to be recruited for this operation and trained. It is not reasonable that such recruitment or calculations can be done for FOI and certain requests have been refused using section 12 on this basis or stating that the information is not held.

74. QMUL also stated that the data collected from the PACE trial is also confidential, having the necessary quality of confidence in that it meets the traditional tests described in *Coco v Clarke* [1969] RPC 41, 47, Megarry J. It was disclosed in a clinician-patient relationship under a clear obligation of confidence. The trial consent forms certify this. The Commissioner has endorsed this on at least one occasion. Moreover, QMUL is complying with the Medical Research Council's policies on access to data and data sharing. Where patient data is concerned there have to be strict guidelines in place about to whom it is released and under what conditions. Since FOI is a disclosure to the world at large, it is not feasible to release swathes of data where individuals may be identifiable. Though it is of course the right of any individual to make a request for information (and to appeal), the inability to accept this premise supports the view that these requesters do not take a reasonable approach to the refusals and are perhaps unrealistic about the likelihood that information will be released or want to depict refusals as evidence that QMUL is trying to conceal different results.
75. The length and complexity of certain correspondence would also indicate a degree of obsessiveness from requesters. Some examples 2017-18 can be seen on the WDTK website. If a refusal is received the immediate conclusion drawn seems to be that QMUL has something to hide or even that it may be lying.
76. As stated above, QMUL believe that this request should be assessed within the context of a campaign, the opposition generally to CFS/ME research of a certain kind, and a motivation to extract more information that can be used in some way to attack QMUL and/or certain researchers. It is not necessarily a straightforward request to fulfil either, due to its multiple parts and the need for input from a number of different departments. All of these points indicate that the request would be likely to have an unjustified and disproportionate effect on QMUL and could lead to distress of certain individuals.

77. QMUL wished to make it clear to the Commissioner that it is also not the case that it only refuses PACE-related requests under section 14(1). In 2016 and 2017 it refused six requests (including this one) under this Section, four of which had nothing to do with the PACE trial or research. The other (PACE) one can be seen here: https://www.whatdotheyknow.com/request/fraudulent_action_by_qmul#outgoing-607535 , which appears to use a pseudonym. A recent decision notice can be seen here: <https://ico.org.uk/media/action-weve-taken/decision-notices/2018/2258216/fs50705869.pdf> as well.

The Commissioner's decision

78. As in many cases which give rise to the question of whether a request is vexatious, the evidence in the present case shows a history of previous and subsequent information requests. Clearly in this case, QMUL considers that the context and history strengthens its argument that the request is vexatious.
79. The purpose of section 14 of the FOIA is to protect public authorities and their employees in their everyday business. In her guidance, the Commissioner recognises that dealing with unreasonable requests can place a strain on public authorities' resources and get in the way of delivering mainstream services or answering legitimate requests. Furthermore, these requests can also damage the reputation of the legislation itself.
80. It is the Commissioner's view that the key issue in this case is the burden imposed by the request on QMUL and whether the effort required to meet the request will be so grossly oppressive in terms of the strain on time and resources, that the authority cannot reasonably be expected to comply, no matter how legitimate the subject matter or valid the intentions of the requester.
81. The Commissioner also accepts that there have been a large number of requests which collectively have the PACE trial as the main focus. From the information provided to the Commissioner, it does not appear that QMUL has informed the complainant that it considers he is acting in concert with the others. However, it is clear to the Commissioner that this is the case. The Commissioner accepts that the cumulative impact of these requests has placed a significant burden on the public authority. Despite this QMUL has responded to the majority of them up until recently.
82. The Commissioner notes QMUL's arguments that Professor White has now retired, and this adds to the burden of complying with the request.

83. Although the latest request is not patently vexatious when taken in isolation the Commissioner acknowledges that any response is likely to result in further requests being made. However the request has to be seen in the context of both the other requests made by the complainant himself and those of the other applicants identified by QMUL. The Commissioner accepts that the cumulative impact of these requests has placed a significant burden on the public authority.
84. As referred to earlier, QMUL has devoted a significant amount of time dealing with the requests made relating to the PACE trial. The Commissioner is satisfied that there would clearly be an impact on QMUL's ability to manage requests from other applicants and disrupt the work of those in the policy and business areas responsible for the issues which the requests relate to.
85. The Commissioner has carefully considered both the QMUL's arguments and the complainant's position regarding the information request in this case. She has also carefully reviewed all the information and evidence presented to her by both parties and finds that this request is part of a campaign that has placed a significant burden on QMUL, to the extent that it can be deemed to be vexatious. She considers, that on this occasion, in all the circumstances of this case, QMUL is entitled to rely on section 14(1).

Right of appeal

86. 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

87. 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.
88. 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

Pamela Clements
Group Manager
Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF