Freedom of Information Act 2000 (FOIA)

Decision notice

Date: 7 November 2018

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

Decision (including any steps ordered)

1. The complainant has requested information associated with the PACE trial. Queen Mary University of London (QMUL) has categorised the request as vexatious under section 14(1) of the FOIA and has refused to comply with it.

2. The Commissioner's decision is as follows:

   - The request is vexatious under section 14(1) of the FOIA.

3. The Commissioner does not require QMUL to take any steps to ensure compliance with the legislation.

Request and response

4. On 26 March 2018 the complainant wrote to QMUL and requested information in the following terms:

   "These requests concern 'Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial'.

1. Please provide minutes of the analysis strategy group.

2. Please provide minutes of the writing and publication oversight committee.

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

5. QMUL responded on 25 April 2018. It categorised the request as vexatious under section 14(1) of the FOIA and refused to comply with it.

6. QMUL provided a review on 9 May 2018. It maintained its position.

Scope of the case

7. The complainant contacted the Commissioner on 23 May 2018 to complain about the way his request for information had been handled.

8. The Commissioner's investigation has focussed on whether the complainant's request is vexatious under section 14(1) of the FOIA.

Background

9. QMUL was the main sponsor of the PACE trial *('Pacing, graded Activity, and Cognitive behaviour therapy; a randomised Evaluation'*). It was funded by the Medical Research Council (MRC), 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.

10. 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.

11. 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 – vexatious and repeat requests

12. Section 14(1) of the FOIA says that a public authority is not obliged to comply with a request for information if the request is vexatious.

13. The term 'vexatious' is not defined in the FOIA but the Commissioner has identified a number of 'indicators' which may be useful in identifying vexatious requests. These are set out in her published guidance and, in short, they include:

- Abusive or aggressive language
- Burden on the authority – the guidance allows for public authorities to claim redaction as part of the burden
- Personal grudges
- Unreasonable persistence
- Unfounded accusations
- Intransigence
- Frequent or overlapping requests
- Deliberate intention to cause annoyance

14. 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.

15. The Commissioner's guidance goes on to suggest 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.

16. Where relevant, public authorities also need to take into account wider factors such as the background and history of the request.

17. In its submission, QMUL has first told the Commissioner that it considers that this request should be viewed in the context of a campaign of

opposition to the PACE trial, its investigators and its findings. QMUL has referred to the Commissioner's decision in FS50722835[1]. That case from July 2018 also concerned the complainant, QMUL, a request for information associated with the PACE trial and an application of section 14(1). In FS50722835, the Commissioner found that the complainant's request could be categorised as vexatious.

18. QMUL has confirmed that since February 2011 it has received a stream of Freedom of Information Act requests (and other correspondence) about this trial. These have either come to the dedicated FOI inbox or to members of staff connected with PACE. All the correspondence has been logged. QMUL says it has considered each of the requests individually on its own merits. Up to the end of September 2018, in total, it has refused 28 requests in their entirety; supplied information in response to 21 requests and in 10 cases the information has not been held. 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).

19. QMUL has provided the Commissioner with a list of these requests. They cover information such as minutes from the trial management/steering groups, raw data from the trial and enquiries about whether and when certain data or results will be published. QMUL has left in the names of requesters where the requester was the complainant or WhatDoTheyKnow.com was used, or where the requester appealed to the Commissioner or where the request is otherwise in the public domain.

20. QMUL says that PACE was the largest clinical trial concerning chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME) to date and the Co-Principal Investigator, who was employed by QMUL but is now retired, was Professor Peter White. Prof White had spent much of his career treating and researching this condition.

21. QMUL has noted that of the 21 decision notices involving QMUL that the Commissioner has served since 2012, to date 16 concern the PACE trial. The First Tier Tribunal (Information Rights) (FTT) has subsequently

[1] https://ico.org.uk/media/action-weve-taken/decision-notices/2018/2259446/fs50722835.pdf

issued three appeal decisions. Two further appeals, both concerning the complainant, are currently live FTT cases.

22. QMUL has acknowledged that CFS/ME is a divisive area of research and that the PACE trial is no exception. It notes that 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 MRC. These have all been dismissed.

23. The MRC has, QMUL says, also received FOI requests about PACE, one of which was from a separate requester who has sent three requests to QMUL. The MRC has told QMUL that the nature of these requests – which ask for the accounts of a sponsored clinical trial - is unprecedented. In QMUL's view, this would suggest an 'anything and everything' approach to making requests related to PACE. It says FOI requests to QMUL started in the run up to the publication of the results in The Lancet in March 2011. QMUL says it has never experienced such quantities of requests on any one subject before or since, especially over such a prolonged period of time and, in its view, it does not seem likely that they will stop any time soon even though the frequency has slowed. According to QMUL, the MRC continues to receive requests and complaints to this day.

24. QMUL has confirmed to the Commissioner that the trial generated a lot of clinical data and this and other information has been repeatedly requested under FOI. Refusals have been upheld by the Commissioner in decision notices when appealed. QMUL says 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.

25. QMUL says 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. It says 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 recommendation for treatment.

26. The results from PACE have been published in a number of journal articles. The research found that cognitive behaviour therapy and graded exercise therapy were better than specialist medical care and pacing therapy as treatments for CFS.

27. QMUL's submission has gone on to discuss the specific request in this case. QML says it recognises that there is a public interest in this

research and the PACE trial generally, but that it firmly believes that the intent of the complainant's requests is not always a true seeking of information, but an attempt to find out information that these requesters, including the complainant, believe will discredit the trial and those who did it. After seven years, QMUL says that it and the PACE team feel harassed by the requests and believe some of them are vexatious. It has noted that the trial team has 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. The trial team has also provided a website with information about the trial, including 50+ frequently asked questions.

28. QMUL says that the current request is linked to another, also from the complainant, which the Commissioner considered in FS50687719 in February 2018. On that occasion, the Commissioner determined that some of the information should be released but she provided comments in the notice and in a confidential annex to that, about what information could be redacted/withheld. QMUL says that reviewing and redacting the sets of minutes requested took a number of days in March 2018 before the information was ready for release. It says that the complainant uploaded this information to the 'cloud' service Dropbox and then posted links on both a 'Phoenix Rising' forum and a 'Science for ME' forum. QMUL sent the complainant the information on Friday 23 March. The present request was received on Monday 26 March.

29. According to QMUL, to locate and extract the requested information in the present case is not straightforward. Moreover, it believes that to review and redact these minutes along the same lines as the Trial Steering Committee and Trial Management Group minutes (requested in FS50687719), would also be extremely time-consuming. Since redaction cannot be taken into account when assessing the provision under section 12 of the FOIA (cost exceeds the appropriate limit), QMUL acknowledges that that option is not available.

30. QMUL considers that it is the requester and the context of the request that justifies its refusal under section 14(1). Proportionally, this request, which is burdensome on its own, is, says QMUL, adding to the burden of a long period of requests on the same topic from different individuals, QMUL believes largely acting in concert. It has referred to the Commissioner's decision in FS50546642 (later upheld by the FTT), which recognised the drain on resources this can have for public authorities, even if a single request alone may not be.

Motive – evidence of a campaign

31. In QMUL's view there is an explicit campaign to discredit the PACE trial and its authors by individuals who are unwilling to accept the results and

believe the results have been 'spun'. QMUL says that, 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. It 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. QMUL says that certain individuals simply do not accept this.

32. The area of research that the PACE trial concerns is, QMUL says, one that elicits strong and opposing views and, as has been discussed, it is seen by some as controversial. There are a number of 'activists' who are vociferous in their opposition and criticism. QMUL has provided as an example:

https://forums.phoenixrising.me/index.php?threads/pace-trial-and-pace-trial-protocol.3928/

(accessed 29/10/18) which has had over 3000 posts since May 2010, and the petitions to the government against Prof White. QMUL says that much can be read into 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*". QMUL has referred to the Commissioner's guidance on dealing with vexatious requests. This says that such material can be taken in to account as evidence of a campaign. QMUL has noted that 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". QMUL says they are not used to promote or support PACE in any way and that 'hostility' would not be too strong a word as it includes the mocking of QMUL's refusals of requests.

33. QMUL has advised the Commissioner that a number of FOI requesters, including the complainant, have all been regular contributors to these fora, and/or have written to related bodies – such as the MRC – or written critical pieces about PACE. These individuals have also written to, or made comments on, the British Medical Journal's website. One of the individuals has directed a series of videos "*illustrating some of the absurdities of the PACE trial and its subsequent series of papers*". The complainant 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'. QMUL says that these individuals' names, along with their world views, are all in the public domain.

34. QMUL has noted an online wiki, which appears to be solely aimed at complaining about, and attempting to demean, the PACE trial. It has noted that 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. QMUL has provided as examples:

    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/

    (both accessed 29/10/18).

35. According to QMUL, whenever anything was published about PACE, and also about the Commissioner's or FTT decisions relating to PACE, there was a concerted effort by a small number of people to write replies, in an attempt it seems to QMUL, to dispute all the issues and to introduce counter arguments. QMUL says that this can 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. It says that on WhatDoTheyKnow.com, many of the annotations are not related to the request or FOI process but unrelated comments about ME/CFS or 'flawed' research.

36. QMUL has told the Commissioner that most, if not all, of the requests it has received have, therefore, been deemed part of a campaign. It says it is possible to show links between the requesters in many cases and, at this point, it says that this has assumed more relevance. QMUL says that the individuals concerned deny that there is any campaign or activism on their part even though there are often published references to "*our case*" or similar. QMUL has provided the Commissioner of evidence of links between particular individuals, which include the complainant – through Twitter and elsewhere – that it says support its view that the individuals are acting in concert as part of campaign. The Commissioner has reviewed this evidence but does not intend to reproduce it in this notice. She notes that QMUL says that these individuals are responsible for well over half of all PACE-related FOI requests.

37. In QMUL's view 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 has noticed that once the FTT has ruled against them, that individual no longer makes requests, but others

do. It does not believe this is a coincidence. It appears to QMUL that the complainant now seems to have taken up the cudgel. Nevertheless, QMUL says that up to now requests have been treated on a case-by-case basis and it has disclosed information in response wherever possible. In other cases it has used exemptions where it was felt appropriate. Where QMUUL has refused a request as vexatious and these have been appealed, the Commissioner has agreed.

38. QMUL has drawn the Commissioner's attention to the decision of the *Information Tribunal of John Mitchell Jr. vs. IC and QMUL* (EA/2013/0019). This notes that when results were published in The Lancet, such was the volume of critical letters that The Lancet received it concluded there was an active campaign to discredit the research. Further at paragraph 27 the FTT recognises itself that a campaign exists. QMUL believes that the evidence presented in its submission supports this and that the complainant is demonstrably part of the campaign.

39. QMUL has noted 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*".

40. It has also noted a response to another paper in 2013, when 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*".

41. QMUL says that in February 2016 and within a few days of each other, 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, QMUL argues, that there is a co-ordinated campaign in operation.

42. Finally, with regards to evidence of a campaign, QMUL has noted that the complainant posted online information he has received from the Department for Work and Pensions. It considers he has done this to allow others to scour the material; one of the responses in the resulting thread is a suggestion of names that have been redacted in one of the documents released. QMUL has noted that the complainant has done this himself: post #438 at

https://www.s4me.info/threads/pace-trial-tsc-and-tmg-minutes-released.3150/page-22

The Commissioner has accessed this link and notes that comment #438 has been written by someone identifying themselves as 'JohnTheJack'; she does not have evidence that JohnTheJack is the complainant and therefore has not included this particular point in her deliberations. She has taken account of QMUL's remaining arguments, however.

43. The focus of QMUL's submission to the Commissioner has been on the campaign that it considers the complainant is part of. But QMUL has also confirmed that evidence it has presented in the past in response to other complaints to the Commissioner – such as in FS50600710[2] and FS50722835 – remain valid. The Commissioner does not intend to reproduce that evidence in detail in this notice – it can be found in those earlier decisions - but the arguments can be summarised as follows:

Burden on QMUL and its staff

44. Due to the subject matter and the nature of the requests, QMUL says that the requests need to be interpreted and dealt with by individuals familiar with the trial. Prof Peter White was the Lead Co-Principal Investigator but, as has been noted, he retired from QMUL in December 2016. When Prof White was still at QMUL, he was the one who had to bear the brunt of the requests as the only person with the knowledge and expertise, which took him away from his other work. Now it is more complicated. When requests have been received since Prof White's retirement, QMUL has to contact the other Principal Investigators who are based at the University of Oxford and King's College London.

45. Individuals critical of the PACE trial analyse in minute detail papers that are published; subsequent comments on message boards lead to more requests and the burden grows further. Managing PACE-related FOI requests takes up a disproportionate amount of the time of a very small number of staff resourced in that role.

46. The history of the requests suggests that further requests will follow even if, on the face of it, any one request standing alone may not be judged vexatious. The FOI requests and other complaints to other

[2] https://ico.org.uk/media/action-weve-taken/decision-notices/2016/1623988/fs50600710.pdf

parties suggests to QMUL that a group of individuals is looking for anything and everything to somehow find fault with the PACE trial and similar research. At this point in time, any value that requests about the PACE may have once had is disproportionate to the burden that dealing with the requests now causes to QMUL.

Harassment

47. Even though he has now retired, QMUL still believes – from comments individuals post online - that requests are being made at least partly for the purpose of attempting to discredit Prof White and his collaborators. From published comments, it seems to QMUL that there are some individuals who want this type of research to be stopped.

48. QMUL says that the PACE trial's Co-Principal Investigators have all previously experienced degrees of harassment by certain individuals who do not agree with such research. It says the complainant has used information it has previously released to him to harass a particular member of staff on Twitter. Prof White expressed the view that the requests had the effect of harassing him personally. Moreover Prof White has said that he considers that researchers will be put off from entering or staying in this area of research by the actions of particular individuals and the generally adversarial nature of this area of medicine.

Unreasonableness

49. QMUL considers that there appears to be an unwillingness on behalf of the complainant, and others, to accept refusals of any type, which it says could be deemed unreasonable or irrational.

50. By way of an example, it says that 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. QMUL has noted that 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.

Conclusion

51. In conclusion, in its submission QMUL says that in its view there is a collective action being waged by sections of the CFS/ME community against QMUL – through FOI and also through wider channels – and QMUL's decisions about what information should be released. Requesters are unwilling to accept that a refusal has been legitimately applied and appear keen to keep the pressure on QMUL by, for example, repeating requests or asking for similar data. QMUL acknowledges that

the requesters would deny that any community exists or that there is anything 'extremist' about the behaviour.

52. QMUL believes that the current 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 says that the material requested would likely take a long time to locate and redact, so is not simple to fulfil. It is more complex given that Prof White is no longer employed by QMUL. All of these points indicate to QMUL that the request would be likely to have an unjustified and disproportionate effect on it.

The Commissioner's decision

53. In FS50722835 the Commissioner had found the complainant's separate request to be vexatious and, as well as having the characteristics of being a disproportionate burden, harassment and unreasonableness she found that it appeared that individuals were using the FOIA as part of a campaign against QMUL and the PACE trial.

54. The Commissioner has considered the submissions both parties have provided with regard to the current case; the background to the case and the wider circumstances including her previous decisions and previous FTT decisions. The Commissioner has no hesitation in confirming that she considers that the complainant's current request of 26 March 2018 can also be categorised as vexatious under section 14(1) of the FOIA. She is satisfied that the request is a continuation of an ongoing campaign that a group of individuals, including the complainant, is conducting against QMUL, and other bodies.

55. In her published guidance on section 14(1), with regards to a campaign the Commissioner advises that an authority will need to have sufficient evidence to substantiate any claim of a link between requests before it can go on to consider whether section 14(1) applies on these grounds. The Commissioner considers that QMUL has provided the Commissioner with strong and compelling evidence of such a coordinated campaign, which she has reproduced in paragraphs 31 to 43.

56. The Commissioner notes a 2013 FTT decision that QMUL has referred to (EA/2013/0019), which concerned a request for PACE-related information, in which the FTT recognised three important points: first the "profound importance" of academic freedom; second that these types of requests were essentially vexatious due to their polemical nature and third, that the requests were part of a campaign. At paragraph 34 of that decision, the FTT said:

"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".

The Commissioner considers that the FTT's point remains salient in 2018.

57. Additionally, QMUL again provided strong evidence to support its position that the request is vexatious by virtue of: compliance with it being a disproportionate burden; the complainant's use of the FOIA to harass QMUL; and his unreasonable approach. For these reasons alone, the Commissioner would find the request vexatious. However, as discussed, she is satisfied that the request is also part of an ongoing and hostile campaign against QMUL. Like the FTT, she is concerned that the complainant, and others, persist in using the FOIA in this way.

Right of appeal

58. 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

59. 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.

60. 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

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