

Freedom of Information Act 2000 (FOIA)

Decision notice

Date: 23 May 2018

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

Decision (including any steps ordered)

1. The complainant has requested information relating to 'Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial'. QMUL confirmed that the requested information was not held under section 1(1)(a) FOIA.
2. The Commissioner considers that the information requested was not held by QMUL under section 1(1)(a) FOIA.
3. The Commissioner requires no steps to be taken.

Request and response

4. On 13 June 2017 the complainant made the following request for information under the FOIA for:

"I refer to FOI 2017/F158, which details why I am requesting the release of some of the objective, physiological and physical raw data from the PACE trial and contains links to letters/articles written by expert scientists, about the misleading claims made by PACE trial authors.

I have amended my request in response to your claim that it would cost more than 450 pounds to provide the objective data requested in FOI 2017/F158, and hence refusal of the request.

In this amended request, I have reduced or removed, the following items:

- (a) the number of time points;
- (b) exercise and activity scale data;
- (c) physical and physiological data specified in version 7 of the PACE manual, but not directly specified, in the 2007, published protocol
- (d) data that separates patients with depressive or psychiatric disorders from those without mental health issues, who "just" have CFS.
- (e) VO2 max test results (which you advise were not obtained)

My amended information request is as follows:

- i/ Actometer results (BMC reference 18) – raw data actometer, baseline measurements.
- ii/ 6 minute walk objective measure of recovery (BMC reference 31).
- iii/ Self-paced step. Test of fitness (BMC reference 43), including the Borg test (scale of perceived exertion) and end heart rate.
This information is requested for two of the specified time periods:
- iv/ Baseline
- v/ Final assessment – 52 week/39 week time point"

- 5. This was a refined request as QMUL had applied section 12 FOIA to an earlier request made on 6 May 2017 as it said it would have exceeded the cost limit to comply with it.
- 6. QMUL responded on 25 July 2017. It said that some information was already in the public domain but the request as a whole still exceeded the cost limit under section 12 FOIA. QMUL had treated this as a continuation to the original request dated 6 May 2017 rather than a new request for information. As the scope of the request had changed by being reduced it should have been dealt with as a new request for information. It was made to try to refine the information required to fall within the cost threshold which is typical where section 12 is applied. However in relation to this refined request, QMUL was still of the view that section 12 FOIA would apply.
- 7. The complainant requested an internal review on 25 July and 11 August 2017. On 21 August 2017 QMUL said that the narrow request was refused as repeated, since it consists of a smaller part of the wider request originally made on 6 May 2017. On 3 October 2017, QMUL said that they did not intend to carry out an internal review in relation to the 13 June 2017 request.
- 8. As explained above this was not a repeat request, it was a new request refined to endeavour to fall within the cost threshold. As this was a new request for information, an internal review should have been carried out.

As QMUL made it clear that it did not intend to conduct an internal review the Commissioner agreed to proceed to investigate the handling of the 13 June 2017 request.

Scope of the case

9. The complainant contacted the Commissioner to complain about the way her request for information had been handled.
10. During the course of the Commissioner's investigation QMUL revised its position. It confirmed that the information requested could no longer be deemed to be held under section 1(1)(a) FOIA.

Reasons for decision

11. In this case QMUL had applied section 12 FOIA to the request. However in terms of extracting the information, QMUL confirmed that its position was the same as in the previous Decision Notice issued under case reference FS50673373. This was a held/not held case under section 1(1)(a) and (b) FOIA. The Commissioner has therefore considered whether or not the requested information can be deemed to be held before considering the application of section 12 FOIA any further.
12. Section 1(1)(a) of FOIA states that, "Any person making a request for information to a public authority is entitled – to be informed in writing by the public authority whether it holds information of the description specified in the request". Section 1(1)(b) of FOIA states that, "If that is the case, to have that information communicated to him".
13. QMUL has explained (in accordance with the Decision Notice previously issued under reference FS50673373) that the Chief Investigator of the PACE trial retired from QMUL on 31 December 2016. It has previously explained that while QMUL remains the holder and owner of the raw data from this clinical trial, it has effectively lost the means to locate and extract it because this requires specialist knowledge. There is no longer anyone at QMUL with the ability to produce data from this trial. QMUL no longer employs anyone involved with the PACE trial. SPSS and Stata software is required to do this. When FOIA requests have been received since the Chief Investigator's retirement, QMUL has sought advice from the Co-Principal Investigators, but these are based at

Oxford University and King's College London respectively. It referred to Decision Notice FS50557646¹, at para. 22 the ICO stated:

"22. The Commissioner considers that all public authorities must be treated fairly. His expectations in terms of their responses to requests for information must be equal. In this case it could be assumed that a statistician capable of analysing the dataset could be found within QMUL. However, this assumption could not equally be applied to other public authorities and is therefore not appropriate. Similarly no public authority could be expected to recruit staff to provide a response to an FOIA request."

14. QMUL considers that the above Decision Notice acknowledges the difficulties faced when public authorities do not employ an individual able to respond to requests for technical information. All of the data analysis on the PACE trial has been done by statisticians, not the Principal Investigators. It reiterated that it would now have to recruit someone qualified to conduct the required extraction, analysis and preparation to comply with the request.
15. QMUL explained that although the Principal Investigator (now retired) did not undertake the detailed analysis of the PACE trial's data, he was the only individual from QMUL with knowledge of the terminology and raw database to actually locate the information. Depending on what data is requested, it is possible that he could have provided some. It said he would have at least been able to confirm what was and was not held and what it consists of. In this case QMUL sought advice from the Co-Principal Investigators, based at the University of Oxford and King's College London. They were able to indicate what data they believed is/was held for the purposes of this request.
16. QMUL explained that the PACE trial finished in 2009. In the few years following this, a number of academic papers have been published in peer-reviewed journals. Following the Chief Investigator's retirement, during 2017, the records from PACE were put in to storage. They are locked in a QMUL-operated building at St. Bartholomew's Hospital in central London and there is a basic inventory of the 18 filing cabinets of records. The master database is held in one of two of these cabinets, which hold various discs and tapes from the trial, although there may also be a copy securely held by the Wolfson Institute of Preventive

¹ https://ico.org.uk/media/action-weve-taken/decision-notices/2015/1043578/fs_50557646.pdf

Medicine where the Chief Investigator worked, which is found on QMUL's Charterhouse Square campus. Once the disc has been located, the database would need to be loaded in to a computer with the appropriate software installed to be able to read the data. Then, someone familiar with both the software and the terminology or notation used in the database would have to run queries to attempt to locate/retrieve the correct data.

17. Further submissions relating to QMUL's inability to extract the requested information as none of the statisticians working on the study were ever employed by QMUL and the fact that it would have to recruit someone qualified to conduct the required extraction, analysis and preparation, can be found in the previous Decision Notice referred to above.
18. In this case QMUL has argued that the technical expertise to provide the information is simply not now available and therefore that it is just not possible to obtain the requested information from the raw data. As highlighted above, previous Decision Notice FS50557646 has confirmed that no public authority could be expected to recruit staff to provide a response to an FOIA request or to refer to other public authorities for help.
19. In this case QMUL could not have established if any information was held without referring to employees of other public authorities since the request was made following the retirement of the Principal Investigator. Notwithstanding the fact that in this case QMUL did seek advice from employees of other public authorities to determine whether any information was held, it would have to employ a technical expert as well as the use of specialised software to extract the information. QMUL would not be expected to recruit staff to respond to an FOIA request.
20. Based upon QMUL's submissions the Commissioner is satisfied that on the balance of probabilities, this information was not held at the time of the request under section 1(1)(a) FOIA.

Right of appeal

21. 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

22. 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.
23. 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

Gerrard Tracey
Principal Adviser

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