

Freedom of Information Act 2000 (FOIA)

Decision notice

Date: 14 March 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 conflict of interest statements associated with the PACE trial, which was concerned with treatments for chronic fatigue syndrome. Queen Mary University of London ('the University') says the information is already reasonably accessible to the complainant and therefore exempt from release under section 21(1) of the FOIA.
2. The Commissioner's decision is as follows:
 - The University incorrectly applied section 21(1) to the requested information.
3. The Commissioner requires the public authority to take the following step to ensure compliance with the legislation:
 - Release to the complainant the information he requested on 13 June 2017.
4. The public authority must take these steps within 35 calendar days of the date of this decision notice. Failure to comply may result in the Commissioner making written certification of this fact to the High Court pursuant to section 54 of the Act and may be dealt with as a contempt of court.

Request and response

5. On 13 June 2017 the complainant wrote to the University and requested information in the following terms:

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

Please provide copies of any and all statements on conflict of interest made to the Trial Management Group made by its members.

To clarify:

I would like copies of the actual statements, where they exist.

I am asking for copies of any statements made by any member at any time.

I am asking for copies of all such statements made by all members, not restricted to 'independent members'.

I am happy to receive this information in electronic format"

6. The University responded on 5 July 2017. It said the information the complainant has requested is already reasonably accessible to him – as it is contained on page 835 of a Lancet paper published in 2011 - and is therefore exempt from disclosure under section 21 of the FOIA. The University invited the complainant to request an internal review if he was not satisfied with its response. It said that if he remained dissatisfied following the review he could submit a complaint to the Commissioner.
7. The complainant requested a review on 8 July 2017; however, on 21 August 2017 the University wrote to him and advised that it would not carry out a review.

Scope of the case

8. The complainant contacted the Commissioner on 21 August 2017 to complain about the way his request for information had been handled. He considers that section 21 cannot be applied to his request because not all the information he requested is already reasonably accessible to him. The complainant is also dissatisfied with the University's handling of the internal review process.

9. The Commissioner's investigation has focussed on whether the University can rely on section 21(1) to withhold the information the complainant has requested. She has considered the University's handling of the internal review under 'Other Matters'.

Background

10. The University was the main sponsor of the PACE trial. 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. 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 2011¹. 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 are 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 the trial's findings are generally accepted within the scientific and medical community. It is fair to say however that the trial attracted some controversy.

¹ [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(11\)60096-2.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(11)60096-2.pdf)

Reasons for decision

Section 21 – information accessible to applicant by other means

12. Under section 1(1) of the FOIA, anyone who requests information from a public authority is entitled (a) to be told if the authority holds the information and (b) to have the information communicated to him or her if it is held.
13. Section 21(1) says that information which is reasonably accessible to the applicant otherwise than under section 1 is exempt information.
14. Section 21 provides an absolute exemption. This means that if the requested information is held by the public authority, and it is reasonably accessible to the applicant by other means, it is not subject to the public interest test.
15. The complainant's request is for actual copies of all conflict of interest (COI) statements made to the Trial Management Group (TMG) by all its members.
16. In his complaint to the Commissioner, the complainant has disputed the University's claim that the requested information is available in the paper published by the Lancet in 2011. He argues that this paper does not say when the COI statements were made (the Commissioner notes that the complainant has not requested this information specifically), whether all TMG members provided such a statement or whether "*the PIs accurately represent the declarations in the [Lancet] paper*". According to the complainant, one Principal Investigator (PI) associated with the trial misled the Trial Steering Committee by saying that COI statements had been received by all TMG members and that other PIs misled the Trial Steering Committee as they did not declare their COIs.
17. The complainant has argued that the copies of the COI statements are not accessible to him, only a summary of some of the information they contain. He wants to see if all TMG members made their COIs known from the beginning of the process, and if the COI summary published in the 2011 paper are a true representation of the COI statements from which they were derived.
18. In its submission to the Commissioner, the University has explained that a TMG is a usual component of a clinical trial and funders like the MRC will usually require these to comply with Good Clinical Practice. The TMG is responsible for the day-to-day running of the trial.
19. The University has also explained that the Principal Investigators of the PACE trial, and other collaborating researchers, have published a

number of academic papers since 2011 in peer-reviewed journals. When papers are submitted to and published in journals, or even in correspondence, authors must declare their interests so that any reader is appraised of these. This is a long established requirement. The University has confirmed that the main outcome paper from PACE was published in the Lancet in 2011 and that the Lancet is a world-renowned medical journal.

20. The University has told the Commissioner that the requested information is not available in its publication scheme, but in this main paper. It says the complainant was directed to the precise page where conflicts of interest are listed in this published paper. A version of the paper can be downloaded by anyone from anywhere in the world without a 'Login' and free of charge. The University also says the 2011 paper was available on the internet at the time the complainant submitted his request.
21. In its submission the University has gone on to explain why it considers it is reasonable to assume the complainant can access the internet and has described other ways the complainant can access the Lancet paper ie via a hard copy from a library, such as the Central Library in Swansea which appears to be local to the complainant. The University has also reproduced the COI information given in the paper and explained how it is possible to work out the names of particular individuals from initials given in the COI information.
22. It is therefore the University's view that the information the complainant has requested is already reasonably accessible to him and so exempt from disclosure under section 21(1) of the FOIA.
23. The Commissioner does not doubt that the complainant can access the published Lancet paper, and that this paper contains a one paragraph summary of relevant COI information on page 835. The Commissioner notes however that the complainant has requested *copies* of all the COI statements made to the TMG by all the TMG members.
24. With regards to having access to 'documents' and access to 'information', the FOIA provides a right to recorded information and not to the documents that hold the information. The Commissioner's published guidance on section 1 of the Act advises that in most cases it may nonetheless be practical and expedient to release whole documents. But the guidance also states that the Act does not confer any explicit rights to copies of original documents.

25. However, the Commissioner has also published guidance on *'The right to recorded information and requests for documents'*². In this guidance the Commissioner again advises that the FOIA provides a right of access to information held by public authorities and does not confer any explicit right to copies of original documents.
26. But this particular guidance also advises that a request for a copy of a document is a valid request for *all* of the recorded information in that document and that this means that, in most cases, the only practicable way to communicate to the applicant all the recorded information in the document will be to provide a copy of the original. The complainant in this case has requested actual copies of the COI statements. In order for section 21 to apply, all the information contained in the statements would need to have been published in the 2011 paper.
27. The Commissioner asked the University to provide her with copies of the original COI statements, which it did. There are 19 statements by 19 individuals, each provided on a five page template that appears to have been created by the International Committee of Medical Journal Editors. As such, and although the paragraph in the Lancet report may well accurately summarise the statements, the Commissioner considers that the individual COI statements contain more information than is published in the Lancet report. She therefore finds that the University was wrong when it told the complainant that the information he had requested was already published and accessible to him. *All* the information the complainant has requested – that is, copies of the COI statements - is *not* already reasonably accessible to him and therefore the University was incorrect to rely on section 21.
28. Section 40(2) of the FOIA says that third person personal data is exempt from disclosure. As the University has noted, it is possible to identify the conflict of interest statements associated with particular individuals from information already published in the Lancet report. The Commissioner therefore considers that this personal data is already in the public domain and releasing the requested information would not breach section 40(2).

² <https://ico.org.uk/media/for-organisations/documents/1621/the-right-to-recorded-information-and-requests-for-documents.pdf>

Other Matters

29. In contrast to the Environmental Information Regulations, provision of an internal review is not a requirement of the FOIA but the Commissioner recommends that public authorities carry out reviews as a matter of good practice.
30. In this case, in its response to his request of 5 July 2017, the University indicated that if the complainant was dissatisfied with the response he could request an internal review. On 8 July 2017 the complainant requested a review. On 21 August 2017, some six weeks later and only after having been prompted by the complainant, the University advised that it would not carry out a review and advised the complainant to contact the Commissioner.
31. In its submission, the University has told the Commissioner that on occasion it is not possible to carry out a review every time one is requested, due to lack of resources. But it also indicated that, in his request for a review, the complainant made what it considers to be potentially libellous remarks about the PIs. Whatever the reason was why the University considered it was unable to carry out a review, it should have either referred the complainant to the Commissioner in its original response of 5 July 2017, or on receipt of his request for a review on 8 July 2017, and not six weeks later.
34. The Commissioner considers that the University's approach to this matter did not assist the complainant; in fact it hindered him as it delayed resolving his complaint by six weeks. She expects public authorities to have clear processes in place in the carrying out of internal reviews if one is offered. However if, in exceptional circumstances, an internal review is not possible it should contact the requester at the earliest opportunity and direct them to the Commissioner to avoid unnecessary delay in its handling of the request.

Right of appeal

35. 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

36. 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.
37. 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
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