

## **Queen Mary University's arguments regarding the application of section 14 to the request**

QMUL believes that the complainant's request should be viewed in the context of a campaign of opposition to the PACE trial, its investigators and its findings.

### **Introduction**

Since February 2011 QMUL has received a stream of Freedom of Information Act requests (and other correspondence) about the PACE trial, either to the dedicated FOI inbox or to members of staff connected with PACE, which have all been logged. It has considered each of the requests individually on its own merits. In total it has refused 16 requests in whole; supplied information in response to 13 requests and in 7 cases the information has not been held. In one other case some information was supplied where held and the rest refused under s.22. Altogether there have been over 160 individual requests for information within the FOIA requests. These 37 requests have covered information such as minutes from the trial management/steering groups, to raw data from the trial, to enquiries about whether and when certain data or results will be published.

The PACE trial, of which QMUL was the main sponsor, was a large-scale, randomised clinical trial testing treatments for chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (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.

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 - asking for the accounts of a sponsored clinical trial - 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.

## **The Specific Request**

Whilst it is recognised that there is a public interest in this research and the PACE trial generally QMUL firmly 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. As will be discussed below, after five years, the PACE team now feel harassed by these requests and believe they 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 giving the latest information about the trial, including 56 frequently asked questions.

In May 2014 QMUL refused a PACE-related request under s.14(1) for the first time. This was upheld at internal review and by the Commissioner in March 2015 under case reference number FS50558352. QMUL relies on that decision in support of its refusal of the current request.

With regards to the complainant's present request, QMUL acknowledges that information has already been published in graphical form (although this was mean and confidence intervals rather than standard deviation) and that it might not be difficult to produce the requested information. However, it is the requester and the context of the request which it believes justified its refusal under s.14(1). Although the current request was the first since August 2014, if QMUL should start to respond to PACE-related requests again, it feels that it could encourage more when it has effectively tried to draw a line. Indeed, a new request was received on 1 November 2015. There is always a flurry of activity on social media when a Decision Notice or a new research paper is published. Even though the complainant has never submitted an FOI request to QMUL, his assumption "my scepticism of the conclusions of the PACE trial, and my wish to analyse the data for myself has played a part here," says a lot about his view of PACE. He has also recently written a parody of a defence of PACE by Sir Simon Wessely. The complainant is also a contributor to the ME Analysis YouTube channel (<https://www.youtube.com/channel/UCvWxvwftcljIQniW3Dgzm5w>), and websites (<http://evaluatingpace.phoenixrising.me/homepageanim.html> and <http://meanalysis.blogspot.co.uk/>), which are designed to challenge PACE. QMUL take issue with his accusation that its refusal should be regarded as 'vexatious' since he must be aware of other FOI requests made to QMUL and the responses given; he has contributed to discussions on these and used WhatDoTheyKnow.com himself for the present request.

Proportionally, this request is adding to the burden of a long period of requests on this topic from different individuals, QMUL 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.

## **1. Motive - Evidence of a campaign**

QMUL believes that there is evidence of a campaign against the PACE trial of which it was the sponsor. 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. 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.

The area of research which the PACE trial concerns is one which 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

<http://forums.phoenixrising.me/index.php?threads/pace-trial-and-pace-trial-protocol.3928/> which has had over 2600 posts since May 2010 and the petitions to the government against Professor White.

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"<sup>1</sup>. The ICO says in its guidance 'Dealing with vexatious requests'<sup>2</sup> that this can be taken in to account as evidence of any campaign. There is even a hashtag on Twitter, #PACEtrial, which individuals and even patient organisations use to promote attacks on the trial. The tweets using this hashtag use language such as "rubbish", "fraudulent", "sleight-of-hand", and "unscientific claims"<sup>3</sup>. It is 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. #PACEgate is also used to criticise the trial.

The complainant<sup>4</sup> is a regular contributor to these fora. Other contributors have written to, or made comments on the British Medical Journal's

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<sup>1</sup> <http://forums.phoenixrising.me/index.php?threads/pace-trial-and-pace-trial-protocol.3928/page-100> (accessed 07/12/15)

<sup>2</sup> Page 23 at: [http://www.ico.org.uk/news/blog/2013/~media/documents/library/Freedom\\_of\\_Information/Detailed\\_specialist\\_guides/dealing-with-vexatious-requests.ashx](http://www.ico.org.uk/news/blog/2013/~media/documents/library/Freedom_of_Information/Detailed_specialist_guides/dealing-with-vexatious-requests.ashx)

<sup>3</sup> <https://twitter.com/hashtag/PACEtrial?src=hash> (accessed 07/12/15)

website<sup>5</sup>. The complainant has directed a series of videos “illustrating some of the absurdities of the PACE trial and its subsequent series of papers”<sup>6</sup>. The names of the contributors, along with their world views, are all in the public domain.

There is even an online wiki, which it seems is solely aimed at complaining about and attempting to demean the PACE trial<sup>7</sup>, and certain individuals clearly dedicate a lot of time to authoring negative and arguably offensive pieces about researchers and PACE, 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/>. Whenever anything is published about PACE, and now also about ICO or Information Tribunal decisions relating to PACE, there is 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<sup>8</sup>, on the British Medical Journal rapid responses<sup>9</sup> and on the *Information Rights and Wrongs* blog<sup>10</sup>, among others.

Most, if not all, of the requests received by QMUL 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. The complainant is one of the main authors of the Evaluating PACE web site<sup>11</sup>. He is linked to a number of other campaigners by that web site and the Phoenix Rising Forum.

Up to now QMUL has treated requests on a case-by-case basis and has disclosed information in response wherever possible. In other cases exemptions have been used where it was felt appropriate and where these have been appealed, refusals have always been ultimately upheld at

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4<sup>□</sup> See [https://www.whatdotheyknow.com/user/graham\\_mcphee](https://www.whatdotheyknow.com/user/graham_mcphee), <http://forums.phoenixrising.me/index.php?members/graham.3615/> and <http://evaluatingpace.phoenixrising.me/comments.html>

5<sup>□</sup> See for example <http://www.bmj.com/content/347/bmj.f5963?tab=responses> (accessed 07/12/15)

6<sup>□</sup> <http://forums.phoenixrising.me/index.php?threads/the-fable-known-as-the-pace-trial.29991/> (accessed 07/12/15)

7<sup>□</sup> [http://www.mecfsforums.com/wiki/PACE\\_Trial\\_Main\\_Menu](http://www.mecfsforums.com/wiki/PACE_Trial_Main_Menu) (accessed 13/11/14)

8<sup>□</sup> For example at [https://www.whatdotheyknow.com/request/pace\\_trial\\_recovery\\_rates\\_and\\_po#comment-t-44532](https://www.whatdotheyknow.com/request/pace_trial_recovery_rates_and_po#comment-t-44532) and [https://www.whatdotheyknow.com/request/raw\\_data\\_for\\_6mwt#comment-52153](https://www.whatdotheyknow.com/request/raw_data_for_6mwt#comment-52153)

9<sup>□</sup> For example at <http://www.bmj.com/content/347/bmj.f5355> (accessed 08/12/15)

10<sup>□</sup> <http://informationrightsandwrongs.com/2013/08/22/academic-freedom-and-foi/> (accessed 07/12/15)

11<sup>□</sup> <http://evaluatingpace.phoenixrising.me/homepageanim.html> (accessed 08/12/15)

internal review and externally, apart from a single case, which is pending an appeal.

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 para. 27 the Tribunal recognises itself that a campaign exists<sup>12</sup>. QMUL believes that the evidence it has presented supports this.

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"<sup>13</sup>. 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"<sup>14</sup>.

QMUL's strategic aims are to create and disseminate knowledge and its staff have a right to be able to carry out the research on which they decide and their peers review. If staff are required to carry out unplanned analysis on data at the whim of any external party, it takes those staff away from their core duties and impacts on the primary purpose of the institution. QMUL does not believe that it was the intention of the legislation for this to occur to such an extent. QMUL holds the raw data from the PACE trial. This consists almost exclusively of personal and sensitive (medical) personal data, which the ICO has already found to be exempt from disclosure<sup>15</sup>. Further analysis is on-going on a planned schedule.

## **2. Burden on QMUL and its staff**

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

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<sup>12</sup>□

<http://www.informationtribunal.gov.uk/DBFiles/Decision/i1069/20130822%20Decision%20EA20130019.pdf>

<sup>13</sup>□ [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60696-X/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60696-X/fulltext) (accessed 01/12/15)

<sup>14</sup>□ <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8955884&fulltextType=LT&fileId=S0033291713001256> (accessed 02/12/15)

<sup>15</sup>□ See Decision Notice FS50484575

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"<sup>16</sup>. QMUL did at one point receive five emails in one week from one requester, though. These were not actually separate requests but requests for clarification, internal review and acknowledgement of receipt. Overall there have been 37 distinct requests to date, plus follow-ups.

Due to the subject matter and the nature of the requests, these need to be interpreted and dealt with mainly by one person, the Lead Co-Principal Investigator of the trial, Prof. Peter White. Prof. White has many other important responsibilities away from which the continuing flow of information requests and analysis that must be undertaken to evaluate whether or not the information can be released, take him. While he recognises fully that it is his legal obligation to respond, this - in addition to such things as providing responses to Parliamentary Questions from members of both Houses of Parliament on the research - has a serious impact on his time to finalise the publications that remain, oversee the current trial of a self-help treatment for patients with CFS, oversee his other research into the causes of CFS, and all of his other academic duties which include teaching, research into helping patients who have survived cancer, and his clinical responsibilities, which include running a clinic for CFS patients, and overseeing psychiatric assessment and care of patients attending St. Bartholomew's Hospital for other health problems, such as cancer. Prof. White has been personally targeted in the past. 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/> 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 favor the "idiot" theory - it's much better supported by the available data."

PACE-related FOI requests take up a disproportionate amount of the Records & Information Compliance Manager's time as well. Notwithstanding the requests drawing staff away from other duties and functions, as with many public authorities at this time, resources are stretched: there is no one else to deal with these. The Records & Information Compliance Manager deals with all FOI requests, this being only part of the role. There is no other 'team' or help. 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

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<sup>16</sup> Para. 30 at: <http://www.bailii.org/uk/cases/UKUT/AAC/2013/440.html> (accessed 01/12/15)



cases requesters have acknowledged that the request they are making has been made previously. From 1 January 2012 to date, the ICO has contacted QMUL 13 times about FOI-related concerns. All but 3 of these have been about PACE.

Prof. White states: "These serial requests have caused my colleagues [who are 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." He is the one at QMUL with the knowledge and expertise meaning he must bear the brunt of such requests; the correspondence can be lengthy and complex and takes him away from his other work.

Requests to QMUL have been for data generally, although there were 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 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 is to create a burden to QMUL and in particular Prof. White.

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.

As has been acknowledged in a previous ruling in QMUL's favour at the Information Tribunal, the importance of defending academic freedom in universities, whose *raison d'être* is to carry out research and advance science, cannot be underestimated. Up to this point QMUL has provided information wherever it could and used exemptions only in line with guidance and the law as appropriate. Paragraph 31 *et seq* of EA/2013/0019 recognises in robust terms the necessity of defending academic freedom and the wasting of time created by diversion of resources by such requests. This includes referencing Article 13 of the Charter of Fundamental Rights of the European Community and the Education Reform Act 1988. Overall, considerable time and effort has been expended in dealing with these requests and it looks as though there will be no end to them. If QMUL supply some data, a request may come back for more. QMUL believes that it is not unreasonable that it should seek at this juncture to reduce the burden on it and its staff.

### **3. Harassment**

Harassment is in many ways linked to the burden on staff. In this particular case it is possible that the ultimate aim of some of the requesters may be to prevent Prof. 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. It is also the case that the requests are likely to continue given the wider context and history. A recent comment directed at Prof. White and colleagues reads, "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"<sup>17</sup>.

This is but one example. It does not matter that the preceding quote is not about FOIA; it demonstrates the animosity and the use of any means to put pressure on Prof. White and colleagues.

Prof. White has previously been harassed by certain individuals who do not agree with his research and, for instance, often receives 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. It is his view that, after such time as this correspondence has continued, the requests are having 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. QMUL has supplied the Commissioner previously with an article demonstrating the concerns in this area<sup>18</sup>. The Guardian has also published a similar article<sup>19</sup>.

Decision Notice FS50568116 found that the online presence of the requester criticising the public authority contributed to the verdict that the request was vexatious. The latest campaign against PACE can be found at <http://www.meaction.net/pace-trial/> which includes another petition; this one is entitled 'Misleading PACE claims should be retracted.'

#### **4. Unreasonableness**

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<sup>17</sup> <http://forums.phoenixrising.me/index.php?threads/trial-by-error-continued-pace-team%E2%80%99s-work-for-insurance-companies-is-%E2%80%9Cnot-related%E2%80%9D-to-pace-really.41309> (accessed 27/11/15)

<sup>18</sup> Hawkes BMJ 2011; 342:d3780

<sup>19</sup> <http://www.theguardian.com/politics/2011/may/25/freedom-information-laws-harass-scientists> (accessed 02/12/15)



QMUL would argue that there appears to be an unwillingness to accept refusals of any type, which could be deemed unreasonable or irrational. The complainant is being disingenuous if he were to claim that he could not understand why a request about PACE would be considered vexatious by QMUL.

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 are discussed with scepticism online<sup>20</sup>. 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.

As of November 2015, nine of the requests related to PACE had been appealed to the ICO<sup>21</sup>, not including this one, and four of these were further considered by the Information Tribunal<sup>22</sup>, in one case following QMUL's instigation<sup>23</sup>. All but one 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"<sup>24</sup> of academic freedom, secondly that these types of requests were essentially vexatious due to their polemical nature<sup>25</sup> and thirdly, that these are part of a campaign<sup>26</sup>. From para. 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".

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20<sup>□</sup> See for example <http://forums.phoenixrising.me/index.php?threads/pace-trial-freedom-of-information-act-2000-foia-decision-notice-minutes-of-meetings-refusal.21313/> (accessed 07/12/15)

21<sup>□</sup> FS50451416, FS50463661, FS50458231, FS50484575, FS50514995, FS50565190, FS50557646 and FS50558352. (FS50533053 was withdrawn)

22<sup>□</sup> EA/2012/0229, EA/2013/0019, EA/2013/0186 and EA/2015/0108

23<sup>□</sup> The MRC has also only ever had two cases go to the Information Tribunal, both about PACE

24<sup>□</sup> Para. 33 of Appeal EA/2013/0019 at:

<http://www.informationtribunal.gov.uk/DBFiles/Decision/i1069/20130822%20Decision%20EA20130019.pdf>

25<sup>□</sup> Ibid at para. 36

26<sup>□</sup> Ibid at para. 27

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

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 QMUL does 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<sup>27</sup>. 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<sup>28</sup>. 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"<sup>29</sup>, the requester was encouraged to re-submit the request, which she did on 3 September 2013 and QMUL subsequently refused under s.14(2). The reaction, behaviour and opinion of opponents of the trial can be seen from comments on online fora and social network sites, see links in footnotes.
- There have been a number of comment pieces, such as on the respected *Information Rights and Wrongs*<sup>30</sup> blog and by the British Medical Journal.<sup>31</sup> 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.

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27<sup>□</sup> <http://forums.phoenixrising.me/index.php?threads/%E2%80%98academic-freedom%E2%80%99-overrides-individual-concerns-in-pace-trial-tribunal.24887/> (accessed 08/12/15)

28<sup>□</sup> <http://forums.phoenixrising.me/index.php?threads/freedom-of-information-request-for-6mwt-data-for-recovered-in-pace-trial-turned-down.25057/> (accessed 08/12/15)

29<sup>□</sup> <https://twitter.com/sjmnotes>

30<sup>□</sup> Ibid.

31<sup>□</sup> Ibid.

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.

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](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”<sup>32</sup>.

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, spread sheets 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 s.12 on this basis or stating that the information is not held.

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

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<sup>32</sup> <http://forums.phoenixrising.me/index.php?threads/ico-rules-in-favour-of-qmul-pdw-over-foi-request-timing-of-changes-to-pace-trial-recovery-criteria.36800/> (accessed 01/12/15)

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.

The length and complexity of certain correspondence would also indicate a degree of obsessiveness from requesters. If a refusal is received the immediate conclusion drawn seems to be that QMUL has something to hide.

## **5. Value and serious purpose**

The PACE trial demonstrated that certain treatments may have positive effects for some patients suffering from CFS/ME. Ultimately the activists believe that the results from PACE have been 'spun'. They claim that the data they request via FOI is necessary to show that either different results were manipulated from the data or because the treatments could be dangerous to certain patients and should be released on those grounds, or simply because they believe QMUL is trying to hide something. All of these requesters no doubt believe that there is a serious purpose to their requests and were it the case that there was indeed some possibility that results have been engineered or that there was some danger posed by the recommended treatments, then QMUL would have to agree. In reality, from their base of mistrust, it is the requesters who are deciding the value on behalf of the community rather than there being a genuine wide public interest in the release of such information in most cases. Indeed, the arguments about whether release of much of the information requested is in the public interest, rather than the private interests of a few, are also pertinent. The PACE trial has enhanced rather than threatened public health and there is no overriding public outcry that CFS/ME research or treatments should be subjected to such scrutiny. There is, however, a vocal minority who are likely to never be happy with certain research and look for any chance to smear or otherwise harm it. They do not believe in it and therefore they attack it, often with obsessional attention to detail and a refusal to accept the integrity of the science.

From the *Dransfield* decision, "the proper application of section 14 cannot side-step the question of the underlying rationale or justification for the request"<sup>33</sup>. If required to produce data or perform other unplanned

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<sup>33</sup> Ibid. at para. 34

analysis at the whim of any requester when there is no statistician in place, the intended analysis, other research and the wider duties of staff are all impacted. Some requesters have pointed to both the fact that the trial was publicly funded and that there is a general shift towards open data i.e. making research and other data available to all through data repositories. Queen Mary's own Research Data Management and Access Policy avows this principle<sup>34</sup>. However, there is a fundamental difference where research data has been collected from a clinical trial and consists of personally identifiable information. The PACE trial data consists of substantial quantities of sensitive personal data<sup>35</sup>. Privacy, consent and participants' reasonable expectations must be taken in to account when considering its use, storage and release. There is no justification to disclose such information where the individuals are likely to be identifiable, even if the present request does not fall in to this category. As such, the aforementioned Policy specifically does not apply to trials involving medical information.

QMUL also takes in to account that some of the requests have been repeated, on one occasion where the requester stated that the sole purpose for this was so that it could be escalated to the ICO because of "timing issues"<sup>36</sup>. Though this is a valid reason for resubmitting a request, the motivation was not to obtain information, but to create more work by appealing to the ICO as he expected it to be refused. No appeal had been made when the request was refused the first time it is claimed because the requester did not get round to it.

It is also not the case that QMUL only refuses PACE-related requests under s.14(1). In 2015 QMUL refused four other requests under this Section that had nothing to do with the PACE trial or research.

The current request is not necessarily lacking serious purpose; QMUL has provided explanations and data wherever possible when previous PACE-related requests have been received in the past. As described above, it is not onerous to supply the data, but QMUL considers in the end that the refusal is justified at this point in time given the context and history. The information itself will not reveal any "truth" that the complainant supposes to either "supporters [or] sceptics"<sup>37</sup>. Starting to respond to certain of these requests could encourage more and the burden that this has imposed on QMUL has reached a tipping point.

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<sup>34</sup> <http://www.arcs.qmul.ac.uk/docs/policyzone/118815.pdf>

<sup>35</sup> This has been confirmed by the ICO in FS50484575

<sup>36</sup> [https://www.whatdotheyknow.com/request/pace\\_trial\\_recovery\\_rates\\_and\\_po#comment-44532](https://www.whatdotheyknow.com/request/pace_trial_recovery_rates_and_po#comment-44532)

<sup>37</sup> Email from Graham McPhee 28/07/2015