

**IN THE FIRST TIER TRIBUNAL**  
**GENERAL REGULATORY**  
**CHAMBER**  
**INFORMATION RIGHTS**

**EA/2015/0269**

BETWEEN:

QUEEN MARY UNIVERSITY OF  
LONDON (“QMUL”)

Appellant

and

(1) THE INFORMATION  
COMMISSIONER (“ICO”)  
(2) ALEM MATTHEES

Respondents

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**NOTE REGARDING DOCUMENTS  
THAT ARE AVAILABLE TO THE  
PUBLIC  
FOLLOWING THE HEARING ON  
20<sup>TH</sup>, 21<sup>ST</sup> AND 22<sup>ND</sup> APRIL 2016**

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This Note has been prepared in order to provide the Tribunal with an indication of those documents relevant to the above proceedings that, in QMUL’s view, can be properly disclosed to members of the public.

This Note arises out of a series of requests that were made to the Tribunal office during the course of the hearing on 20th, 21st and 22nd April 2016 for public access to documents. QMUL has not seen these requests, but understands that they were substantial.

During the hearing QMUL provided an ‘Open Bundle’ of documents for review by members of the public who wished to follow the proceedings. This bundle contained certain key documents including pleadings, witness statements and the parties’ Skeleton

Arguments. This bundle was provided on the basis that it was not to be copied nor removed from the Tribunal room.

On 20 April 2016 Judge Peter Lane ordered the release to a member of the public (Ms Eliot Smith) the following documents:

- (a) the list of attendees for the hearing;
- (b) the notice of decision;
- (c) the notice of appeal and grounds;
- (d) the IC's response; and
- (e) the second respondent's response.

These documents have now been made publicly available online, via Ms Eliot-Smith's blog: <https://valerieeliotsmith.com/2016/04/28/qmul-v-the-information-commissioner-and-matthees-tribunal-hearing-and-open-justice/>

The Tribunal has asked QMUL to consider which additional documents may be disclosed to members of the public seeking to follow these proceedings. There is a sizable amount of documentation in this matter. The following table sets out, with web-links for ease of access, those documents included in the hearing bundles that can be readily accessed online by members of the public.

<b>Information released by QMUL relating to PACE Trial</b>		
QMUL Statement - Release of Individual Data from the PACE Trial	18 December 2015	<a href="http://www.qmul.ac.uk/media/news/items/smd/168729.html">http://www.qmul.ac.uk/media/news/items/smd/168729.html</a>
Participant Consent Forms	1 February 2006	<a href="https://www.whatdotheyknow.com/request/selected_data_on_pace_trial_part#comment-64718">https://www.whatdotheyknow.com/request/selected_data_on_pace_trial_part#comment-64718</a>

<b>Third Party Publications relating to CFS/ME or PACE</b>		
Nice Guidelines - Chronic fatigue syndrome-myalgic encephalomyelitis (or encephalopathy) - diagnosis and management	22 August 2007	<a href="https://www.nice.org.uk/guidance/cg53">https://www.nice.org.uk/guidance/cg53</a>
'Magical Medicine - How to Make a Disease Disappear'	February 2010	<a href="http://www.meactionuk.org.uk/magical-medicine.pdf">http://www.meactionuk.org.uk/magical-medicine.pdf</a>
The Lancet Editorial – 'Patients' power and PACE'	17 May 2011	<a href="http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60696-X/fulltext?rss=yes">http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60696-X/fulltext?rss=yes</a>
British Medical Journal – Dangers of Research into CFS	22 June 2011	<a href="http://www.bmj.com/content/342/bmj.d3780">http://www.bmj.com/content/342/bmj.d3780</a>
The Guardian – "CFS Syndrome Reporters Face Death Threats From Militants"	21 August 2011	<a href="http://www.theguardian.com/society/2011/aug/21/chronic-fatigue-syndrome-myalgic-encephalomyelitis">http://www.theguardian.com/society/2011/aug/21/chronic-fatigue-syndrome-myalgic-encephalomyelitis</a>
Sunday Times – "This man faced death threats and abuse. His crime? He suggested ME was a mental illness"	5 May 2013	<a href="http://www.thesundaytimes.co.uk/sto/Magazine/Features/article1252529.ece">http://www.thesundaytimes.co.uk/sto/Magazine/Features/article1252529.ece</a>
ShoutAboutME article – 'Rocky Start for CFS_ME Research Collaborative'	29 November 2013	<a href="http://www.shoutoutaboutme.com/advocacy/whats-wrong-with-the-uk-cfsme-research-collaborative/">http://www.shoutoutaboutme.com/advocacy/whats-wrong-with-the-uk-cfsme-research-collaborative/</a>
The Lancet Editorial - What's in a name - Systemic exertion intolerance disease	21 February 2015	<a href="http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60270-7/fulltext?rss=yes">http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60270-7/fulltext?rss=yes</a>
MRC CFS-ME Highlight Notice 2016	2016	<a href="https://www.mrc.ac.uk/funding/how-we-fund-research/highlight-notices/cfs-me-highlight-notice/">https://www.mrc.ac.uk/funding/how-we-fund-research/highlight-notices/cfs-me-highlight-notice/</a>
Research Councils UK - Gateway to Research – PACE Trial Summary	accessed 22 March 2016	<a href="http://gtr.rcuk.ac.uk/project/7EC0DBA0-0FC2-44F1-8708-8676EBEDA4C9?pn=0&amp;fetchSize=25&amp;selectedSortableField=date&amp;selectedSortOrder=ASC">http://gtr.rcuk.ac.uk/project/7EC0DBA0-0FC2-44F1-8708-8676EBEDA4C9?pn=0&amp;fetchSize=25&amp;selectedSortableField=date&amp;selectedSortOrder=ASC</a>

<b>Third party publications relating generally to research impact, research governance, research ethics, confidentiality, data-sharing, data-security</b>		
WMA Declaration of Helsinki	June 1964	<a href="http://www.wma.net/en/30publications/10policies/b3/">http://www.wma.net/en/30publications/10policies/b3/</a>
MRC Guidelines for Good Clinical Practice in Clinical Trials	March 1998	<a href="https://www.mrc.ac.uk/documents/pdf/good-clinical-practice-in-clinical-trials/">https://www.mrc.ac.uk/documents/pdf/good-clinical-practice-in-clinical-trials/</a>
MRC Ethics Series - Personal Information in Medical Research	October 2000	<a href="https://www.mrc.ac.uk/documents/pdf/personal-information-in-medical-research/">https://www.mrc.ac.uk/documents/pdf/personal-information-in-medical-research/</a>
Department of Health - Research Governance for Health & Social Care	2005	<a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf</a>
GMC Council - 'Confidentiality'	12 October 2009	<a href="http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp">http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp</a>
Paul Ohm – Broken promises of privacy - UCLA Law Review, 2010	2010	<a href="http://www.uclalawreview.org/pdf/57-6-3.pdf">http://www.uclalawreview.org/pdf/57-6-3.pdf</a>
MRC Guidance - Sharing of Research Data from Patient Studies	23 November 2011	<a href="http://www.mrc.ac.uk/research/research-policy-ethics/data-sharing/policy/">http://www.mrc.ac.uk/research/research-policy-ethics/data-sharing/policy/</a>
The Royal Society – Science as an Open Enterprise	June 2012	<a href="https://royalsociety.org/topics-policy/projects/science-public-enterprise/report/">https://royalsociety.org/topics-policy/projects/science-public-enterprise/report/</a>
ICO Code of Practice on Anonymisation	November 2012	<a href="https://ico.org.uk/media/1061/anonymisation-code.pdf">https://ico.org.uk/media/1061/anonymisation-code.pdf</a>
Article - Identifying Personal Genomes by Surname Inference	18 January 2013	<a href="http://science.sciencemag.org/content/339/6117/321">http://science.sciencemag.org/content/339/6117/321</a>
AllTrials Agreement	September 2013	<a href="http://www.alltrials.net/wp-content/uploads/2013/09/What-does-all-trials-registered-and-reported-mean.pdf">http://www.alltrials.net/wp-content/uploads/2013/09/What-does-all-trials-registered-and-reported-mean.pdf</a>
EAGDA Statement for funders on re-identification	October 2013	<a href="http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/wtp055972.pdf">http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/wtp055972.pdf</a>

MRC - Maximising the value of UK population cohorts	February 2014	<a href="http://www.mrc.ac.uk/publications/browse/maximising-the-value-of-uk-population-cohorts/">http://www.mrc.ac.uk/publications/browse/maximising-the-value-of-uk-population-cohorts/</a>
Joint Response (MRC, ESRC, CRUK, Wellcome Trust) to EAGDA Statement	March 2014	<a href="http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/wtp055971.pdf">http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/wtp055971.pdf</a>
Executive Office of the President – Big Data Seizing Opportunities, Preserving Values	May 2014	<a href="https://www.whitehouse.gov/sites/default/files/docs/big_data_privacy_report_may_1_2014.pdf">https://www.whitehouse.gov/sites/default/files/docs/big_data_privacy_report_may_1_2014.pdf</a>
Health & Social Care Information Centre – Data Release Review	June 2014	<a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/367788/Sir_Nick_Partridge_summary_of_the_review.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/367788/Sir_Nick_Partridge_summary_of_the_review.pdf</a>
Journal of Tech Science – Care.data and access to UK health records	August 2015	<a href="http://techscience.org/a/2015081103/">http://techscience.org/a/2015081103/</a>
Outputs, Outcomes and Impact of MRC Research – Report 2013_2014	2013/2014	<a href="http://www.mrc.ac.uk/publications/browse/outputs-outcomes-and-impact-of-mrc-research-2013-14/">http://www.mrc.ac.uk/publications/browse/outputs-outcomes-and-impact-of-mrc-research-2013-14/</a>
Nuffield Council on Bioethics - Collection Linking and Use of Data	February 2015	<a href="http://nuffieldbioethics.org/wp-content/uploads/Biological_and_health_data_web.pdf">http://nuffieldbioethics.org/wp-content/uploads/Biological_and_health_data_web.pdf</a>
Medical Schools Council – ‘Health of the Nation’	2015	<a href="http://www.medschools.ac.uk/SiteCollectionDocuments/MS-C-Health-of-the-Nation.pdf">http://www.medschools.ac.uk/SiteCollectionDocuments/MS-C-Health-of-the-Nation.pdf</a>

<b>Other Tribunal and Information Commissioner decisions about the PACE Trial</b>		
Decision Notice FS50451416	26 September 2012	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2012/762736/fs_50451416.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2012/762736/fs_50451416.pdf</a>
Decision Notice FS50458231	9 January 2013	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2013/793998/fs_50458231.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2013/793998/fs_50458231.pdf</a>

Decision Notice FS50463661	9 January 2013	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2013/797232/fs_50463661.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2013/797232/fs_50463661.pdf</a>
Decision Notice FS50484575	1 August 2013	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2013/892246/fs_50484575.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2013/892246/fs_50484575.pdf</a>
Decision Notice FS50485606	29 July 2013	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2013/882740/fs_50485606.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2013/882740/fs_50485606.pdf</a>
Decision Notice FS50514995	23 January 2014	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2014/947420/fs_50514995.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2014/947420/fs_50514995.pdf</a>
Decision Notice FS50557646	17 March 2015	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2015/1043578/fs_50557646.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2015/1043578/fs_50557646.pdf</a>
Decision Notice FS50558352	18 March 2015	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2015/1043579/fs_50558352.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2015/1043579/fs_50558352.pdf</a>
Decision Notice FS50565190	27 October 2015	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2015/1560081/fs_50565190.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2015/1560081/fs_50565190.pdf</a>
Decision Notice FS50609018	9 March 2016	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2016/1623721/fs50609018.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2016/1623721/fs50609018.pdf</a>
Decision Notice FS50604808	10 March 2016	<a href="https://ico.org.uk/media/action-weve-taken/decision-notices/2016/1623720/fs50604808.pdf">https://ico.org.uk/media/action-weve-taken/decision-notices/2016/1623720/fs50604808.pdf</a>
Tribunal Decision EA-2012-0229 re: FS50451416	22 May 2013	<a href="http://www.informationtribunal.gov.uk/DBFiles/Decision/i1020/20130522%20Decision%20EA20120229.pdf">http://www.informationtribunal.gov.uk/DBFiles/Decision/i1020/20130522%20Decision%20EA20120229.pdf</a>
Tribunal Decision EA-2013-0019 re: FS50463661	22 August 2013	<a href="http://www.informationtribunal.gov.uk/DBFiles/Decision/i1069/20130822%20Decision%20EA20130019.pdf">http://www.informationtribunal.gov.uk/DBFiles/Decision/i1069/20130822%20Decision%20EA20130019.pdf</a>

<b>Additional Documents</b>		
Cochrane Collaboration - Exercise therapy for chronic fatigue syndrome (individual patient data) (Protocol), Issue 4	2014	<a href="http://www.cochrane.org/CD011040/DEPRESSN_exercise-therapy-for-chronic-fatigue-syndrome-individual-patient-data">http://www.cochrane.org/CD011040/DEPRESSN_exercise-therapy-for-chronic-fatigue-syndrome-individual-patient-data</a>
MRC Guidance - Good Practice Principles For Sharing Individual Participant Data From Publicly Funded Clinical Trials	1 April 2015	<a href="http://www.methodologyhubs.mrc.ac.uk/files/7114/3682/3831/Datasharingguidance2015.pdf">http://www.methodologyhubs.mrc.ac.uk/files/7114/3682/3831/Datasharingguidance2015.pdf</a>
BMC Medicine - How should individual participant data (IPD) from publicly funded clinical trials be shared? C. Tudur Smith, C. Hopkins, M. R. Sydes, K. Woolfall, M. Clarke, G. Murray and P. Williamson	17 December 2015	<a href="http://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-015-0532-z">http://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-015-0532-z</a>

The following further material about the trial is also available online from the website of the Wolfson Institute of Preventive Medicine at <http://www.wolfson.qmul.ac.uk/current-projects/pace-trial>, alongside much other information relevant to the PACE Trial:

<b>Documents available from the Wolfson Institute</b>	
Full PACE paper and web appendix	18 February 2011
APT Participant Manual	November 2004
APT Therapist Manual	November 2004
CBT Participant Manual	November 2004
CBT Therapist Manual	November 2004
GET Participant Manual	16 November 2004
GET Therapist Manual	16 November 2004
SSMC Doctor Manual	2 December 2004

Trial Protocol	8 March 2007
Participant Information Sheet	22 February 2006
Participants Newsletter - Issue 1	June 2006
Participants Newsletter - Issue 2	March 2007
Participants Newsletter - Issue 3	December 2008
Participants Newsletter - Issue 4	February 2011
PACE FAQ 1	written during the progress of the trial
PACE FAQ 2	[undated]

**TIMOTHY PITT-PAYNE QC**

**11KBW**

29<sup>th</sup> April 2016