

Our reference: FOI19/60



DECISION ON YOUR ACCESS APPLICATION

I refer to your application under section 30 of the *Freedom of Information Act 2016* (FOI Act) received by Canberra Health Services (CHS) on 2 September 2019.

This application requested access to:

- 1) "All documents related to planning, funding and approval of ANU Grand Challenges projects by Canberra Health Services from January 2017 to date.
- 2) All documents related to the planning, funding and approval of the MRI research scans requested/organised by HOD Neurology from January 2017 to date."

I am an Information Officer appointed by the Chief Executive Officer of Canberra Health Services (CHS) under section 18 of the FOI Act to deal with access applications made under Part 5 of the Act. CHS was required to provide a decision on your access application by **Friday 21 February 2020** following the decision of the ombudsman.

I have identified 3 documents holding the information within scope of your access application. These are outlined in the schedule of documents included at Attachment A to this decision letter.

Decisions

I have decided to:

grant full access to 3 document;

My access decisions are detailed further in the following statement of reasons and the documents released to you are provided as <u>Attachment B</u> to this letter.

In reaching my access decision, I have taken the following into account:

- The FOI Act;
- The contents of the documents that fall within the scope of your request; and
- The Human Rights Act 2004.

Full Access

I have decided to grant full access to all three documents.

Public Interest Factors Favouring Disclosure

The following factors were considered relevant in favour of the non-disclosure of the documents:

• Schedule 2.1 (a) (i) promote open discussion of public affairs and enhance the government's accountability.

Public Interest Factors Favouring Non-Disclosure

The following factors were considered relevant in favour of the non-disclosure of the documents:

Charges

Processing charges are not applicable to this request.

Disclosure Log

Under section 28 of the FOI Act, CHS maintains an online record of access applications called a disclosure log. The scope of your access application, my decision and documents released to you will be published in the disclosure log not less than three days but not more than 10 days after the date of this decision. Your personal contact details will not be published.

https://www.health.act.gov.au/about-our-health-system/freedom-information/disclosure-log.

Ombudsman review

My decision on your access request is a reviewable decision as identified in Schedule 3 of the FOI Act. You have the right to seek Ombudsman review of this outcome under section 73 of the Act within 20 working days from the day that my decision is published in ACT Health's disclosure log, or a longer period allowed by the Ombudsman.

If you wish to request a review of my decision you may write to the Ombudsman at:

The ACT Ombudsman GPO Box 442 CANBERRA ACT 2601

Via email: ACTFOI@ombudsman.gov.au

Website: ombudsman.act.gov.au

ACT Civil and Administrative Tribunal (ACAT) review

Under section 84 of the Act, if a decision is made under section 82(1) on an Ombudsman review, you may apply to the ACAT for review of the Ombudsman decision. Further information may be obtained from the ACAT at:

ACT Civil and Administrative Tribunal Level 4, 1 Moore St GPO Box 370 Canberra City ACT 2601 Telephone: (02) 6207 1740 http://www.acat.act.gov.au/

Further assistance

Should you have any queries in relation to your request, please do not hesitate to contact the FOI Coordinator on (02) 5124 9831 or email HealthFOI@act.gov.au.

Yours sincerely

Jacqui Taylor

Executive Director
Division of Medicine

(1. 11. Taylor

19 February 2020

FREEDOM OF INFORMATION REQUEST SCHEDULE

Please be aware that under the *Freedom of Information Act 2016*, some of the information provided to you will be released to the public through the ACT Government's Open Access Scheme. The Open Access release status column of the table below indicates what documents are intended for release online through open access.

Personal information or business affairs information will not be made available under this policy. If you think the content of your request would contain such information, please inform the contact officer immediately.

Information about what is published on open access is available online at: http://www.health.act.gov.au/public-information/consumers/freedom-information

NAME	WHAT ARE THE PARAMETERS OF THE REQUEST	File No
	All documents related to planning, funding and approval of ANU Grand Challenges projects by Canberra Health Services from January 2017 to date. All documents related to the planning, funding and approval of the MRI research scans requested/organised by HOD Neurology from January 2017 to date.	FOI19/60

Ref No	No of Folios	Description	Date	Status	Reason for non-release or deferral	Open Access release status
1.	1-11	Email – From Professor Abhayaratna to Dr Lahoria	31 October 2019	Full Release		Yes

2.	12 - 22	Email – From to Dr Lahoria to Associate Professor Shadbolt	30 October 2019	Full Release		Yes
3.	23 - 27	Email – From to Dr Lahoria to multiple doctors	26 September 2019	Partial Release	Schedule 2.2 (a) (ii) Personal Privacy	Yes
Total No of Docs						

nith, Cathie (Health)

From:

Abhayaratna, Walter (Health)

Sent:

Friday, 31 January 2020 10:51 AM

To:

Smith, Cathie (Health)

Subject:

FW: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Sensitivity:

Confidential

UNCLASSIFIED Sensitive: Legal

From: Abhayaratna, Walter (Health) < Walter.P.Abhayaratna@act.gov.au>

Sent: Thursday, 31 October 2019 6:31 PM

To: Lahoria, Rajat (Health) <Rajat.Lahoria@act.gov.au>; Marchesi, August (Health) <August.Marchesi@act.gov.au>

Cc: Taylor, Jacqui (Health) <Jacqui.H.Taylor@act.gov.au>; Hannan, Ross (Health) <Ross.Hannan@act.gov.au>

Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Sensitivity: Confidential

No reason at all.

Dr Walter Abhayaratna MBBS, DrPH, MHA, AFRACMA, FACC, FRACP

Consultant Cardiologist,

Executive Clinical Director, Division of Medicine,

Director, Clinical Trials Unit,

Canberra Health Services.

Professor of Cardiovascular Medicine,

College of Health and Medicine,

The Australian National University

Phone: +61 2 6244 2445 Fax:+61 2 6244 4964

From: Lahoria, Rajat (Health) < Rajat. Lahoria@act.gov.au>

Sent: Thursday, October 31, 2019 9:32:39 AM

To: Abhayaratna, Walter (Health) < Walter.P.Abhayaratna@act.gov.au >; Marchesi, August (Health)

< August. Marchesi@act.gov.au>

Cc: Taylor, Jacqui (Health) < <u>Jacqui.H.Taylor@act.gov.au</u>>; Hannan, Ross (Health) < <u>Ross.Hannan@act.gov.au</u>>

Subject: RE: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Dear Walter,

Thanks for your email.

I wish to clarify that I have not provided all details and hence may not be possible to determine whether my complaint should only be investigated as bullying.

To be clear, my request is that I am allowed to submit my complaint to Research Office and not the Division of Medicine. Is there any reason that I cannot do that?

Many thanks,

Rajat

From: Abhayaratna, Walter (Health)

Sent: Wednesday, 30 October 2019 9:17 PM

To: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au>; Marchesi, August (Health) < August.Marchesi@act.gov.au> Cc: Taylor, Jacqui (Health) < Jacqui.H.Taylor@act.gov.au>; Hannan, Ross (Health) < Ross.Hannan@act.gov.au>

Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Sensitivity: Confidential

Hi Rajat,

May I clarify with you the following:

- 1. Is your complaint related to research misconduct. If so, could you provide details. To date, I have not seen anything in your email correspondence that would relate to research misconduct.
- 2. If your complaint is related to bullying; as I have previously suggested, I would recommend you deal with the matter in the Division.

Thanks,

Walter

Dr Walter Abhayaratna MBBS, DrPH, MHA, AFRACMA, FACC, FRACP Consultant Cardiologist

Executive Clinical Director, Division of Medicine Director, Clinical Trials Unit Canberra Health Services

Professor of Cardiovascular Medicine College of Health and Medicine The Australian National University

Phone: +61 2 6244 2445 Fax: +61 2 6244 4964

From: Lahoria, Rajat (Health) < Rajat. Lahoria@act.gov.au>

Sent: Friday, 25 October 2019 16:43

To: Abhayaratna, Walter (Health) < Walter.P.Abhayaratna@act.gov.au >; Marchesi, August (Health)

<August.Marchesi@act.gov.au>

Cc: Taylor, Jacqui (Health) < Jacqui.H.Taylor@act.gov.au >; Hannan, Ross (Health) < Ross.Hannan@act.gov.au >

Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Dear Walter,

Thank you for your email. It is much appreciated.

Please note that I have not yet documented all my concerns relating to the research activities nor provided all the supporting evidence which will be crucial for the investigation. I have been waiting for further advice from the Research

Office on how to make a formal complaint as per the standard institutional procedures. I have also not received any explanation for the unsubstantiated comments made in the excel sheet.

I would also like to clarify that the Division of Medicine and ACTH executives have been made aware of some of these concerns, more than once, since mid 2017. I am not aware of any actions that ever taken in response, but I may be mistaken.

My understanding based on the information provided in ACT Health Policy Research Practice (DGD15-034), specifically Attachment A of the document, is that research related complaints are handled by the Office of Research although it states that Heads of Division where the research was conducted may also play a role in the investigation. This would align with the information provided in section 5.1.37 (HREC Procedures) and sections 5.4.1 to 5.4.6 and sections 5.6.1 to 5.6.7 of the National Statement on Ethical Conduct in Human Research (2007).

In the first instance, I wish to be advised about the standard procedure for making such a compliant so it can be dealt with formally. After reviewing my complaint, the Research and Ethic department can of course refer the complaint to division of medicine if it is considered appropriate and notify me of their decision in writing.

Kind regards,

Rajat

From: Abhayaratna, Walter (Health) < Walter.P.Abhayaratna@act.gov.au>

Sent: 22 October 2019 08:34

To: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au >; Marchesi, August (Health) < August.Marchesi@act.gov.au > Cc: Taylor, Jacqui (Health) < Indiana | Jacqui.H.Taylor@act.gov.au > Hannan, Ross (Health) < Ross.Hannan@act.gov.au >

Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Hi Rajat,

I suggest that your concerns stated below regarding research matters are managed within the Division of Medicine.

Thanks,

Walter

Dr Walter Abhayaratna MBBS, DrPH, MHA, AFRACMA, FACC, FRACP Consultant Cardiologist

Executive Clinical Director, Division of Medicine Director, Clinical Trials Unit Canberra Health Services

Professor of Cardiovascular Medicine College of Health and Medicine The Australian National University Phone: +61 2 6244 2445 Fax:+61 2 6244 4964

From: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au>

Sent: Tuesday, 22 October 2019 08:02

To: Marchesi, August (Health) < August. Marchesi@act.gov.au>

Cc: Abhayaratna, Walter (Health) < Walter.P.Abhayaratna@act.gov.au >; Taylor, Jacqui (Health)

<<u>Jacqui.H.Taylor@act.gov.au</u>>; Hannan, Ross (Health) <<u>Ross.Hannan@act.gov.au</u>> **Subject:** RE: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Dear August,

I am writing to you again to determine the status of my compliant. I have not received an acknowledgement of my compliant since 1 September 2019. It should be noted that many of these concerns are shared by other members of the neurology department. Therefore, the issues raised are serious and must not be dismissed without a thorough investigation.

It has now come to my attention that there is an active ethics and governance approval for the CRESST project. This was not included in the list of neurology projects provided by you on 28 August 2019. You may or may not be aware that almost all TCH neurologist raised significant concerns regarding the implementation of the CRESST scale in 2017. I have also not received any explanation or supporting evidence to substantiate the remarks made about me in the research project Excel sheet.

Furthermore, it is deeply concerning that subsequent to my complaint, CHS research office and executives have hastilyendorsed and approved Professor Lucck's proposal (see attached email trail) which will allow him to carry on with the research activities without the need for transparency or any accountability. After my most recent exchange in this email trail, I directed myself to further understanding of processes involved in official document generation and management at CHS. I have also sought advice from the CHS Policy team (email attached). Based on my understanding, I have reached the conclusion that proper procedures were largely bypassed to allow Professor Lucck to force this policy document on us. Through my non-exhaustive search, I have been unable to find any local, national or international research policies which aligns with the 'approval process' outlined by Professor Lucck granting him unchallengeable powers as the unit directors to disregard the opinion and concerns of his peers. Unless an alternative explanation is offered, I cannot help but think that Professor Lucck's document is an attempt to intimidate and silence me and others for raising their concerns about how research is conducted within the neurology department. Putting all this together, I am more concerned that Professor Lucck seems to enjoy unconditional support and protection from the CHS research office and hospital executives to conveniently disregard the concerns of his colleagues and carry on as he pleases.

Please take note that my concerns relate to breach of Principles and Responsibilities set out in the Australian Code for the Responsible Conduct of Research (2018) and relate to one of more of the following: a) research misconduct; b) conflict of interest; and c) systematic bullying. I request that my complaint be formally acknowledged and investigated as per the provisions in the ACT Health Policy Research Practice (DGD15-034); Section 5 of the National Statement on Ethical Conduct in Human Research (2007); and Sections 5-7 of the Guide to Managing and Investigating Potential Breaches of the Australian Code for the Responsible Conduct of Research (2018).

Please advise if I need to submit a formal complaint to the CHS research office or any other department at CHS for it to be taken seriously.

I look forward to hearing from you soon.

Kind regards,

Rajat

From: Lahoria, Rajat (Health)

Sent: Thursday, 26 September 2019 8:10 PM

To: Marchesi, August (Health) < August. Marchesi@act.gov.au >

Cc: Abhayaratna, Walter (Health) < Walter.P.Abhayaratna@act.gov.au>; Taylor, Jacqui (Health)

<Jacqui.H.Taylor@act.gov.au>; Hannan, Ross (Health) <Ross.Hannan@act.gov.au> Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Importance: High Sensitivity: Confidential

Dear August,

I am following up on my email on 1 September 2019 for which I have not yet received an acknowledgement or response.

I'm sure you will agree that the concerns raised by me are quite serious and warrant a thorough investigation. I did discuss these issues broadly with you and Sarah Flood during our meeting on 2 August 2019. It was not possible to delve into the specific details at the time as I did not have any information about the department's research activities. However, based on our discussion, it was acknowledged that the way research is being conducted in our department would not be in accordance with the expected ethical standards.

Please find attached the email trail which highlights the lack of transparency with regards to department's research activities, especially the MS projects. There have also been previous instances where research activities have been prioritised over clinical service (for e.g. unvalidated acute stroke scale currently being used in ACT) disregarding the concerns of the majority of neurologists. I did bring this to the attention of the hospital executives back then.

Please also find attached a letter from November 2015 which validates my role within CHS with regards to the MS service and consequently for any MS registry based research. My role and responsibilities have not changed since. As previously mentioned, the informed decision to not participate in the MSBase registry in 2015 and thereafter was due to the concerns about the quality of their dataset. This decision was based on my experience and expertise as an MS specialist.

I would very much appreciate if you could let me know what I am required to do this have this formally investigated? Please do not hesitate to ask if you require any further clarification.

Kind regards,

Rajat

From: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au>

Sent: 01 September 2019 19:52

To: Marchesi, August (Health) < August. Marchesi@act.gov.au>

Cc: Abhayaratna, Walter (Health) < Walter.P.Abhayaratna@act.gov.au >; Taylor, Jacqui (Health)

<Jacqui.H.Taylor@act.gov.au>;Hannan, Ross (Health) <Ross.Hannan@act.gov.au> Subject: FW: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Dear August,

Many thanks for providing me with the list of the current neurology research projects. I have heard about some other projects which do not feature on the list. It is possible these projects did not require ethics approval, are still in the pipeline, or I am simply mistaken.

The imbalance in research activities within our department is unmistakable with only two of the six neurologists doing any research, 90% (if not 100%) of research being performed by Professor Lueck, and half of the ongoing projects facilitating the work of his external collaborators without transparency within our department (departmental data or resources being allocated to these projects?).

I note the comment "Rajat refused to be involved" in relation to the two-multiple sclerosis (MS) projects for Grand Challenges. This is the first time I have learnt thatMSBase registry is being developed for ACT. I request clarification by whom and on what basis this specific remark has been made and whether there is any evidence to back it up? Furthermore, for the sake of argument, even if I did refuse to participate in research, it does not automatically grant others the right to deliberately blindside me indefinitely about the research activities related to and/or dependent on the clinical service I run.

I continue to receive extremely inconsistent statements in relation to the MS research projects and about my involvement or 'refusal to be involved' with these projects.

In her letter to me dated 11 April 2019, Ms JanineHammat (ED People and Culture) stated "You have made reference to working on research for CHS. You have also made reference to the fact that you do not believe that you are receiving credit for that research. I have followed up with Professor Lueck and Dr Talaulikar on this matter and

they have stated that they have not required you to do any research on behalf of CHS and are not sure what research you are referring to. They have confirmed that any research in relation to neurology performed within CHS must be approved by the Clinical Director before it can proceed." Professor Lueck and Dr Talaulikar had no idea of what research I might have been referring to during my discussions with the executive and yet it is being asserted that I refused to participate in the MS projects.

On 6 August 2019, the FOI officer made the following remarks when my FOI application to obtain the list of the current MS research projects returned no document: "I was informed as part of the FOI Process that you would be managing MS research projects. I assume this information would have come from Christian. I have never spoken to Christian." Someone was quite convinced until very recently that I am the one managing these projects and should be naturally aware of what is going on. It is not possible for me to manage these projects if I have refused to be involved prior to the ethics approval being sought.

That the narrative keeps changing so drastically is of great concern and brings into question whether the ethical standards required for research involving human subjects are being maintained within the neurology department and/or CHS. This lack of transparency and deliberate undermining is creating a toxic environment which has implications for delivery of safe and efficient healthcare. This should be taken into consideration by the ethics team at the time of evaluating applications for clinical projects.

MSBase: This software was originally designed by a pharmaceutical company as a tool to monitor patient outcomes. Subsequently, it transformed into a research database. This registry has inherent problems with the quality and accuracy of the clinical data but generates publications based on a large dataset with the intent of having a direct impact on the clinical care of MS patients worldwide. Many MS experts share substantial concerns about the quality of this dataset and the conclusions drawn from their research. And hence, regardless of their productivity and claims of generating research based on real-world data, the clinical utility of such research is limited and questionable. MSBase is not a national benchmark for excellence in MS care (as might have been stated in the ethics application), participation is voluntary, and generally at the discretion of the neurologist leading the MS service, with many Australian centres not participating.

We have been using theMSBase software for our MS Clinic at TCH for nearly two years to keep track of the MS patients and monitor treatment-related adverse outcomes. However, I elected not to participate inMSBase registry since 2015 because of the serious concerns about the quality issues. I have previously shared my concerns with Professor Lueck and others, but my viewpoint has been conveniently ignored.

With regards to the MS projects/MSBase registry, I have the following comments/ questions:

1) Did Professor Lueck or Dr Jo Lane seek consent of clinicians whose MS patients are being (or will be) recruited for the projects? Has Professor Lueck followed the ethics guidelines to ensure there is transparency within the neurology department about these clinical projects? What measures were taken by him to avoid 'conflict of interest' prior to signing off these ethics' applications without the knowledge of his consultant colleagues? At least, I was not spoken to at any stage.

- 2) It also appears that a number of MS projects are being sanctioned under the Grand Challenges umbrella as addons. Is it not a breach of the ethical standards that the person running the MS service for CHS is being intentionally blindsided and the approvals continue to be granted without their knowledge?
- 3) How will the clinical data be abstracted for MSB as e registry? Will clinical assessments of other neurologists, including myself, be used (clinic letters etc.) to extract this information? If yes, did Professor Lueck and Dr Lane discuss it with any of the relevant neurologists? If so, why not with me?
- 4) If the clinical data will be directly obtained from patients via interview by the non-clinical team or non-neurologists or clinicians not directly involved in the care of these patients, how will Professor Lueck and Dr Lane ensure accuracy of this information given its potential impact on the MS patients.
- 5) TheMSBase registry policy is that the MS neurologists from each site qualifies for authorship if they agree for their data to be included for the specific project/ publication. This is because the data used is primarily derived from the clinical assessments performed by the MS specialists in their clinics. Who is listed as the clinical lead for ACT in theMSBase registry and on what basis?
- 6) Has CHS or DOM received/exchanged monies with ANU to facilitate these MS projects?

With regards to the Grand Challenges/ MS research at ANU, I had to bow out because of the following: agreed arrangements/ leadership position for the project were nothonoured; complete disregard of my concerns/inputs/perspective as an MS specialist for the MS project; intentional exclusion from budgetary and meaningful project planning; forced expectations to contribute in my personal time but at the terms and conditions of non-clinicians or non-MS specialists for a clinical MS project; sabotage of my ongoing MS research efforts; and attempts to use patient samples from my other MS project for GC (this was reported to ethics office but conveniently brushed off as miscommunication). At the time of my negotiations with ANU, my position was deliberately weakened by Professor Lueck projecting himself as the MS lead by proxy, assuring access to clinical data to ANU team regardless of my involvement, and creating the misconception that my unfunded research work at ANU is subject to his approval. There was also repeated blackmailing that I must quit my secondary employment in order to participate in GC.

It is important to note, that my discussions occurred with ANU or the ANU researchers and not with CHS or CHS staff. I made it absolutely clear, and I was not advised otherwise, that the ANU Grand Challenges project will not involve or have any impact on my MS patient cohort or work at CHS either directly or indirectly, if they elected to exclude me. Hence, from my perspective, the CHS ethics department cannot use 'refusal to be involved' argument to justify my exclusion and granting approvals.

My concerns are about the misuse of position of power to provide excess to clinical data and diversion of department resources to external collaborators at the expense of the patients and person(s) running the service in a resource poor state. My concerns are that the attitude in our department and perhaps more broadly within CHS, is that if you do not agree to participate in research in your private time, at the terms and conditions of others, you

will be sidelined and humiliated to protect the personal interests of those in positions of power (amounts to slavery). My greatest concern is that in order to facilitate these MS projects for GC, the clinical MS service is being intentionally compromised which is a major disadvantage to the MS community and a risk for patient safety. The visibility and access to MS service is being intentionally diminished, review of service provision in accordance with best practice guidelines is being prevented, and there is unwillingness to fix issues related to operations of the service to incite MS patients to seek treatment privately or interstate. This would naturally help the research projects but not the patients.

I have repeatedly highlighted these concerns to the highest levels of management, as well as to the Minister for Health and Wellbeing, but there is reluctance to appreciate that the two issue (prioritising research over MS service provision and deteriorating state of the MS service) are intimately related.

In my opinion, this amounts to serious breach of the expected ethical standards which warrants a thorough investigation. I am happy toparticularise my concerns more explicitly if required and provide supporting evidence. I am available to discuss this further with anyone who is willing to listen.

I have copied Ross, Jacqui and Walter to make them aware of my concerns.

Kind regards,

Rajat

From: Marchesi, August (Health) < August.Marchesi@act.gov.au >

Sent: 28 August 2019 10:07

To: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au>

Subject: RE: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Hi Rajat,

Apologies for the delay in getting back to you. I have reviewed our records and listed the projects on the attached spreadsheet.

Please let me know if you have any queries.

Kind regards, Augie

August Marchesi | Director

Research Ethics and Governance

Centre for Health & Medical Research

Health Directorate | ACT Government

Ph: 02 5124 7968 | E:august.marchesi@act.gov.au



From: Lahoria, Rajat (Health)

Sent: Monday, 12 August 2019 2:13 PM

To: Marchesi, August (Health) < August. Marchesi@act.gov.au>

Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Thanks, August. Kind regards,

Rajat

Get Outlook for iOS

From: Marchesi, August (Health) < August.Marchesi@act.gov.au >

Sent: Monday, August 12, 2019 1:53:46 PM

To: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au>

Subject: RE: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Dear Rajat,

Thanks for your email. Sorry for the delay in getting back to you. I can confirm that we have received your request and are working on a reply.

Kind regards, Augie

From: Lahoria, Rajat (Health)

Sent: Monday, 12 August 2019 9:34 AM

To: Marchesi, August (Health) < August. Marchesi@act.gov.au > Subject: Re: Request for list of neurology research projects

Good morning August,

I shall be most grateful if you could acknowledge that my request has been received.

Kind regards,

Rajat

From: Lahoria, Rajat (Health) Sent: 05 August 2019 09:12

To: Marchesi, August (Health) < August. Marchesi@act.gov.au> Subject: Request for list of neurology research projects

Dear August,

I would like to request list of all current research projects in neurology that have ethics and governance approval.

The reason to obtain this information is for transparency and to avoid competing with the already approved projects within the neurology department.

I have not been able to obtain this information from the neurology department or the division of medicine despite my multiple requests.

Please do not hesitate to contact me should you require any further information or clarification.

Kind regards, Rajat

Smith, Cathie (Health)

From:

Abhayaratna, Walter (Health)

Sent:

Friday, 31 January 2020 10:34 AM

To:

Smith, Cathie (Health)

Subject:

FW: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Importance:

High

Sensitivity:

Confidential

UNCLASSIFIED

From: Lahoria, Rajat (Health) <Rajat.Lahoria@act.gov.au>

Sent: Wednesday, 30 October 2019 11:47 AM

To: Shadbolt, Bruce (Health) <Bruce.Shadbolt@act.gov.au>; Hannan, Ross (Health) <Ross.Hannan@act.gov.au>

Cc: Marchesi, August (Health) <August.Marchesi@act.gov.au>; Abhayaratna, Walter (Health) <Walter.P.Abhayaratna@act.gov.au>; Taylor, Jacqui (Health) <Jacqui.H.Taylor@act.gov.au>

Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Importance: High
Sensitivity: Confidential

Dear Bruce and Ross,

I am writing to you directly because I have not received a direct response from the Research Officer since I raised my concerns on 1 September 2019.

At this point, I am requesting acknowledgement of my previous emails and further advice on how to submit a formal compliant as per the institutional procedures so I can particularise my concerns with supporting evidence. After reviewing my formal complaint, if Research Office considers that my complaint should be managed by the Division of Medicine, I request that I be informed of this decision in writing.

Could I please request a response by COB 5 November 2019? If I do not hear back from either of you by then, I will assume that the Research Office will not allow me to submit a formal complaint. In that case, I will be left with no option but to explore external pathways. If I am forced to do that, any intuitional breaches that might occur would not be my responsibility.

I am hoping that this matter can be addressed internally. Please let me know if you have any questions or wish to discuss?

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Kind regards,
Rajat
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From: Lahoria, Rajat (Health) < Rajat. Lahoria@act.gov.au > Sent: 25 October 2019 16:43
To: Abhayaratna, Walter (Health) < <u>Walter.P.Abhayaratna@act.gov.au</u> >; Marchesi, August (Health) < <u>August.Marchesi@act.gov.au</u> >
Cc: Taylor, Jacqui (Health) < <u>Jacqui.H.Taylor@act.gov.au</u> >; Hannan, Ross (Health) < <u>Ross.Hannan@act.gov.au</u> > Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]
Dear Walter,
Thank you for your email. It is much appreciated.
Please note that I have not yet documented all my concerns relating to the research activities nor provided all the supporting evidence which will be crucial for the investigation. I have been waiting for further advice from the Research Office on how to make a formal complaint as per the standard institutional procedures. I have also not received any explanation for the unsubstantiated comments made in the excel sheet.
I would also like to clarify that the Division of Medicine and ACTH executives have been made aware of some of these
concerns, more than once, since mid 2017. I am not aware of any actions that ever taken in response, but I may be mistaken.
My understanding based on the information provided in ACT Health Policy Research Practice (DGD15-034), specifically Attachment A of the document, is that research related complaints are handled by the Office of Research although it states that Heads of Division where the research was conducted may also play a role in the investigation. This would align with the information provided in section 5.1.37 (HREC Procedures) and sections 5.4.1 to 5.4.6 and sections 5.6.1 to 5.6.7 of the National Statement on Ethical Conduct in Human Research (2007).
In the first instance, I wish to be advised about the standard procedure for making such a compliant so it can be dealt with formally. After reviewing my complaint, the Research and Ethic department can of course refer the complaint to division of medicine if it is considered appropriate and notify me of their decision in writing.
Kind regards,
Rajat

From: Abhayaratna, Walter (Health) < Walter.P.Abhayaratna@act.gov.au >

Sent: 22 October 2019 08:34

To: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au >; Marchesi, August (Health) < August.Marchesi@act.gov.au >

Cc: Taylor, Jacqui (Health) < <u>Jacqui H.Taylor@act.gov.au</u>>; Hannan, Ross (Health) < <u>Ross.Hannan@act.gov.au</u>>

Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Hi Rajat,

I suggest that your concerns stated below regarding research matters are managed within the Division of Medicine.

Thanks,

Walter

Dr Walter Abhayaratna MBBS, DrPH, MHA, AFRACMA, FACC, FRACP Consultant Cardiologist

Executive Clinical Director, Division of Medicine Director, Clinical Trials Unit Canberra Health Services

Professor of Cardiovascular Medicine College of Health and Medicine The Australian National University

Phone: +61 2 6244 2445 Fax:+61 2 6244 4964

From: Lahoria, Rajat (Health) < Rajat. Lahoria@act.gov.au >

Sent: Tuesday, 22 October 2019 08:02

To: Marchesi, August (Health) < August. Marchesi@act.gov.au >

Cc: Abhayaratna, Walter (Health) < Walter.P. Abhayaratna@act.gov.au >; Taylor, Jacqui (Health)

<<u>Jacqui.H.Taylor@act.gov.au</u>>; Hannan, Ross (Health) <<u>Ross.Hannan@act.gov.au</u>> **Subject:** RE: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Dear August,

I am writing to you again to determine the status of my compliant. I have not received an acknowledgement of my compliant since 1 September 2019. It should be noted that many of these concerns are shared by other members of the neurology department. Therefore, the issues raised are serious and must not be dismissed without a thorough investigation.

It has now come to my attention that there is an active ethics and governance approval for the CRESST project. This was not included in the list of neurology projects provided by you on 28 August 2019. You may or may not be aware that almost all TCH neurologist raised significant concerns regarding the implementation of the CRESST scale in 2017. I have also not received any explanation or supporting evidence to substantiate the remarks made about me in the research project Excel sheet.

Furthermore, it is deeply concerning that subsequent to my complaint, CHS research office and executives have hastilyendorsed and approved Professor Lueck's proposal (see attached email trail) which will allow him to carry on with the research activities without the need for transparency or any accountability. After my most recent exchange in this email trail, I directed myself to further understanding of processes involved in official document generation and management at CHS. I have also sought advice from the CHS Policy team (email attached). Based on my understanding, I have reached the conclusion that proper procedures were largely bypassed to allow Professor Lueck to force this policy document on us. Through my non-exhaustive search, I have been unable to find any local, national or international research policies which aligns with the 'approval process' outlined by Professor Lueck granting him unchallengeable powers as the unit directors to disregard the opinion and concerns of his peers. Unless an alternative explanation is offered, I cannot help but think that Professor Lueck's document is an attempt to intimidate and silence me and others for raising their concerns about how research is conducted within the neurology department. Putting all this together, I am more concerned that Professor Lueck seems to enjoy unconditional support and protection from the CHS research office and hospital executives to conveniently disregard the concerns of his colleagues and carry on as he pleases.

Please take note that my concerns relate to breach of Principles and Responsibilities set out in the Australian Code for the Responsible Conduct of Research (2018) andrelate to one of more of the following: a) research misconduct; b) conflict of interest; and c) systematic bullying. I request that my complaint be formally acknowledged and investigated as per the provisions in the ACT Health Policy Research Practice (DGD15-034); Section 5 of the National Statement on Ethical Conduct in Human Research (2007); and Sections 5-7 of the Guide to Managing and Investigating Potential Breaches of the Australian Code for the Responsible Conduct of Research (2018).

Please advise if I need to submit a formal complaint to the CHS research office or any other department at CHS for it to be taken seriously.

I look forward to hearing from you soon.

Kind regards,

Rajat

From: Lahoria, Rajat (Health)

Sent: Thursday, 26 September 2019 8:10 PM

To: Marchesi, August (Health) < August. Marchesi@act.gov.au>

Cc: Abhayaratna, Walter (Health) < Walter.P.Abhayaratna@act.gov.au >; Taylor, Jacqui (Health)

<Jacqui.H.Taylor@act.gov.au>; Hannan, Ross (Health) < Ross.Hannan@act.gov.au>
Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Importance: High
Sensitivity: Confidential

Dear August,

I am following up on my email on 1 September 2019 for which I have not yet received an acknowledgement or response.

I'm sure you will agree that the concerns raised by me are quite serious and warrant a thorough investigation. I did discuss these issues broadly with you and Sarah Flood during our meeting on 2 August 2019. It was not possible to delve into the specific details at the time as I did not have any information about the department's research activities. However, based on our discussion, it was acknowledged that the way research is being conducted in our department would not be in accordance with the expected ethical standards.

Please find attached the email trail which highlights the lack of transparency with regards to department's research activities, especially the MS projects. There have also been previous instances where research activities have been prioritised over clinical service (for e.g. unvalidated acute stroke scale currently being used in ACT) disregarding the concerns of the majority of neurologists. I did bring this to the attention of the hospital executives back then.

Please also find attached a letter from November 2015 which validates my role within CHS with regards to the MS service and consequently for any MS registry based research. My role and responsibilities have not changed since. As previously mentioned, the informed decision to not participate in the MSBase registry in 2015 and thereafter was due to the concerns about the quality of their dataset. This decision was based on my experience and expertise as an MS specialist.

I would very much appreciate if you could let me know what I am required to do this have this formally investigated? Please do not hesitate to ask if you require any further clarification.

Kind regards,

Rajat

From: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au>

Sent: 01 September 2019 19:52

To: Marchesi, August (Health) < August. Marchesi@act.gov.au >

Cc: Abhayaratna, Walter (Health) < Walter.P. Abhayaratna@act.gov.au >; Taylor, Jacqui (Health)

<<u>Jacqui.H.Taylor@act.gov.au</u>>;Hannan, Ross (Health) <<u>Ross.Hannan@act.gov.au</u>>

Subject: FW: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Dear August,

Many thanks for providing me with the list of the current neurology research projects. I have heard about some other projects which do not feature on the list. It is possible these projects did not require ethics approval, are still in the pipeline, or I am simply mistaken.

The imbalance in research activities within our department is unmistakable with only two of the six neurologists doing any research, 90% (if not 100%) of research being performed by Professor Lueck, and half of the ongoing projects facilitating the work of his external collaborators without transparency within our department (departmental data or resources being allocated to these projects?).

I note the comment "Rajat refused to be involved" in relation to the two-multiple sclerosis (MS) projects for Grand Challenges. This is the first time I have learnt thatMSBase registry is being developed for ACT. I request clarification by whom and on what basis this specific remark has been made and whether there is any evidence to back it up? Furthermore, for the sake of argument, even if I did refuse to participate in research, it does not automatically grant others the right to deliberately blindside me indefinitely about the research activities related to and/or dependent on the clinical service I run.

I continue to receive extremely inconsistent statements in relation to the MS research projects and about my involvement or 'refusal to be involved' with these projects.

In her letter to me dated 11 April 2019, Ms JanineHammat (ED People and Culture) stated "You have made reference to working on research for CHS. You have also made reference to the fact that you do not believe that you are receiving credit for that research. I have followed up with Professor Lueck and Dr Talaulikar on this matter and they have stated that they have not required you to do any research on behalf of CHS and are not sure what research you are referring to. They have confirmed that any research in relation to neurology performed within CHS must be approved by the Clinical Director before it can proceed." Professor Lueck and Dr Talaulikar had no idea of what research I might have been referring to during my discussions with the executive and yet it is being asserted that I refused to participate in the MS projects.

On 6 August 2019, the FOI officer made the following remarks when my FOI application to obtain the list of the current MS research projects returned no document: "I was informed as part of the FOI Process that you would be managing MS research projects. I assume this information would have come from Christian. I have never spoken to Christian." Someone was quite convinced until very recently that I am the one managing these projects and should be naturally aware of what is going on. It is not possible for me to manage these projects if I have refused to be involved prior to the ethics approval being sought.

That the narrative keeps changing so drastically is of great concern and brings into question whether the ethical standards required for research involving human subjects are being maintained within the neurology department and/or CHS. This lack of transparency and deliberate undermining is creating a toxic environment which has implications for delivery of safe and efficient healthcare. This should be taken into consideration by the ethics team at the time of evaluating applications for clinical projects.

MSBase: This software was originally designed by a pharmaceutical company as a tool to monitor patient outcomes. Subsequently, it transformed into a research database. This registry has inherent problems with the quality and accuracy of the clinical data but generates publications based on a large dataset with the intent of having a direct impact on the clinical care of MS patients worldwide. Many MS experts share substantial concerns about the quality of this dataset and the conclusions drawn from their research. And hence, regardless of their productivity and claims of generating research based on real-world data, the clinical utility of such research is limited and questionable. MSBase is not a national benchmark for excellence in MS care (as might have been stated in the ethics application), participation is voluntary, and generally at the discretion of the neurologist leading the MS service, with many Australian centres not participating.

We have been using theMSBase software for our MS Clinic at TCH for nearly two years to keep track of the MS patients and monitor treatment-related adverse outcomes. However, I elected not to participate inMSBase registry since 2015 because of the serious concerns about the quality issues. I have previously shared my concerns with Professor Lueck and others, but my viewpoint has been conveniently ignored.

With regards to the MS projects/MSBase registry, I have the following comments/ questions:

- 1) Did Professor Lueck or Dr Jo Lane seek consent of clinicians whose MS patients are being (or will be) recruited for the projects? Has Professor Lueck followed the ethics guidelines to ensure there is transparency within the neurology department about these clinical projects? What measures were taken by him to avoid 'conflict of interest' prior to signing off these ethics' applications without the knowledge of his consultant colleagues? At least, I was not spoken to at any stage.
- 2) It also appears that a number of MS projects are being sanctioned under the Grand Challenges umbrella as addons. Is it not a breach of the ethical standards that the person running the MS service for CHS is being intentionally blindsided and the approvals continue to be granted without their knowledge?
- 3) How will the clinical data be abstracted for MSB as registry? Will clinical assessments of other neurologists, including myself, be used (clinic letters etc.) to extract this information? If yes, did Professor Lueck and Dr Lane discuss it with any of the relevant neurologists? If so, why not with me?
- 4) If the clinical data will be directly obtained from patients via interview by the non-clinical team or non-neurologists or clinicians not directly involved in the care of these patients, how will Professor Lueck and Dr Lane ensure accuracy of this information given its potential impact on the MS patients.
- 5) TheMSBase registry policy is that the MS neurologists from each site qualifies for authorship if they agree for their data to be included for the specific project/ publication. This is because the data used is primarily derived from the clinical assessments performed by the MS specialists in their clinics. Who is listed as the clinical lead for ACT in theMSBase registry and on what basis?
- 6) Has CHS or DOM received/exchanged monies with ANU to facilitate these MS projects?

With regards to the Grand Challenges/ MS research at ANU, I had to bow out because of the following: agreed arrangements/ leadership position for the project were nothonoured; complete disregard of my concerns/inputs/perspective as an MS specialist for the MS project; intentional exclusion from budgetary and meaningful project planning; forced expectations to contribute in my personal time but at the terms and conditions of non-clinicians or non-MS specialists for a clinical MS project; sabotage of my ongoing MS research efforts; and attempts to use patient samples from my other MS project for GC (this was reported to ethics office but conveniently brushed off as miscommunication). At the time of my negotiations with ANU, my position was

deliberately weakened by Professor Lueck projecting himself as the MS lead by proxy, assuring access to clinical data to ANU team regardless of my involvement, and creating the misconception that my unfunded research work at ANU is subject to his approval. There was also repeated blackmailing that I must quit my secondary employment in order to participate in GC.

It is important to note, that my discussions occurred with ANU or the ANU researchers and not with CHS or CHS staff. I made it absolutely clear, and I was not advised otherwise, that the ANU Grand Challenges project will not involve or have any impact on my MS patient cohort or work at CHS either directly or indirectly, if they elected to exclude me. Hence, from my perspective, the CHS ethics department cannot use 'refusal to be involved' argument to justify my exclusion and granting approvals.

My concerns are about the misuse of position of power to provide excess to clinical data and diversion of department resources to external collaborators at the expense of the patients and person(s) running the service in a resource poor state. My concerns are that the attitude in our department and perhaps more broadly within CHS, is that if you do not agree to participate in research in your private time, at the terms and conditions of others, you will be sidelined and humiliated to protect the personal interests of those in positions of power (amounts to slavery). My greatest concern is that in order to facilitate these MS projects for GC, the clinical MS service is being intentionally compromised which is a major disadvantage to the MS community and a risk for patient safety. The visibility and access to MS service is being intentionally diminished, review of service provision in accordance with best practice guidelines is being prevented, and there is unwillingness to fix issues related to operations of the service to incite MS patients to seek treatment privately or interstate. This would naturally help the research projects but not the patients.

I have repeatedly highlighted these concerns to the highest levels of management, as well as to the Minister for Health and Wellbeing, but there is reluctance to appreciate that the two issue (prioritising research over MS service provision and deteriorating state of the MS service) are intimately related.

In my opinion, this amounts to serious breach of the expected ethical standards which warrants a thorough investigation. I am happy toparticularise my concerns more explicitly if required and provide supporting evidence. I am available to discuss this further with anyone who is willing to listen.

I have copied Ross, Jacqui and Walter to make them aware of my concerns.

Kind regards,

Rajat

From: Marchesi, August (Health) < August. Marchesi@act.gov.au>

Sent: 28 August 2019 10:07

To: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au>

Subject: RE: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Hi Rajat,

Apologies for the delay in getting back to you. I have reviewed our records and listed the projects on the attached spreadsheet.

Please let me know if you have any queries.

Kind regards, Augie

August Marchesi | Director
Research Ethics and Governance
Centre for Health & Medical Research
Health Directorate | ACT Government
Ph: 02 5124 7968 | E:august.marchesi@act.gov.au



ACT Health

From: Lahoria, Rajat (Health)

Sent: Monday, 12 August 2019 2:13 PM

To: Marchesi, August (Health) < August. Marchesi@act.gov.au >

Subject: Re: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Thanks, August. Kind regards, Rajat

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From: Marchesi, August (Health) < August. Marchesi@act.gov.au >

Sent: Monday, August 12, 2019 1:53:46 PM

To: Lahoria, Rajat (Health) < Rajat. Lahoria@act.gov.au>

Subject: RE: Request for list of neurology research projects [SEC=UNCLASSIFIED]

Dear Rajat,

Thanks for your email. Sorry for the delay in getting back to you. I can confirm that we have received your request and are working on a reply.

Kind regards,

Augie

From: Lahoria, Rajat (Health)

Sent: Monday, 12 August 2019 9:34 AM

To: Marchesi, August (Health) < <u>August.Marchesi@act.gov.au</u>> Subject: Re: Request for list of neurology research projects

Good morning August,

I shall be most grateful if you could acknowledge that my request has been received.

Kind regards,

Rajat

From: Lahoria, Rajat (Health) Sent: 05 August 2019 09:12

To: Marchesi, August (Health) < <u>August.Marchesi@act.gov.au</u> > **Subject:** Request for list of neurology research projects

Dear August,

I would like to request list of all current research projects in neurology that have ethics and governance approval.

The reason to obtain this information is for transparency and to avoid competing with the already approved projects within the neurology department.

I have not been able to obtain this information from the neurology department or the division of medicine despite my multiple requests.

Please do not hesitate to contact me should you require any further information or clarification.

Kind regards, Rajat

Smith, Cathie (Health)

From:

Lahoria, Rajat (Health)

Sent:

Thursday, 26 September 2019 11:00 AM

To:

Das, Chandi (Health); Hughes, Andrew (Health); Dr McColl;

Jones, Brett (Health)

Cc:

Lueck, Christian (Health)

Subject:

RE: Academic Collaboration within Neurology [SEC=UNCLASSIFIED]

Dear all,

I have now spoken to each one of you individually and you have confirmed that none of you were consulted prior to the submission of the ethics application(s) for ACT MSBase registry or any other MS research projects. You have also confirmed that you were not aware that these MS research projects had been approved by the ethics department prior to 3 September 2019 when I shared with you the list provided to me by the ethic department. I have also confirmed this with Marie (MS Nurse) who was also not aware of any of this.

Please let me know if I have stated anything inaccurately.

Kind regards,

From: Lahoria, Rajat (Health)

Sent: Tuesday, 3 September 2019 2:28 PM

To: Lueck, Christian (Health) < Christian. Lueck@act.gov.au>; Das, Chandi (Health) < Chandi. Das@act.gov.au>; Hughes,

Andrew (Health) < Andrew. Hughes@act.gov.au>; Dr McColl

Cc: Jones, Brett (Health) <Brett.Jones@act.gov.au>

Subject: RE: Academic Collaboration within Neurology [SEC=UNCLASSIFIED]

Dear Christian,

Many thanks for clarifying that work on MSbase registry has not yet commenced.

However, the project has already been granted ethics and governance approval.

I am interested to find out from my colleagues if they were consulted and agreed to participate in this registry before the ethics applications were submitted for these projects?

Kind regard,

Rajat

From: Lueck, Christian (Health)

Sent: Tuesday, 3 September 2019 8:20 AM

To: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au >; Das, Chandi (Health) < Chandi.Das@act.gov.au >; Hughes,

Andrew (Health) < Andrew. Hughes@act.gov.au >; Dr McColl

Cc: Jones, Brett (Health) < Brett.Jones@act.gov.au>

Subject: RE: Academic Collaboration within Neurology [SEC=UNCLASSIFIED]

Thanks, Rajat.

Just to clarify: the MS Base registry is still a 'work in progress' in the ACT so no one is using it at the moment. I will let everyone know when it does go 'live' and will provide details of how to become involved if interested at that point.

Kind regards, Christian

From: Lahoria, Rajat (Health)

Sent: Tuesday, 3 September 2019 8:03 AM

To: Lueck, Christian (Health) < Chandi.deck@act.gov.au; Hughes,

Andrew (Health) < Andrew. Hughes@act.gov.au >; Dr McColl

Cc: Jones, Brett (Health) < Brett.Jones@act.gov.au>

Subject: Re: Academic Collaboration within Neurology [SEC=UNCLASSIFIED]

Dear all,

As promised, please find attached the list of department research projects provided by the ethics department. If anyone is aware of projects not included in the list please advise.

I'm interested to know how many of you are participating in the ACT MSBase registry?

Kind regards;

Rajat

From: Lueck, Christian (Health) < Christian.Lueck@act.gov.au>

Sent: Friday, August 30, 2019 10:31:28 AM

To: Das, Chandi (Health) < Chandi.Das@act.gov.au >; Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au >; Hughes,

Andrew (Health) < Andrew. Hughes@act.gov.au>; Dr McColl

Cc: Jones, Brett (Health) < Brett.Jones@act.gov.au

Subject: RE: Academic Collaboration within Neurology

Thanks for this, Chandi.

I would be supportive of anything which is going to improve departmental research output.

As you know, I am currently on annual leave and will then be occupied next week with NOSA and the week after with the SSA.

I'll aim to write back to everyone with a considered response after that.

I am sorry about the delay but hope everyone will understand.

Kind regards, Christian

From: Das, Chandi (Health)

Sent: Thursday, 29 August 2019 12:26 AM

To: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au >; Lueck, Christian (Health) < Christian.Lueck@act.gov.au >;

Hughes, Andrew (Health) < Andrew. Hughes@act.gov.au >; Dr McColl <

Cc: Jones, Brett (Health) < Brett.Jones@act.gov.au Subject: Re: Academic Collaboration within Neurology

Dear All,

As mentioned below, I am attaching a draft of some sort of guideline for Academic Collaboration within Neurology.

This is particularly for activity involving patients that all of us collectively contribute to their care, either as out-patients or in-patient.

It does NOT include individual collaboration that people may have with other organisations (provided the patients seen at CHS are NOT included).

I have taken the liberty of including Brett, due to his avid academic interest in stroke (which is the commonest in-patient neurological condition).

Christian I have raised the issue of research many times, verbally and in writing over many years. High time we stream-line it.

Could I request each one of you to share your thoughts / comments / suggestions?

Hope we can come up with a consensus

Kind regards, Chandi

From: Das, Chandi (Health) < Chandi.Das@act.gov.au>

Sent: Thursday, August 22, 2019 11:43

To: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au >; Lueck, Christian (Health) < Christian.Lueck@act.gov.au >;

Hughes, Andrew (Health) < Andrew. Hughes@act.gov.au >; Dr McColl

Subject: Re: Consultants' meeting [SEC=UNCLASSIFIED]

Thanks Christian/Rajat.

My idea/purpose was independent of Rajat approaching the Ethics committee, and best treated separately.

I have raised the issue of research much earlier in previous consultants meeting and previous years. Not sure when Rajat approached the Ethics committee.

Happy to formally draw up / share thoughts about Research Guidelines from my experience elsewhere.

Regards, Chandi

From: Lahoria, Rajat (Health) < Rajat.Lahoria@act.gov.au>

Sent: Thursday, August 22, 2019 11:13

To: Lueck, Christian (Health) < Christian.Lueck@act.gov.au>; Das, Chandi (Health) < Chandi.Das@act.gov.au>; Hughes,

Andrew (Health) < Andrew. Hughes@act.gov.au >; Dr McColl <

Subject: RE: Consultants' meeting [SEC=UNCLASSIFIED]

Thanks, Christian,

Chandi, I can confirm that I have already requested this list from the ethics department.

This after exhausting all channels, including freedom of information, to access this information as well as other department information relating to budget/expenses etc.

Despite being advised by the Director of ethics that such lack transparency about clinical research projects did not meet the expected ethical standards, based on my personal experience, I would not be surprised if someone or other applies unreasonable discretion to prevent the release of this information.

Your preference to request this information on behalf of HOD is fundamentally different to my individual request and more likely to succeed and hence you may still wish to consider this. Nonetheless, if I do obtain this information from the ethics department, I would be very happy to share it with everyone.

Kind regards,

Rajat

From: Lueck, Christian (Health)

Sent: Wednesday, 21 August 2019 9:20 PM

To: Das, Chandi (Health) < Chandi. Das@act.gov.au>; Hughes. Andrew (Health) < Andrew. Hughes@act.gov.au>; Dr

McColl Lahoria, Rajat (Health)

<Rajat.Lahoria@act.gov.au>

Subject: RE: Consultants' meeting

Thanks, Chandi.

I think Rajat has already approached the Ethics committee to obtain a list.

Kind regards, Christian

From: Das, Chandi (Health)

Sent: Tuesday, 20 August 2019 12:37 PM

To: Lueck, Christian (Health) < Christian.Lueck@act.gov.au; Hughes, Andrew (Health)

<<u>Andrew.Hughes@act.gov.au</u>>; Dr McColl

Lahoria,

Rajat (Health) < Rajat. Lahoria@act.gov.au >

Subject: RE: Consultants' meeting

Dear Christian,

We need to finalise the list of ongoing departmental research projects as discussed in the May and August meetings. I realise that in item 5 (Agenda 1 of August meeting), you had mentioned CL/CD as persons responsible. We had discussed/written earlier on 5th June (attached).

You would have a record of the submission to ethics committee, as all projects/audits have to pass through you, so hope it won't be too difficult. Alternatively, do you wish for me to contact someone in the ethics committee, on your behalf? I am happy to do it, if it helps progress things faster.

The other issue is to have a stream-line process about any research project / audit / quality improvement etc within the department. This would improve transparency, and proper allocation of resources as per need (based on discussion).

It would also give people opportunity to offer inputs, particularly if it involves patients that they see in clinics or as in-patients.

Kind regards, Chandi

From: Lueck, Christian (Health)

Sent: Wednesday, 7 August 2019 6:23 PM

To: Hughes, Andrew (Health) < Andrew. Hughes@act.gov.au >; Das, Chandi (Health) < Chandi. Das@act.gov.au >; Dr

McColl Lahoria, Rajat (Health)

< Rajat.Lahoria@act.gov.au > Subject: Consultants' meeting

Dear All,

The next consultants' meeting is scheduled for 5:30 next Tuesday (13th August). Please find attached the minutes of the last meeting along with a draft agenda for Tuesday's meeting.

Please let me know if you have any items you wish added to the agenda.

Many thanks.

Kind regards, Christian

Christian J. Lueck, PhD FRACP FRCP(UK) FAAN
Director, Neurology Department, Canberra Hospital
Professor, Australian National University Medical School
Ph: 51247090 | Fax: 51244629 | E: christian.lueck@act.gov.au
Neurology Department, Canberra Hospital
PO Box 11, Woden ACT 2606, Australia
Australia



Canberra Health Services



Australian National University







Charlotte Sartori

Provider No:

2490981B

Study Coordinator, MSBase Foundation Department of Neurology The Royal Melbourne Hospital Grattan St, Parkville Victoria, 3050, Australia

Date:

18/11/2015

(Fax: +61 3 9342 8070)

Dear Ms. Sartori,

RE: Dr. Rajat Lahoria

I am writing to confirm that Dr. Lahoria Is a Staff Specialist here at the Canberra Hospital. He is responsible for the Canberra Hospital's MS service and I think it entirely appropriate that he be considered as the Principal Investigator for this hospital from the point of view of MS Base.

I hope this is adequate information. Please let me know if there is anything else you need.

With many thanks.

Kind regards.

Yours sincerely,

Professor Christian Lueck PhD, FRACP, FRCP (UK)

Head, Department of Neurology Canberra Hospital & Health Services Professor, ANU Medical School

CL:SR

CC:

Medical Records Department, Canberra Hospital & Health Services

ENC: