The UK ME/CFS Biobank – an internationally accessible bio-resource (Poster 2)

Caroline C Kingdon[1], Shennae O'Boyle[1], Jack Butterworth[1], Kathleen Mudie[1], Luis Nacul[1], and Eliana M Lacerda[1]

[1] London School of Hygiene and Tropical Medicine, London

Introduction

The UK ME/CFS Biobank (UKMEB) provides human tissue samples to internationally based biomedical researchers. Academic, non-commercial and commercial researchers are eligible to apply to use samples and/or data if they present a sound scientific rationale and have ethical clearance. Once the MTA/DTA is signed by both parties, the teams at the UCL/RFH BioBank prepare the requested samples to be shipped and CureMe transfers the appropriate accompanying data. International distribution of samples involves logging the temperature of samples whilst in transit, and being aware of local differences in working days and customs requirements for the import of biological materials. Further information about the application process can be found at cureme.lshtm.ac.uk

The case study 'Differential microRNA profiles in PBMCs and plasma EVs of severely affected ME/CFS patients'[1] describes work from Dr Elisa Oltra and team at the Universidad Católica de Valencia after successfully applying to use UKMEB samples.

Objectives

- To support researchers internationally by providing high quality samples and extensive accompanying data to enhance research in ME/CFS, as described in the chosen case study
- To ensure harmonisation of sample and data collection internationally to facilitate collaboration and validation
- To encourage international collaboration, capitalising on the research capabilities of people in other institutions
- To provide resources for the validation of earlier studies

Methods

In this case study, the application process (Figure 1) for UKMEB samples began in February 2017 with samples released in June 2017.

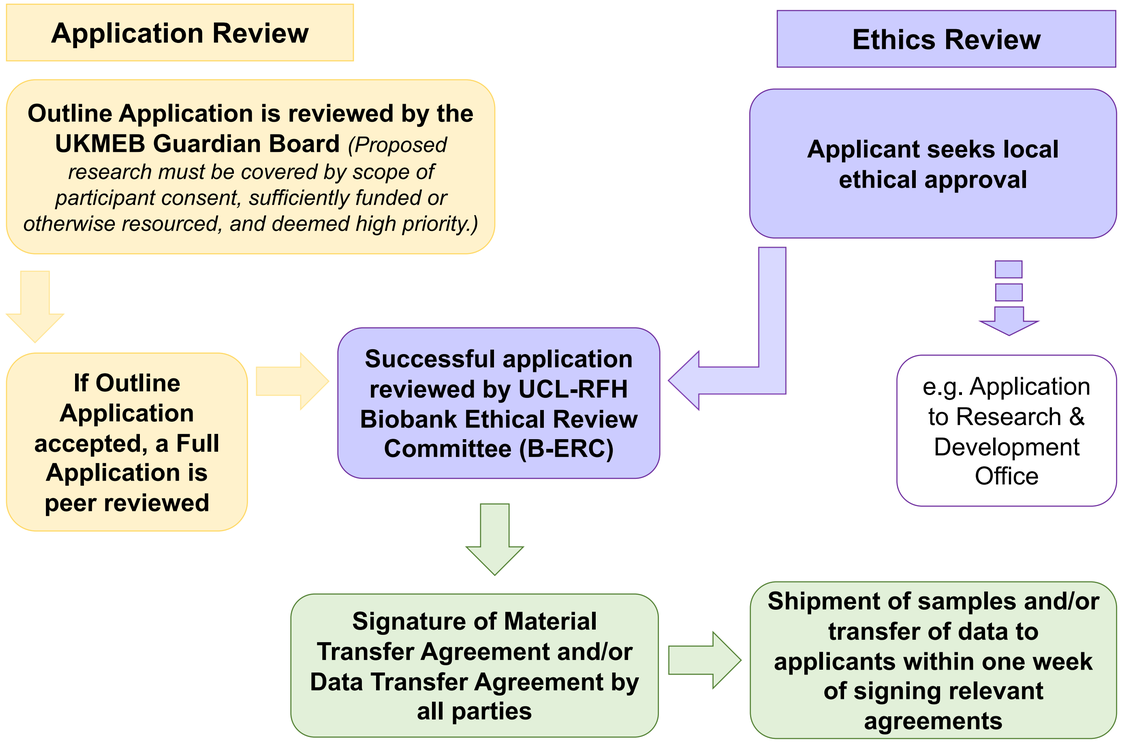

Figure 1 – Procedures for researchers to access samples and/or data

Methods (cont.)

Ethical approvals were granted by DGSP-CSISP Ethics Committee, Spain (Ref. UCV201701), and B-ERC (Ref. number EC2017.01).

For the case study 'Differential microRNA profiles in PBMCs and plasma EVs of severely affected ME/CFS patients',[1] blood samples were accessed to determine differences in miRNA profiles of PBMCs or EVs isolated from plasma (Invitrogen cat. 4484450) of ME/CFS patients and population-based, sex, age and BMI-matched healthy participants (N=15 per group) using Nanostring technology (nCounter Human v3 miRNA Expression Assay Kit). The samples were also used to determine disrupted cellular functions in ME/CFS using gene ontology (GO) and the Kyoto encyclopaedia of genes and genomes (KEGG).

Results

After sharing preliminary results with CureME, 'Differential microRNA profiles in PBMCs and plasma EVs of severely affected ME/CFS patients'[1] results were presented as a research poster to the ME/CFS biomedical and patient community at the international CMRC conference in Bristol, England (Sept, 2018). The full paper, the first report of paired PBMCs and EV miRNA profiles of ME/CFS patients is pending publication; therefore the results cannot be presented here.

Since the launching of the UKMEB as an open access resource in late 2016, there have been >15 formal applications to use UKMEB samples and data (Table 1), six of which were from internationally based research groups. Four international groups are already working with UKMEB samples and/or data, with some preliminary results presented in international conferences.[1,2]

Table 1 – Applications for UKMEB samples and data

Applicant	Institute	Country/ Region	Status	Year
Professor Eleanor Riley and Team	LSHTM	UK	Samples delivered	2016
Dr Karl Morten	University of Oxford	UK	Samples delivered	2017, 2018
Professor Hazell Dockrell and team	LSHTM	UK	Samples delivered	2017
Professor Dockrell and Professor Jo Cambridge collaboration	LSHTM/UCL	UK	Samples delivered	2018
Professor Dockrell and Professor Sir Stephen Riley collaboration	LSHTM/University of Cambridge	UK	Samples delivered	2018
Professor Faisel Khan	University of Dundee	Scotland, UK	Application in progress	Release planned 2018
Professor Chris Ponting	University of Edinburgh	Scotland, UK	Application in progress	
Professor Duncan Baird,	University of Cardiff	UK	Application in progress	
Professor Ester Sabino	Universidade de São Paulo	Brazil	Samples delivered	2017
Dr Elisa Oltra	Universidad Católica de Valencia	Spain	Samples delivered	2017
Professor Eran Segal	Weizmann Institute of Science	Israel	Samples delivered	2018
Dr Rachael Hunter (Socio-Economic Working Group)	EUROMENE	Europe	Data transferred	2018
Professor Derya Unutmaz	The Jackson Laboratory	USA	Application in progress	
Dr. Francisco Westermeier	Institute of Biomedical Science, Graz.	Austria	Application in progress	
Professor Mercedes Rincon	University of Vermont	USA	Application in progress	

Conclusions

- The international sharing of samples is being accelerated by the UKMEB with three international institutions currently working with UKMEB samples and data, with further research groups expected to start soon. CureME works to standardise protocols for collecting, and distributing data and samples, acting as a model biorepository for the integration of ME/CFS bio-resources, promoting synergy of protocols and maximising available sample sizes for ME/CFS research.
- Further to the success of the UKMEB, CureME has contributed expertise to projects in Europe, the US, Canada and Australia. Members of CureME participate in a range of committees and networks in the UK and abroad, including as contributors to the working groups of National Institute of Neurological Disorders and Stroke (NINDS) – Common Data Elements.
- Recently hosting a European meeting in London, CureME team members participate in the leadership of EUROMENE, a group funded by a COST Action to accelerate research into ME/CFS. A number of publications have emerged since the formation of this collaborative network.[3,4]
- The UKMEB has been showcased as an example of biobanking at international conferences (USA, Canada, and the UK).[5-11]

References

1. Almenar-Pérez, E. et al. (2018). Differential microRNA profiles in PBMCs and plasma EVs of severely affected ME/CFS patients. Manuscript in preparation
2. Hunter, R. (Sept, 2018) Oral presentation – The economic impact of CFS/ME, CMRC Conference Bristol - UK
3. Estévez-López, F et al. (2018). Prevalence and incidence of myalgic encephalomyelitis/chronic fatigue syndrome in Europe-the Euro-epiME study from the European network EUROMENE: a protocol for a systematic review. *BMJ Open* 8 (9) ISSN 2044-6055
4. Scheibenbogen, C et al (2017). The European ME/CFS Biomarker Landscape project: an initiative of the European network EUROMENE. *Journal of Translational Medicine*, 15 (1). p162. ISSN 1479-5876
5. Nacul, L. (Sept, 2018). Oral presentation - The UK ME/CFS Biobank: Accelerating global research in ME/CFS, CMRC Conference Bristol - UK
6. Nacul, L. (Feb, 2018). Oral presentation - UK ME/CFS Biobank: A Resource for International Research, Montreal, Canada
7. Kingdon, C. & Lacerda, E. (2017). Oral presentation - A Disease Specific Biobank Story – challenges and lessons learned towards sustainability. Oral presentation. International Conference on Biobanking. London-UK
8. Kingdon, C. (2016). Oral presentation - Patient and public involvement in research: the ME/CFS Biobank. London, UK
9. Lacerda, E. (2016). Oral presentation - Biobank samples and protocols for the study of ME/CFS in UK/Europe. Biomedical Research into ME, London, UK
10. Bowman, E. (2014). Oral presentation - The UK ME/CFS Biobank: Two years of experience. IACFS – Conference, San Francisco, USA
11. Lacerda, E. (2014). Oral presentation - The lay-scientific partnership that shaped the development of the UK ME/CFS Biobank. IACFS – Conference, San Francisco, USA