This response was submitted to the consultation held by the Nuffield Council on Bioethics on *The linking and use of biological and health data* between 17 October 2013 and 10 January 2014. The views expressed are solely those of the respondent(s) and not those of the Council.

Nuffield Council on Bioethics consultation - The linking and use of biological and health data

Submission from the Physiological Society January 2014

Summary

- The Society believes that data linking will have significant benefits in medical practice
- The speed at which information technologies develop makes accurate prediction of potential health benefits difficult
- Appropriate privacy and ethical oversight should continue, but we believe there are significant benefits for access to anonymised medical data but with an opportunity to opt-out

The Physiological Society

1. The Physiological Society brings together over 3,000 scientists from over 60 countries. Since its foundation in 1876, our members have made significant contributions to our knowledge of biological systems and the treatment of disease.

2. We promote physiology and support those working in the field by organising world-class scientific meetings and by publishing the latest developments in our three leading scientific journals, *The Journal of Physiology, Experimental Physiology and Physiological Reports*.

Consultation response

Consultation question 2: What are the new privacy issues?

3. 'Big data' and new information technologies are developing at a speed and manner which makes it very difficult to accurately predict the full potential of these technologies. It will be important that appropriate safeguards are in place to ensure that data remains

anonymised and that these safeguards continue to evolve at a similar pace to the technological advances.

Consultation question 3: What is the impact of developments in data science and information technology?

4. The UK Biobank with biomedical data on over 500,000 people is an excellent resource for the UK to develop potential health related data science. The introduction of universal electronic patient records in the NHS would allow the collection of anonymised consolidated patient records. This could provide significant benefits to research and dramatically improve patient outcomes in the longer term. It would also create a real competitive advantage for the UK.

Consultation question 4: What are the opportunities for, and the impacts of, use of linked biomedical data in research?

5. Biometric data which is presented in an anonymised manner should be collected universally with the ability for patients to opt-out. This data should then be open to any study that can make use of the data to allow maximum benefit to be achieved. In situations where it would be beneficial to allow the identification of individuals, for example specific disease areas or cohort studies, an opt-in system would be more appropriate.

Consultation question 5: What are the opportunities for, and the impacts of, data linking in medical practice?

6. Whilst acknowledging the challenge in predicting the impact of these technologies, we believe data linking has great potential to play a significant role in advancing epidemiology and epigenetics. More broadly it has the potential to both improve the health of the population, and advance biomedical research in the UK, though of course suitable safeguards must be put in place to maintain data anonymity.

For any queries, please contact Ed Hayes at Physiological Society, Hodgkin Huxley House, 30 Farringdon Lane, London, EC1R 3AW. Email: policy@physoc.org