

BADGEM Informatics Group Meeting Minutes
13:00, 28th January 2019

British Association of Dermatologists
Willan House, 4 Fitzroy Square, London W1T 5HQ

ATTENDED / TC

NAME	POSITION
Neil Rajan	Chair
Marie-Louise Lovgren	Member
Celia Moss	Member
Edel O'Toole	Chair of BADGEM Steering Committee Chair
Simon Tso	Member

APOLOGIES

NAME	POSITION
Irene Leigh	Member
Zoe Venables	Member
Mozheh Zamiri	Member

1. Apologies.

See Tables above.

2. Minutes of previous meeting held on 4th July 2018.

The minutes of the previous meeting were approved.

3. Progress with NCARDS

This item covered an ongoing discussion regarding use of the National Congenital Anomaly and Rare Disease Registration Service (NCARDS).

NR advised the Committee that over the last 6 months he has been in discussions with Mary Bythell about the insights gained from ZV's work on existing data within the PHE system, primarily looking at rare skin diseases. The coding that exists within the PHE system maps to either a range of phenotypes or to specific disease(s). After he completed this exercise, a short list of ichthyoses that could be pursued as pilot studies was generated, which was then further discussed with Mary Bythell. Their discussion confirmed that PHE require an honorary contract to be able to access any of their data (due to section 251 permission policy), which firstly requires a project being in place. NR therefore submitted a proposal, last October/November, based on a successful model of rheumatology, which was approved by

PHE with the following reservations: would there be a plan for public engagement and how many cases would be expected to be found? NR then responded to PHE's reservations by advising them that this would be a pilot study and that he would report to them on an ongoing basis.

4. Regional Representatives.

The Committee agreed at previous meetings that the role of the Regional Representatives will be to actively enrol patients and register their data from scratch within their local practice.

This item was not discussed at this meeting.

5. Rare Disease Trainee Representatives.

The Committee agreed at previous meetings that the role of the Rare Disease Trainee Representatives will be to work in research 0.5 days per week to extract data from existing registries with NCARDRS under supervision.

NR informed the Committee that he had met some of the Rare Disease Trainee Representatives at the BAD Research Techniques Course in Newcastle last year. The next steps to involve these Trainees need to be finalised.

M-LL is the first Rare Disease Trainee Representative to formally join the BADGEM Informatics Group and to attend this meeting.

The Committee agreed to invite all other Rare Disease Trainee Representatives to the next BADGEM Informatics meeting in July at the BAD AM.

Action Point 1: BAD Research Administrator to send invitations to the Rare Disease Trainee Representatives to attend the BADGEM Informatics meeting in July at the BAD AM.

6. Collaboration with external registries/databases.

a. HIC – Mozheh to give update on recruitment to Scottish Registry

MZ sent her apologies for this meeting and therefore an update was not provided.

b. OpenApp.

This item was not directly discussed at this meeting.

c. DECIPHER.

NR advised the Committee that the people from DECIPHER had spoken with Sara Brown (a member of the BADGEM Steering Committee) at the training course in

Cambridge with regards to functionality in DECIPHER. There has been little activity from dermatologists registering patients in DECIPHER.

A brief discussion emerged regarding phenotyping data in DECIPHER and the functionality and limitations of the system, but no decisions nor action points were agreed.

Finally, the Committee decided that the best course of action would be for BADGEM to continue to pursue the link with PHE.

7. Any other business.

Rare Disease Trainee Representative M-LL briefed the Committee on her interests and previous work, and her current position within dermatology.

EOT informed the Committee that she recently attended a meeting on how to get into the research environment, whereby she successfully got into the research environment after passing a cyber security course. This course was related to information governance and subsequent access permitted browsing genomes.

Lastly, EOT notified the Committee that there is grant writing course for 100K in February at Charter House where both the MRC and Wellcome Trust will be attending and she is keen to write to these bodies to ask if the presentation slides would be available.

8. Date of next meeting.

0800 – 0900 hrs 3rd July 2019 at the BAD Annual Meeting, Liverpool.

ACTION POINTS:

Action Point 1: BAD Research Administrator to send invitations to the Rare Disease Trainee Representatives to attend the BADGEM Informatics meeting in July at the BAD AM.