

BADGEM Informatics Group Meeting Minutes
14:00, 4th July 2018

British Association of Dermatologists Annual Meeting
The Exchange Edinburgh, 150 Morrison St, Edinburgh EH3 8EE

Attended

Neil Rajan (Chair)
Celia Moss
Edel O'Toole
Simon Tso
Zoe Venables
Mozheh Zamiri

1. Apologies. Irene Leigh, Kenny Morrison, Leandro Tramma and Dmitri Wall.

2. Minutes of previous meeting held on 29th January 2018.

The minutes of the previous meeting were approved. All action points were completed.

3. Funding and Collaboration with External Registries/Databases.

a. NCARDS.

Chair NR advised the group that Public Health England (PHE) are interested in rare disease registration and this is being considered as an extension of the National Congenital Anomaly and Rare Disease Registration Service (NCARDS). PHE plan to achieve this by following their cancer registration model led by Jem Rashbass, National Director for Disease Registration in Public Health England. NR informed the group that PHE have a mechanism to share data (under Section 251) and re-contact patients, and therefore the aim is to get an honorary contract between BADGEM Informatics and PHE to collaborate with resources.

b. HIC.

MZ provided an update on the Scottish Registry, explaining that the current project went ahead as a research database (which has limitations) as opposed to a research study and utilises the HIC platform, which could be modified to go UK-wide in future. MZ suggested that although collecting a minimal dataset had been originally recommended by both the BADGEM SC and Informatics Group, a complex dataset with predetermined research questions (i.e. a research study) may be more appropriate for expanding the registry to England, for the purposes of R&D. Staffing, costings and funding for the administration of expanding the registry together with publication policy need to be considered.

Finally, MZ advised that two options are available: (1) extend the HIC registry to England and Wales under the existing ethical approval or (2) submit a new research ethical approval application for new study/registry in England and Wales.

c. OpenApp.

NR and EOT advised the group that OpenApp is a more expensive option than the databases discussed in agenda items 3a and b, and they have both been in discussions with Dmitri Wall regarding costings for this platform.

d. DECIPHER.

NR advised the group that the DECIPHER database may be more cost effective than OpenApp and remains an option for use by BADGEM Informatics.

EOT raised concerns about limitations on the type of data that can be stored on DECIPHER. NR addressed this concern by stating that DECIPHER supports the needs of storing a minimal dataset that will be used by BADGEM Informatics.

4. Rare Diseases Trainee Representative Posts (advertised this year).

At the previous meeting, it was agreed to recruit a dermatology trainee interested in working in research 0.5 days per week to extract data from existing registries with NCARDRS under supervision. Volunteers were sought from the BAD Trainee Network to appoint a Trainee Representative(s), based in a City/Town with access to NCARDRS.

Five applications were reviewed and considered successful, and therefore a letter was sent to the applicants to inform them of their success and that further information about their involvement will be provided in due course.

5. Regional Representative Posts (advertised last year).

The role of the Regional Representatives will be to actively enrol patients and register their data from scratch within their local practice (as opposed to the Trainee Rep post [agenda item 4] tasked with extracting existing data from NCARDRS).

6. Any other business.

NR recommended to the group to consider attending the next European Conference of Rare Disease for an update on the work carried out by ERNs, clinicians and researchers across various countries.

7. Date of next meeting: 1300hrs Monday 28th January 2019, at the BAD, London.

INFORMATICS GROUP

NAME	EMAIL
Chair: Neil Rajan	neil.rajan@ncl.ac.uk
Irene Leigh	I.M.Leigh@dundee.ac.uk; i.m.leigh@qmul.ac.uk
Kenny Morrison	k.z.morrison@dundee.ac.uk
Celia Moss	celia.moss@bch.nhs.uk
Edel O'Toole	e.a.otoole@qmul.ac.uk
Leandro Tramma	l.tramma@dundee.ac.uk
Simon Tso	simontso@doctors.org.uk
Zoe Venables	Zoe.Venables@phe.gov.uk
Dmitri Wall	dmitri.wall@gmail.com
Mozheh Zamiri	Mozheh.Zamiri@glasgow.ac.uk