

BADGEM Informatics Group
Meeting Minutes
13:00, 29th January 2018

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

1. In attendance: Celia Moss; Edel O'Toole; Simon Tso; Zoe Venibles.

TC Dial-in: Neil Rajan (Chair).

Apologies: Irene Leigh; Kenny Morrison; Leandro Tramma; Dimitri Wall; Mozheh Zamiri.

2. Minutes of previous meeting held on 05-Jul-17.

- It was decided against acquiring site-specific approval for extending the Scotland-based registry to England.

3. Progress update regarding funding.

- Current funds for the Scotland-based registry are not available for an England-based registry.

4. Discussion of alternative external registries.

- The possibility of BADGEM interacting with the HIC Registry database was discussed.
- It was agreed to contact Charlotte Proby in Dundee or another person associated with HIC to discuss forming a separate England-based rare disease registry. Neil will have preliminary discussions with Edel and decide how best to contact.
- The use of OpenApp informatics software for a registry and its set-up, data capture capacity and limitations were discussed.
- It was suggested that pre-consented data in existing registries may be accessed for BADGEM projects following granted permissions for data sharing from database owners. Section 251 of data sharing governance and its restrictions were also discussed.
- Data extraction from the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) was also discussed. ZV is happy to potentially mentor an SpR 0.5 days per week to extract existing data from a partnership with NCARDS. It was suggested to seek part funding from NCARDRS in collaboration.
- Neil will discuss with Mary Bythell and report back about practicalities and projects.
- The potential of using the genetic database DECIPHER as a platform for the BADGEM rare disease registry was also discussed.
- Concerns were expressed about the cost of setting up an independent registry.

5. Reponses and CVs from candidates volunteering to be regional representatives.

Name	Region
Daniele Torchia	Gorleston-on-sea
Michelle Oakford	Southampton
Layla Hanna-Bashara	Cheshire

- 22 candidates in total.
- NR to draft emails to be sent to all 22 successful regional representatives to inform them that the BADGEM Informatics Group are happy to recruit them and to update them on BADGEM's plans to move this registry forward.

6. Any other business.

- EOT suggested applying for an NIHR programme grant to pursue rare skin diseases research in collaboration with other groups that are interested.

Date of next meeting: 4th July 2018, 1400-1500hrs at the BAD Annual Meeting, Edinburgh

ACTIONS

- NR to draft emails to be sent to all 22 successful regional representatives to inform them that the BADGEM Informatics Group are happy to recruit them and to update them on BADGEM's plans to move this registry forward.
- Neil to discuss with Edel regarding discussions with HIC.

BADGEM INFORMATICS GROUP

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