

UKPID Registry Committee Telephone Conference,
Monday 30th January 2017 3pm

Present: , Matthew Buckland, Austen Worth, David Guzman, Andrew Gennery, Ben Shillitoe, Sarita Workman, Cathy Bangs

1. ***Apologies:*** None
2. ***Minutes of the last meeting:*** (20th June 2016 telephone conference): accepted
3. **Transfer of level 2 Code:**
 - a) The level 2 code is now available on all antibody deficiency entries (CVID, SPAD, IgG Subclass def, IgA with IgG subclass deficiency, Selective IgA deficiency, Selective IgM deficiency, Unclassified Ab deficiency) and shows as unPAD (Lvl 2). Agamma isn't included. This level 2 data doesn't include any quality of life data such as number of infections/overnight stays in hospital since the last visit. Matthew will discuss adding this extra data with Nizar . If we want to collaborate with Bridge to match phenotype and genotype then this more detailed data will be needed.
 - b) Matthew asked David if the existing data on the old system could be imported and David said he didn't see why not, but will discuss with Gerhard.
 - c) Matthew asked if everyone can log in to the registry to see the level 2 data and asked Cathy to sort out access for anyone having difficulty with login.
 - d) Sary asked if all centres use a template questionnaire for patients to fill in at clinic visits as at the Royal Free . Some do – there is the ESID baseline and follow up questionnaire available for this. At the moment it's not that useful as a lot of the Level 2 data is about lab results pre diagnosis and needs to be found from the notes/clinic letters/lab results etc. but will be really useful for collecting the quality of life data directly from patients. At some centres it's a difficult task persuading the local team to take consent let alone organise giving out and collection of questionnaires at each visit.
 - e) Sary also asked if there could be a financial incentive for centres to enter level 2 data, but Matthew said there is no current funding available and the only way to take this forward would be to have a level 3 study that qualified for NIHR funding

which could then be adopted by local CRNs. The study doesn't need to be complicated as there are simple things we haven't done. Sara Marshall is looking at some ideas with Matthew.

- f) UKPIN would be looking to offering a second coordinator post later in the year.
- g) If we can get NIHR funding then we would be in a better position to ask Freiburg to add level 2 datasets for 2nd HGG.

4. Recruitment and Validation progress:

Cathy sent out the centre progress report. Over 3000 entries have now been validated with all but 3 sites having at least some of their entries validated. The plan to move forward with GOSH is to submit an HRA amendment to add GOSH as a site for the 04/ MRE07/68 study and transfer to this study from the paediatric study. Newcastle are already using this in addition to the paediatric study so eventually the paediatric study will be defunct and we can close it.

The UKPIN consent form differs slightly from the ESID English version 2 one, which may potentially cause problems for acceptance by Level 3 studies if they want something not covered by our form. Novartis for the APDS study reviewed the UKPIN consent form and confirmed it was acceptable so we will stick with our existing consent forms unless it causes problems in the future.

5. Research Proposal – Agamma study (Andrew Gennery) :

Approved by the committee.

6. UKPID Registry Comparison with IOS (Hilary Longhurst)

This has previously been approved by the registry committee and Cathy had emailed the PI's to ask for confirmation that they are happy for their data to be included. It has taken a very long time to get replies but we can now proceed with all but 2 centres. Cathy has emailed David to request the query to be run.

7. APDS Study Progress:

20 patients have been registered , 13 of which have a completed baseline form and qualified for payment, which has now been received by UKPIN. Sary asked if the Royal Free baseline forms had been completed , but they haven't as yet.

8. Thymoma and XLA studies (peter Arkwright) :

The Thymoma study has now been completed but data collection is on-going for the XLA study.

9. AOB

Collaboration with MDSAS – David G has pulled the data and David Edgar has done the preliminary analysis for the comparison with the registry report. There are a lot of similarities but a discrepancy in the hospital/home treatment data, which maybe due to looking at different subsets. Patients may be in the IG database but not in the registry. The IG database contains entries for a lot of non PID conditions.

Matthew said we need to publish another paper on the registry and asked if anyone had an Spr or PhD student who would be willing to make the first draft. Ben said he may be interested. (Note added post meeting – Ben has kindly agreed to undertake this and David is going to pull the relevant queries).

10. Next Meeting: Cathy to arrange in 3 months.