UKIVAS Steering Group Meeting Minutes
Tuesday 16th January 2018
Royal Free Hospital, 9am – 12pm

Present:
Neil Basu (NBa, Co-Chair), Mark Little (ML, Co-Chair), John Mills (JM), Peter Lanyon (PL), Sarah Hardy (SH), Ann Morgan (AM), Stephen McAdoo (SMA), Fiona Pearce (FP), Lynn Laidlaw (LL), Nina Brown (NBr), David Jayne (DJ), Alan Salama (AS), Jo Robson (JR), Mike Robson (MR)

In attendance:
Julie Power (JP), Patricia Ryan (PR), Tze Liang Goh (TG), James de Boisanger (JB, **minutes**), Lucy Smyth (LS), Joanna Tieu (JT)

Apologies:
Raashid Luqmani (RL), Anthea Craven (AC), Paul Lyons (PL), Lars Erwig (LE), Jackie Andrews (JA), Sian Griffin (SG)

1. Delphi feedback exercise: Joanna Tieu
   A series of statements and proposed treatment algorithm regarding use of Rituximab as maintenance therapy are being developed by JT. These were brought to the steering committee for comment. There was broad agreement in the thrust of the statements, although most committee members did not have sight of them before the meeting, so it was felt that more time was required to give a considered response.

2. Delphi feedback exercise: FP

- Online survey of rheumatology and renal trainees. 76 replies - majority from rheumatology, with good spread across training grades.

- Summary of findings: Some disagreed that they could manage vasculitis with the majority stating they were only somewhat confident in dealing with vasculitis cases. There was an overwhelming appetite for more training, with support for all training options offered (education course, placement, online teaching).

- Proposal to add responsibility to mentor and support trainees to the UKIVAS mission statement accepted (**FP enact**)

- 2nd EUVAS Course due to take place in Florence in 2018 – 300 people expected. 100 attended inaugural course in Cambridge 2017. Intention to have smaller course in 2019 again in Cambridge. Audience largely composed of experienced vasculitis doctors from around the world (DJ).

- Suggestion of 1 day vasculitis teaching course aimed at trainee level doctors, with standardised curriculum, that would be delivered at different locations around country (AS) – Vasculitis Masterclass Roadshow (JM). Suggested to link this to SPR training days (SM, MR), and that it be multidisciplinary (DJ). Course to have centralised curriculum but delivered by local faculty (DJ, AS).

- Discussion around target audience, with different content and delivery for senior trainee/junior consultant level vs experienced specialist. Suggestions that would be best to have clinicians of all levels attend course (brief mention also of GP's and CNS's). Well received suggestion that course day could comprise both general advice session (targeted at trainees), and 'best practice' session (targeted at experienced doctors – but also useful for trainees) (AS).

- Funding for course: Option of £50pp suggested (AS,ML). Might provide income for UKIVAS. Suggestion that BSR or RA may be able to help fund. Pharmaceutical company funding also suggested (JM). **DJ offers to arrange some funding for admin costs. NBa agrees to explore pharma funding options.**

- Project Echo discussed: hub-and-spoke networks - expert teams videoconferencing to conduct virtual clinics with community providers (JP). Heberden Lectures similarly discussed (JM). Consensus that remotely streamed teaching would be complimentary to face-to-face and not replace it (DJ)

- Suggestion that course could be booked centrally through UKIVAS website, and comments that this course, if well delivered, could raise the profile of the group.

- Conclusion (summarised by Chair): Plan first course and evaluate after. Develop curriculum and get volunteers to deliver. **NBa, NBr, PL and FP offer to move this forward for next meeting.**

3. UKIVAS registry V.2. update: Mark Little (on behalf of Anthea Craven)

- Mission statement uploaded to website, and circulated to group prior to meeting. No objections. Comments can be sent after the meeting.

- Recruitment: 67 sites now recruiting. Largest contributing sites are Cambridge, Royal Free and Aberdeen. ANCA Vasculitis patient body estimated at 18,000. Most cases likely to be enrolled with existing sites, but will take time.

- PatientView offers interaction/reward to patients. RaDaR automatically consents for PatientView.

- Breakdown of Vasculitis subsets in registry: GPA, MPA are 50% of all recruits. LL expresses patient feeling that sometimes 'it is all about ANCA'. 128 Behcet's disease cases, but not specifically targeted. Discussion around formally incorporating Behcet's. Specific dataset would be required with, perhaps, costly programming implications. Suggestion that pharma may be willing to help contribute to costs. Discussion to be continued.

- Updated Database: Web based – no longer app based. DCVAS backbone, but now heavily based on REVAS database. Allows longitudinal data collection. NHS number included. Expanded consent section. Shows if patient also included in other study.

- Irish patients can no longer be included due to consent issues. Option to include as separate but linked registry suggested.

- New feature: 'Encounters'. Comorbidities pre and post diagnosis recorded. Relevant drug exposure section added. Some auto-populate fields.

- Discussion regarding how to enter steroid dosing regimes – decision to enter data as category (i.e. high dose, medium dose, low dose). Decision also to incorporate intended drug prescription rather than retrospective drug course.

- Comprehensive 'industry-standard' adverse events section included. View was that this might be attractive feature to help with future funding, and to aid with service provision for clinicians/centres entering data (if it formed part of medical record) (NBa). Steroid complications not recorded (recorded partially in VDI).

3.1. Funding

- Decision that research question should now be formulated and funding sought. Areas of particular interest for research questions include disease relapse and therapy duration. **AS and SMA agreed to lead grant writing group.**

- Suggestion that MRC may be interested. **AM will explore this at future meeting with them**. Previous MRC funded SLE study (Masterplans) has floundered. UKIVAS database should be advocated as great strength of any project proposal.

- Alternative funding options discussed: GSK UK not interested. Teva and AZ possible, but no contacts for TEVA, and AZ contact not progressing fruitfully (DJ). NHS England suggested as possible source, as they are funding eGPA indirectly through severe asthma pathway. Roche, in context of tocilizumab for Takayasu, also mentioned.

- IHD review: Detailed review of governance, linkage permissions, GDPR compliance, and linkage to NHS England. Co-Chairs acknowledges this as very worthwhile investment, and thanks paid to Vasculitis UK for their support.

- Chemocentryx/Vifor, companies behind avacopan (C5a receptor blocker), are promising funding lead. ML met with Peter Sutherland who encouraged application for funding package. News welcomed by members. **ML to draft application.**

- Recognition that pharma companies interested in steroid complications. To this end, including steroid adverse events in UKIVAS discussed. Adding glucocorticoid toxicity index to website suggested (AS). ARUK (Arthritis Research UK) also likely to be interested (DJ).

- Linkage discussed, with view to obtaining further steroid data. NBa has had successful experience in Scotland. Linkage options more limited for England but some possibilities (FP). One option could be patients entering their own steroid data, potentially via PatientView (DJ,ML). **AS and SMA will scope out potential grant proposals before next meeting.**

4. UKIVAS-RaDaR Link update: Mike Robson

- 3000 patients on vasculitis RaDaR database. 63% have diagnosis recorded, the majority of which are ANCA positive. 37% are in vasculitis cohort but without specific diagnosis – considered to be important weakness (ML). 73% have ethnicity recorded. 50% are on PatientView – important strength (MR). Key feature is link to laboratory results (excluding immunology). Overall, data not very useable (MR).

- RaDaR only recently has ethical approval to link to other registries. Already entered patients (vast majority) not consented for this link. These will be re-consented gradually. If duplicates could be identified, these could be prioritised. Suggestion, by JB pre-meeting, of having pseudo-anonymised patient data released by RaDaR, e.g. elements of NHS number, which could be compared to UKIVAS data to identify duplicates. This has been accepted by RaDaR. **JB and MR will progress this with RaDaR secretariat.**

- PatientView and RaDaR traditionally considered to be renal rather than rheumatology focused. However, NBa consents all his rheumatology patients for PatientView, and considers that it useful for rheumatology. Rheumatology would require co-location with renal unit in order to use PatientView, but consensus view that this would be the case in the vast majority of cases. Prospect of having PatientView linked to UKIVAS via RaDaR is exciting (NB), particularly if patients can enter data, as well as simply view it.

- RaDaR has sustainable capitation funding through renal registry (Renal association), in contrast to UKIVAS. It also has longitudinal data over many years (laboratory data link), but this is CKD focused and not necessarily of use in Vasculitis. Question whether CRP included (NBa) – unclear. **MR will follow up**.

- Consensus that all patients should be dual consented for both RaDaR and UKIVAS. Acceptance that both databases will not become a single entity. Conclusion that UKIVAS will be main vasculitis database, with linkage to RaDaR for PatientView and laboratory data.

5. Treasurer Report – Steve McAdoo

- Net balance £12,373.92. Legal and professional work £2,500 – unclear exactly what this is related to. **More clarification to be obtained: SMA**.

6. Website Developments – Nina Brown

- Clinical information section arranged as general overview of vasculitis with information for specific conditions being spread across multiple sections. Would be more useful to have it arranged by vasculitis type, perhaps organised by vessel-size, and all relevant information to that type contained within its section.

- Missing information on Medium Vessel Vasculitis, PAN and Takayasu. Will ask relevant people to contribute.

- Goal to establish templates for local Care Pathways, agreed by UKIVAS group. These could then be used by trusts. Benefit of establishing standardisation and parity across UK – would be welcomed by patients (LL). Robust method for keeping pathways up to date is needed (MR, FP).

- Agreement that UKIVAS meeting afternoon presentations should be made available on website – implied consent. Sensitive patient information will not be published. Education section of website to be created for these resources. Idea of linking to existing webinars suggested (NBa).

- BSR (British Society of Rheumatology) and Renal Association are main sources of clinical information. FP has asked that they might offer more signposting to RareRenal website.

- Importance of having clear governance system in place, as charity responsible for website ultimately responsible for the information on the website (PL). A panel may have to 'peer review' guidance and teaching material on website (FP).

7. BSR/CRG update, Health service systems: David Jayne, Peter Lanyon, Alan Salama

- AS representing Renal Association. PL representing BSR. 2 things discussed: i) Extending rituximab usage beyond 2 years in some cases & ii) Mepolizumab to be looked at for eGPA.

- Mepolizumab approved for eosinophilic asthma but not for eGPA. NICE can only approve 'label', whereas NHS England able to approve alternative doses or regimes (DJ). Variable reports of ability to use Mepolizumab in eGPA.

- DJ contacted by James Palmer, clinical director of NHS specialised services, who has recognised need for rapid introduction of therapy in rheumatology and immunology, and that these will be priorities.

- Draft Implementation plan (for England) of UK Rare Disease Strategy due to be published in coming weeks. Rare Disease Research Networks due to be set up based on ERN (European Research Network) model. Rare Disease Board 'Task and Finish' group now looking at ANCA vasculitis, attempting to improve the diagnostic odyssey (PL).

- NBa setting up study to quantify disparity of care between ANCA patients in different parts of UK. Wishes to brand it a UKIVAS study.

8. ERN-RITA update: Mark Little

- ERN-RITA (European Reference Network for immunodeficiency, autoinflammatory and autoimmune diseases) is now active. Represented for autoimmunity (vasculitis) in UK by Leeds. Call for applications from other centres, but number will be limited in each country. Virtual network of centres under UKIVAS umbrella is possible option that would allow other large UK centres to be involved (ML).

- Clinical Patient Management System: Virtual diagnosis and treatment system, whereby board of doctors from around Europe are tele-linked to discuss complex cases.

- European Joint Programme due to be set up March 2018 - Q1 2019. This is a structure that will allocate European funds to ERN-linked research projects. Early information suggests they will be favourable to registries – possible source of funding. Some concern regarding how Brexit will impact this is expressed.

Next meeting: 7th June in Edinburgh