

Minutes of the MATURA Patient Advisory Group (MPAG) – Eighth meeting

Room: Room G.06 Joseph Rotblat Building, Charterhouse Square

Date and Time: Wednesday 17th October 2018 2pm-4pm

Attendees:

Zoe Ide, MPAG Chair
Dr Frances Humby, Consultant Rheumatologist, Barts
Caroline Wallis, Lay member of MPAG
Sonia Jeevanason, Lay member of MPAG
Chris Wills (CW), Lay member of MPAG
Gaye Hadfield, MATURA Project Manager, QMUL
Jo Peel, STRAP Clinical Trial Manager, QMUL
Isabelle Garvey, Study Coordinator, QMUL
Hamit Soyel, Computer Science, QMUL
Paul Curzon, Computer Science, QMUL
Amy MacBrayne, Clinical Fellow, QMUL

Apologies:

Professor Costantino Pitzalis, MATURA Lead
Professor Anne Barton, MATURA Co-Lead
Lesley Cooke, Lay member of MPAG
Eleanor Goddard, Lay member of MPAG
Charlotte Austin, Research Involvement Officer, Versus Arthritis

1. Welcome:

Zoe welcomed everyone to the eighth MATURA Patient Advisory Group (MPAG) meeting and thanked them for attending. Apologies were noted. There were no comments on the minutes of the previous meeting.

Actions from the previous meeting:

Gaye reported that feedback to individual patients on pathotypes (a query raised at the previous meeting) would not be given whilst this is still an area of research, and it was noted that this is what was specified in the ethics application for the STRAP & R4RA studies.

Lay summaries of MATURA publications are now available on the MATURA website see:
<http://www.matura.whri.qmul.ac.uk/news.php>

2. DASApp and developing RA personas – Paul Curzon

Following on from the previous discussions on the development of a DASApp and the potential use of ‘artificial intelligence’ applications to support people with RA, Paul had circulated draft personas of RA patients. These are descriptions of fictional people with rheumatoid arthritis and will be used to help developers of software understand and take the real problems of living with the condition seriously. Each of the 6 personas aims to capture some distinct aspect of living with RA, as well as specific goals related to it that many sufferers might want support with. In the future sensors e.g. of movement could be incorporated in the system. See:

<http://bit.ly/RApersonas>

Overall the group thought the personas to be very realistic and could have wider applications in helping those recently diagnosed, carers and health professionals to understand the condition.

Specific feedback on the individual personas was captured by Paul.

Additional points included:

1. Consider including personas for:
 - a. Senior manager/director
 - b. Young person (in 20s)
 - c. Children (but noted that JIA is considered a different disease)
2. It might be best to restrict the display of measures of well-being to a single day as it could be depressing to see that one had had a series of ‘bad days’
3. Note that a patient’s response to RA evolves and is different for a long term sufferer and a newly diagnosed patient.
4. Levels of fatigue/energy levels are generally easier to report than ‘pain’
5. When a treatment works well patients have a tendency to ‘overdo it’ and then suffer later on, or to stop taking the medication
6. Would be good to include a planning function in the App for patients to keep track of appointments.

Members agreed they were happy to have one-to-one telephone discussions with Paul to clarify any points.

3. STRAP

Jo Peel (STRAP trial manager) presented an update:

- 164 patients have been recruited (out of a target of 207)
- 26 hospitals are open and recruiting patients (21 in the UK and 5 in mainland Europe)
Up to 5th October:
- 1952 study visits had been completed
- 133 patients had reached the primary endpoint (16 week visit)
- 164 baseline synovial samples plus 47 taken at week 16 have been analysed and are in storage
- 957 blood samples have been processed and stored
- 612 Ultrasound assessments have been performed

The final UK site, Western General in Edinburgh, and five sites in mainland Europe have opened since the last MPAG meeting.

Regular communications are sent to sites to encourage recruitment:

- Monthly recruitment updates
- Emails from the Chief Investigator, Prof Pitzalis
- Letters have been sent from the chair of Trial Steering committee and the funder (MRC)

However, recruitment remains behind schedule and a request to the MRC to extend the recruitment period is being prepared. An additional 6 months will be needed to meet to the target.

Action: Feedback at the next meeting on recruitment status

4. R4RA timelines

The R4RA study is the first randomised, biopsy driven stratified medicine trial in RA:

- Recruitment ended in December 2017 with 164 patients recruited
- Synovial tissue was collected from an inflamed joint prior to treatment (Tocilizumab or Rituximab)
- The main analysis will focus on whether Tocilizumab is better than Rituximab in histologically defined 'B cell poor' patients.
- Follow-up period for the last patient recruited is expected to end in January 2019 (Last Patient Last Visit)

Results will be made available (~mid-2019) through:

- R4RA public website <http://www.r4ra-nihr.whri.qmul.ac.uk/>
- Publications arising from R4RA will be available on a public registry for clinical research called the 'ISRCTN registry' (www.isrctn.com) (R4RA = ISRCTN97443826)
- All clinical trials using investigational medicinal products in the EU are registered on the EudraCT website and results must be posted within 1 year of the end of the trial <https://www.clinicaltrialsregister.eu/ctr-search/search> (EudraCT: 2012-002535-28).
- Participants are given a letter on completion of the trial which provides information on where results will be published

Members were asked to think about ways of disseminating the results to patients and public, and to keep in mind that we could present at patient meetings.

Suggestions included using social media - Instagram and Facebook

Action: Preliminary R4RA results to be presented at the next meeting

Action: Social Media to be used to disseminate results

5. Update on grant applications

- 5.1. NIHR fellowship – Felice Rivellesse’s application was successful
- 5.2. The MRC turned down our application to the Experimental Medicine Challenge Grant call, as the first two objectives were considered to be outside remit, these will be reconsidered for a different funding stream.
- 5.3. Prof Pitzalis and Prof Barton are co-applicants in an EU grant on stratified medicines, this has reached the second stage.

Prof Pitzalis is a co-applicant in 3 grants:

- 5.4. Investigating fatigue in RA – EU funded
- 5.5. Investigating psychological well-being, this will use data from R4RA- MRC
- 5.6. Using PEAC data to look at long term outcomes - MRC

6. General update

- On the 4th May 2018 MATURA was reviewed at MRC, we were congratulated on our PPIE activities
- There was a CiTi, QMUL meet the researcher patient event with afternoon tea on the 1st June 2018. It was well attended and MPAG hosted a stand.
- 20th June 2018 was the Barts/QMUL annual Science Festival where MPAG hosted a stand.
- Our Diagnostics article was published in the Spring edition of NRAS magazine
- The next MRC review is 15th November 2018.

Zoe requested that the ‘Terms of Reference’ and membership are reviewed at the next meeting

Action: Gaye to include in next agenda

The next MPAG meeting will be held 2-4pm (refreshments from 1.30pm) on Wednesday 24th of April 2019 in G0.5 Joseph Rotblat Building, Charterhouse Square, QMUL.