

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

**Room:** B02/B03, Heart Centre, Charterhouse Square (Basement seminar room)

**Date and Time:** Monday 8<sup>th</sup> June, 2pm – 4pm (UK time BST)

### Attendees:

Zoe Ide (ZI), MPAG Chair  
Deborah Maskell (DM), MATURA Project Manager  
Dr Frances Humby (FH), Consultant Rheumatologist  
Hannah Maltby (HM), Lay member of MPAG  
Sonia Jeevanason (SJ), Lay member of MPAG  
Chris Wills (CW), Lay member of MPAG  
Eleanor Goddard (EG), Lay member of MPAG  
Lauren Coombes (LC), Research Administrator

### Dial In:

Cameron Neil (CN), Lay member of MPAG  
Kanta Kumar (KK), Nurse Specialist and Lecturer

### Apologies:

John Game (JG), Lay member of MPAG  
Simon Stones (SS), Lay member of MPAG  
Caroline Wallis (CW), Lay member of MPAG  
Carolyn Carter (CC), Lay member of MPAG  
Bev Davis (BD), Lay member of MPAG  
Philip Bell (PB), Lay member of MPAG  
Dr Michelle Korda (MK), MATURA Project Manager

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### 1. Welcome: Zoe Ide

ZI welcomed everyone to the second MATURA Patient Advisory Group (MPAG) meeting and introduced two new members, Chris Wills and Eleanor Goddard.

### 2. MATURA STRAP update: Dr Francis Humby

FH provided a review and update on the MATURA consortium and the STRAP trial. FH explained that within the current standard treatment pathway up to 40% of patients fail DMARD therapy and as patients progressed through the treatment pathway their quality of life was affected. FH advised that stratified medicine was to move away from this trial and error treatment practice, maximise therapeutic efficacy of current drugs, and develop novel drugs tailored to specific non-responder patient groups.

FH provided an overview of the two Work Streams within MATURA, explaining the Work Stream 1 is based at Queen Marys and is investigating synovial tissue biomarkers within the STRAP clinical trial, whilst Work Stream 2 is based in Manchester and is investigating genetic biomarkers from existing and new nationwide blood collections.

FH provided an update on the STRAP trial and advised that the trial had been greenlight at the Mild End site with first patient recruited on 8<sup>th</sup> June 2015. It was noted that there had been a delay in opening the trial partially due to the need to complete biopsy training with participating sites.

### **3. MATURA EPIC RA study: Dr Kanta Kumar**

ZI introduced KK and advised that the presentation on EPIC RA would be for them to see how they could help inform decisions about the research and potentially form a focus group. KK explained that EPIC RA was a qualitative project investigating how patients perceive tests used and what influences them in their decision to take the tests or not. It was explained that the members of the MPAG were being invited to form a second focus group which would then form a template for a much larger survey involving other patient groups looking at what type of questions would be valid and the most effective in engaging patients in this topic. CW noted that there was a need for clear use of language and tone in order to elicit good quality answers. KK advised that the answers provided from the pilot stage focus groups would help to create the dialogue needed with patients and it was explained that KK would be conducting the interviews which would be tape recorded and from this the data there would be analyses and any themes arising would be used to form the main survey as well.

KK advised that ideally two more focus groups would be conducted in July, one based in London with the other based in Manchester with approximately 5-6 people per group. DM agreed to circulate potential dates to the MPAG members for consideration.

**Action: DM to circulate provisional dates to MPAG members.**

### **4. MATURA website PPI section: Deborah Maskell**

DM presented an overview of the Work Stream 2 programme of work explaining that it involves multiple studies providing samples for an integrated analysis with the eventual plan for the analysis and STRAP trial data to be pooled together. DM provided an update of advances since the last report and advised that 500 samples from patients on Anti-TNF treatment had been genotyped, as well as 500 methotrexate DNA samples currently being genotyped. The collection of samples from patients on Rituximab is ongoing with 312 currently recruited, 8 short of the current target. DM also noted that two new industry partners (Protagen Diagnostics and Avacta Life Science) were also on board to start some proteomics work on existing samples.

DM presented the MPAG members with the current MATURA website PPI section and explained that feedback and suggestions for improving the site would be greatly appreciated. Some members advised that the x-ray picture used in the PPI section was off putting and that the text needed to be broken down into smaller sections. CW advised that due to his background he would be happy to work with DM on the website. SJ suggested

that a section regarding how treatment has advanced would be a useful section and FH proposed splitting the pages into specific questions to be answered.

EG noted that the term involvement used was somewhat misleading as there is no way to currently be involved until the EPIC RA study is implemented and advised that this had caused frustration previously when looking to get involved.

DM noted that the FAQ section had not yet been populated.

ZI advised that the first task would be to discuss content and who it would be aimed at. ZI suggested DM/CW in contact with Vladan, the Website/IT developer, regarding the sites capabilities. DM advised that the STRAP website would also require updating as it linked into the MATURA website.

CW also noted that there may be search engine optimisation issues to investigate further.

**Action: DM to initiate contact between CW and Vladan.**

**Action: MPAG members to provide feedback and suggestions for PPI section of MATURA website.**

## **5. General discussion, feedback, Q&A session, AOB: Zoe Ide**

### **5.1. Wider Publicity**

ZI explained that one element of the MPAG was to advise generally on patient/public information about the project and to help expand MATURA to a wider audience. ZI advised that it needed to be noted what information MPAG members were comfortable talking about and informing others with and using contacts within organisations to help. ZI also noted that a compliance element would be needed.

ZI raised the query regarding what organisations the MPAG should be engaged with and noted some examples including ARUK, NRAS, ArthritisCare, INVOLVE, Nowgen, as well as the local press and wider communication maybe through the Industry partners. Discussion arose concerning the potential for MATURA to have a section on the NRAS site with a brief summary which could also be used for the MATURA website.

ZI concluded in summary that there was a need for materials to inform others, including the MATURA website and a summary to be used for the NRAS website amongst others, and a strategy on engaging with organisations.

### **5.2. Next Meeting Date**

The next meeting is to be scheduled for November 2015. Date and time to be confirmed.

### **5.3. Travel reimbursement forms**

LC advised MPAG members that completed travel reimbursement forms, with travel receipts, could be handed in at the end of the meeting or returned via email or post.

## **Action Log**

- DM to circulate provisional EPIC RA focus group dates to MPAG members.
- DM to initiate contact between CW and Vladan.
- MPAG members to provide feedback and suggestions for PPI section of MATURA website.