

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

Room: Room G.05 Joseph Rotblat Building, Charterhouse Square

Date and Time: Wednesday 24th April 2019 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
Eleanor Goddard, Lay member of MPAG
Louise Boyce, Lay member of MPAG (via Zoom).
Caroline Vass, Health Economist University of Manchester (via Zoom).
Gaye Hadfield, MATURA Project 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
Jo Peel, Trial Manager, QMUL.

1. Welcome:

Zoe welcomed everyone to the ninth MATURA Patient Advisory Group (MPAG) meeting and thanked them for attending. Zoe welcomed Louise Boyce as a new member to MPAG. Louise provided a background how she came to the MPAG group via the NRAS article. All members introduced themselves. There were no comments on the minutes of the previous meeting.

Actions from the previous meeting:

Zoe advised that the action points have become part of the main agenda. Referring to outstanding actions about updates to the terms of reference to include dissemination of study results which have been included. There would be an allowance for members to have flexibility with attendance in the terms of reference. Gaye also highlighted the panel's continued participation with grant applications as long as everyone is happy to be involved.

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

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>

2. "Understanding people's preferences for a new stratified approach to treatment of RA" results of the survey - Caroline Vass.

Caroline Vass presented on the above topic discussing her research and the results on how people value goods and services within healthcare. The main points which were covered were:

- There is a growing body of research which is investigating how biologic medication is targeted towards those who would benefit most (prescribing algorithms). Yet it is not known how receptive patients are to these ways of deciding treatment.
- Her research was designed to quantify preferences and how patients balanced risk and benefits of treatment using prescribing algorithms.
- To determine patient's preference, a discreet choice experiment survey was performed. These have also been used within private/commercial sector and the FDA has incorporated these types of surveys within their policies on devices.
- The Survey was provided to patients with RA and members of the public. Participants were provided with training materials, choice sets and background questions.
- The choice sets were composed of attributes identified by researchers.
- Data was analysed to demonstrate how each attribute affected the probability of a person choosing that option as their preferred approach.
- 293 people completed the survey.
- Participants showed no preference over approach, but disliked delay and risk, and valued higher predictive value and cost savings.

Zoe asked about the next steps from the research. Caroline advised that further analysis is being done. The plan is to produce a model that can be put online and other researchers can use to enter their own algorithms to see how the public responds. It would be helpful to talk to developers.

Gaye asked if any clinicians participated. Caroline advised they had very few responses and this part of the survey was not completed due to lack of engagement.

A copy of the presentation is available.

3. Clinical Trial Updates - Gaye Hadfield.

Gaye provided update on clinical trials since last MPAG meeting.

- 15th November was the MATURA 6 month review at MRC.
- The 6 month extension to the recruitment period for the STRAP study and reduced follow up to 24 weeks was approved.
- STRAP recruitment now ends in May 2019.
- The next MRC review is on the 8th of May 2019
- MATURA has a good level of industry contribution and publications underway.
- Continued patient contribution after close of consortium would support dissemination of the results and review of grant applications .
- Scientific Symposium is on 24th September 2019 and all are welcome.

A clinical Trial update was provided for STRAP.

- 203 patients recruited out of 219.
- 27 hospitals open and recruiting patients (21in the UK & 6 in mainland Europe)
- Only 5 weeks left to recruit remaining patients – regular newsletters going to sites & emails from Prof. Pitzalis.
- Last date for patient consent is 31st May 2019.
- Expanding the trial to Europe has been extremely beneficial for the trial.

A clinical trial update was provided for R4RA.

- Recruitment ended in December 2017 with 164 patients recruited.
- The main analysis will focus on whether Tocilizumab is better than Rituximab in histologically defined B-cell poor patients.
- Last patient last visit was January 2019
- Database lock 31st Jan 2019
- Analysis is ongoing.
- A list of where study results will be published was provided.

Grant Applications were reviewed:

- Costantino & Anne were co-applicants in European Horizon 2020 Grant application (3TR Consortium). Total award €40M, £1,975K to QMUL & £683K to UoM. This will provide funding for stratified medicine research including PEAC and STRAP replication studies. Funding has been approved and now at the contract stage.
- NIHR EME Precision medicine Programme application. Costantino lead applicant & Anne co-applicant. Stage 1 application submitted in March, requested £1.6M.

- Reviewed in June
- If successful, predicted start Sep/Oct 2020.
- Wellcome Trust application Costantino lead applicant & Anne co-applicant. Submitted 8th April 2019.
 - Requested funding to maintain and expand Bio-resource (infrastructure support)
 - £1.4M over 5 years.
 - Will be informed in July 2019 if successful.

Engagement Events

- 8 lay summaries are now available on the MATURA website. (See link above).
- Anne Barton has published “Under the spotlight: Precision Medicine what does it mean and why should we care?” Arthritis Digest (2019, Issue 1). Copy of the article on MATURA website.
- EMR Twitter account now active @EMR_QMUL , please follow if you are a Twitter user
- Barts Science Festival is on the 19th June 2019, the 3rd year of our involvement. All welcome.
- Tate Exchange – see below.

4. Tate Exchange Festival - Eduardo Prediletto - Versus Arthritis PhD student

- This will be a workshop 10th -16th June 2019 at the TATE Modern Gallery in London
- Exploring the relationship between impaired mobility and artistic expression.
- Based on the Tate Exchange festival. It is an open experiment which is exploring the role of art in society and will include international artists, contributors from different fields and the public.
- The aim is to create a team programme of participatory artworks, workshops, activities and talks.
- Members of the public & organisations are invited to create a platform to discuss the role of art in our society.
- The theme for Tate Exchange this year is “Movement and Migration”.
- The project is entitled “Creating without Constraint – Arthritis & Art” which will be an interactive workshop.
- Activities:
 - Arthritis Simulation Gloves with public and ask participants to complete artistic activity and provide feedback.
 - Exploring the joints with an ultrasound machine.
 - 3 LED screens with images and projections, to provide information about famous artists with arthritis - such as Renoir.
 - Modern artists with arthritis such as the artist John Pickering. Collaboration with Rebecca Ibatz (Pint of Science festival), where she painted John Pickering while he worked. Rebecca will be giving some talks. – Eduardo suggested perhaps having an open conversation with a panel and discussing John Pickering’s experience. Interesting story around John Pickering, who was before the era of biologic treatment. Due to subsequent treatment with Infliximab, he was able to extend his career for 20 years. Interesting to learn how he dealt with his arthritis and managed his art.
- Gaye invited members to take part if they wished to be involved.
- Eduardo advised they will be reviewing the space on 25th April. Official meeting in May.

- Zoe asked if it is focused on RA in particular? Eduardo confirmed that the Tate exchange exhibition is on “movement” but that the EMR contribution will be focusing on RA.
- Zoe advised that it will attract people who wouldn’t normally engage with Arthritis and will reach a much wider audience.
- Eduardo advised that the exhibition it will take place on level 5 in the Blavatnik Building of the Tate Modern.
- Gaye indicated it was a wonderful way to demonstrate how treatment has improved since Renoir.
- Caroline asked if the exhibition would transfer to the North. Gaye advised we can ask if there is a Tate Exchange in Liverpool? EP advised he would check it out.
- Isabelle asked if it would be possible in Manchester due to our strong partnership with the UoM.

5. The Pambayesian Project (Patient Managed Decision-Support using Bayesian Networks).

5.1: Bio-T-App Project Update – Isabelle Garvey.

- This project is part of larger strategy investigating the role of technology in patient health management and support.
- Background and description to the study was given: App which allows patients to submit joint counts using an app on their phone. This is received by clinical team which combined with blood results gives a snap shot of a patients DAS28 at a particular timepoint.
- Study is run over 6 months and patients submit joint counts when they take their biological medication, which can be weekly or monthly. Telephone consultation at 12 weeks.
- Study opened on the 15th November 2018 and the first patient was consented on the 11th December.
- Technical issues around internet access for some, but overall the experience has been positive.
- Recruiting 60 patients (30 intervention, 30 control). Currently halfway toward our target on the intervention arm.
- Original plan was to run the study until July 2019, but due to the late start of the study, we have submitted an amendment to request an extension to the study until 30th November 2019.

Gaye asked about patients’ experience of app. Isabelle confirmed there has been no difficulty in terms of submitting a joint count.

Isabelle advised that the long-term aims of the study are to improve management of care, reduce number of appointments with appointments being targeted to specific patient need and reduction of medication in line with their true disease activity.

The “Notes” function of app was discussed, patients value that it enables a quick response from the clinical team in relation to specific issues e.g. medication not being provided in a timely manner .

5.2: Patient Surveys & Patient Personas - Dr Amy MacBrayne & Paul Curzon

- Amy provided images of the Bio-T-App and the database to further demonstrate how it works.
- The Pambayesian project represents the next step beyond simple disease monitoring via an app.

Intelligent technology which can support your care and clinicians. The PEAC data is being used to ‘teach’ the care models developed in conjunction with the computer scientists in order to develop decision support tools for patients and clinicians.

- How to build this into routine care. – qualitative study, patient and clinician needs in RA care.
- Asking patients and clinicians via interviews and questionnaires about life with Rheumatoid Arthritis and managing rheumatoid Arthritis care. Particularly to identify the gaps in care where technology might be able to help.
- Questionnaires and interviews have been completed with some of the group.
- Zoe – found the personas very helpful.
- Amy – asked if the interviews will be challenging for people when disease is well controlled.
- Zoe – difficult to capture bad days and things that are not well controlled using the personas.
- Amy- We also want to know what your life is like, through semi-structured interviews (takes about an hour) and a questionnaire that you could complete in clinic.
- Paul – we want to capture what it is like as much as possible on good days and bad days. Where is help needed? Trying to make sure we are covering things of real use. Knowing what the opportunities are, would like to capture all the elements that play a role apart from pain and DAS.
- Zoe - thought the personas stand alone very well.
- Paul - we are trying to cover the different kind of emotions that people may have. Some are specific opportunities and some are features to make the characters realistic. Can't capture everything that could go wrong, but need example scenarios for design tools.
- Caroline spoke about a recent issue she had had, and Paul discussed how in the future technology might help to reduce the time taken for a clinical intervention with decisions made sooner rather than later.
- Eleanor advised when you feel fine you tend to forget the details of the bad days.
- We hope to validate what we currently understand and get much deeper understanding.
- Sonia(?) asked about language barriers. Fran advised that data will be collected and will report back at the end of the study.
- Hamit advised that the integration of this knowledge and data with technology will allow you to be better supported and for example might encourage someone to take additional rest if necessary as reflected in their data.
- Amy reported that we have been able to provide additional support, scan etc due to information which we have received via the app.
- Gaye suggested that the group review the additional personas and give feedback directly to Paul. Paul encouraged anyone to get in touch with feedback.
- Paul gave update on new additions to patient personas based on previous patient feedback.
 - The inclusion of a late teen persona with issues around relationships.
 - The potential to miss clinic appointments.
 - The inclusion of a persona who is a high flyer.
 - Having parts of life disappearing.
 - Inclusion of persona who is struggling with their mental health, this was considered to be a dark description that may need modification.

Zoe confirmed what is needed from the panel - to feedback to Paul if any of the personas have any gaps or areas if they need improvements and are they realistic?

Zoe thanked all for attending & closed the meeting.

The next MPAG meeting will be held in the Autumn, date to be confirmed.